



## **A visit to the doctor: shared decision making supported by outcome information in chronic kidney disease**

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# PART TWO

Discussing outcome information during  
healthcare visits – current practice and  
preferences



# 3

## Shared Decision Making in Healthcare Visits for CKD: Patients' Decisional Role Preferences and Experiences

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[1] In recognition of **World Kidney Day** on March 14, 2024, the editors of American Journal of Kidney Diseases, presented a collection of articles that highlight kidney disease research from around the world. This article was selected to be a part of this special collection. <https://www.ajkd.org/content/worldkidneyday>

[2] An editorial in American Journal of Kidney Disease was written regarding this article by Dale E. Lupu et al. 2023. [https://www.ajkd.org/article/S0272-6386\(23\)00750-3/fulltext](https://www.ajkd.org/article/S0272-6386(23)00750-3/fulltext)

## **Abstract**

### **Rationale & Objective**

Research on shared decision making (SDM) in chronic kidney disease (CKD) has focused almost exclusively on the modality of kidney replacement treatment. We aimed to explore what other CKD decisions are recognized by patients, what their preferences and experiences are regarding these decisions, and how decisions are made during their interactions with medical care professionals.

### **Study design**

Cross-sectional study.

### **Setting & participants**

Patients with CKD receiving (outpatient) care in one of two Dutch hospitals.

### **Exposures**

Patients' preferred decisional roles for treatment decisions were measured using the Control Preferences Scale survey administered after a healthcare visit with medical professionals.

### **Outcomes**

Number of decisions for which patients' experienced a decisional role that did or did not match their preferred role. Observed levels of SDM and motivational interviewing in audio recordings of healthcare visits, measured using the 4SDM and Motivational Interviewing Treatment Integrity-coding tools.

### **Analytical Approach**

Results were characterized using descriptive statistics, including differences in scores between patients' experienced and preferred decisional roles.

## **Results**

According to the survey (n=122) patients with CKD frequently reported decisions regarding planning (112 of 122), medication changes (82 of 122), or lifestyle changes (59 of 122). Of the 357 reported decisions in total, patients preferred that clinicians mostly (125/357) or fully (101 of 357) make decisions. For 116 decisions, they preferred a shared decisional role. For 151 of 357 decisions, the patients' preferences did not match their experiences. Decisions were experienced as 'less shared/patient-directed' (76 of 357) or 'more shared/patient-directed' (75 of 357) than preferred. Observed SDM in 118 coded decisions was low (median 4, range, 0 – 22). Motivational interviewing techniques were rarely used.

## **Limitations**

Potential recall and selection bias, and limited generalizability.

## **Conclusions**

We identified multiple discrepancies between preferred, experienced, and observed SDM in healthcare visits for CKD. Although patients varied in their preferred decisional role, a considerable number of patients expressed a preference for shared decision making for many decisions. However, SDM behavior during the healthcare visits was observed infrequently.

## 1. Introduction

In nephrology, the importance of shared decision making (SDM) is increasingly recognized. SDM entails the collaborative process of sharing information and preferences between patients and clinicians in order to jointly decide on the option that best fits the patient. [1-3] International nephrology guidelines recommend SDM in the decision regarding kidney replacement therapy (KRT), a major preference-sensitive decision between the different available types of kidney replacement therapies and conservative management. [4,5] Until now, most research on decision making in nephrology has focused on the KRT decision and not on other chronic kidney disease (CKD) decisions.[6] However, an abundance of other decisions are made in the management of CKD, starting from diagnosis and during the progression toward kidney failure. Many of these decisions relate to the aim of slowing down kidney function deterioration and the prevention of cardiovascular disease. They are often considered routine care decisions, including decisions regarding lifestyle, long-term medication, and planning of care - for example, starting a salt- restricted diet, antihypertensive medication, or lipid-lowering therapy.

Although these “common CKD decisions” can be viewed as relatively minor when compared to the KRT decision, they do impact patients’ daily life. In addition, for successful treatment, adherence to these common CKD decisions de- pends on patient commitment. SDM might therefore be especially valuable here because it can help improve the fit between care and patient circumstances, enhance the patient-clinician relationship, and activate patients and in- crease their disease knowledge.[7-9] Ultimately, these factors may stimulate therapy adherence and treatment efficacy.

From other chronic conditions we know that the majority of patients prefer to make shared decisions with their clinicians.[10] However, it is as yet unclear whether this also applies to patients with CKD and the common CKD decisions they encounter. Additionally, it is unknown *how* these decisions are made. Besides SDM, motivational interviewing might be a valuable conversational approach. Motivational interviewing focuses on “strengthening patients’ personal motivation and commitment to change”[11] and is particularly applicable in case of decisions in which patients seem unwilling to make or incapable of making the required behavioral change. SDM and motivational interviewing can be applied sequentially: SDM focuses on what to choose, including weighing different options, and motivational interviewing focuses on how to carry out a decision requiring a behavioral change.[12]

Because decision making in routine CKD management to date has not been extensively studied, it is unknown whether SDM or motivational interviewing is applied in common CKD decisions. With this study, we explored (1) which decisions frequently occur during healthcare visits for CKD (other than the KRT decision), (2) what patients' preferred role is in making these decisions in comparison to their experienced role, and (3) which elements of SDM or motivational interviewing is observed during the healthcare visits.

## 2. Methods

This study is an observational cross-sectional study. From January 2021 through June 2021, we collected surveys filled out by patients after their healthcare visit and audio-recorded (the same) visit (1 per patient). The surveys and audio recordings were collected in the context of a larger evaluation study of a CKD dashboard. The healthcare visits were routine follow-up consultations (face to face, by telephone, or by videoconference) of patients and their known nephrologist. Data were collected in two Dutch hospitals. In both hospitals, all clinicians (both nephrologists and nurse practitioners) providing CKD outpatient care were informed. They all participated except 1 nurse practitioner due to logistic reasons. The eligible patients were adult patients with CKD stages 3b-4, sufficient in Dutch language, not cognitively impaired, and able to fill in the digital survey by themselves or with assistance from a partner or relative. To minimize selection bias, clinicians could only recruit patients from a predetermined list based on dates when patients would visit, which had been selected randomly by a research team member not conducting the healthcare visits. Written informed consent was obtained from all participating patients. The Medical Research Ethics Committees United (MEC-U) confirmed that the study was not subject to the Medical Research Involving Human Subjects Act, study number: W20.245.

### 2.1 Exposure

Patients were characterized using a post-healthcare visit survey. The survey included an assessment of patient characteristics and the patients' preferred decisional role in decisions they had encountered in their last visit for CKD. The survey was sent via email 1 day after the visit. Health literacy was measured with the Set of Brief Screening questions[13]; a score of  $\leq 3$  was considered low.[14] Education levels were measured using the International Standard Classification of Education (ISCED); levels 0-2 were considered low, 3-4 medium, and 5-8 high.[15] The patients were asked to report what decisions were discussed during their last visit from a predetermined list of decisions. This list was built by researcher D.E.M.H., who observed healthcare visits for CKD for 4 days, and

nephrologist W.J.W.B., who counted the decisions that occurred in his consultations for 2 weeks. The patients were offered an open text field to add decisions that were not on the list. Subsequently, the patients were asked to report who in their experience had made the decision and what their preferred decisional role would be in making such decisions. The Control Preferences Scale (CPS) was used for both questions (**Box 1**).[16]

**Box 1. Control Preferences Scale.**

Participants were asked to select one of five statements of the CPS on preferred and experienced role in decision making:

‘Only patient’: the patient makes the decision alone

‘Mostly patient’: the patient makes the decision after seriously considering the clinician’s opinion

‘Shared’: the patient makes the decision together with the clinician

‘Mostly clinician’: the clinician makes the decision after seriously considering the patient’s opinion

‘Only clinician’: the clinician makes the decision alone

## 2.2 Outcomes

Outcomes include the number of (mis)matches between the patient-reported experience and the preferred decisional role, measured with the CPS, and the observed levels of SDM and motivational interviewing in audio recordings of the healthcare visits. The observed level of SDM was measured with the 4-step SDM instrument (4SDM) coding scheme.[17] The 4SDM assesses whether and how the 4 steps of SDM are applied (**Box 2**). It allows for an explicit distinction between the 4 SDM steps and focuses on both clinicians’ and patients’ behavior.[17;18] The possible scores per SDM step range from 0- 6, and the total SDM score ranges from 0-24. Additionally, we coded per item of the 4SDM whether the behavior corresponding with the item was initiated by the patient or by the professional. Decisions were transcribed and immediately coded. Two researchers (D.E.M.H. and N.H.) coded the audio recordings. In case of disagreement a third researcher (A.H.P.) was consulted. In **Box S1**, 2 illustrative examples of coded decisions are provided. Per healthcare visit a maximum of 2 decisions were coded on SDM. If there were more than 2 decisions, the 2 most prominently discussed during the healthcare visit were coded. For the decisions that were coded on the level of SDM, we also coded what decision characteristics were mentioned during the conversation. Decision characteristics are features that define a particular decision, such as uncertainty regarding the options, the existence of 1 best option, or a decision being preference-sensitive.[19] When a behavioral change goal was explicitly mentioned during the healthcare visit, for example, and when a decision resulted in the need for a behavior change, we used the Motivational Interviewing Treatment Integrity (MITI) coding scheme to get an overall impression on

whether/how motivational interviewing was used. The MITI provides global ratings of relational components (partnership and empathy, scale 1-5, where >3.5 is sufficient), and technical components (cultivating change talk and softening sustain talk, scale 1-5, where >3 is sufficient). For a full list of MITI items, see **Box S2**.[20]

**Box 2. Items of the 4SDM**

**STEP 1 Setting the agenda**

- Item 1. It is stated (or re-affirmed) that a decision about management or treatment needs to be made.
- Item 2. It is stated (or re-affirmed) that the decision depends on the values and preferences of the patient.

**STEP 2 Informing about options**

- Item 3. The available management or treatment options are stated (or re-affirmed).
- Item 4. The pros and cons of each option are stated or re-affirmed.

**STEP 3 Exploring values and preference construction**

- Item 5. The patient states the outcomes that are important to him/her (values).
- Item 6. The patient states how s(h)e appraises the (characteristics of) the management or treatment options.

**STEP 4 Making or deferring a decision in agreement**

- Item 7. The patient expresses or confirms his/her preference or the (provisional) lack of a preference
- Item 8. The moment of making (or deferring) the decision is explicit and decision making occurs in agreement

Every item is scored as 0 (no behavior identified); 1 (minimal); 2 (sufficient) or 3 (good).<sup>17</sup>

*Every item is scored as 0 (no behavior identified), 1 (minimal), 2 (sufficient), or 3 (good).<sup>17</sup> Abbreviations: SDM, shared decision making; 4SDM, 4-step shared decision making instrument.*

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### 2.3 Statistical Analyses

Data from the audio recordings and surveys were analyzed with SPSS Statistics 27 (IBM SPSS Inc). Data were presented either as mean and standard deviation, median and interquartile range, or number with percentage, depending on the distribution. Experienced decisional role and preferred decisional role were compared at the patient level by subtracting the CPS "preferred" from the CPS "experienced." To compare observed levels of SDM to the patients' experienced decisional role, the level of SDM of coded decisions was recoded into 3 groups: (1) no to minimal SDM, 0-8; (2) minimal to sufficient SDM, 9-16; (3) sufficient to good SDM, [17-24]. Kruskal-Wallis H tests were used to compare SDM scores between different decisional topics.

### 3. Results

#### 3.1 Patient Characteristics

In total, 122 patients (75 male and 47 female) filled in the post-healthcare visit survey. **Table 1** shows the patients' and clinicians' characteristics. Education levels were predominantly low or medium. Health literacy was high (median, 4.5 [IQR, 1.0]). Patients had been visiting their nephrologists for a median of 6.5 years (IQR, 7.2).

**Table 1.** Characteristics of participants

Patient characteristics, total survey participants	N=122 (100%)
<b>Sex (male), n %<sup>a</sup></b>	75 (61.5%)
<b>Age, median (IQR)<sup>a</sup></b>	73 (15.3)
<b>Number of years since first nephrologist visit, median (IQR)<sup>a</sup></b>	6.5 (6.9)
<b>SBSQ score, median (IQR)</b>	4.5 (1.0)
<b>Education level, n(%)</b>	
<i>Low (ISCED<sup>b</sup> levels 0-2)</i>	52 (42.6%)
<i>Medium (ISCED levels 3-4)</i>	38 (31.1%)
<i>High (ISCED levels 5-8)</i>	29 (23.8%)
<b>Etiology of CKD<sup>a</sup></b>	
<i>Hypertension/vascular disease</i>	53 (43%)
<i>Diabetes (with or without vascular disease)</i>	20 (16%)
<i>Glomerulonephritis</i>	15 (12%)
<i>Unknown</i>	8 (7%)
<i>Polycystic kidney disease</i>	5 (4%)
<i>Obstructive kidney disease</i>	5 (5%)
<i>Other<sup>c</sup></i>	14 (11%)
<b>Comorbidities<sup>a</sup></b>	
<i>Myocardial infarction</i>	29 (9.7%)
<i>Peripheral vascular disease</i>	27 (9.1%)
<i>Diabetes with chronic complication</i>	27 (9.1%)
<i>Any malignancy without metastasis</i>	24 (8.1%)
<i>Rheumatic disease</i>	19 (6.4%)
<i>Chronic pulmonary disease</i>	15 (5.0%)
<i>Diabetes without chronic complication</i>	11 (3.7%)
<i>Cerebrovascular disease</i>	10 (3.4%)
<i>Congestive heart failure</i>	8 (2.7%)
<i>Leukemia</i>	3 (1.0%)
<i>Metastatic solid tumor</i>	3 (1.0%)
<i>Peptic Ulcer disease</i>	2 (0.7%)

**Table 1. (Continued)**

Patient characteristics, total survey participants	N=122 (100%)
<b>Clinician characteristics, total clinicians recording healthcare visits n=14 (100%)</b>	
<b>Age</b> , median (IQR)	49 (18.3)
<b>Sex (male), n%</b>	8 (57.1%)
<b>Function</b>	
<i>Nephrologist</i>	13 (92.8%)
<i>Nurse practitioner</i>	1 (7.1%)
<b>Years of experience in current position</b>	
0-5 years	2 (14.3%)
6-10 years	4 (28.6%)
11-15 years	3 (21.4%)
>15 years	5 (35.7%)

IQR=Interquartile range. SBSQ= Set of Brief Screening Questions (self-report health literacy measure), CKD=Chronic Kidney Disease

a) Extracted from electronic health record

b) ISCED = International Standard Classification of Education framework [15]

c) Other = mono-kidney, repeated urinary infections, prerenal (heart failure), nephrotoxic medication, nephrophtosis, myeloma cast nephropathy, acute tubular necrosis (due to sepsis)

### 3.2 Patient-reported Decisions in Healthcare Visits for CKD

The median number of decisions per healthcare visit was 4 (IQR 3.0). Only 3 patients reported that no decision was made during the visit. In total, the 122 patients reported 357 different decisions. Patients most frequently reported decisions regarding care planning (e.g., time to next follow-up visit, or whether patients preferred face-to-face or telephone/video conference consultations; 112 of 122 patients, 92%), followed by decisions regarding medication changes (82 of 122 patients, 67%), and decisions regarding lifestyle (59 of 122 patients, 48%).

**Table 2. Survey: Patients' preferred role in decision making**

Decision topic	Patients Who Preferred the Following Decisional Roles				
	Patients Who Indicated Having Discussed the Decision in the Previous Healthcare Visit	Only clinician	Mostly clinician	Clinician and patient equally	Mostly patient
Planning	112	46 (41% <sup>a</sup> )	37 (33%)	28 (25%)	1 (1%)
Medication change <sup>b</sup>	82	17 (21%)	35 (43%)	28 (34%)	2 (2%)
Lifestyle <sup>c</sup>	59	6 (10%)	18 (31%)	24 (41%)	9 (15%)
Treatment goals	45	8 (18%)	20 (44%)	16 (36%)	1 (2%)
Diagnostic testing	33	14 (42%)	7 (21%)	12 (36%)	0 (0%)
Referral	10	2 (20%)	6 (60%)	2 (20%)	0 (0%)
Other <sup>d</sup>	16	8 (50%)	2 (13%)	6 (38%)	0 (0%)
<b>Total decisions mentioned by patients</b>	<b>357</b>	<b>101 (28%<sup>5</sup>)</b>	<b>125 (35%)</b>	<b>116 (32%)</b>	<b>13 (4%)</b>
					<b>2 (1%)</b>

**Table 3. Survey: Patients' experienced role in decision making**

Decision topic	Patients Who Indicated Having Discussed the Decision in the Previous Healthcare Visit	Patients Who Experienced the Following Decisional Roles				Only patient
		Only clinician	Mostly clinician	Clinician and patient equally	Mostly patient	
Planning	112	52 (46%) <sup>a</sup>	35 (31%)	24 (21%)	1 (1%)	0 (0%)
Medication change <sup>b</sup>	82	24 (29%)	27 (33%)	29 (35%)	2 (2%)	0 (0%)
Lifestyle <sup>c</sup>	59	3 (5%)	15 (25%)	34 (58%)	5 (8%)	2 (3%)
Treatment goals	45	9 (20%)	13 (29%)	23 (51%)	0 (0%)	0 (0%)
Diagnostic testing	33	14 (42%)	12 (36%)	7 (21%)	0 (0%)	0 (0%)
Referral	10	3 (30%)	3 (30%)	2 (20%)	2 (20%)	0 (0%)
Other <sup>d</sup>	16	7 (44%)	2 (13%)	7 (44%)	0 (0%)	0 (0%)
<b>Total decisions mentioned by patients</b>	<b>357</b>	<b>112 (31%)<sup>e</sup></b>	<b>107 (30%)</b>	<b>126 (35%)</b>	<b>10 (3%)</b>	<b>2 (1%)</b>

Abbreviation: CPS, Control Preferences Scale.

a) Percentage of total patients who experienced that decision.

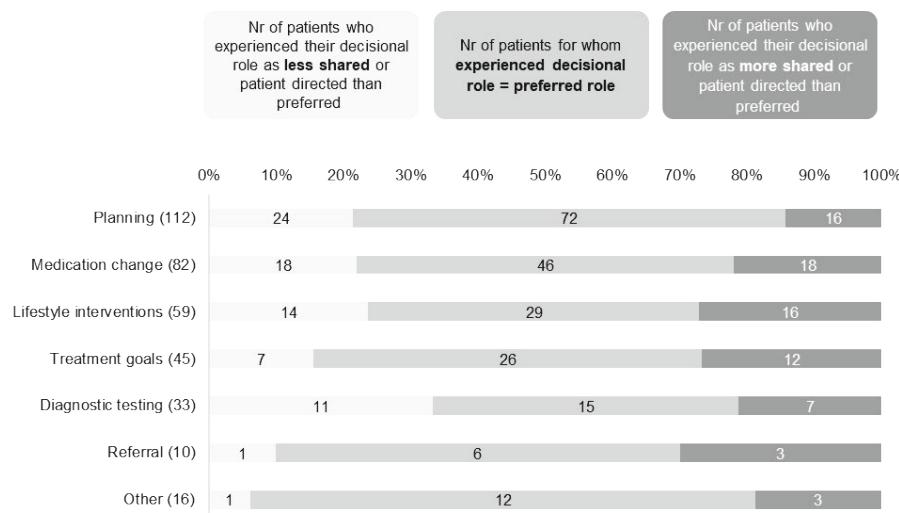
b) Medication change is a combination of 4 decision topics regarding medication change: (1) starting new medication ( $n = 50$ ), (2) change medication dosage ( $n = 63$ ), (3) stop medication ( $n = 17$ ), (4) start erythropoletin injections ( $n = 7$ ). When 1 patient experienced multiple decisions regarding medication change the mean CPS was calculated.c) Lifestyle interventions are a combination of 4 decision topics regarding lifestyle interventions: (1) limit salt intake ( $n = 44$ ), (2) lose weight ( $n = 25$ ), (3) stop smoking ( $n = 7$ ), (4) limit protein intake ( $n = 9$ ). When 1 patient experienced multiple decisions regarding medication change the mean CPS was calculated.

d) Other decisions that patients reported related to vaccination against COVID-19, desire to have children, vitamin B12 injections, medication (unspecified), medication (unspecified), diagnostics (X-rays, thyroid function, additional blood tests), cholesterol, melanoma resection, and potassium-restricted diet.

e) Percentage of total amount of experienced decisions.

### 3.3 Patients' Preferred and Experienced Decisional Role in CKD Decisions

The patients' preferred decisional role for making the reported decisions is shown in **Table 2**. Taking all decisions together, the patients most frequently preferred to leave the decision "mostly" to the clinician (125 of 357), closely followed by wanting to "share" decision making (116 of 357) or leave the decision completely to the patient (101 of 357). The patients preferred these 3 decisional roles for each decision topic. Which decisional approach was most prominent varied per decision topic. A patient-directed approach (mostly/only patient) was preferred in 15 of 357 decisions, mainly for the decisions regarding lifestyle. **Table 3** shows that patients' experienced decisional roles show a similar distribution: both clinician-directed (only/mostly clinician) and a shared decisional role were experienced most frequently in the decisions they encountered.



**Figure 1:** Survey: patients' experienced versus preferred decisional role per decision topic

*Survey: patients' experienced versus preferred decisional role per decision topic: visualization per decision topic of the total number of patients whose preferred decisional role did or did not match their experienced role. In the left column, the decision topic includes the number of patients who indicated having discussed the decision in the previous healthcare visit. Light grey: number of patients who experienced their decisions as less shared or patient directed than preferred; darker grey: number of patients for whom experienced decisional role matched their preferred role; darkest grey: number of patients who experienced their decisional role as more shared or patient directed than preferred.*

**Figure 1** illustrates the number of patients whose preferred decisional role did or did not match their experienced role. In 151 out of 357 decisions, the patients experienced their decisional role as either less or more shared or patient-directed than they would have preferred. The proportion of mismatches was highest in the decisions regarding lifestyle, diagnostic testing, and medication changes. For most decision topics, the proportion of patients who felt "more" versus "less" involved than they would have preferred was relatively balanced.

### 3.4 Healthcare Visit Observations

In total, 93 healthcare visits by 14 different clinicians were successfully recorded. All healthcare visits were conducted by a nephrologist except 1, which was done by a nurse practitioner. In 64 healthcare visits (69%) the clinician was male. The median length of the visits was 10.05 minutes (IQR, 7.0). From the 93 recorded visits, 141 decisions were identified (median of 1.0 per visit [IQR, 1.0]) of which 118 were coded on the level of SDM.

#### 3.4.1. Decision Characteristics

**Table 4** shows how often clinicians explicitly mentioned decision characteristics for the 118 decisions. The most frequently mentioned decision characteristics were needing patients' commitment to carry out the decision (18 of 118), the decision having multiple options (16 of 118), the decision entailing a trade-off (14 of 118), or the decision being preference-sensitive (14 of 118).

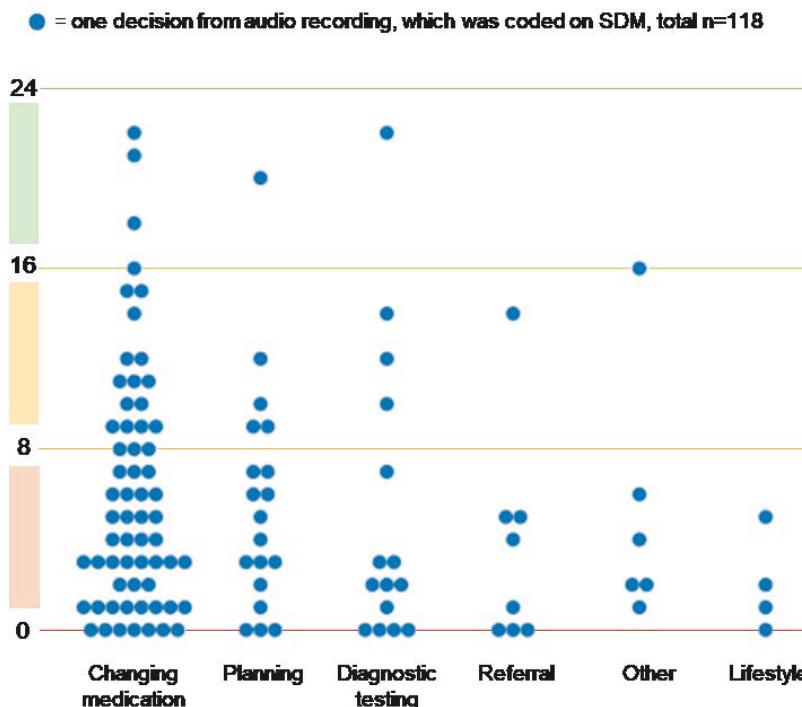
**Table 4: Audio recordings:** Number of decision characteristics mentioned for the coded decisions (n=118)

Decision characteristics	Decisions in which the decision characteristic was coded <sup>a</sup>
None mentioned	50
Patient commitment needed to carry out decision	18
Multiple options	16
Preference-sensitive	14
Trade-off	14
Long window of opportunity to make decision	11
Impact of the decision	10
Reversibility of the decision	9
Uncertainty	3
Certainty	3
Value-sensitive decision	1
Total weight of decision	1

a) Absolute numbers (multiple decision characteristics may have been mentioned per decision).

### 3.4.2. SDM Scores of the Decisions

Of all coded decisions, the median SDM score was 4.0 (IQR 8.0), min-max: 0-22. **Figure 2** illustrates all coded decisions and their total SDM scores. There was no statistically significant difference in total SDM score between different topics of decisions ( $\chi^2 [10,118] = 13.4$ ,  $P = 0.199$ ). **Table 5** presents the different SDM steps and mean scores of observed SDM behavior in these steps. Behaviors related to step 2 (informing about options) and 4 (making or deferring a decision in agreement) were observed slightly more frequently than those related to the other steps.



**Figure 2:** Audio recordings: All coded decisions and their 4SDM score

(note: the higher on the y-axis the higher the 4SDM scores/more SDM behavior observed)

Audio recordings: all coded decisions and their 4SDM score. Each plotted blue dot represents a decision that was observed from the audio recordings of healthcare visits and coded for the level of SDM. On the x-axis, the different decision topics are plotted in which the decisions are categorized. The y-axis represents the SDM score—the level of SDM, coded with the 4SDM coding scheme: 0-8 = no SDM to minimal SDM (red); 9-16 = minimal to sufficient SDM (yellow); and 17-24 = sufficient to high SDM (green). The higher on the y-axis indicates the higher the 4SDM scores/more SDM behavior observed. Abbreviation: SDM, shared decision making.

**Table 5: Audio recordings: Overview of the 4SDM scores and who initiated the corresponding behaviors**

Steps 4SDM	Mean score step (min-max, range 0.0-6.0)	Items 4 SDM	Mean score Item (min-max, range 0.0-3.0)	Who initiated (valid percent)
Step 1: setting the agenda	1.2 (0.0-6.0)	1. It is stated (or re-affirmed) that a decision about management or treatment needs to be made. 2. It is stated (or re-affirmed) that the decision depends on the values and preferences of the patient.	0.7 (0.0-3.0)	37.3% Patient <sup>a</sup> 63.7% HCP
Step 2: Informing about options	1.5 (0.0-6.0)	3. The available management or treatment options are stated (or re-affirmed). 4. The pros and cons of each option are stated or re-affirmed.	0.5 (0.0-3.0)	8.3% Patient 91.7% HCP
Step 3: Exploring values and preference construction	1.3 (0.0-6.0)	5. The patient states the outcomes that are important to him/her (values). 6. The patient states how s/he appraises the (characteristics of) the management or treatment options.	0.5 (0.0-3.0)	81.8% Patient 18.2% HCP
Step 4: Making or deferring a decision in agreement	1.7 (0.0-6.0)	7. The patient expresses or confirms his/her preference or the (provisional) lack of a preference 8. The moment of making (or deferring) the decision is explicit and decision making occurs in agreement	0.8 (0.0-3.0)	88.9% Patient 11.1% HCP

a) Patient or patient companion.

### 3.4.3. Initiation of SDM Behaviors

The majority of behaviors corresponding with the items of the 4SDM (**Table 5**) were initiated by clinicians, in particular step 1 (setting the agenda) and step 2 (informing about options). Exploration of values and preferences (step 3) and the expression or confirmation of patients' preferences (step 4) were mostly initiated by patients.

### 3.4.4. Motivational Interviewing

In 15 healthcare visits a behavioral change was explicitly discussed. The mean global scores were  $1.9 \pm 1.0$  (SD) for cultivating change talk;  $3.3 \pm 1.0$  (SD) for softening sustain talk;  $2.9 \pm 0.9$  (SD) for partnership;  $2.7 \pm 1.3$  (SD) for empathy. The global scores for relational components and technical components were  $2.7 \pm 1.0$  (SD) and  $2.6 \pm 0.6$  (SD), respectively.

### 3.4.5. Observed Versus Patient-reported Decision Making

Of the 118 coded decisions, 87 decisions were also reported by patients in the post-healthcare visit survey. For these 87 decisions, **Table 6** presents the correspondence between patients' experienced decisional role and observed level of SDM. In 29 of 87 decisions (33%), the patients' experiences about who made the decision did not seem to match the observed level of SDM. For the decisions that were coded as "no to minimal SDM" ( $n = 66$  of 87), 21 of those 66 patients (32%) reported that the decision had been shared. In decisions in which "minimal to sufficient" or "sufficient to good" SDM behavior was observed, some patients ( $n = 8$ ) still reported that the clinician alone made the decision.

**Table 6:** Audio recordings versus survey: Correspondence between observed level of SDM and patients' experienced decisional role (n=87 decisions)

Observed SDM (audio recordings)	No. of decisions <sup>a</sup>	Patients' experience who made decision (survey):				
		Only clinician	Mostly clinician	Shared	Mostly patient	Only patient
17-24 sufficient-good SDM	4	3	0	1	0	0
9-16 minimal-sufficient SDM	17	5	5	6	1	0
0-8 no-minimal SDM	66	27	18	21	0	0

*a) Only the decisions that were both mentioned by patients in the post- healthcare visit surveys and coded in the audio recordings of the same visits. Red= mismatch, Green= patients' experiences (largely) resemble observational SDM scores.*

## 4. Discussion

We identified a variety of decisions that occur frequently in routine healthcare visits for CKD: decisions regarding planning, medication changes, lifestyle changes, treatment goals, and diagnostic testing. For all these decision topics, around a third of the patients preferred a shared decisional role, another third preferred to leave the decision mostly to the clinician, and almost a third preferred to leave the decision completely up to the clinician. Patients seldom preferred to make the decision (largely) by themselves, except for some lifestyle change decisions. In the audio recordings of the healthcare visits, the overall observed level of SDM behavior was low. The results include 2 main comparisons. First, the patients' preferred decisional role was compared with their experienced decisional role, which matched in the majority of decisions that patients had encountered. For the decisions in which patients' experienced and preferred decisional roles did not match, the patients equally often experienced being "more" or "less" involved in making the decision than preferred. Second, the patients' experiences were compared with the observations based on audio recordings of their healthcare visits. Patients' experiences did not always match the observations; for a substantial number of the patients who had experienced decisions as "shared," the observers rated as low levels of SDM; and some patients experienced decisions as having been made fully by the clinician that observers rated as high levels of SDM. Patients also reported a larger number of decisions being made than the observers identified from the audio recordings.

There may be several reasons for the discrepancies between the patients' experiences and the observations from the audio recordings. The patients may have reported more decisions than were observed in the audio recordings because of (1) recall bias—the patients may have reported decisions that were made in earlier healthcare visits; and (2) the patients might have a different perception of what a decision entails. Patients may be quicker to view topics that were discussed as a decision than would an independent observer because the topics concern themselves and their lives. The discrepancy between patients' experiences and observed levels of SDM may be explained by the different metrics that were used; patients were asked who made the final decision, while observers coded SDM behaviors throughout the decision process. Additionally, patients might have a different understanding of what sharing a decision incorporates, compared with how SDM is currently framed in literature. A study showed that in healthcare visits that scored high on SDM, patients were still often uncertain who had made the decision.[21]

Another explanation for the discrepancy between patient-reported and observed decision making in this study is that the coding scheme used might be too strict for the

evaluation of SDM levels for routine care decisions. The 4SDM was developed in the context of palliative cancer care decisions, which can be considered major preference-sensitive decisions, dissimilar to the routine care decisions identified in this study. This may also be one of the reasons that the SDM scores were low in this study. Driever et al [22] also reported low levels of SDM in routine care decisions. They coded 727 healthcare visits for different specialties on the level of SDM with the OPTION-5, an observer-based coding instrument for SDM based on the 3-talk model of Elwyn et al,[12] which covers largely the same dimensions as the 4SDM coding instrument yet with a focus on clinician behavior. They found that treatment decisions scored significantly higher on SDM than did the diagnostic, follow-up, or “other” decisions.[23] Lower SDM scores for these nontreatment decisions may be the result of limited awareness that SDM might apply in these circumstances; or SDM might be less appropriate in these decisions, and coding on all SDM steps may be too strict.

This raises the question whether the full SDM process is required in routine care decisions, such as the common CKD decisions identified in this study, and if not, which elements of SDM could be particularly important. “Exploring patient preferences” is often proposed as an important element of SDM, both in cases of “major preference-sensitive” decisions and for less major decisions.[19] In both our observations and those of Driever et al [22] “exploring preferences” is less frequently observed compared with other SDM elements such as “informing on options.” Notably, in this study the patients often initiated the exploration of preferences. However, the patients participating in this study might not reflect the level of communicative initiative of the average patients with CKD, as suggested by the high level of health literacy in the present sample. “Making explicit that a decision needs to be made” may be another essential element of SDM in common CKD decisions. Because our study suggests that SDM is currently not integrated in these routine care decisions, patients may not anticipate being actively involved and may adopt a passive role. Making it clear that a decision is required and that the patients’ input is essential, can encourage them to participate more actively. [24]

Motivational interviewing was observed to a limited extent. Key elements and skills of motivational interviewing—including partnership, empathy, exchanging information, active listening, and summarizing—are not limited to discussions regarding behavioral changes, and are also relevant in SDM. Educating clinicians on motivational interviewing and its sequential application with SDM could improve healthcare visits for CKD and enhance patients’ involvement in CKD management. [12]

This study can inform training and educational programs for clinicians to create awareness that SDM may be warranted in more decisions than the KRT decision alone. Patient preferences regarding their role in decision making differ between patients and between topics. Also, patients might hold different perspectives on what sharing a decision looks like. It is therefore important that clinicians explore patients' desired decisional role throughout the decisional process. Attempts to involve patients in common CKD decisions should always be made to the extent that patients prefer. Not attempting a SDM process might result in overlooking hidden preferences and resistance, which could affect patients' commitment to the treatment plan. Furthermore, increasing application of SDM in common CKD decisions may better prepare patients to participate more actively in major decisions, such as the KRT decision, later on.[25]

3

There are several limitations to our study, which are important to consider. First, selection bias may have occurred, even though we tried to minimize this by letting clinicians recruit patients from a randomly selected patient sample based on consultation dates. Second, reflexivity issues need to be addressed: 2 participating nephrologists, 1 from each hospital, were also members of the research team. Although they were not involved in the analysis, they knew the study's outcomes, which could have led to bias. Furthermore, SDM training was provided to the clinicians of both hospitals months before the start of this study and in the context of another project. This training focused on the KRT decision, which differs from the decisions included in this study. Nevertheless, the clinicians participating in this study were potentially more familiar with the concept of SDM than are other clinicians in nephrology. Third, being aware that the healthcare visits were recorded may have resulted in desirable behavior of patients and clinicians, although studies indicate that this effect is often minimal.[26,27] In the study information, patients and clinicians were made aware that decision making would be evaluated. Although some impact cannot be ruled out, we feel that the impact of this on participants' behavior was limited because the information was provided several weeks before the recordings. Fourth, it is unknown how many patients filled in the survey with assistance from a partner or relative, which may have influenced their answers. We do not believe that such influence would be systematic. Fifth, most of the healthcare visits were conducted by male clinicians, and clinician gender may have implications regarding the observed SDM levels. A meta-analysis of 7 RCTs has suggested these implications may be limited because they did not show significant differences in the level of observed SDM depending on the gender of the clinician.[28] Finally, there was no patient involvement in conducting this study; however, 2 CKD patient representatives and 1 representative from the Dutch Kidney Patient Association had a steering role in the program of which this study was an essential part.

In conclusion, by analyzing healthcare visits for CKD from 2 perspectives, the patients (including their experiences and preferences) and observations, we identified a set of common CKD decisions. Depending on the decisional topic, patients with CKD varied in whether they wanted to share these decisions or preferred a more clinician-directed approach. A considerable number of patients expressed a preference to share decisions, which is currently not met according to the low levels of observed SDM during the healthcare visits. When the decisions entailed a behavioral change, motivational interviewing was applied to a limited extent, which indicates a need for training clinicians in the use of motivational interviewing in CKD care. The findings of this study create awareness that in nephrology SDM is not to be reserved for the major KRT decision. Future research may help to further explain what elements of SDM are minimally required for more common CKD decisions.

## References

- [1] Bomhof-Roordink H, Gartner FR, Stiggelbout AM, Pieterse AH. Key components of shared decision making models: a systematic review. *BMJ Open*. 2019;9(12):e031763. doi:10.1136/bmjopen-2019-031763
- [2] Stiggelbout AM, Pieterse AH, de Haes JCJM. Shared decision making: concepts, evidence, and practice. *Patient Educ Couns*. 2015;98(10):1172-1179. doi:10.1016/j.pec.2015.06.022
- [3] Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. *Patient Educ Couns*. 2006;60(3):301-312. doi:10.1016/j.pec.2005.06.010
- [4] Kidney Disease: Improving Global Outcomes (KDIGO) CKD Work Group. KDIGO 2012 clinical practice guideline for the evaluation and management of chronic kidney disease. *Kidney Int Suppl*. 2013;3:1-150.
- [5] Renal Physicians Association Working Group. Shared Decision Making in the Appropriate Initiation and Withdrawal From Dialysis: Clinical Practice Guideline. 2nd ed. Renal Physicians Association; 2010.
- [6] Murray MA, Brunier G, Chung JO, et al. A systematic review of factors influencing decision-making in adults living with chronic kidney disease. *Patient Educ Couns*. 2009;76(2):149-158. doi:10.1016/j.pec.2008.12.010
- [7] Montori VM, Gafni A, Charles C. A shared treatment decision-making approach between patients with chronic conditions and their clinicians: the case of diabetes. *Health Expect*. 2006;9(1): 25-36. doi:10.1111/j.1369-7625.2006.00359.x
- [8] Joosten EA, DeFuentes-Merillas L, de Weert GH, Sensky T, van der Staak CP, de Jong CA. Systematic review of the effects of shared decision-making on patient satisfaction, treatment adherence and health status. *Psychother Psychosom*. 2008;77(4):219-226. doi:10.1159/000126073
- [9] Langford AT, Williams SK, Applegate M, Ogedegbe O, Braithwaite RS. Partnerships to improve shared decision making for patients with hypertension—health equity implications. *Ethn Dis*. 2019;29(suppl 1):97-102. doi:10.18865/ed. 29.S1.97
- [10] Chewning B, Bylund CL, Shah B, Arora NK, Gueguen JA, Makoul G. Patient preferences for shared decisions: a systematic review. *Patient Educ Couns*. 2012;86(1):9-18. doi:10.1016/j.pec.2011.02.004
- [11] Miller W, Rollnick S. *Motivational Interviewing: Helping People Change*. 3rd ed. Guilford Press; 2013.
- [12] Elwyn G, Dehlgendorf C, Epstein RM, Marrin K, White J, Frosch DL. Shared decision making and motivational interviewing: achieving patient-centered care across the spectrum of healthcare problems. *Ann Fam Med*. 2014;12(3):270-275. doi:10.1370/afm.1615
- [13] Chew LD, Bradley KA, Boyko EJ. Brief questions to identify patients with inadequate health literacy. *Fam Med*. 2004;36(8): 588-594.
- [14] Fransen MP, van Schaik TM, Twickler TB, Essink-Bot ML. Applicability of internationally available health literacy measures in the Netherlands. *J Health Commun*. 2011;16(suppl 3):134-149. doi:10.1080/10810730.2011.604383
- [15] UNESCO Institute for Statistics. The International Standard Classification of Education (ISCED). UNESCO-UIS; 2012. <https://uis.unesco.org/sites/default/files/documents/international-standard-classification-of-education-isced-2011-en.pdf>
- [16] Degner L, Sloan J, Venkatesh P. The Control Preferences Scale. *Can J Nurs Res*. 1997;29(3):21-43.
- [17] Henselmans I, Smets EMA, de Haes JCJM, Dijkgraaf MGW, de Vos FY, van Laarhoven HWM. A randomized controlled trial of a skills training for oncologists and a communication aid for patients to stimulate shared decision making about palliative systemic treatment (CHOICE): study protocol. *BMC Cancer*. 2018;18(1):1-13. doi:10.1186/s12885-017-3838-8

- [18] Henselmans I, Laarhoven HWM, Maarschalkerweerd P, et al. Effect of a skills training for oncologists and a patient communication aid on shared decision making about palliative systemic treatment: a randomized clinical trial. *Oncologist*. 2019;25(3):578-588. doi:10.1634/theoncologist.2019-0453
- [19] Van der Horst DEM, Garvelink MM, Bos WJW, Stiggelbout AM, Pieterse AH. For which decisions is shared decision making considered appropriate? A systematic review. *Patient Educ Couns*. 2023;106:3-16. doi:10.1016/j.pec.2022.09.015
- [20] Moyers TB, Manuel JK, Ernst D. Motivational Interviewing Treatment Integrity Coding Manual 4.2.1. Author; 2014. [https://casaa.unm.edu/download/miti4\\_2.pdf](https://casaa.unm.edu/download/miti4_2.pdf)
- [21] Edwards A, Elwyn G. Inside the black box of shared decision making: distinguishing between the process of involvement and who makes the decision. *Health Expectations*. 2006;9(4):307-320. doi:10.1111/j.1369-7625.2006.00401.x
- [22] Driever EM, Stiggelbout AM, Brand PLP. Do consultants do what they say they do? Observational study of the extent to which clinicians involve their patients in the decision-making process. *BMJ Open*. 2022;12(1):e056471. doi:10.1136/bmjopen-2021-056471
- [23] Driever EM, Stiggelbout AM, Brand PLP. Shared decision-making in different types of decisions in medical specialist consultations. *J Gen Intern Med*. 2022;37(12):2966-2972. doi:10.1007/s11606-021-07221-6
- [24] Joseph-Williams N, Edwards A, Elwyn G. Power imbalance prevents shared decision making. *BMJ*. 2014;348(3):291-309. doi:10.1016/j.pec.2013.10.031
- [25] Towle A, Godolphin W. Framework for teaching and learning informed shared decision making. *BMJ*. 1999;319(7212):766-771. doi:10.1136/bmj.319.7212.766
- [26] Arborelius E, Timpka T. In what way may videotapes be used to get significant information about the patient-physician relationship? *Med Teach*. 1990;12(2):197-208. doi:10.3109/01421599009006697
- [27] Pringle M, Stewart-Evans C. Does awareness of being video recorded affect doctors' consultation behaviour? *Br J Gen Pract*. 1990;40(340):455-458.
- [28] Wyatt KD, Branda ME, Inselman JW, et al. Genders of patients and clinicians and their effect on shared decision making: a participant-level meta-analysis. *BMC Med Inform Decis Mak*. 2014;14:81. doi:10.1186/1472-6947-14-81

## Supplement 1 Box S1 – Illustrative examples of coded decisions

### Box S1. Examples of decisions coded with the 4SDM (translated from Dutch)

#### Example 1: high SDM score

*Clinician: Your blood pressure remains a bit too high. Living more healthy and exercising did make it go down enough. Patient: I really changed my lifestyle drastically... I did so much. Even started playing tennis again regularly... My blood pressure went down a bit, didn't it? Clinician: It is not your fault, once the kidneys are damaged, the body's blood pressure regulation doesn't work that well anymore. You cannot always influence that. Not that I want to discourage you.. If you had not done all these things it might have worsened even quicker. [...] An extra reason to want to lower blood pressure is to prevent protein leakage in the kidneys. We want to reduce the pressure on the kidneys and slow down deterioration of kidney function. Patient: but with those medication we get those problems again.. those other problems occur.. with Viagra and stuff. Clinician: Yes, it's easy for me to say: just take that [antihypertension] pill. However, it causes you those kind of problems. Patient: yeah, I don't know. Clinician: it was the reason why we stopped the diuretic. Now, we could start amlodipine instead, which is less known to cause those side effects. Let's try that? If you don't try you don't know. Let's see whether your blood pressure then decreases and whether the erection problems stay away. Patient: and that choice is not worse for the kidneys right? Do I understand it correctly that it actually helps the kidneys? Clinician: that's right. Patient: what would you propose? Clinician: I would propose stating a new pill for the blood pressure, amlodipine, which causes erection problems less often than the diuretic you had before. For now, I think that is the main thing we can improve in order to prevent further kidney function deterioration. Patient: OK, so that's what you propose? Clinician: if this does not work we can always stop the new tablets. So, I will prescribe amlodipine. Do you agree? Patient: yeah I do. And I don't think I have many options now, right? None maybe. Clinician: yes I do think we need to try everything to prevent kidney damage.*

4 SDM scoring: Step 1 item 1: 2; step 1 item 2: 2; step 2 item 3: 3; step 2 item 4: 3; step 3 item 5: 3; step 3 item 6: 3; step 4 item 7: 2; step 4 item 8: 3. Total: 21.0

**Example 2: low SDM score**

*Clinician: your blood pressure was good earlier, and if you say that you are currently retaining fluid, I would like to start a diuretic tablet in order to reduce fluid retention on the one hand, but on the other hand also reduce potassium levels. So that is a win-win. The only reason not to start a diuretic would be when the blood pressure is too low, but I don't expect it is actually, since it has always been quite stable. Patient: but then I need to go to the toilet a lot of times... Clinician: yes, that's probably correct, because of the diuretic you pee salt which means you have to pee more often. However, I would only give the diuretic once a day and only in the morning, so you don't have this is issue during the night, because that may be annoying. At night, the effect of the pill will have worn off. Yeah.. because with my lung disease I notice that when I go to the toilet at night, my saturation levels are quite low. Clinician: losing fluid will probably benefit your lungs as well at night. If you have fluid retention in your legs it is likely that you have some fluid in your lungs as well. [examines legs] Alright, so there is fluid in your legs, so we will start the diuretic. Once a day. Patient: hm yeah...*

4SDM scoring: Step 1 item 1: 0; step 1 item 2: 0; step 2 item 3: 0; step 2 item 4: 2; step 3 item 5: 0; step 3 item 6: 2; step 4 item 7: 1; step 4 item 8: 1. Total: 6.0

These two transcripts of decisions illustrate how they were coded. In the first example, the decision scored high on SDM. Preferences are explicitly discussed, which led to choosing an alternative treatment option that better fits the patients' preferences and circumstances. In the second the SDM score is low. The score is only 'sufficient' on informing on pros and cons of the proposed treatment and (the patient) explaining what she feels regarding the proposed treatment.

## Supplement 2 Box S2 – Items MITI (Motivational Interviewing Treatment Integrity)

### Box S2 Global scores Motivational Interviewing Treatment Integrity<sup>20</sup>

#### Cultivating change talk

1. Clinician shows no explicit attention to, or preference for, the client's language in favor of changing.
2. Clinician sporadically attends to client language in favor of change – frequently misses opportunities to encourage change talk.
3. Clinician often attends to the client's language in favor of change, but misses some opportunities to encourage change talk.
4. Clinician consistently attends to the client's language about change and makes efforts to encourage it.
5. Clinician shows a marked and consistent effort to increase the depth, strength, or momentum of the client's language in favor of change.

#### Softening sustain talk

1. Clinician consistently responds to the client's language in a manner that facilitates the frequency or depth of arguments in favor of the status quo.
2. Clinician usually chooses to explore, focus on, or respond to the client's language in favor of the status quo.
3. Clinician gives preference to the client's language in favor of the status quo, but may show some instances of shifting the focus away from sustain talk.
4. Clinician typically avoids an emphasis on client language favoring the status quo.
5. Clinician shows a marked and consistent effort to decrease the depth, strength, or momentum of the clients language in favor of the status quo.

#### Partnership

1. Clinician actively assumes the expert role for the majority of the interaction with the client. Collaboration or partnership is absent.
2. Clinician superficially responds to opportunities to collaborate.
3. Clinician incorporates client's contributions but does so in a lukewarm or erratic fashion.
4. Clinician fosters collaboration and power sharing so that client's contributions impact the session in ways that they otherwise would not.
5. Clinician actively fosters and encourages power sharing in the interaction in such a way that client's contributions substantially influence the nature of the session.

#### Empathy

1. Clinician gives little or no attention to the client's perspective.
2. Clinician makes sporadic efforts to explore the client's perspective. Clinician's understanding may be inaccurate or may detract from the client's true meaning.
3. Clinician is actively trying to understand the client's perspective, with modest success.
4. Clinician makes active and repeated efforts to understand the client's point of view. Shows evidence of accurate understanding of the client's worldview, although mostly limited to explicit content.

5. Clinician shows evidence of deep understanding of client's point of view, not just for what has been explicitly stated but what the client means but has not yet said.

**Calculation global scores:** Global scores are assigned on a five-point Likert scale: minimum =1, maximum = 5. Relational global score is calculated by partnership + empathy / 2, and the technical global score is measured by cultivating change talk + softening sustain talk / 2.