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1 Patient perspectives on chronic kidney disease
2 and decision-making about treatment.
3 Discourse of participants in the French CKD-
4 REIN cohort study

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18

1 **Abstract**

2 **Background**

3 Little is known about psychological issues in patients with chronic kidney disease (CKD)
4 facing transition to kidney failure and the involvement of their family in decision-making
5 about kidney replacement therapy (KRT). This study investigated patients' experience of
6 their illness, their views on KRT choice and their perception of the influence of their
7 relatives.

8 **Methods**

9 We conducted a qualitative study nested in the CKD-REIN prospective cohort study which
10 included non-dialysis CKD patients from 40 nationally representative nephrology clinics.
11 Among 1555 patients who returned a self-administered questionnaire, we used a purposive
12 sampling to select 50 participants who underwent semi-structured phone interviews with a
13 psychologist.

14 **Results**

15 The patients' mean age was 62.2 ± 12 years, 42% were women, and 68% had CKD stage 4-5.
16 The analysis yielded 4 lexical classes: "illness rhythm", "considering dialysis", "family and
17 transplantation", and "disease, treatment choice and introspection". When experiencing
18 few or mild symptoms, patients tended to avoid thinking about CKD, for the prospect of
19 dialysis was the most stressful part of their experience. Surprisingly, the importance of
20 family appeared when they talked about transplantation decision-making, but not about
21 choice of dialysis modality.

22 **Conclusions**

23 Cognitive avoidance seems common in patients with advanced CKD. Transplantation and
24 dialysis decision-making appear to be two distinct processes, with different levels of family
25 involvement. More research is needed to better understand the frequency and impact of
26 cognitive avoidance on patients' well-being and decision-making.

27

1 Introduction

2 Anxiety and depression are frequent in patients with moderate or advanced chronic kidney
3 disease (CKD)(1, 2), and both are associated with worse outcomes(2, 3). Moreover, patients
4 reaching CKD stage 4 to 5 must make decisions about KRT, a stressful process(4). Little is
5 known about patients' experience during this period. Most studies are retrospective and
6 interviewed patients already on dialysis, who reported feeling they lacked control over
7 treatment choice, despite guidelines recommending shared decision-making(5, 6). To make
8 their choice, patients consider their preferences, and are influenced by professionals, other
9 patients and their families(7–9). A recent study did not find that depression and anxiety
10 were associated with the choice of dialysis modality(10). However, patients' experience is
11 likely to influence and be influenced by their mental health.

12 Previous studies on CKD have shown that patients often discuss treatment choices with
13 their family(11, 12). Qualitative studies investigating patients' perspectives indicate that
14 relatives provide support and information, and/or help patients accept KRT(6, 13). Some
15 patients consider the potential burden on their family in their choice(14). As most of these
16 studies are retrospective, investigating family influence on patients' decision-making before
17 KRT is necessary.

18 Statistical text analysis allows to investigate individuals' experience through a quantitative
19 analysis of their discourse. It investigates speech patterns (i.e., what they talk about and
20 how they tell their experience). It aims to explore discourse through the words participants
21 use and how these are associated with each other. It also allows to examine associations
22 between parts of patients' discourse and categorical variables. This method has previously
23 been used in nephrology research(15, 16).

24 The aim of this study was to investigate patients' experience of moderate and advanced CKD
25 and their perception of KRT and the influence of their relatives.

26 Methods

27 *Design and setting*

28 The CKD-Renal Epidemiology and Information Network (CKD-REIN) study is a prospective
29 cohort which enrolled 3,033 patients with non-dialysis CKD from 40 nationally

1 representative nephrology clinics between 2013 and 2016. This work was conducted under
2 the approval of relevant ethics committees (including CCTIRS, N°12.360). Data were
3 collected annually, including self-administered questionnaires. The study protocol and
4 patient baseline characteristics have been published(17, 18). At the third-year follow-up
5 (2016-2019), 2,260 patients who had not initiated KRT were invited to participate in a
6 qualitative investigation with a phone interview with a psychologist. Among the 1,555 pre-
7 KRT patients who returned the self-administered questionnaire, 719 agreed to take part to
8 the interview. We then used a purposive sampling to select 50 participants to ensure
9 diversity in our sample for age, gender and CKD stage. The goal of this type of sampling is to
10 intentionally select participants so they represent some explicit predefined traits. This
11 provides for relatively equal numbers of different categories to enable exploration of the
12 lived experience of each of these groups(19).

13 *Data collection*

14 Clinical research associates collected clinical data from medical records. The CKD-EPI
15 equation was used to estimate glomerular filtration rates (GFR). Participants completed a
16 questionnaire collecting sociodemographic information and several patient-reported
17 measurements. The Hospital Anxiety and Depression Scale, was used with possible scores
18 ranging from 0 to 21(20, 21). A score above 8 was used to identify patients with significant
19 anxiety symptoms.

20 The Center for Epidemiologic Studies-Depression scale was used to screen for depression
21 symptoms(22). Psychometric properties were explored among the patients participating in
22 the CKDREIN-*Famille* study. Two items with poor saturation were excluded. A final eight-
23 item version, with possible scores ranging from 0 to 24, showed satisfactory internal
24 consistency (Cronbach's $\alpha = 0.82$) and fit (Comparative Fit Index= 0.98, Goodness-of-Fit
25 Index= 0.98, Standardized Root Mean Square Residual= 0.027). A score above 8 was used to
26 identify patients with significant depression symptoms. This cut-off was determined with a
27 cross-multiplication based on the initial version threshold. A first interview guide was pilot
28 tested with 3 patients. Then, qualitative data were collected by LM from audio-recorded
29 semi-structured individual phone interviews (see interview guide in Box 1). She was a PhD
30 student and received training by AU regarding qualitative research. She did not know the
31 participants beforehand. She introduced herself as a psychologist-researcher then

1 presented the interview as a mean to know more about patients' experience of CKD.
2 Participants were asked to be in a room alone for the interview The interviews, which took
3 place between January 2018 and January 2019, lasted a median of 42 minutes [range: 16–
4 95]. LM took notes during the interviews to help her prompt the participants, however no
5 field notes were made after the exchanges. All data were transcribed verbatim and included
6 in the analysis. A short subjectivity statement and a description of the interpretation
7 process are available as a supplementary material. We used the Consolidated Criteria for
8 Reporting Qualitative Research (COREQ)(23) to report key aspects of our study.

9 *Analysis*

10 We described patient characteristics at the time of interview and compared them for
11 patients who consented to be interviewed and those who did not. All interviews were
12 transcribed. We used ALCESTE® software (Analysis of Co-occurring Lexemes in a Set of Text
13 Segments) to perform quantitative analyses of qualitative data based on the units of
14 contexts, i.e., elements of the interviews roughly equivalent to sentences used by
15 individuals(24). It allows for an inductive analysis of the data. Although ALCESTE® software
16 was developed in France it is available and used in several other languages. ALCESTE®
17 performs a descending hierarchical classification (DHC) which yields classes of words, to
18 which the researcher then gives meaning by investigating the words comprised in each class
19 and their associations (see supplementary material regarding the interpretation process).
20 The association of each word with each class is tested by a Chi-square test. A detailed
21 description of the ALCESTE® process is available as a supplementary file. This type of
22 analysis was chosen because it allows a quantitative analysis of large text data while keeping
23 the strength of a qualitative approach. The software provides an automatic analysis of
24 speech, which forms classes with no a priori and without the subjectivity of the
25 researcher(15). Moreover, ALCESTE® emphasize not only *what* participants talk about but
26 also *how* they tell their experience, allowing to identify patients' implicit views.

27 Data saturation is a methodological principle in qualitative research referring to the point in
28 the analytic process when no new information is discovered in the analysis and data
29 become redundant(25). Data saturation often occurs after 12 interviews(26). As stated
30 above, we chose to undertake 50 to ensure diversity. LM analyzed ALCESTE® outputs

1 supervised by AU. The detail of her interpretation process is available in a supplementary
2 material.

3 A chi-square test was also performed to assess the strength of the association between
4 patient characteristics and the classes. The following categorical variables were considered
5 in this analysis: CKD stage, participation in patient education sessions about KRT in the past
6 year (yes/no), discussion of treatment choices within the family (yes/no), anxiety (yes/no),
7 and depression (yes/no).

8

9 **Results**

10 *Patients' characteristics*

11 Patients who consented to be interviewed were younger, were less likely to be widowed,
12 had a higher education level, greater anxiety, had better literacy skills and had more often
13 discussed KRT with relatives than those who did not consent to an interview (see
14 supplementary material). Interviewed patients' mean age was 62.2 (\pm 12.2), 42% were
15 women and 68.0% had stage 4-5 CKD (Table 1).

16 *Results of the lexicometric analysis*

17 The corpus comprising all the interviews contained 264,875 different lexical forms (i.e.,
18 words) and 5,715 units of context. The DHC shows the lexical forms and the supplementary
19 forms associated with each class and how the classes are linked with each other (Figure 1).
20 ALCESTE® classified 68% of the corpus into four classes.

21 *Class 1: Rhythm of the illness*

22 The first class encompasses 29% of the classified corpus, it is characterized by temporal
23 indicators, e.g., "week" and "year", and words showing temporal relationships, e.g., "since"
24 and "when". It is divided into two subclasses.

25 The "**CKD monitoring**" subclass is composed of words such as "month" and month names.
26 These terms co-occur with words pertaining to monitoring such as "result", "appointment",
27 "blood" and "test/taken/sample". CKD manifests itself through these medical events and
28 their repetition (Table 2, Class 1, Excerpt 1).

1 CKD does not hurt, even though “pain” belongs to the “**Managing an illness among others**”
2 subclass. This word appears in negative sentences or refers to other diseases (Class 1,
3 Excerpt 2). Moreover, this subclass is composed of words designating medical fields:
4 “cardiologist” and “urologist”. This result shows that CKD is one illness among others (Class
5 1, Excerpts 3-4).

6 Words pertaining to KRT and decision-making, e.g., “choice” or “dialysis”, are significantly
7 absent in class 1 and suggest that before they face kidney failure, patients are not thinking
8 about KRT. Moreover, the absence of the terminology of family from this class indicates that
9 CKD monitoring is an individual experience.

10 This class is associated with several variables: anxious and depressed patients, non-
11 attendance at patient education about KRT, and not talking about KRT with relatives.
12 Patients with stages 3 and 5 CKD are associated with this class while those living with stage
13 4 CKD are significantly absent from it.

14 *Class 2: Considering dialysis*

15 This class covers 15% of the classified corpus and is divided into two subclasses.

16 “Dialys+”, “machine”, “peritoneal+” and “house/home” appear in the “**Dialysis modalities**
17 **and daily life**” subclass. Patients describe different types of dialysis and how these could be
18 implemented in their life. “Know”, “sort/kind”, “near” (found in the expression “à peu près”,
19 literally, “a little near”, or roughly/almost) and “uh” show how patients may perceive their
20 knowledge on this subject as approximate (Class 2, Excerpt 1).

21 Dialysis modalities are described according to where they can be implemented
22 (“house/home”, “hospital”, “at”), when and how long the treatment takes place (“hour”,
23 “night”) and the degree of freedom allowed (“autonom+”, “free”) (Class 2, Excerpt 2). “Opt”
24 and “choose” show the beginning of a decision-making process (Class 2, Excerpt 3).

25 The “**Patient education and treatment choice**” subclass includes words related to patient
26 education (e.g., “meeting”, “to show” and “information”) (Class 2, Excerpt 4) which allows
27 patients to grasp how treatments “function”, obtain information and understand the
28 “advantages”/“disadvantages” of each modality (Class 2, Excerpt 5). “Have to”, “can/be
29 able”, “etc.” and “constraint” show that the obligations of dialysis are perceived as

1 numerous and burdensome (Class 2, Excerpt 6). Words referring to family are significantly
2 absent from class 2, relatives may not be considered in reflections on dialysis modalities.

3 This class is associated with: stage 4 CKD, attendance at patient education sessions,
4 discussions about treatment with their family, and no depression.

5 *Class 3: Family and transplantation*

6 The third class comprises the smallest part of the classified corpus (13%). It can be divided
7 into two subclasses.

8 “To bother+”, “to recount”, “mother” and “colleague” belong to the **“Talking about the**
9 **illness”** subclass. Patients sometimes choose (not) to speak about their illness. The quantity
10 of details they go into depends on who they are speaking to. They do not want to
11 overwhelm their relatives (Class 3, Excerpts 1–3).

12 Patients are also informers. “Hide”, “current” (found in the expression “au courant” which
13 means know about/be informed), “world” (found in the expression “tout le monde”, literally
14 “all the world”, everyone) and “hear” show who patients share information and their
15 experience with (Class 3, Excerpts 2-3).

16 The **“Talking about transplantation”** subclass includes “to give”, “compatible”, “to de cease”
17 and “to refuse.” When patients think about transplantation, they also think about their
18 family. Relatives may, for example, offer a kidney, which may or may not be possible (Class
19 3, Excerpt 4). Moreover, patients may refuse a donation perceived as unthinkable to accept
20 (e.g., a son offering a kidney to his mother) (Class 3, Excerpt 5).

21 More rarely, patients mention they have asked relatives if they could be donors or have
22 talked to them about deceased-donor transplantation (Class 3, Excerpts 6-7). Interestingly,
23 “dialysis” is significantly absent from this class.

24 Class 3 is associated with depression and attendance at patient education sessions.
25 Moreover, Class 3 opposes Class 2 in the factorial correspondence analysis (Figure 2).
26 Dialysis (Class 2) and transplantation (Class 3) do not appear together in patients’ discourse.
27 They belong to different decision-making processes.

1 *Class 4: Disease, treatment choice and introspection*

2 The fourth class contains the largest portion of the classified corpus (43%). It includes
3 markers of discursive relations (e.g., “but”, “if”) and modal words (e.g., “no”, “I think”).
4 These terms show how this class pertains to reflections about CKD. It is divided into three
5 subclasses.

6 The **“A normal life”** subclass highlights how patients say they have a “normal” “life.” Their
7 illness is not an important element of their day-to-day life (e.g., “sick”, “health”).The only
8 symptom they report is fatigue (Class 4, Excerpts 1-2).

9 However, some words temper this idea. A French expression equivalent to “quotation
10 mark” (found in the expression “in quotation marks”), “impression”, “to evolve” and “to
11 arrive/to happen” show how this normality is perceived as relative. Patients know their
12 disease will progress and fear its development (Class 4, Excerpts 3-4). “Haha”, “Pff” and
13 other interjections show the participants’ affective attitudes (Class 4, Excerpt 5).

14 The **“Avoiding thinking about CKD”** subclass shows that as CKD has little impact on patients’
15 day-to-day life, participants say they do not “think” much about their illness (Class 4, Excerpt
16 6). However, words such as “instant” (found in the expression “for the instant”, for right
17 now), “mind” and “happen” temper this conclusion. Patients do not want to “stress” in
18 advance, but they are aware of the temporary nature of their situation (Class 4, Excerpt 7).
19 “Try” and “manage” are used to describe the management of CKD. They can refer to present
20 and future ways to cope with it (Class 4, Excerpts 9-10).

21 Class 4 is characterized by demonstratives, relatives and indefinites (e.g., “other”, “what+”)
22 that designate without naming. Moreover, “thing” is strongly associated with these class
23 and subclass. These words are used to talk about CKD, KRT or their physical/psychological
24 consequences (Class 4, Excerpt 8).

25 The subclass **“Research participation, treatment choice and acceptance”** shows how
26 patients accept their illness under certain conditions (e.g., “to continue”). They do not think
27 of themselves as sick. Therefore, “to accept” refers mainly to KRT (Excerpts 11-12).
28 “Question” can refer to questions patients ask others (e.g., their nephrologist) and
29 questions they ask themselves (e.g., about KRT). Moreover, patients feel decision-making is

1 not a current concern, which makes “answering” the interview questions hard (Class 4,
2 Excerpt 13).

3 This class is associated with patients neither depressed nor anxious.

4 Discussion

5 This study is one of the first to interview a diverse sample of patients about treatment
6 decision-making before KRT and to investigate participants’ experience with moderate to
7 advanced CKD. It shows that statistical text analysis is an interesting method as it allows the
8 simultaneous investigation of *what* participants are talking about and *how* they are doing it.
9 Our results show that CKD is manifested for patients not through symptoms but through its
10 monitoring. They also emphasize how common cognitive avoidance about disease
11 progression is in pre-KRT patients. Cognitive avoidance encompasses a variety of coping
12 strategies aimed at escaping thoughts about undesirable situations, including denial of the
13 disease(27). It may be used by patients to reduce their anxiety regarding KRT decision-
14 making. Although effective for reducing negative emotions in the short-term, avoidance
15 probably leads to heightened negative affects (e.g., depression, anxiety) in the long term, as
16 it has been shown in other populations(28, 29). Moreover, transplantation and dialysis
17 belong to two distinct decision-making processes. Family plays an important role in
18 transplantation choice by sharing opinions and by (not) offering a kidney. The novelty of this
19 study is that patients were interviewed before KRT and thus provides an accurate and
20 contemporaneous understanding of patients’ decision-making process.

21 The analysis encompasses 68% of the entire corpus, which is satisfactory according to
22 recommendations (>50%)(30). The most important class in terms of analyzed corpus
23 quantity shows that patients report having a normal life (class 4). It is patients’ monitoring
24 that attests to the existence of CKD (class 1). What makes it stressful is not its physical
25 impact but its progression towards kidney failure. Previous studies showed similar
26 results(31, 32). Patients' current health status may lead to cognitive avoidance, which may
27 delay decision-making(31, 33). It might nonetheless be adaptive in the short term, especially
28 at stage 3, if it does not prevent patients from engaging in healthy behaviours. Further
29 research should investigate the frequency and impact of cognitive avoidance in advanced-
30 stage CKD patients.

1 Regarding KRT decision-making, dialysis choice seems guided by patient education, whereas
2 family has a central role in decision-making about transplantation, especially living donation.
3 Interestingly, family does not influence the consideration of dialysis in this pre-decision
4 stage, according to patients. Yet, other authors have emphasized how family influences the
5 choice of home dialysis(34). Two reasons might explain these conflicting results. First, most
6 past studies are retrospective(6, 8, 34). Thus, patients may have experienced retrospective
7 bias and overestimated family influence. Second, nearly half of our participants were at
8 stage 3 and might not yet have reached this decision-making process. Patients may
9 contemplate dialysis only when transplantation is impossible, while most of them undergo
10 dialysis before transplantation(35). Some patients have a strong aversion toward
11 dialysis(36). Consequently, some may talk about dialysis with their relatives in a second
12 phase.

13 Classes identified by our analysis were associated with categorical variables. Class 1
14 (“Rhythm of the illness”) does not include KRT decision-making. It is associated with patients
15 with stage 3 or 5 CKD whereas class 2 (“Considering Dialysis”) is associated with stage 4 CKD.
16 This may show that treatment choice occurs during stage 4. Patients in stage 3 may not feel
17 concerned by KRT whereas stage 5 patients may have already made their choice. This result
18 is consistent with the current guidelines for KRT decision-making(5). Class 4 is associated
19 with low levels of depression and anxiety, it is characterized by self-reflection linked to
20 better mood(37–39). Treatment choice may be hindered by mental health issues. Indeed,
21 several studies showed that decision-making is affected by depression and anxiety(40).

22 Limitations in our study warrant mention. First, it is cross-sectional and what the patients
23 said reflected what they were experiencing at the time of the interview. Some participants
24 were not facing impending KRT decision-making. Treatment choice requires further research
25 aimed at advanced-stage patients to assess changes in their discourse. Second, despite the
26 strengths of statistical text analysis, it is based on word count(24). Yet people may use
27 different words to describe similar experiences. Some topics could be mentioned once and
28 be meaningful without being statistically significant (e.g., thoughts about death). Moreover,
29 due to the qualitative nature of this study and the use of purposive sampling, the results are
30 not generalizable. Indeed, qualitative research usually do not aim for generalizability but

1 rather for transferability(41). Finally, we can hypothesize that the interviewees were more
2 concerned by KRT as they are younger, more educated, with stage 4 or 5 CKD and anxious.

3 *Clinical perspectives*

4 Investigating patients' perspective on CKD and their care path allows to open new
5 perspectives to improve care and patients' quality of life. Attending to education programs
6 to select KRT is important, but does not seem to be sufficient(42). Patients should be
7 educated and empowered to achieve the health outcomes and life goals that are
8 meaningful and important to them, through communication and education skills, patient
9 resilience, strengthening social connections, and access to support(42, 43). Social workers,
10 fellow patients and psychologists should be included in the conception of such programs in
11 order to help reduce patient cognitive avoidance and decisional conflict(44). Our results also
12 highlight the importance to include patients' families in educational interventions, especially
13 regarding transplantation, which have proved to be effective(45). Moreover, coordinating
14 patients' care pathways, as recently implemented for those with CKD stage 4 or higher in
15 France, could reduce cognitive avoidance and lead to more satisfying KRT choices.

16

17 **Conclusion**

18 This study underlined that cognitive avoidance is common in patients and that dialysis and
19 transplantation belong to two distinct decision-making processes. Although cognitive
20 avoidance may be adaptive, healthcare teams should be watchful as it may affect patients'
21 well-being and their satisfaction with decision-making. Patients seem not to contemplate
22 dialysis when transplantation is an option and may rush their dialysis modality choice when
23 reaching kidney failure. Finally, family plays an important role in treatment choice,
24 especially when transplantation is considered. Thus, caring for patients and their families
25 seems relevant during KRT decision-making. Further research should investigate relatives'
26 experiences to better understand their role.

27

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18

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20 LM drafted the article. GD, ES, KL, CA, CC, BS and AU contributed to the study design and/or
21 the conception of questionnaires, provided intellectual content to the work described and
22 revised the manuscript. LM performed the analyses supervised by AU. All authors approved
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24

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10

- 1 **Box 1:** Subjects addressed in the interview guide
- 2 - Current experience with CKD
- 3 - Knowledge and perception of KRT
- 4 - Discussions of KRT with healthcare professionals
- 5 - Discussions with family and friends and factors affecting treatment choice
- 6 - Roles in decision-making
- 7

1 **Table 1:** Characteristics of the sample who participated in the interview

Variables	Patients who took part in an interview N = 50
Sociodemographics	
Age (Mean (SD))	62.2 (12.2)
Gender (% women)	42.0%
GFR (Mean (SD))	24.5 (11.6)
CKD stage at 3-year follow-up	
Stage 2-3	28.0%
Stage 4-5	68.0%
NA	4.0%
Attended patient education on KRT (% Yes)	
NA	8.0%
Marital status	
Single	16.0%
Divorced	8.0%
Married	66.0%
Widowed	8.0%
NA	2.0%
Lives alone	22.0%
Occupational situation	
Retired	50.0%
Full-time job	28.0%
Part-time job	6.0%
Unemployed	4.0%
Disability leave	10.0%
Education level	
≤ 9	2.0%
10 - 12	46.0%
> 12	50.0%
Good literacy skills¹	84%
Depression²	
Mean (SD) (HADS score ≥ 8)	7.4 (5.0)
Depressed (CES-D score ≥ 8)	38.0%
NA	10.0%
Anxiety³	
Mean (SD)	5.3 (3.3)
Anxious	24.0%
NA	0.0%

Discussion with family members	78.0%
NA	0.0%

- 1 GFR for glomerular filtration rate; NA for Missing Data; KRT for Kidney Replacement
- 2 Therapy; ¹Patients were considered as having good health literacy skills when they reported
- 3 they never needed help when they read documents written by health professionals.
- 4 ²Measured with the Center of epidemiological studies depression scale (Kohout et al., 1993)
- 5 ³Measured with the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983)

Class 1 (29%) <i>Illness rhythm</i>		Class 2 (15%) <i>Considering dialysis</i>		Class 3 (13%) <i>Family and transplantation</i>		Class 4 (43%) <i>Disease, treatment choice and introspection</i>	
<i>Lexical Forms</i>	<i>Chi²</i>	<i>Lexical forms</i>	<i>Chi²</i>	<i>Lexical forms</i>	<i>Chi²</i>	<i>Lexical forms</i>	<i>Chi²</i>
Month	335	Dialysis+	355	Brother	352	Thing	67
Result	171	Peritoneal+	298	Sister	261	To say+	52
Blood	159	Machine	187	Family	200	Haha	45
Sample	129	Hospital	155	Son	171	To think	43
Last	108	House/Home ¹	149	Girl/Daughter ¹	162	Live ²	37
Analysis	105	Domicile/Home ¹	137	Child	160	To try	37
Pressure/tension ¹	92	Hemodialysis	137	Husband	133	To accept	36
Nephro	83	Method	135	Mother	126	Decision	35
Examination	75	Night	114	Father	114	Question	35
To go up/to climb ¹	63	Arm	109	Compatible	92	Sense	34
Appointment	57	Constraint	104	Boy	80	Instant	33
Nephrologist	56	Centre	94	Relative	73	Normal	32
Year	50	Bedroom/room ¹	93	To decease	71	Moment	31
Assessment/work-up ¹	50	Hour	80	To recount	71	To ask/to put ¹	26
Doctor	50	Tube/tubing/tip ¹	73	To give	68	Health	25
Creatinine	50	Autonom+	73	Living/alive ¹	65	Life	24
Morning	45	Connect/plug in ¹²	72	Together	54	To live ²	22
Stable	42	Day	70	In-law/step/beautiful ¹	53	To stop	22
Clearance	42	Stomach/Belly ¹	60	Niece	53	Subject	21
Pain	40	Device/Instrument ¹	60	Friend	50	Action	21
To send	40	Way/Type ¹	56	World	47	Blow/shock/assault ¹	20
Renal	39	To connect/to plug in ¹²	56	Pal	47	To manage	20
Cardiologist	39	To show	50	To receive	46	Sick	20
To see	36	To displace/to move ¹	49	Donation	42	To continue	20
<i>Supplementary forms</i>		<i>Supplementary forms</i>		<i>Supplementary forms</i>		<i>Supplementary forms</i>	
Had	58	The		My		There you are	63
Since	44	By	40	My	155	No	47
				You	72		

Have	37	Home	20	My	71	No	34
Was	27	Self	19	Him	49	Maybe	23
Me	21	In	17	They	42	What +	21
So/then	21	Elsewhere	16		37	That	15
			16	<i>Significant absences³</i>			
<i>Significant absences³</i>		<i>Significant absences³</i>		Dialys+		<i>Significant absences³</i>	
Life	-48	My	-23	Month	-21	Month	-108
Thing	-46	Month	-22	It's	-19	Hospital	-98
Dialysis+	-42	Say+	-21	That	-17	Blood	-76
Talk	-35	Give	-20	Say+	-14	Result	-52
Family	-35	I	-19		-14	Peritoneal+	-48
Choice	-32	Moment	-17			Brother	-44
				<i>Variables</i>			
<i>Variables</i>		<i>Variables</i>		Women		<i>Variables</i>	
Anxious	90	Stage 4	62	Depressed	129	Non-anxious	43
Without patient therapeutic education	52	With patient therapeutic education	55	80 years old or more	43	50 years old or less	39
Depressed	51	Discussion with family	42	Retired	34	Non-depressed	18
No discussion with family	44	Men	36	Patient education	16	Non-retired	14
Stage 3	42	Non-depressed	30		15		
Stage 5	14						

¹These occurrences have different meanings in French

²Some conjugated forms of these verbs were analysed separately from their lemmatised form because they can have homonyms.

³As a chi-square cannot be negative, when a minus precedes the Chi-square value it is used by the software to indicate a “relative absence” of the word in the class.

Figure 1: Figure of the descendant hierarchical classification

Table 2: Excerpts from the analysis

Class 1: Illness Rhythm	CKD monitoring	Excerpt 1	"I hope that on the 30th, when I go see her, she doesn't say to me 'We're at that stage!' To say to you, uh, so yeah. Um. Bah, she makes me anxious each time I go see her. Each time I'm waiting for a result, each time I go see her." Tony, age 54
	Managing an illness among others	Excerpt 2	"The arthritis in my hands worries me more than my kidney insufficiency! Yes! Because ... <coughing sound> at the end of the day, at the end of the day, pain comes." Guillaume, age 55
		Excerpt 3	"I had a blood sample and then I saw my general practitioner the day or two before ... seeing the nephrologist. And in the results that, that there were, there were numbers that were very very bad. And that was really a blow to my morale. And then two days later, I saw the nephrologist. I talked to her about it. She said to me, 'But that, that's a rate that's part of the analysis but we never do anything about it!' " Samuel, age 54
		Excerpt 4	"I go see the cardiologist, I go see the diabetes specialist, and I go see the nephrologist." Monique, age 82
Class 2: Considering dialysis	Dialysis modalities and day-to-day life	Excerpt 1	"Uh I know that there are people who do dialysis at home, uh, who spend the night with a machine that uh do the session/purification purifies the blood of its, its toxins." Joël, age 82
		Excerpt 2	"Peritoneal dialysis at one's house, eh, well, at home, uh I think that it avoids spending hours in the hospital, so to be able to stay home, but under what conditions?" André, age 65
		Excerpt 3	"I don't know, I'd like to opt for dialysis at, at night. So yeah, it's that." Adèle, age 69
	Patient education and treatment choice	Excerpt 4	"I am pretty much aware of everything and, not all of course, I'm pretty much up to date, so yeah. Well, uh, good, he explained to me first, how things were going and he sent me to take some classes, and in those courses they taught me the different systems of dialysis and the possibilities I had." Dimitri, age 69
		Excerpt 5	"I don't know how it goes, but it must certainly be very aseptic, anyway well, both systems have their advantages and their disadvantages. I know, I think, anyway, that the system with dialysis in the arm, uses up the veins more, according to what I've read." Pedro, age 56
		Excerpt 6	"You have to go to the hospital, I don't know anymore if it was 2, 3, or 4 times a week! With some, there! It's a huge constraint! Huge huge constraint!" Samuel, age 54
Class 3: Family and transplantation	Talking about the illness	Excerpt 1	"I don't tell my mother all of it, to not bother her too much with it. Uh, and then you have to have some privacy, so I am not always going to recount what I have, what's well, what's not well." Jérôme, age 61
		Excerpt 2	"Everyone turned their back on me. So uh well I don't talk about it. No, no I don't see anyone anymore." Judith, age 61
		Excerpt 3	"But otherwise, with the family, my nephews, all of that, everyone is, I have cousins who know, my sister-in-law, etc." No, no among us, it's ok, we talk about it easily. But not with Granny" Anouk, age 66
	Talking about transplantation	Excerpt 4	"[About a transplant from a living donor or a deceased donor] I have no brother or sister, mom is a little too old. 80 years old, she's my mother so, good, an 80-year old kidney, knowing that she's sick... So a deceased donor, yes." Paul, age 61

Excerpt 5	<i>"My son did them [the predonation examinations] and he's compatible but I don't want to. No. No, he's too young, he's 25, I don't want it, he has his whole life in front of him." Nicole, age 52</i>
Excerpt 6	<i>"With my husband ... we talked about it. I said to him: 'You know, it would be good ...' and all, and 'ooh la la' he said to me, 'but wait', he says to me 'to give a kidney but you realize, after uh', so it's these things you see, you talk a little in a vacuum, you don't really know because uh he tells me 'but you know that if I give you one of my kidneys, if of course, I'm compatible, if I give you one my kidneys,' he says to me, "to live with only one kidney, it's uh, it must not be easy.'" Christine, age 61</i>
Excerpt 7	<i>"It's not more complicated. It's something else. First, someone has to die, and they have to be compatible. And well, I have no desire for someone to die to save my life." Ezra, age 60</i>

Class 4: Disease, treatment choice and introspection	<i>A "normal" life</i>	Excerpt 1	<i>I don't feel sick, I, for me, I'm not sick, in fact." Audrey, age 65</i>
		Excerpt 2	<i>"Pff, what I'm living <dealing with> badly, it's the fatigue. The impression of being, uh, passive. Anouk, age 66</i>
		Excerpt 3	<i>"That doesn't bother me in my life! I find myself, in quotes, uh "normal." Céline, age 50</i>
		Excerpt 4	<i>"I don't know. No one knows, and no one is able to say really how it is going to develop! Especially, to say to yourself for a moment, uh, bah, all the uncertainties around a transplant, since I, I myself would like to avoid dialysis at any cost!" Cassandre, age 46</i>
		Excerpt 5	<i>"Pff, well, I don't want to live like him. But I'm way younger than him, my dad died when he was 80, 81 uh pff. I have time to see this coming. Haha." Abby, age 61</i>
	<i>Avoiding thinking about CKD</i>	Excerpt 6	<i>"I try not to think about it, I don't want to anticipate what's going to happen. It will already be, uh, yeah. Uh complicated, when the time comes. Céline, age 50</i>
Excerpt 7		<i>"I don't think about it. No. Bah, it's a little like a sword of Damocles, so, and I say to myself, when is it going to fall?" Cassandre, age 46</i>	
Excerpt 8		<i>"Still, it's one of those things you think about, anyway, I'm not going to tell you that I'm completely uh ignorant of all those questions and that I totally never think about those questions." Ginette, age 73</i>	
Excerpt 9		<i>"From the perspective of a good state of mind, I try to be careful about a lot of things, my meals, stuff like that." Ginette, age 73</i>	
Excerpt 10		<i>"I know that it's going to be very complicated for me to manage. Um, uh I, my morale is going to be very beaten down." Céline, age 50</i>	
	<i>Treatment choice and acceptance facing research participation</i>	Excerpt 11	<i>"If it continues like this, it's fine. I sleep well, I eat well, I walk in the woods a lot." Colin, age 80</i>
Excerpt 12		<i>"I have trouble accepting that uh that one day or another I might have to start dialysis! Céline, age 50</i>	
Excerpt 13		<i>"It's not easy to answer this question because it's true that I realize, well I realize, yes, that I haven't asked myself them really." Michel, age 70</i>	

Figure 2: Schematic representation of the factorial analysis of patients' discourse

