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► To cite this version:

Lucile Montalescot, Géraldine Dorard, Elodie Speyer, Karine Legrand, Carole Ayav, et al.. The experience of relatives and friends of patients with moderate to advanced chronic kidney disease: Insights from the CKD-REIN cohort study. *British Journal of Health Psychology*, 2023, 28 (4), pp.930-951. 10.1111/bjhp.12662 . hal-04161116

HAL Id: hal-04161116

<https://hal.science/hal-04161116v1>

Submitted on 13 Jul 2023

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THE EXPERIENCE OF RELATIVES AND FRIENDS OF PATIENTS WITH MODERATE TO ADVANCED CHRONIC KIDNEY DISEASE: INSIGHTS FROM THE CKD-REIN COHORT STUDY

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ABSTRACT

Objectives. The transition from chronic kidney disease (CKD) to kidney failure requiring kidney replacement therapy (KRT; i.e., dialysis or transplantation) to sustain life is a stressful event for patients. Families play a role in patients' treatment decision-making, but little is known about how they are involved. This study aimed to explore the experience of CKD among relatives and friends, their views and involvement in KRT choice.

Design/Methods. We conducted a qualitative study among 56 relatives or friends of patients with moderate to advanced CKD who were enrolled in the CKD-REIN cohort study. A psychologist conducted semi-structured interviews about their experience with CKD, treatment decision-making, and their role in this process. Data were analysed using statistical text analysis.

Results. The mean age of participants was 56.4 ± 14 years; 75% were women, 61% were patients' partners, and 48% had a relative or friend with stage G4 CKD. The analysis yielded four lexical classes: listeners with an opinion, coping with CKD on a daily basis, narrating patients' nephrological monitoring, and emotions behind facts. Participants reported a listening role in the decision-making period and information needs. Some reported that CKD had no impact on their own daily lives, but others talked about its current and future physical, psychological and social consequences on them, the patients and their relationships.

Conclusions. Most relatives/friends reported having little influence on KRT decision-making but expressed opinions on these treatments. Including relatives/friends in education on KRT and providing them with decision aids, especially when family members are supportive, may allow for more suitable decisions.

INTRODUCTION

Chronic kidney disease (CKD) is associated with the gradual loss of kidney function and often develops as a complication of diabetes and/or hypertension. In early stage CKD, medication and diet are used to slow the progression to kidney failure (International Society of Nephrology, 2012). When patients reach the kidney failure stage, kidney replacement therapy (KRT, i.e., dialysis or transplantation) becomes necessary to sustain life. These treatments affect not just patients but also the mental health and quality of life of relatives/friends (Nagasawa et al., 2018; Ogutmen et al., 2006; Sezer et al., 2003). Worldwide, 9% of people live with CKD who are not on KRT. Between 1990 and 2017, the global incidence of dialysis and kidney transplantation increased by 43% and 34%, respectively. Furthermore, KRT incidence varies greatly depending on the country's access to these treatments (Bikbov et al., 2020). In France, 1.6 million people live with moderate or severe CKD, defined by an estimated glomerular filtration rate (eGFR) below 60 mL/min/1.73 m², of whom approximately 90 000 patients are on KRT, whereas about 11 300 people start KRT each year (Agence de la Biomédecine, 2018; Olié et al., 2021). This indicates that thousands of families may be impacted by dialysis initiation as well.

Although previous research and theory have shown how patients' and relatives/friends' adjustment to chronic illness is interdependent, little is known about the experience of relatives and friends of people living with moderate to advanced CKD (Berg & Upchurch, 2007; Khaira et al., 2012; Nagasawa et al., 2018; Untas et al., 2012). Research has mainly focused on cancer or diabetes (Lister et al., 2013; Traa et al., 2015). The mental health of a member of a dyad (i.e., a social system in which two individuals are linked) can influence the other members (Kershaw et al., 2015; Segrin et al., 2020). Similarly, coping strategies that may be used by one have an impact on the others regarding how the members cope as a dyad and on their respective health outcomes (Baumstarck et al., 2018;

Bodenmann, 1995; Rottmann et al., 2015). Dyads may consider the illness an individual or mutual stressor (i.e., 'we-disease'), affecting how they cope (Badr & Acitelli, 2017). Therefore, chronic illness affects patients, their relatives, and the family as a system (Rolland, 2005). Most studies on patients' relatives have focused on their partners. Moreover, although several studies have investigated the role of family/couple functioning in patients' adjustment and survival, little is known about the mental health of relatives (Gee et al., 2005; Tkachenko et al., 2019; Untas et al., 2011, 2012). In CKD, studies on the mental health of relatives have mainly focused on kidney failure, showing that anxiety and depressive symptoms are commonly experienced by the relatives of patients treated by haemodialysis (Avsar et al., 2013; Pereira et al., 2017). However, these studies were often conducted on small samples and had several methodological limitations. To the best of our knowledge, only one study to date has focused on the spouses of patients with moderate to advanced CKD (Paschou et al., 2018). The results have highlighted a low level of depressive symptoms and anxiety. The spouses of patients undergoing dialysis and those of people with CKD did not significantly differ in anxiety or depressive symptoms, but the scope of the results was limited by the small sample size ($n = 21$).

Despite the lack of data, the question of relatives is an important one, as the literature on chronic illness shows that they may either directly or indirectly influence the choice of treatment (Rini et al., 2011). They may adopt several roles that either facilitate or slow the decision-making process, and their involvement may vary over the course of the patient's illness. Furthermore, relatives tend to be more involved in the decision-making process when they have a strong relationship with the patients and/or when the treatment may impact them (e.g., sexuality) (Lamore et al., 2017). Patients who reach CKD stage G4 (severe; GFR 15 to <30 mL/min/1.73 m²), or G5 (kidney failure; eGFR < 15 mL/min/1.73 m²) face KRT decision-making, which is a stressful event (Harwood & Clark, 2013). Few studies have

focused on patients' perspectives on treatment choice prior to KRT initiation. These studies showed that patients avoid thinking about CKD progression, as they experience few symptoms (Lissanu et al., 2019; Montalescot et al., 2022). Therefore, delaying decision-making is common (Lovell et al., 2017).

Several studies of family influence on KRT decision-making have analysed the data of patients and their relatives together, without distinguishing whether answers were from the patient or the relative (Baillie & Lankshear, 2015; Griva et al., 2013; Karlin et al., 2019; Morton et al., 2010). Whereas, other studies have shown that patients and relatives may experience the illness in very different ways (e.g., patients feel like a burden to their relatives, and relatives need their knowledge of the patients recognised by the staff) (Lamore et al., 2017; Morton et al., 2010). Moreover, there may be differences in treatment preferences between patients and their relatives (Ozdemir et al., 2019). The literature on CKD shows that relatives may provide emotional, informative and instrumental support during this process (de Rosenroll et al., 2013; O'Hare et al., 2017). They may also share their opinions about the different options with the patient and engage with the medical teams (e.g., sharing information, being the patient's spokesperson) (Griva et al., 2013; Loiselle et al., 2016; Morton et al., 2010; O'Hare et al., 2017). Moreover, the extent of the family's influence depends on the treatments being considered. For example, relatives are more prone to participate in the decision-making process when home dialysis is envisaged (Chanouzas et al., 2012; Tong et al., 2013). However, none of these studies included separate interviews with patients' relatives prior to KRT. Therefore, these results may be subject to retrospective bias. Furthermore, relatives may have a different point of view on their involvement in KRT decision-making than patients.

Statistical text analysis is a novel and interesting approach to qualitative data analysis. The ALCESTE® (or Reinert) method helps identify 'lexical worlds,' and allows the study of

the lexical structure of a corpus by investigating the co-occurrences of lexical forms in a corpus (Reinert, 1993). Statistical analyses are performed on the words and units of context (UCs) of the corpus (roughly equivalent to sentences) based on punctuation and significant word distribution. This method has been used across a wide range of research fields, including psychology (Lelorain et al., 2012; Pelagalli et al., 2010; Robieux et al., 2018; Vioulac et al., 2016). This method is of particular interest to study how a subject is discussed by individuals or institutions.

Although previous research has shown that families may influence KRT decision-making, studies investigating relatives' views about treatment choices are rare. To address this gap, we investigated relatives' and friends' experiences (i.e., their subjective perspectives) with CKD and KRT decision-making through qualitative interviews.

METHODS

Design and setting

The French Chronic Kidney Disease-Renal Epidemiology and Information Network (CKD-REIN) is a prospective cohort study that was conducted in 40 nationally representative nephrology outpatient facilities in France. Eligible patients were at least 18 years of age; had a confirmed CKD diagnosis of either Stage G3 (moderate; eGFR < 60 mL/min/1.73 m²), Stage G4 (severe; GFR 15 to <30 mL/min/1.73 m²), or Stage 5 (kidney failure; eGFR < 15 mL/min/1.73 m²); were not on dialysis; and had not been transplanted. The study included 3033 patients between July 2013 and March 2016, who then were annually followed up. The study protocol and patients' baseline characteristics have been published elsewhere (Anonymized et al., 2014, 2019).

A psychological ancillary study, named CKDREIN-Famille, was set up in the third year of follow-up (2016–2019). A letter was sent to 2260 patients, together with the Year 3

self-report questionnaire, informing them about CKDREIN-Famille and its aims. A month later, they received a questionnaire for a relative or friend and a consent form. If patients wished to include a relative or a friend, they could give them the questionnaire to complete and return. Inclusion criteria for relatives/friends were: family member or friend chosen by the patient to participate in the study, and aged 18 years or older. Of the 438 relatives/friends (19%) who returned a completed questionnaire, 230 (53%) agreed to take part in a subsequent phone interview with a psychologist about their experience with CKD and KRT decision-making.

Consequently, 56 participants were selected purposively to ensure diversity in our sample regarding age, sex, and CKD stage, as well as the relationship with the patient (e.g., partner, child). To include participants, we identified characteristics that would make them key informants (e.g., age, relationship with the patient). A projected inclusion sampling process was set up so our results would not reflect the experience of a specific profile of relatives/friends. Our inclusion goal ($n = 74$) could not be reached because most relatives who participated were partners (79%) (see Table S1). Nevertheless, in view of our research characteristics (e.g., aim, sample specificity), a satisfying information power was reached, indicating the richness of information (Braun & Clarke, 2013, 2021b; Malterud et al., 2016).

The institutional review board of the French National Institute of Health and Medical Research (INSERM; ref. IRB00003888) approved the protocol, and the study was registered at ClinicalTrials.gov (NCT03381950).

Data collection

Patients completed a self-report questionnaire, and trained clinical research associates collected patient-level data from patient interviews and medical records (i.e., illness stage). Relatives and friends were asked to respond to questions on their sociodemographic

characteristics (i.e., age, sex, relationship with the patient) and several participant-reported outcomes (i.e., anxiety and depressive symptoms).

Anxiety was measured with a 7-item subscale of the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983). A cut-off subscore of 8 was used to distinguish between patients with and without severe anxiety. The subscale had acceptable internal consistency ($\alpha = 0.78$). Depressive symptoms were assessed with an 8-item version of the Center for Epidemiologic Studies-Depression scale (Kohout et al., 1993). The final scale had a satisfactory fit and internal consistency ($\alpha = 0.82$) (Anonymized et al., 2022). A score above 6 was used to identify patients with significant self-reported depressive symptoms. This cut-off was determined with a cross-multiplication based on the initial version threshold.

Qualitative data were collected from the recordings of semi-structured individual phone interviews conducted by a psychologist (LM). She did not know the participants beforehand and presented herself as a researcher who was interested in their experience with CKD. She asked the participants to be alone in a quiet room during the interview. Then she guided the course of the interview, while leaving room for participants to express themselves and broach new subjects (see Box 1 for the interview guide). LM took notes during the interviews to help her prompt the participants; however, no field notes were made after the exchanges. The interviews, which took place between January 2018 and January 2019, were audio-recorded and lasted a median of 44.4 min (range: 19.4–80.6). We used the Consolidated Criteria for Reporting Qualitative Research (Tong et al., 2007) to report key aspects of our study.

Analyses

All data were transcribed verbatim and included in the qualitative analyses. Relevant excerpts have been translated into English for the purposes of this article. Analysis of Co-Occurring

Lexemes in a Set of Text Segments (ALCESTE®) (Illia et al., 2014; Reinert, 1990) was used to perform quantitative analyses of the words used by participants, based on punctuation and the number of word occurrences. ALCESTE® carries out several analytic steps. The researcher intervenes only in the final stage. They give meaning to the classes yielded by the software and identify semantic rather than purely lexical and syntactic classes, by examining the words and their associations. LM analysed ALCESTE® outputs supervised by AU. ALCESTE® reduces the words to their lexical roots by lemmatising the corpus (e.g., diabet+ can refer to “diabetes” or “diabetic”). It identifies UCs, namely text segments roughly equivalent to sentences. A descending hierarchical classification (DHC) accounting for word distribution and co-occurrences allows UCs to be divided into lexical classes. These classes contain words sufficiently close together in the same sentence or group of sentences, considering repeated word associations. Significant absences are words that never or very rarely appear conjointly with the words in the class. They are therefore negatively associated with said class.

A chi-square test is performed automatically by ALCESTE® to establish the strength of the associations between the words and their classes. The cut-off for the chi-square value is automatically determined by ALCESTE® in a way that all words presented in the outputs are significant at $p < 0.05$. Grammatical words (e.g., articles, pronouns) are therefore considered supplementary forms and content words (e.g., nouns, verbs) as active forms. As a result, words conveying meaning (i.e., content words) are considered by the software when constructing the classes, but not grammatical words. The links between classes and grammatical words are computed by ALCESTE® in a second step. The DHC also includes a correspondence analysis (CA) of contingency tables showing UCs crossed with the classes. Again, active forms contribute to the construction of the CA axes but not supplementary forms. Lastly, ALCESTE® performs an ascending hierarchical classification (AHC) showing

the links between words in the same class. This makes it possible to identify subclasses, highlighting how frequently words appear in the same sentence.

This type of analysis was chosen because it allows quantitative analyses of large text data while keeping the strengths of a qualitative approach. It automatically classifies the words used by the participants with no *a priori* (Vioulac et al., 2016). Moreover, ALCESTE® emphasises not only what participants talk about but also how they tell their experience, allowing patients' implicit views to be identified. Data saturation is a methodological principle in qualitative research referring to the point in the analytic process when no new information is discovered in the analysis and data becomes redundant (Saunders et al., 2018). Data saturation may occur after 12 interviews but vary greatly according to the researchers' method of analysis and definition of saturation (Braun & Clarke, 2021a; Guest et al., 2006). Saturation was assessed during data collection and defined as the absence of new information regarding the research question. As stated above, we undertook 56 to ensure diversity. We chose to stop the recruitment process to avoid having too many interviews with patients' partners. Since the analysis was statistical, an overrepresentation of partners would twist the results (i.e., the classes identified would mainly reflect partners' lived experiences and not that of other relatives/friends).

The software can consider categorical variables related to the interviewees and report their association with each class. When ALCESTE® determines UCs from each interview, they are assigned with the characteristics of the participant who said this fragment in an interview. The chi-square indicating the strength of association between a participant's characteristic and a class indicates that most UCs (fragments of the text) classified in this class are extracted from interviews with participants presenting this characteristic. It helps identify how certain classes are associated with participants' characteristics. The following variables were considered in our analysis: sex, living or not living with the patient, nature of

the relationship with the patient (i.e., partner, parent, child, other family member, or close friend), patient's CKD stage (i.e., Stage G3, G4, or G5), discussions with the patient about treatment choices (i.e., yes or no), anxiety (anxiety symptoms vs. non-significant anxiety symptoms) and depression (depressive symptoms vs. non-significant depressive symptoms). A more detailed explanation of ALCESTE® analysis is available as a supplementary file.

RESULTS

Descriptive results

The participants were mainly patients' partners (61%). The majority had retired. Half of the relatives/friends reported at least one illness, but very few had CKD (Table 1). Participants who consented to an interview were younger, and more likely to be anxious and to have had discussions about KRT. However, they did not differ regarding the patient's CKD stage, which was severe for 60% of them (see Table S1).

The 56 relatives and friends who were interviewed had a mean age of 56.4 years; 75% were women, 61% were partners, and 66% were living with the patient. As we wished to interview a diverse sample of relatives/friends, they were younger, had a higher level of education, were more likely to be children or other family members, and were less likely to live with the patients than participants who were not interviewed. Anxiety was very high in our sample: 41% had significant anxiety symptoms. Although depression was less frequent than anxiety, and its prevalence was high (25%) in our participants.

Results of qualitative data analysis

Figure 1 illustrates the four classes identified by the DHC, which encompassed 63% of the corpus. When participants reported very specific aspects of their experience using words that were not used by other interviewees, these words could not be linked to any class, as there

were too few occurrences in the corpus (e.g., one participant compared her own experience of schizophrenia with her father's illness). Therefore, non-classified parts of the interviews could be due to patients mentioning personal elements and/or the diversity of our sample (e.g., patients' partners and children did not share the same experience). An illustration of the AHC for each class is available as supplementary material.

Class 1: Listeners with an opinion

Class 1 was composed of 33% of the analysed corpus. Words such as 'question,' 'talk,' 'choice,' and the *family* lexical field showed that this class referred to treatment choice and the roles of relatives and friends in this process.

Family discussions

'Give/donate,' 'ask,' 'talk,' and 'compatible' were associated with this first subclass. Some participants wondered whether they wished to be donors and/or whether they could give a kidney to their relative/friend. This subclass contained discourses on transplantation, especially living donor transplantation. Relatives/friends could give a kidney but also advice regarding this process. However, some of them refrained from expressing their opinion to the patient (Table 2, Quotes 1–3). Participants talked about the illness, especially transplantation, with different people. Words pertaining to family (e.g., 'brother,' 'family/entourage') and health professionals (e.g., 'doctor') were also included in this subclass. According to participants, the views of professionals, whether or not they were involved in the patient's care (e.g., friends), were very important and deemed to be more trustworthy (Table 2, Quotes 4–6).

Discussions with the patient

Relatives and friends might also have conversations solely with the patients. This second subclass included words such as 'organ,' 'donation,' and 'blood' (as an adjective: 'blood

type'). Participants explained their actions to become a donor in detail (Table 2, Quotes 7 and 8). Some participants mentioned their roles in the decision-making process: they might advise patients and share their opinions (e.g., 'advice,' 'exchange,' 'decision,' 'role'). However, some participants said they did not want to influence patients' choices. They also stressed that the final choice lay with the patient (e.g., 'choice,' 'belong') (Table 2, Quotes 9–11).

'If' was present in this class and marked a condition, in particular, what determines participants' intervention in this process (Table 2, Quotes 12 and 13). Although treatment choice might be perceived as non-existent or as a mutual decision between the participant and the patient, the final choice was often described as that of the patient.

Information-seeking as a role, need, and concern in KRT decision-making

'Question' and 'put/ask' made up this subclass and might refer to a variety of situations, including the decision-making process that was or was not evident, but also the roles of relatives and friends in this period. Most participants mentioned the role of listener (e.g., 'listen'), and deemed that they had no influence on the decision to be made. As we mentioned earlier, participants indicated whether they gave their opinion or refrained from doing so (Table 2, Quotes 14–16).

This subclass was associated with disjuncts. This type of locution or word is used to express the speaker's judgement and feelings (e.g., certainties, doubts, criticisms) on their own statement (e.g., 'no,' 'okay/in agreement with,' 'I think'). In this way, participants highlighted how their position regarding KRT decision-making was personal. Personal pronouns (e.g., 'you,' 'I,' 'me') were associated with Class 1. They were used to report conversations that participants had with their relatives/friends living with CKD in direct speech. They also appeared in sentences in which participants reported their own needs and opinions or those of the patients. They indicated a need to obtain information and to ask

questions during consultations (e.g., ‘need,’ ‘information,’ ‘put/ask’) (Table 2, Quotes 17 and 18). Relatives and friends mentioned their sources of information: television, newspapers, patient therapeutic education, or the Internet (e.g., ‘Internet,’ ‘meeting,’ ‘inform/inquire’). However, participants also criticised the Internet. They talked about the people they asked about CKD: their relative/friend living with CKD, the nephrologist, but also the interviewer. Lastly, participants asked themselves questions (Table 2, Quotes 19–21).

As we previously mentioned, this class included parts of the interviews in which participants directly questioned the interviewer (e.g., ‘interview,’ ‘answer’). Words such as ‘listen’ and ‘question’ could refer either to questions the interviewees asked the researcher or those the interviewer asked the participants. Participating in the interview led to questions about the research and the participants’ own experiences (Table 2, Quotes 22–24). This class was associated with participants who were neither depressed or anxious, and whose relative/friend lived with stage G4 CKD.

Class 2: Coping with CKD on a daily basis

Class 2 encompassed 33% of the analysed corpus and focused on the diversity of participants’ ways of coping. It was composed of three subclasses.

Impact on lifestyle

This first subclass focused on the changes brought about by CKD (e.g., ‘life,’ ‘change,’ ‘take,’ ‘preoccupy,’ ‘force’ as a verb, ‘aliment+’). Participants and patients had to change their lifestyle (e.g., ‘aliment+’). ‘Thing’ could designate things they had to change in their life, but also what they could still do despite CKD and future challenges. Some participants did not feel that CKD had a particular impact on their daily life, and ‘thing’ also appeared in sentences such as ‘It’s not something we’re thinking about all the time’ or ‘It does not prevent us from doing a lot of things’ (Table 2, Quotes 25 and 26). Participants talked about

how they coped individually or in dyads with CKD and the changes it imposed (e.g., ‘way,’ ‘do/make,’ ‘take,’ ‘together’) (Table 2, Quotes 27–29).

Current and future constraints on the couple

‘Attent+,’ ‘realise/give back,’ and ‘realise/count’ showed how close others and patients tried to maintain the best possible quality of life (Table 2, Quotes 30 and 31). Although ‘dialysis’ was not included in this class, participants implicitly referred to this treatment through the words ‘holidays,’ ‘move,’ ‘complicate,’ ‘house/home,’ and ‘constraint.’ However, these words were also used to refer to current constraints (Table 2, Quotes 32–34). Moreover, ‘house/home’ and ‘couple’ highlighted the specificities of living with patients (e.g., home dialysis). Vocabulary pertaining to family, ‘doctor’ and words linked to kidneys (e.g., ‘kidney,’ ‘renal’) was conspicuous by its absence in this class. This may indicate that this class focused on participants’ life with CKD more than CKD itself. The absence of words referring to other people (i.e., other relatives/friends and medical staff) may indicate that participants and patients were the only ones involved in the day-to-day management of CKD (Table 2, Quotes 35 and 36).

Physical and emotional impact

This last subclass encompassed the physical and psychological consequences of CKD (e.g., ‘morale,’ ‘physical,’ ‘think’). These could be minimal, and participants sometimes talked about the ones to come or the ones they dreaded (Table 2, Quotes 37–39). The words ‘try,’ ‘manage,’ ‘live,’ and ‘daily’ showed how participants tried to cope with life with CKD. This illness imposed and would impose changes and had to be managed daily. These words were also used in sentences describing how participants helped patients, by keeping an optimistic outlook on life and making plans for the future (Table 2, Quotes 40–42). This class was

associated with women and anxious participants. By contrast, relatives who were parents were significantly absent from this class.

Class 3: Narrating patients' nephrological monitoring

This class encompassed 18% of the classified corpus and was composed of two subclasses.

Significant events

Participants mentioned several significant events in patients' monitoring, such as visits to hospital emergency departments (e.g., 'emergen+', 'night,' 'hour,' 'car') (Table 2, Quotes 43 and 44). The telling of these events interspersed the narration of their daily life, and some of these events were quite old (e.g., 'morning,' 'sleep,' 'pee') (Table 2, Quotes 45 and 46).

Furthermore, this class encompassed several words indicating a narration, such as temporal and spatial indicators (e.g., 'night,' 'Monday,' 'hospital,' 'city names'), as well as markers of temporal and spatial relations (e.g., 'then,' 'right now,' 'when,' 'to,' 'there'). Indicators of duration and rhythm were also present (e.g., 'month,' 'hours'). Participants did not talk about patient monitoring, they narrated it.

Nephrological monitoring

The 'nephrologist' and 'urologist' were central figures in this second subclass, and participants mentioned them by name. The general practitioner was also mentioned. Words pertaining to medical monitoring were present (e.g., 'examination,' 'sample/taken,' 'blood,' 'analysis'). 'Era/time,' appearing in sentences such as 'at that time,' was used to refer to past events (Table 2, Quotes 47–49). Transcripts were often in the past (imperfect) tense, as were non-lemmatised verbs (i.e., secondary forms). This tense was characteristic of narration, especially the description of a spatial and temporal setting. Although 'machine' appeared in this class, 'dialysis' did not. Similarly, the vocabulary of transplantation and treatment decision-making was significantly absent (e.g., 'give,' 'choice,' 'treatment,' 'decision').

Therefore, participants' accounts of patients' nephrological monitoring in this class contained very few references to KRT. This class was more likely to concern patients' parents, depressed participants, and those who had talked about KRT choices with patients. By contrast, patients' children were significantly absent from this class.

Class 4: Emotions behind facts

Class 4 encompassed the smallest part of the classified corpus (16%), and was the least specific class. It took the form of a list of patients' health problems (e.g., 'auto,' 'immun+,' 'diabetes,' 'heart') and their impact on participants' emotional well-being. It was composed of two subclasses.

Fearing the future

Like the second subclass, the first one contained words describing other illnesses (e.g., 'diabetes,' 'cardiac,' 'auto,' 'immune+'). Terms pertaining to diabetes were part of this subclass (e.g., 'pump,' 'insulin'). These words appeared alongside 'permanent' and 'constant' (Table 2, Quotes 50–52). This subclass comprised words pertaining to patients' care pathways, but discourses in Class 4 were different from those in Class 3. Class 4 comprised very few verbs. 'Since,' 'above,' 'because,' and 'there is' indicated that participants recounted patients' monitoring in a very descriptive way (Table 2, Quotes 53 and 54). Beyond these factual descriptions of health problems and care pathways, this subclass was composed of words describing negative thoughts or emotions (e.g., 'die,' 'fear,' 'oh dear'). In the AHC, these words were close to words designating health problems (e.g., 'heart') and relative to kidney transplant (e.g., 'list,' 'perform a transplant,' 'antirejection'). The idiom 'Damocles' sword' was also included in this subclass. Therefore, these health problems affected participants, and kidney transplants (in particular deceased-donor transplantation) seemed to be associated with negative emotions. Furthermore, laughter was significantly absent from this class (Table 2, Quotes 55–57).

CKD, one illness among others

CKD was portrayed as one illness among others. Participants and patients often had to contend with several diseases (e.g., ‘cancer,’ ‘gout’) (Table 2, Quotes 58 and 59). In the AHC, ‘renal+’ and ‘insufficien+’ were close to ‘severe,’ ‘big,’ and ‘long.’ This indicates that within Class 4, the links between these words were very strong. Therefore, CKD and the patients’ and/or participants’ medical context was a heavy and complex burden to bear (Table 2, Quotes 60 and 61). This could induce negative emotions (e.g., ‘worry,’ ‘violent’) (Table 2, Quotes 62 and 63). This class was more likely to concern men and relatives/friends of patients with Stage G3 CKD. By contrast, relatives/friends of patients with stage G4 CKD were significantly absent from this class.

DISCUSSION

This study was the first to interview a diverse sample of relatives and friends about treatment decision-making before KRT initiation. Our analysis allowed us to investigate both what participants talked about and how they recounted their experiences. Although our participants described mainly the role of listener, they also broached a variety of other roles. This may indicate a more implicit kind of influence. Moreover, lexical analysis showed that they also acknowledged how adopting one or another of these roles is a personal decision (cf. use of disjuncts in Class 1). This contrasts with previous studies that highlighted a wide range of family behaviours, including the sharing of opinions on KRT (Griva et al., 2013; Loiselle et al., 2016; Morton et al., 2010). Relatives and friends also reported information needs regarding KRT and CKD, as previously reported (Baay et al., 2019; Donald et al., 2019).

CKD seems to have physical, social and psychological impacts on the lives of some relatives and friends (Class 2). This is congruent with the high prevalence of anxiety and depressive symptoms in our sample. Other participants reported that CKD had little impact on their lives and that it was an illness among others and part of a complex medical context.

As anxiety in participants is associated with Class 2 ('coping with CKD on a daily basis'), relatives and friends who are most involved in the management of the illness may be at greater risk of mental health issues. Indeed, the number of caregiving tasks is linked to poor mental health in caregivers (Cossette & Lévesque, 1993; Pinguart & Sörensen, 2003). As the difficulties included in this class regarded conjugal and/or home life, partners and people living with patients may face more CKD-related consequences and mental health problems than other relatives and friends. Indeed, living with the patient and caring for a child or spouse are linked to poorer mental health (Nijboer et al., 1999; Penning & Wu, 2016).

A study of patients' discourse showed that cognitive avoidance is common in patients with moderate to advanced CKD (Anonymized et al., 2022). Cognitive avoidance seemed less common in the relatives/friends we interviewed, and the content of class 2 showed how some participants were anticipating a future with CKD (e.g., keeping a positive outlook, and anticipating future constraints). As in Anonymized et al. (2022), analysis of the discourse of relatives and friends showed that the classes encompassing words pertaining to KRT decision-making were associated with stage G4 CKD. Therefore, we hypothesise that this process takes place during this stage for both patients and their relatives and friends, as indicated in the current guidelines (Covic et al., 2010). Moreover, patients, relatives and friends who talked about KRT decision-making generally reported good mental health (see variables associated with Class 1). This could indicate that the treatment choice process is hindered by anxiety and depression symptoms (Bishop & Gagne, 2018).

Although relatives and friends seemed to report a broader range of family behaviours pertaining to treatment choice, the discourses of patients and relatives/friends converged regarding the roles of family in KRT decision-making. Both analyses showed that, according to participants, family plays a limited role in this process, and the final decision belongs to the patients. Relatives and friends have a limited influence except when a living donor

transplantation is being considered. These results contrast with the conclusions of previous studies (Morton et al., 2011; Valson et al., 2018). Three factors could explain this divergence. First, these studies were retrospective, whereas in our study and Anonymized et al. (2022), patients and relatives/friends were interviewed prior to KRT initiation. Moreover, some of them may not have been in a decision-making process because of the early stage of the disease, which could explain the limited role of the family reported by participants. Second, retrospective biases may have influenced the previous results, leading to an overestimation of the roles of relatives and friends. Third, the family may impact treatment decision-making, but patients and relatives/friends may not be aware of this influence. In this study, we found that the discourse of relatives and friends on KRT (Class 1) contained a high number of disjuncts, indicating how they express their subjectivity regarding the roles they may adopt in this context.

Strengths

First, this study was based on a large cohort of patients selected from a nationally representative sample of nephrology clinics. This allowed us to include a large and diverse sample of relatives and friends. As we analysed their data separately from the patient's data, we were able to undertake a more precise investigation of their experience. Moreover, the classes identified by our analysis encompassed 63% of the whole corpus, which is satisfactory according to recommendations (>50%) (Rastier et al., 1994). One of the main strengths of statistical text analysis is that it investigates how participants recount their experiences, revealing implicit elements of interviewees' discourse (e.g., use of disjuncts in Class 1).

Limitations

Statistical text analysis is based on word count (Reinert, 1990). However, participants may not use the same words to describe a similar experience. Moreover, some topics mentioned

just once in an interview may be meaningful without being statistically significant (e.g., discourses on intimacy), and vice versa. Qualitative analyses focused on meaning, such as interpretative phenomenological analysis, could overcome this limitation (Smith & Osborn, 2003). Furthermore, the sample for this general exploration of the discourse of relatives and friends was quite heterogeneous and may not highlight truthfully the specificities of some subgroups.

Finally, relatives and friends were chosen by the patients to participate in the study. This has several implications for the results reported here. First, this could indicate a particular family functioning. Indeed, it has been shown that patients who participate in a study with a relative report higher relationship satisfaction (Hagedoorn et al., 2015; Untas et al., 2012). Second, it also highlights the availability of social support for these patients: most participants live with the patient. Third, this may indicate that patients and their relatives/friends are disposed to discuss KRT (see Tables 1 and S1).

Agenda for future research

Future research should include analyses among subgroups such as patients' children or young partners, who have received little attention in the literature to date (Morton et al., 2010; O'Hare et al., 2017; Tong et al., 2013). A focus on dyads of patients and relatives from the same family could allow an exploration of how they influence each other. Using an observation methodology could also help to identify relatives' behaviours during appointments about KRT.

Research has shown that family plays an important role in decision-making (Morton et al., 2010). However, some relatives may feel disregarded by health professionals (Lamore et al., 2017). Including relatives in education on KRT options, especially when family relations are supportive may allow for more adequate decisions. Until now, decision aids (i.e., online, print or video media informing people about treatment options) in nephrology are

intended for patients only (Davis & Davison, 2017; Drug and Therapeutics Bulletin, 2013). Creating a decision-aid addressed to patients and their relatives/friends could inform relatives about KRT and help families take part in treatment decision-making if they so wish. It could also be used as a discussion material between patients, their relatives/friends and the multidisciplinary team.

By focusing on how relatives and friends expressed their experiences, statistical text analysis allows us to highlight implicit elements of their discourse. In particular, for researchers who wish to study controversial topics, such as family's influence on decision-making, it allows an investigation of how individuals/institutions talk about it. In that, it helps answer very specific research questions at the border of psychology and linguistics.

Conclusion

The results of this study showed how relatives and friends adapt to CKD and the crucial role they play in KRT decision-making. Interventions targeting patients' relatives and friends would help prevent the emergence of anxiety and depressive symptoms. It seems appropriate to offer patients the possibility of inviting relatives/friends to education sessions if they so wish. This would bring recognition for the role that relatives and friends may play during this period and provide them with the information they need. The results showed that relatives and friends mainly report a listening role during the KRT decision-making period, but also describe other roles (e.g., expression of opinions). The use of disjuncts emphasises their subjectivity regarding their role in KRT decision-making, highlighting how their position in this process is inherently personal. Their role depends on them, the patients, the family and social context. Moreover, they report information needs. Although some of our participants stated that CKD had little effect on their day-to-day lives, some of them talked about the physical, psychological and social effects the illness has had and would have on their lives.

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Box 1: Topics addressed in the interview guide

- Current experience with CKD
- Knowledge and perception of KRT
- Discussions with the patient regarding KRT decision-making
- Roles in decision-making

Table 1. Descriptive statistics of the interviewed relatives and friends

	Interviewed
	<i>n</i> = 56
Sex (% women)	75%
Mean age in years (<i>SD</i>)	56.4 (13.9)
Relationship to the patient	
Partner (%)	61%
Child (%)	21%
Other (%)	18%
Living with the patient (% yes)	66%
Occupational status	
Full-time employment	39%
Part-time employment	11%
Unemployed (with compensation)	1.8%
Unemployed (without compensation)	1.8%
Disability leave	1.8%
Retired	43%
Other	1.8%
Level of education	
≥12 years	54%
9–12 years	34%
≤9 years	13%
Missing	0.0%
Presence of chronic illness	
Any illness %	55%

CKD (%)	0%
Hypertension (%)	25%
Diabetes (%)	5.4%
Other (%)	32%
Missing	1.8%
Patient's CKD stage	
Stage G3	45%
Stage G4	48%
Stage G5	7.1%
Depression	
Mean score (<i>SD</i>)	4.5 (3.8)
Status (% depressed participants)	16%
Missing	7.1%
Anxiety	
Score	7.2 (4.6)
Status (% anxious participants)	39%
Missing	1.8%
Close other's influence of treatment choice	
Discussion about treatments (% yes)	64%
Missing	0.0%
Mean influence (<i>SD</i>)	11.1 (6.5)
Missing	8.3%

¹Stage G3: moderate CKD, eGFR 30 to <60 mL/min/1.73 m²; Stage G4: severe CKD, eGFR 15 to <30 mL/min/1.73 m²; Stage G5: kidney failure, eGFR < 15 mL/min per 1.73 m².

Class 1 (33%)		Class 2 (33%)		Class 3 (18%)		Class 4 (16%)	
<i>Listeners with an opinion</i>		<i>Coping with CKD on a daily basis</i>		<i>Narrating patients' nephrological monitoring</i>		<i>Emotions behind facts</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>
Give	254	Life	183	Local	315	Renal	537
Question	204	Try	109	Hospital	169	Insufficien+	452
Talk	121	Live	103	Blood	136	Kidney	110
Listen	111	Way	66	Hour	136	Heart	104
Ask/put*	97	Daily	65	Professor	94	Illness/disease*	87
Brother	92	Manage	62	Month	89	Surger+	80
Sister	88	Morale	59	Follow	78	Diabet+	70
Ask	82	Thing	51	Night	75	Immun+	68
Opinion	67	Force	50	Examination	64	Auto	67
Compatible	65	Take	47	Bed	62	Crisis/outbreak*	66
Information	54	Do	41	Call+	60	Affected	66
Donation	53	Give back	34	Urologist	60	Cortisone	57

Answer	49	Easy	32	Sleep	59	Cardiac	56
Need	48	Complicate	30	Car	59	Rejection	55
Hear	47	Think	29	[Names]	59	Stabilise	55
Doctor	43	Certainly	26	Sample/taken*	56	Problem+	50
Alive/living	39	Realise/count*	25	Doctor	56	Decrease	46
Know+	35	Constraint	25	Analysis	55	Antirejection	45
Offer	35	Yeah	24	Call	54	Sword	44
Discussion	35	Physical	24	Go out/leave*	52	Rate	44
Dad	34	Keep	22	Scanner	52	Damocles	44
Choose	34	Say+	21	Visit	50	Perform a transplant	43
Choice	34	Action	21	Machine	50	Gout	40
Daughter/girl	33	Change	21	Day	48	Level	40
<i>Supplementary forms</i>		<i>Supplementary forms</i>		<i>Supplementary forms</i>		<i>Supplementary forms</i>	
No	45	That	22	Was (<i>third person</i>	51	Since	24

I	44	Our	22	<i>singular)</i>		Is	19
Me	29	Like/as*	21	By	41	Above	17
Have (<i>second person plural)</i>	26	Finally/well*	19	Have (<i>third person singular)</i>	29	Anti	15
Would be	24	It is	19	There	29	There is	15
Have (<i>first person singular)</i>	23	Have to/must*	17	He/It*	26	Because	13
		<i>Significant absences</i>		Had (<i>third person singular)</i>	26	<i>Significant absences</i>	
		Kidney	-68			I	-40
<i>Significant absences</i>		Renal	-63			Go	-33
Life	-74	Give	-60	<i>Significant absences</i>		See	-29
Renal+	-58	Question	-52	I think	-35	Not	-23
Live	-41	Ask/put*	-51	Give	-31	Give	-23
Insufficien+	-40	Insufficien+	-48	Life	-28	Listen	-19
Local	-38			No	-24		
Try	-32	<i>Variables</i>		Live	-24	<i>Variables</i>	
		Anxiety	29	It is	-24	Stage G3	44

<i>Variables</i>		Women	14	<i>Variables</i>		Men	35
Stage G4	29			Parents	70		
No anxiety	27			Depressive symptoms	39		
No depressive symptoms	18			Discussions about treatment choices	21		

*This word has different meanings in French

Note: all chi-square values are significant at $p < 0.05$

Figure 1. Descending hierarchical classification

Table 2. Examples for each class

Class 1: Listeners with an opinion	
	Quote 1 <i>‘We first talked about [living donor transplantation] with his family because he was pondering on it. For diverse reasons, he did not want to ask his brother, and my in-laws are too old, so the question is, haha, well there weren’t a lot of other possibilities!’</i> Claudia, 68, partner
	Quote 2 <i>‘When uh my wife needs to talk about it, well, I listen, I give my opinion, I try to have a benevolent and I’d say reassuring answer.’</i> Elias, 40, partner
Family discussions	Quote 3 <i>‘Oh well, that I can’t tell! Describe my role. Well, I was, I offered to be a living donor full stop.’</i> Claudia, 68, partner
	Quote 4 <i>‘I’ve talked a lot uh with friends who are nurses, physicians, uh... to find the available options.’</i> Nour, 40, partner
	Quote 5 <i>‘There’s the third element of the family, my daughter, who is uh she’s worked, she’s a pharmacist but she did a 6-month internship in nephrology, so she knows the practical stuff. If ever [patient’s name] need a practical advice on this topic, it’s my daughter who would intervene.’</i> Jade, 59, mother
	Quote 6 <i>‘We’ve talked about [living donor transplantation] in front of his brother who did not offer to be a donor for all that.’</i> Claudia, 68, partner
Discussions with the	Quote 7 <i>‘It’s, it’s [the procedures to be living donor] something worthy of a crime investigation from the police. Everything,</i>

<i>patient</i>	<p><i>everything is covered! So, it's a serious thing. Not only your blood type has to be the same, the rhesus too!! Okay good, now we go on.'</i> Idris, 73, partner</p>
Quote 8	<p><i>'Once again, I've been favourable to organ donation for a long time, and well, organ donation between living people, as long as we know that we are monitored way better than in the daily life of an average individual...'</i> Claudia, 68, partner</p>
Quote 9	<p><i>'I tell him: "How do you want to make a decision? If you had to make a decision tonight, would you be able to make it serenely?"'</i> Anaïs, 52, partner</p>
Quote 10	<p><i>'But it's him alone who will make the decision, yes.'</i> Corinne, 65, partner</p>
Quote 11	<p><i>'I give her advice, well they are ridiculous, I am not a doctor uh, I have no medical knowledge.'</i> John, 71, brother</p>
Quote 12	<p><i>'I think he would want, regarding his own experience, to know what she thinks about this. Know what she thinks about this topic. But she would intervene only if he asks her too.'</i> Virginia, 51, partner</p>
Quote 13	<p><i>'I told him: "If we are married or anything, I give all my organs if it can help, oh it is so necessary to do it!" So we had already talked about it.'</i> Claudia, 68, partner</p>
Information-seeking as a role, need and concern	<p data-bbox="419 1751 1374 1859">Quote 14 <i>'It's his choice. Of course. No, no, I don't think I had an influence. I didn't try to have any.'</i> Violette, 72, partner</p> <p data-bbox="419 1899 1374 1998">Quote 15 <i>'That's it, it's not me, I didn't impose anything. She asked for my opinion, I gave it to her, we talked about it and that's all.'</i></p>

in KRT	Robin, 58, partner
decision-making	Quote 16 ‘The role I have? Well, I am attentive to what he tells me because he knows his illness.’ Bertrand, 55, partner
	Quote 17 ‘ <i>[The consultations] go well. As I told you, I listen, I can ask questions when I find there are not enough information, or I can give information he forgets to give.</i> ’ Romane, 68, partner
	Quote 18 ‘ <i>I told him: “Listen, I need to know,” so I still got tested to know if it was possible for me to be a donor.</i> ’ Ines, 57, partner
	Quote 19 ‘ <i>I do some research and I inquire, and well ask questions to physicians.</i> ’ Maryam, 63, partner
	Quote 20 ‘ <i>I’m not going to look for an answer on the Internet, my occupation is not to be a doctor.</i> ’ Solène, 42, child
	Quote 21 ‘ <i>As long as he [the patient] does not ask me any questions, I do not bring the topic. Because I think it’s not good.</i> ’ Carla, 63, mother
	Quote 22 ‘ <i>But the question well the last question so it, what will the interview be used for? First, the questionnaire, what was it used for? And your interview what will it be used for?</i> ’ Julie, 59, sister
	Quote 23 ‘ <i>We haven’t talked much about this, yeah. We should rediscuss it, it’s a good question to ask her haha. I think I’m going to talked about it as soon as this evening.</i> ’ Yassine, 47, partner
	Quote 24 ‘ <i>You asking this question, you make me rack my brains in a way.</i> ’ John, 71, brother

Class 2: Coping with CKD on a daily basis

**Impact on
their way of
life**

Quote 25 *'He loves everything that is bad for him now, so there are almost always restrictions. A radical change in alimentation, activity.'* Ines, 57, partner

Quote 26 *'We aren't restrained a lot. We can still do a lot of things.'*
Anne, 68, partner

Quote 27 *'I think that when it happens, we will try to face this together.'*
Karen, 65, partner

Quote 28 *'I'm under the impression that she's gone into a life-long battle to try to live as well and as long as possible.'* Justine, 48, child

Quote 29 *'We've made, we've adapted, we've made a positive spin out of it, to move forward.'* Virginia, 51, partner

Quote 30 *'I'm not here to repeat him every time: "You must be careful, you have to do this, to do that." At one point, you must take responsibility for your own life.'* Armelle, 69, partner

**Current and
future**

Quote 31 *'He realises that yeah there are solutions and that, indeed, there will be complicated times but uh, times we will face uh together.'* Nour, 40, partner

**constraints on
the couple**

Quote 32 *'He's fed up with this life full of constraints! Dialysis would be an enormous constraint more!'* Anaïs, 52, partner

Quote 33 *'What I struggle with is not being able to, it's been 4 years since we last left on holidays. We can't do anything.'*
Maryam, 63, partner

Quote 34 *'I told him: "Do you realise that we won't be able to move as*

		<i>we wish etc.</i> ”’ Anaïs, 52, partner
	Quote 35	<i>‘And there’s a whole ritual of, yeah... To be clear, it’s [home dialysis] a bit of a mood killer, a bit, or a lot. It really touches the couple in its intimacy.’</i> Ines, 57, partner
	Quote 36	<i>‘It wouldn’t medicalise our home. It’s, how to put it, the disease wouldn’t come into the home, into the bedroom.’</i> Maud, 71, partner
	Quote 37	<i>‘It’s not something we’re thinking about all the time and, and it does not limit our life.’</i> Karen, 65, partner
	Quote 38	<i>‘I imagine him very weak and uh, not at all in a good emotional state.’</i> Anaïs, 52, partner
	Quote 39	<i>‘There are times when they blow hot so we are in high spirits and there are other times when they blow cold so we are in low spirits.’</i> Claudia, 68, partner
Physical and emotional impact	Quote 40	<i>‘It’s a whole logistical organisation to manage daily life in his place, trying to help him manage his everyday life.’</i> Solène, 42, child
	Quote 41	<i>‘I’m still trying to make plans, things so we can tell ourselves: “Well, we’ll see what happens next.”’</i> Armelle, 69, partner
	Quote 42	<i>‘We want to keep our spirits up, we always have. Well, we’ve always tried to move forward and without looking back.’</i> Idris, 73, partner
Class 3: Narrating patients’ nephrological monitoring		
Significant events	Quote 43	<i>‘I’ve called the emergency medical services and the man told me: “It’s most likely a renal colic, bring him at the hospital’s</i>

emergency service.” We’ve got there, fortunately we knew, so I tell the girl: “Most importantly with the disease he has, no anti-inflammatory drugs.” Carla, 63, mother

Quote 44 *‘I had to take the car, go fetch the car, take the car, uh come back here, go back, see?’* Naomi, 56, partner

Quote 45 *‘He has uh fragmented sleep, that’s to say, at night he goes to sleep between 9 or 11, in front of the tv of course.’* Hélène, 65, partner

Quote 46 *‘He had trouble going at other people’s house because he wetted his bed until he was 15.’* Carla, 63, mother

Quote 47 *‘I’m telling you uh we’re waiting for January to listen to what the doctor has to say regarding the last blood tests.’* Joseph, 67, partner

***Nephrological
monitoring***

Quote 48 *‘[Naming nephrologists] were very good. Well now they are retreated.’* Carla, 63, mother

Quote 49 *‘The surgeon who performed the surgery at the time was doctor [name], not to mention names.’* Joseph, 67, partner

Class 4: Emotions behind facts

Quote 50 *‘To me it’s a constant uncertainty about the disease evolution, so it’s hard to look ahead.’* Axel, 67, partner

***Fearing the
future***

Quote 51 *‘When they have diabetes, when they have cholesterol, well all of that, of course diabetes or other diseases uh prevent from staying out of dialysis for as long as possible.’* Artus, 71, partner

Quote 52 *‘I might as well not talk about the cardiac thing, because to*

him it's way more... The heart is way more emblematic than the kidney for sure. And the kidney, it's as if he was forgetting about it.' Aline, 57, child

Quote 53 *'Well, he was between life and death because during the surgery his heart stopped twice.'* Naomi, 56, partner

Quote 54 *'He's had an eye tumour uh a few years back.'* Erika, 45, child

Quote 55 *'I really didn't want for him to endure a very long dialysis, to be on a long waitlist and to live with this constant fear that the phone won't ring.'* Agathe, 30, partner

Quote 56 *'And there's always this Damocles's sword above our heads that is here, here for her and for me too because of other things pff.'*
Idris, 73, partner

Quote 57 *'We had been told that dialysis was terrible, we had been told that transplantations oh dear, we had to be on a waitlist for 3, 4 years, 5 years. Well, anyway.'* Nour, 40, partner

Quote 58 *'It's going uh well, with gout attacks but in general it's okay. We're moving forward with the challenges as they come.'*
Solène, 42, child

**CKD, one
illness among
others**

Quote 59 *'I had one. 'Which cancer?' 'Breast', that's it. 'So you can't give your kidney.'* Claudia, 68, partner

Quote 60 *'Apparently he said that it was really, it was severe.'* Maryse, 71, partner

Quote 61 *'As well as her kidney disease, she had big problems, her*

illness also attacked her lungs.’ Axel, 67, partner

Quote 62 *‘It’s [CKD] a source of concern among others because I
always worry about the rest too.’ Yassine, 47, partner*

Quote 63 *‘With kidney disease what I find very uh violent to live with is
the wait.’ Agathe, 30, partner*
