General Practitioners' representation of early-stage CKD is a barrier to adequate management and patient empowerment: results of a phenomenological study.

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TITLE PAGE

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Author contributions

AOE and OM conceived the study, with developments also supported by GT and IK.

AOE, GT and IK coordinated the study promotion, inclusions, and collected and transcribed the data.

AOE, GT and IK analyzed and triangulated the data with the help of GB and OM.

AOE and OM drafted the manuscript, with significant contributions from GB, GT and IK.

All authors viewed the different versions of the manuscript and provided critical input prior to final approval.

ABSTRACT

Background: In high-income countries, chronic kidney disease (CKD) affects over 10% of the population. Identifying these patients early on is a priority, especially as new treatments are available to reduce the risk of cardiovascular and renal morbidity. We aimed to understand the management and care pathway of patients with early-to-moderate CKD defined by an estimated glomerular filtration rate (eGFR) $\geq$ 45 mL/min/1.73m^2 (CKD-EPI), by analyzing the experience of general practitioners (GPs) in a region in France.

Methods: This qualitative semiopragmatic phenomenological study analyzed in-depth interviews held with a purposive sample (age, gender, training, type of practice, rural/urban context) of 24 GPs, with triangulation of research until data saturation.

Results: From diagnostic, etiological and prognostic viewpoints, the GPs in our study perceived CKD as a complex, poorly-defined clinical entity in asymptomatic and multimorbid patients. They distinguished it from a rare condition they considered as 'mainly renal'. The fact that they did not perceive early-stage CKD as a disease was a hindrance to patient care, which aims to protect the kidneys in a preventive approach. Indeed, GPs perceived CKD patient management as a care pathway requiring a personalized, multidisciplinary integrative model, common to all chronic diseases, without necessarily involving a nephrologist.

Conclusions: This study demonstrates how the GPs' representations influence their attitudes and interventions. Clarifying the concept of early-stage CKD by taking factors like age and etiology into account would facilitate personalized management of this heterogenous, often multimorbid, population. Finally, organizational models to support patient empowerment in an integrative care pathway must be validated.

KEY WORDS

Care pathway

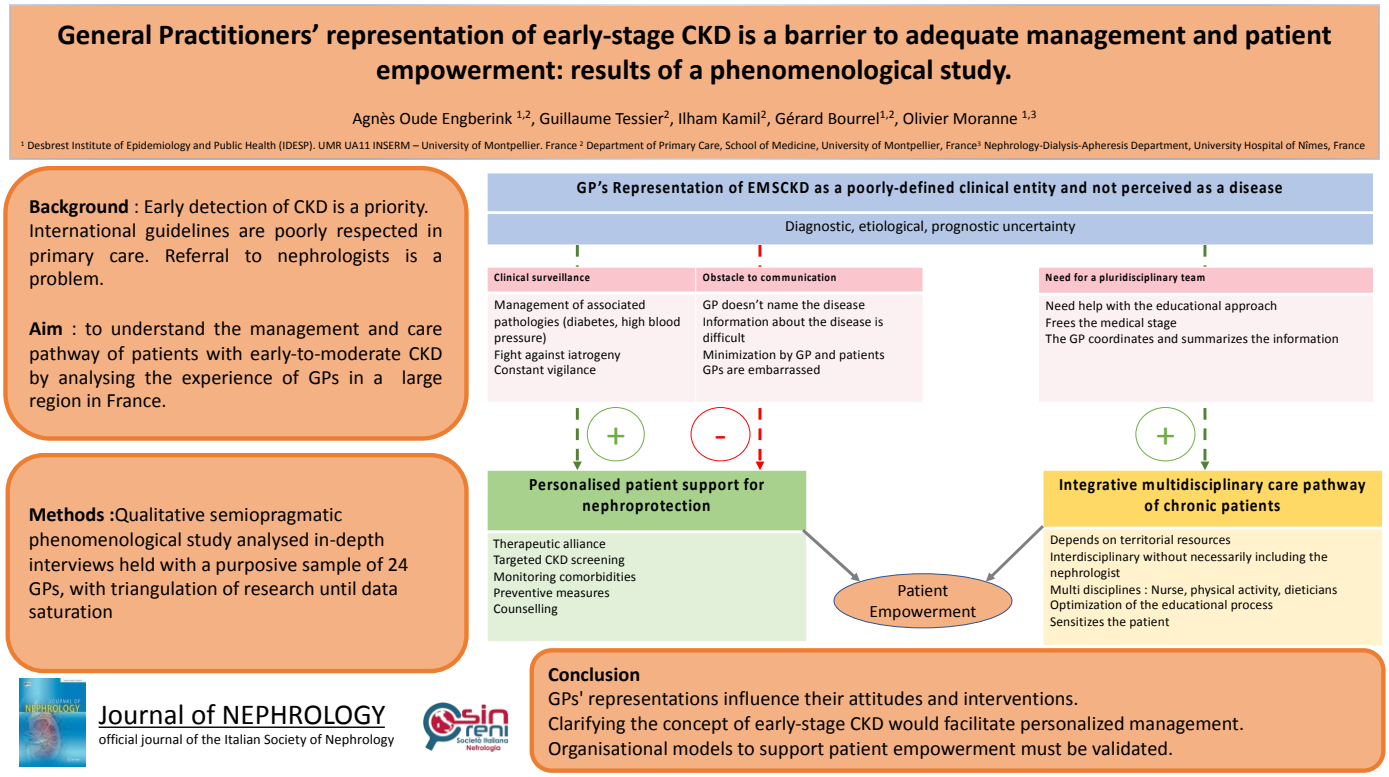
Chronic Kidney Disease

General Practitioners

Primary care

Qualitative study

GRAPHICAL ABSTRACTS



INTRODUCTION

Chronic non-communicable diseases (CNCDs) are a global public health issue. To manage patients with these diseases, it is necessary to establish a care pathway shared by several different professionals and develop specific models [1]. Among all CNCDs, Chronic Kidney Disease (CKD) affects over 10% of the population in high-income countries and is associated with a high risk of morbidity and mortality, particularly from cardiovascular events and end-stage kidney disease [2,3].

Identifying these patients early on is essential to improve their care cost-effectively, especially as new treatments to reduce the risk of cardiovascular and renal morbidity in the early stages are available [4]. Indeed, renal replacement therapy is costly for a small number of patients with a lower quality of life [5]. In 2019, the KDIGO (Kidney Disease Improving Global Outcomes) conference on 'Early Identification and Intervention in CKD' reached a consensus that early detection and management should ideally be performed in primary care, adapting to the local context [6]. But such care is subject to the prevalence of the disease in the general population, the shortage of nephrologists [7] and the fact that serum creatinine and albuminuria are the only main accepted screening tools for patients at risk [8]. However, Tonelli's work [9] suggests that, although early screening is relevant regardless of the country's level of wealth, uncertainties remain as to the best way to avoid over-

screening and what strategies should be adapted to optimize the management of screened patients in rich countries. Moreover, according to the various indicators [10] CKD is reported as being the disease with the most complex care pathway, and Elliot *et al.* highlighted clinical pathways that differed in design, content and implementation [1].

In view of this complexity, the KDIGO international guidelines [8] and the recommendations of the French Haute Autorité de Santé (HAS) [11] suggest that patients should be managed according to a prognostic classification in stages, defining a care pathway that includes screening for the early stages (defined by an estimated glomerular filtration rate (eGFR) $\geq$ 45 mL/min/1.73m^2) in populations at risk, implementing nephroprotective measures, then referring advanced-stage patients to a nephrologist for treatment. However, in their systematic review, Weckmann *et al.* showed that clinical practice guidelines may vary from one country to another [12].

Although it is essential to involve primary care providers like GPs, nurses and advanced practice nurses (APNs) to manage the early stages [13], co-management by GPs with nephrologists appears complex in practice [14]. Guidelines are not well-respected [15] as early CKD is often missed by GPs [16]. Studies highlight the difficulties experienced by primary care professionals when faced with a pathology affecting asymptomatic subjects. Discussing the diagnosis is complex, with a lack of conviction for guidelines that may lead to a risk of overdiagnosis [17]. Keeping up-to-date and applying the latest guidelines is problematic for GPs [18]. In a systematic review of qualitative research about barriers and levers to detecting and/or managing CKD in primary care, Neale *et al.* suggest that there is a need to develop practice guidelines tailored to multimorbid patients [19]. In this context, care pathway procedures to improve the management of early-stage CKD in primary care, in accordance with the guidelines, remain to be identified [6]. A few studies have addressed the subject with qualitative research methods adapted to understand complex phenomena such as the behavior of GPs, their perception of the disease and the gap between guidelines and practices [14,17-18]. No studies have ever used semiopragmatic phenomenology to study the real-life experience of GPs. This is the only analysis method that uses a principle of ordering, limiting the researcher's interpretation bias, without restricting the emergence of innovative data [20].

Our aim was to better understand the management and care pathways of patients with early-to-moderate-stage CKD (i.e eGFR $\geq$ 45 mL/min/1.73m^2 (CKD-EPI)) by analyzing the experience of GPs in a region in France through a semiopragmatic qualitative study.

MATERIALS AND METHODS

COREQ recommendations were applied to write this paper [21].

Study population and participant characteristics: purposeful sampling of general practitioners (GPs) in a French region.

GPs were recruited via listings kept by the Departmental Council of the Order of Physicians and by the on-call medical centers from all five departments in the East Occitania region, covering a catchment area of approximately three million inhabitants. An information letter was sent to the GPs by e-mail beforehand, and completed by a face-to-face or remote interview for those who volunteered. We carried out purposeful sampling aimed at a diversity of experiences of the GPs. Recruitment criteria were: age, gender, race, type, location and practice setting (rural, semi-rural, urban), and nephrology training or experience. These data were collected through a questionnaire.

Purposeful sampling [22] is used in qualitative research to select participants whose experience will provide a wealth of information about the phenomenon under study.

The following recruitment criteria were used to recruit participants with a variety of singular experiences relevant to our research question: age, gender, ethnic origin, location (rural, peri-urban, urban) and practice setting (individual, group practice, group practice with prevention nurse or interdisciplinary care structure) as well as training or experience in nephrology/geriatrics. These data were collected through a questionnaire added to Supplementary Information.

Two thousand and twenty-two GPs were informed by e-mail from lists held by the Departmental Council of the Order of Physicians and the on-call medical centers from all five departments in the East Occitania region. Twenty-six GPs, with a variety of characteristics, were contacted directly by the investigators. None of them refused to take part, so they were considered as a group of volunteers. An information letter was sent to them by e-mail beforehand. This was followed either by a face-to-face or remote interview.

Data collection method: in-depth interviews

Two investigators trained in the method (GT (male), IK (female), junior GPs preparing their practice thesis) conducted in-depth, semi-structured interviews using an interview guide focusing on true experience, designed by a methodological team composed of two researchers in qualitative methodologies (AOE, GB) and one

nephrologist (OM). The guide was elaborated from phenomenological questioning to stimulate the participant's reflexivity and explore the different dimensions of the phenomenon under study (management of early-to-moderate-stage CKD patients and their care pathway) (Supplementary Information 2). The first question explored GPs' representations of early-to-moderate stage CKD (EMSCKD), the second explored their general experience with these patients, the third aimed at recalling a singular true experience with an EMSCKD patient, the fourth explored their care pathway management relative to the nephrologist, and the fifth proposed a summary of essential points.

The methodological team checked the relevance and comprehensibility of the questions during the first two test interviews and proposed a final version incorporating a question on etiological diagnosis and their sources of information (Supplementary Information 3). Follow-up questions or prompts sought to explore true experience as authentically as possible. In practice, the investigator explained the principles of the interview (confidentiality, benevolence and freedom of speech). Interviews were recorded with sufficient sound quality to produce audible, understandable voice files. Each interview was transcribed verbatim by the investigators and anonymized by coding (G1 for the first interview, G24 for the last). Nonverbal data were not analyzed. Data collection and analyses occurred simultaneously, enabling concurrent quality control checks of transcripts, iterative adjustments to the interview guide, and assessment of data saturation when new data did not provide any new insights.

Data analysis method : semiopragmatic phenomenological analysis

Semiopragmatic analysis is a specific phenomenological approach for categorizing real-life experience recorded in interview transcripts [20].

Analytical procedures are listed in Table 1 and were performed according to a semiopragmatical data interpretation procedure inspired by C.S. Peirce [23], completed by a constant comparison process [24]. The researcher takes into account all the semiotic elements of a text, including linguistic and contextual clues. Empirical categories emerge by constant comparison within a verbatim and between verbatims. This analysis leads to the logical ordering of these empirical categories. Typically, as a result of this ordering, the conceptually densest category (i.e., of the highest level in the hierarchy of signs) commands the meaning of the phenomenon at stake. The last stage consists of restoring the global meaning of the phenomenon in all its dimensions in the form of an integrative summary statement. Continuous comparison increases the generality of the categories to

the point of theoretical saturation, at which point the analysis no longer provides any new information and sampling can be stopped.

Analytical procedures are listed in Table 1, A more detailed description of the semiopragmatic approach is available in supplementary information 4. The analyses of the two experts, two investigators and the nephrologist were compared by triangulation (a process whereby several researchers combine their analyses).

The configuration of a saturated category is then presented in boxes.

Research ethics

This study was conducted in accordance with the Declaration of Helsinki and the General Regulations on Data Protection. All participants had given written consent before inclusion.

RESULTS:

Characteristics of participants

Out of 26 volunteers, saturation was obtained after including 24 GPs. Out of 26 volunteers, saturation was reached after the 22nd interview, confirmed by the analysis of 2 additional interviews which did not provide any new categories. Inclusion therefore ended after the interview with the 24th GP.

The sample is described in Table 2.

Data analysis:

Three categories emerged from the semiopragmatic analysis: (1) The GPs' perception of EMSCKD, (2) How they manage patients with EMSCKD and (3) Their experience of the care pathway. Each is written in the form of a phenomenological statement in the present tense, in italics, as a paragraph heading, incorporating all the subcategories or dimensions. Their logical construction is explained below each heading. Text boxes are used to highlight the most illustrative quotations, chosen for their relevance to the general category. They do not present the answers to the questions in the interview guide but illustrate the construction of the phenomenological categories from the verbatim. When several participants expressed the same idea, we only added their code after the chosen quote.

Participants were coded according to their role and inclusion number (GP1 for the first general practitioner and GP24 for the last).

Category 1: GPs consider early-to-moderate-stage CKD as a common, complex, clinical entity, still not perceived as a disease because its diagnostic, etiological and prognostic aspects are poorly-defined in asymptomatic patients, making them feel uncomfortable.

When general practitioners were asked what EMSCKD represented for them, they mentioned a clinical entity that was 'ultra-common' (GP11) and complex because it was 'unclear' and 'silent' due to its 'asymptomatic' nature (GP1). Based on the eGFR alone, the interpretation of which varied from one physician to another, they diagnosed it as an 'alteration in renal function'. It was still not perceived as a disease but, rather, as 'a symptom or syndrome' (GP6, GP18), both by themselves and the patients 'who don't feel ill' (GP20). GP22 complained about not having a clear clinical definition of EMSCKD, with 'an eGFR > 60 or between 45 and 60'. The question about the etiology of renal failure made them feel uncomfortable (GP2, GP20) because it reminded them of the 'obscure' 'undigestible' (GP1) pathophysiological facts they had learned during their studies. All GPs reduced the etiology of CKD to cardiovascular risk factors and associated chronic pathologies (diabetes, hypertension), which they identified as a concept of polypathology, iatrogenic problem, or aging. As a result, the question of renal function cropped up for them 'several times a day' (GP11).

For GPs, the prognosis of EMSCKD was uncertain but not worrisome at the beginning, evolving slowly over the years, because many of their patients 'live very well with a low eGFR' (GP9). However, GP8, GP10, GP17 and GP24 felt helpless faced with the 'inescapable' progression of which they felt as if they were 'onlookers' and for which they had 'no means of curative intervention' (GP17).

Finally, they distinguished EMSCKD from the nephrologist's CKD, a rare clinical entity whose etiology was an isolated or purely renal 'glomerular or tubular disease' (GP20). Its evolution and management were beyond their competences, particularly when 'deciding whether to do a kidney biopsy' (GP3). See Box 1: Verbatim details of GPs' representations of EMSCKD.

Category 2: GPs experience the management of EMSCKD patients as long-term, patient-centered support with a nephroprotective purpose through preventive and educational measures requiring a reflective, participative approach towards patient empowerment. However, it requires vigilance, constant reactiveness and investment from GPs, which some experience as a constraint, with representations that seem to be a major obstacle to implementing support effectively.

Faced with what they saw as a poorly-defined clinical entity with a progressive evolution, GPs used the word 'support' to describe the essence of long-term EMSCKD patient management. This was a global approach

‘focused on patients rather than the disease’ (GP8) seeking therapeutic alliance and commitment based on a relationship of trust, considered as a priority for good follow-up. Its purpose was to ‘slow down the progression of CKD as far as possible’ (GP2) with preventive nephro- and vasculo-protection measures, hygiene and dietary rules, control of associated pathologies and ‘paying attention to nephrotoxic therapies’ (GP3). Support was a dynamic process requiring a reflective approach towards prevention and health education, starting with the announcement, and its purpose was to ‘make patients aware’ and ‘make them understand’ the risk of potential disease at an asymptomatic stage. The aim was to lead them towards autonomy ‘by making them participate actively in their own monitoring’ (GP21). In practice, it began with an initial clinical, blood and urine workup and ultrasound assessment, followed by ‘regular monitoring adapted to the patient to assess how far it has progressed’ (GP18) according to the decline in eGFR, albuminuria and age, with the help of a computerized medical record that some GPs have adapted. All GPs said they did ‘proteinuria’ or ‘albuminuria’ tests to monitor the patient but not for diagnostic purposes. If the condition worsened, some GPs anticipated the complications of CKD ‘by updating vaccines’ (GP10, GP12). This follow-up required constant vigilance, paying ‘special attention’ to therapy and responsiveness, experienced as a difficult, restrictive investment (GP7). Although they felt comfortable establishing a therapeutic alliance, the fact that EMSCKD was not perceived as a disease seemed to be a major obstacle to providing clear information about ‘a pathology that is difficult to popularize’ (GP1). Indeed, it made it difficult to tell patients, and there was a tendency to minimize the situation with evasive speech ‘without talking about illness but about tired kidneys’ (GP18), reassuring them about the slow progression and favoring counselling messages. This minimization by GPs led to ‘patient minimization’ (GP3) which hindered the implementation of a reflective approach essential to empowerment, giving them a feeling of frustration.

See Box 2: Details of the verbatim for EMSCKD patient management by GPs

Category 3: For GPs, the care pathway for EMSCKD is part of a global pathway for patients with chronic disease. Ideally, they want to see a pathway starting with screening campaigns, integrating care professionals early on, to optimize support. In practice, it depends on territorial resources and does not necessarily require the nephrologist’s intervention at the early stages of CKD.

GPs felt that support could be optimized by a personalized, ‘integrated care pathway as in any global multifactorial approach to chronic disease’ (GP11). They believed that screening campaigns (GP18) and support with multi-professional skills (public health nurses, advanced practice nurses, dieticians, coaches for suitable

physical activity, psychologists) for the management of risk factors (sedentary lifestyle, overweight, smoking, stress) would save medical time and optimize the preventive, educational approach (GP12, GP22). In the field, this assistance depended on their mode of practice and territorial resources. Physicians practicing in integrated care systems with multidisciplinary teams felt that their preventive, educational work was optimized by multi-disciplinarity. In this process, general practitioners considered they had a central role in anticipating and coordinating care. Being the 'first link' (GP5) gave them the additional responsibility of monitoring deterioration and the information could circulate through them between the different participants. They summarized all the relevant information and made appropriate decisions for patients. Multidisciplinary providers (cardiologists, endocrinologists etc.) could also be involved in managing associated pathologies, but without necessarily including the nephrologist who had 'better things to do' (GP12) or did not seem 'interested in early-to-moderate stages' (GP17). The GP's felt their role was to 'prepare for the nephrologist's intervention' with regular check-ups if CKD progressed (GP18). For all of them, it was only when CKD worsened, or when they feel 'overwhelmed' (GP20), that patients should be referred to a nephrologist. Only a few doctors sought an initial contact beforehand to reassure themselves if things suddenly went wrong. They expected the nephrologist to supervise them with joint follow-up on specific points: further etiological investigations (like kidney biopsies), prognostic evaluation, management discussions. Regarding their relationship with nephrologists, their opinions varied: some GPs reported that nephrologists were not always available or involved in the early stages and 'not doing much more than GPs', but that they lost sight of patients when they were on renal replacement. For others, contact was simplified by telephone or referral platforms or by organizing advanced consultations in their territory.

Box 3: Details of verbatim for the EMSCKD patient care pathway

DISCUSSION

The general practitioners in our study seem to consider EMSCKD as a complex clinical entity in its diagnostic, etiological and prognostic dimensions in asymptomatic and multimorbid patients. The fact that GPs still do not consider EMSCKD as a disease for all patients is the main difficulty in caring for these patients. This seems to be an obstacle to providing communication and support, with the purpose of protecting the kidneys through a preventive, educational approach.

This was evoked in qualitative studies, one of which concluded that almost all practitioners doubted that EMSCKD was a real disease and that the reality of the disease was minimized to avoid upsetting patients in the

early stages [14]. Our results seem to reinforce the results of the third study [17] in which Dutch GPs perceived CKD as an abstract, rather than clinical, concept, concluding that it could hinder self-management and that educational strategies were required to improve the understanding of EMSCKD. The etiological approach to EMSCKD by general practitioners, reduced to the existence of a comorbidity, seems uncertain. Variations in international recommendations on prognostic stages warranting referral to a nephrologist [12] seem to reinforce their idea of a poorly defined entity [16]. This suggests the need to better specify the syndromic pattern with the etiology and age to help GPs differentiate between a risk marker, disease or ageing, in order to better plan the care pathway and indication for referral to a nephrologist [25]. In this context, GPs do not seem to know exactly what they should tell patients, and what, if anything, they can do beyond monitoring. This issue could be detailed in guidelines clearly addressing primary care [18], and with educational tools to improve communication and messaging for patients in the early stages [6].

Moreover, the question of when and how to announce chronic kidney disease seems complex, even for nephrologists [26].

Contrary to the literature stating that GPs rarely measure proteinuria [27], all those interviewed in our study measured it to monitor pathologies like diabetes. However, as reported by James *et al.* [28] and Weckman *et al.* [29], none seemed to have integrated it for CKD screening. Developing specific quality indicators for CKD screening and follow-up in primary care, subject to a performance-based payment system [30], could improve this strategy [31].

To date, the only recommended screening tools are the eGFR, though its significance according to age is debated [32], and the urine albumin-creatinine ratio (uACR), integrating both cardiovascular and renal risks [8,33]. The observation that patients are referred to nephrologists in breach of the guidelines [15, 34], and our results, raises the question whether the tools available to date are relevant for personalized patient care.

In practice, the participants envisaged their support from the early stages, as with any CNCD, as part of a personalized care pathway integrating competent care staff to support them, in a reflective, educational approach necessary for patient empowerment. Also, Vassalotti [35] showed that, for optimal management, a coordinated, multi-disciplinary system should be integrated to support GPs and meet the patients' educational needs.

Today in France, patients have free access to the GP of their choice. Our GPs represent the different modes of practice, with the majority coming from Multi-Professional Health Centers. These newly-created, coordinated care structures were inspired by models for global multidisciplinary care [36]. They include physician, nurses, advanced practice nurses, physiotherapists, pharmacists, and supportive care, and can accommodate student

placements. GPs working in these structures highlight the possibility of co-constructing 'personalized, integrative care pathways for chronic patients' facilitating access to local and territorial resources. This remains to be evaluated with a need to clarify the care pathway of the chronic kidney patient for primary care [9].

Finally, our study also raises the question of training for primary care stakeholders. Recently, Pesce *et al.* [37] demonstrated that providing training and network support from nephrologists for GPs could improve CKD awareness and increase its identification among patients in primary care, notably in high-risk categories.

This is confirmed by the review of Taylor *et al.* [38] which also underlines why such complex interventions on CKD are difficult to implement and require support at many levels.

The strength of our study is that it analyses EMSCKD by including GPs with diverse experience, but without specific training in nephrology, with varied modes of practice in different territories, representing a region of 3 million inhabitants. The qualitative semiopragmatic approach is original as it is the only methodology that includes a data ordering system, limiting the interpretation bias, and designating the GPs representation as the strongest determinant of their interventions.

However, the study does have limitations, with a possible bias in the selection of volunteers and doubts about the transferability of results to other populations with other health systems. Comparing our sample with that of regional GPs [39], in our study we observed a majority of GPs practicing in peri-urban areas and in multi-professional structures with a slightly younger median age. This could have introduced a selection bias. However, in a purposeful sampling approach, it is the experience of each individual that is essential, by interviewing doctors whose practice resembles the current reality. Nevertheless, the concordance of our results with those of qualitative studies carried out in countries with other health care organizations seems to favor transferability. Analyzing the data up to saturation point strengthens internal validity.

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No funding was received for conducting this study.

The authors declare they have no financial interests.

Ethical approval

This study was performed in line with the principles of the Declaration of Helsinki and was approved by the ethical committee of Nîmes University Hospital under the IRB number 201207.

Consent to participate

Informed consent was obtained from all individual participants included in the study.

Consent to publish

The authors affirm that human research participants provided informed consent for publication of this work.

Data Availability Statement:

Data (French anonymous verbatim) are available upon request from the corresponding author and may be provided to researchers with an analysis protocol.

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TABLES

Table 1: Stages of the semiopragmatic analysis.

Word-for-word transcription of recordings (French verbatim).
Reading using a floating attention, followed by focused reading.
Dividing the text into meaningful sections and assigning a theme to each one.
Identifying all textual and contextual clues relevant to the research question.
Semiotic characterization of these themes according to the theory of signs by C.S. Peirce.
Assembling and ordering these semiotic items to construct first-level empirical categories.
Raising these categories into a more general category by constant comparison up to theoretical saturation.
Modelling by ordering the main results into a comprehensive summary statement.

Table 2 Characteristics of the study participants

Characteristics	Participants (n=24)
Female sex	13 (54%)
Median age, yrs [IQR]	44 [36-61]
Department in a region of around 3 million inhabitants	
A	5 (21%)
B	6 (25%)
C	6 (25%)
D	6 (25%)
E	1 (4%)
Area of exercise	
Rural	1 (4%)
peri-urban	15 (62.5%)
Urban	8 (33.5 %)
Type of practice	
Individual	4 (16.5%)
Group practice	2 (8.5%)
Group practice + prevention group nurse	1 (4%)
integrative interdisciplinary care structure	17 (71%)
Median number of yrs of practice as a GP [IQ]	15 [6-33]
Time devoted to GP	
<25 %	1 (4%)
25-50%	2 (8%)
>50 %	21 (88%)
Number of patients per week	
<100	13 (54%)
>100	11 (46%)
Number of CKD patients per week	
<10	12 (50%)
10-30	11(46%)
>30	1 (4%)
Training, specific experience	
Geriatrics (home for elderly, diploma gerontology)	16 (67%)
Training course in nephrology (3 months)	1 (4%)
2 days training in nephrology	2 (8%)
Training in general medicine	5 (21%)
None	6 (25%)
Median duration of the interview min [IQR]	27 [20-32]

Category 1: GPs' representations of EMSCKD: a common, complex clinical entity, still not perceived as a disease.

Box 1

A common, complex entity for doctors, abstract for patients

GP5 'It was the daily bread'

GP8 'It's something complicated, not obvious or easy'

GP15 'Chronic Kidney Disease is an abstract idea for patients. They may well understand about heart attacks but what's chronic kidney disease?'

The GPs' diagnostic procedure is only based on the eGFR results in asymptomatic patients

GP10 'For me it's just a figure. I base myself on the eGFR. I consider chronic kidney disease as an eGFR below 45.'

GP3 'Below 60 you have to monitor closely'

GP12 'The patient doesn't necessarily feel ill.' GP20 'For the patients, kidney disease isn't something that really worries them.'

They reduce the etiology to the consequences of associated chronic pathologies, aging or iatrogeny, hampered by complex physiopathological knowledge.

GP1, GP22 'I often identify one thing: It's poorly-balanced diabetes which is beginning to turn into renal micro-angiopathy, or the badly-controlled hypertense patient who's starting to get nephro-angiosclerosis.'

GP9, GP18 'It's rather a consequence of something I already know, so I know the etiology most of the time.' 'Diabetes, hypertension, comorbidities, iatrogeny, aging.'

GP20 'Afterwards, the main obstacle may be a lack of knowledge of all glomerular and tubular diseases, which means that I get confused about the pathologies as soon as it starts to get a bit more detailed. So that can be a hindrance.'

An uncertain prognosis, not worrisome at the beginning due to slow, progressive evolution but inescapable for some helpless GPs.

GP9 'On the other hand, I know a lot of people who live very well with a much-impaired kidney function, so... It doesn't really scare me either.' GP11 'Most of the time, impaired filtration rates remain stable for a long time... I mean, take a long time to deteriorate.'

GP17 'Here, we're more of a spectator. We can give advice, we can guide them, but we're not going to be therapeutic and, it's a bit depressing.

GP21 'It's like a sword of Damocles [...], something the patient doesn't feel but is likely to cause great damage if it evolves'.

They distinguish this frequent entity from a rare entity, specific to the nephrologist, whose etiology and evolution are beyond their competence.

GP2 'From there on, very specific nephrological pathologies - if you like, nephropathies - and other glomerular pathologies, and others, I mean yeah, well, we're a bit confused.'

GP22 'After the second case, it will be chronic renal disease of immediate renal origin, discovery of a nephrotic syndrome, or something other than diabetes - for example, a systemic disease - and there we might get quicker access to nephrology.'

Box 2

Category 2: Management of EMSCKD patients by GPs : patient-centered support to slow down the evolution via preventive measures requiring a participative approach to health education, difficult to put into practice.

Long-term patient-centered support, based on a therapeutic alliance that requires commitment

GP7 'The relationship was very important [...]. And that required a little more investment from me, and demanded a little more energy.'

GP11 'So the patients need us to be there to accompany them throughout their pathology'.

GP21 'I think when you have illnesses like that which have a very uncertain evolution, if you have managed to build a relationship of trust, you will succeed in dealing with the patient'.

The aim is to slow the progression of CKD through preventive measures of nephrology and vascular protection

G10 'Well, to avoid this evolution, I tell you, I make sure that he eliminates the risk factors or that he/she treats his diabetes, that he treats his hypertension, I avoid the drugs that are not compatible with this chronic renal failure. I give him/her advice on physical activity, to move around a bit, not to stay at home, to stay well hydrated and lose weight if he's overweight.'

GP11 'The support is essentially support with hygienic and dietary measures. Support in adapting treatment and dosage'.

It requires a reflective and participatory approach to health education.

GP3 'We try above all to involve the patient so that he…that's to say, for management, the most important thing is that they also understands their illness and the issues at stake.'

GP9 'Once again, with the help of their values, of what's important to them, that's what motivational interviewing is all about.'

GP12 'Their place is also essential. They're the ones who'll really be able to manage the evolution of their disease, so it's true that one of our roles is also not to dramatize, to make them understand that it's something important and that they must adhere to this care project.'

It consists of a basic clinical, biological and ultrasound assessment, followed by regular personalized follow-up, using a computerized medical record.

GP2 'Generally, I have a minimal check-up that I do when there's a failure, once I've eliminated the problems of dehydration. Afterwards, depending on the associated pathologies [...] generally I do at least a proteinuria test, to see if there is a glomerular pathology, I do a renal ultrasound. To see if there is any obstacle, or any morphological renal anomaly.'

GP12 'Well, listen, we take a personal and family history, weight, height, check the blood test…if she/he's had a urine test…medication.'

GP19 'And then it's biological monitoring, so when it's at the beginning in general, I do an annual check-up, in the classic follow-up of these patients [...] And then, at a second stage, complementary exams if necessary. But I don't do it systematically, I try to adapt to each patient [...] especially as it depends on their age.'

GP11 'Ah, well, it's mostly kinetics. It's the kinetics. It's a function that changes significantly between two check-ups, so yes, I'll refer them quickly to the nephrologist.'

GP22 '…to define the stage, to see if there are predictive factors for poor evolution. I look at the previous check-ups.'

It requires vigilance, constant reactivity and investment on the part of GPs, which some experience as a constraint.

GP1 'especially a pathology with constraints, which is going to bother me.'

G16 'these are patients you always have to keep tabs on, as they can quickly deteriorate'.

GP14 'I think you have to be very pragmatic and you have to be very vigilant and very responsive'.

Their representation of an entity not perceived as a disease seems to be an important obstacle to patient empowerment, making the communication of information to the patient difficult with minimisation.

"Their representation of an entity that is not perceived as a disease seems to be a major obstacle to patient empowerment, making it difficult to communicate with the patient and minimising information."

GP12, GP20, GP21, GP24 'I don't talk to them about disease, because if it doesn't progress, I'm not sure it's a disease, at least as we understand it or as the patients understand it. I talk to them about alteration of the renal function and renal functions to preserve the kidney'. 'Your kidneys are a bit tired, and we're going to try and monitor that, and also rehydrate properly so that we can see, and check all that again.'

GP18 *'Well, in the early stages, I don't think they really realize. Maybe I don't tell them enough that their condition might get worse 'you have renal failure', 'I don't even know whether I mark it down properly in the file, in the case history'...*

GP3 'I think it's minimized, maybe by me and by the patients. [...] it destabilizes me, I didn't manage to convince them before.'

GP1 'I experienced it as a failure [...] patient education is interesting but complicated for a pathology that is more difficult to popularize.'

Box 3

Category 3: The EMSCKD care pathway: a global pathway focused on the needs of the chronically ill patient. Ideally, it would include screening campaigns and early integration of supportive care professionals to optimize support, but in practice it depends on the practice patterns and territorial resources and does not necessarily require a nephrologist to intervene.

A patient-centered global pathway to accompany patients with chronic disease

GP11 'Do we need a specific pathway? or a patient-centered pathway, rather than a disease-centered pathway? That's it.'

GP8 'it's the accompaniment [...] I don't make any more difference between a chronically ill kidney patient than with a diabetic, or any other pathology we have to deal with.'

GP22, GP13, GP16, GP21 GP6

Ideally, it is a multidisciplinary care pathway starting with screening for the early stages and then setting up regular follow-up integrating support from care professionals to develop prevention and health education.

GP19 'Maybe it could start with raising awareness about this disease, because there are also many patients who escape us, there are people who live to 65 years old who have not seen a doctor for 15 years...'

GP20 'So the great thing would be to have dieticians who are reimbursed so, regarding food, I think that would be really good.'

[...] some sessions with a psychologist (GP7) and then a sports coach for suitable sports to accompany them also on a daily basis.'

GP9 'Primary prevention, secondary prevention, even tertiary prevention. Obviously, that's what needs to be developed. But, in my opinion, it's not just the role of the attending physician who is in the care, because they can't do everything [...] The physician must have a role of orientation, of identification, of taking care of acute things and so on. But then they must be able to count on their team for this therapeutic education.'

GP21 'I think if there were therapeutic education nurses or similar professional profiles, it could be a resource to make them aware that there is a disease, even if it is very

early, even if it is asymptomatic.' GP2, GP11

It depends on the mode of practice of GPs and the resources in their territory. The development of coordinated practice structures could make it possible to set up structured chronic disease education programs and include patient associations.

GP22 'That's it, but I think it's a more general question, for all pathologies it's important to be in contact with all the professionals who take care of the patients, that's why I changed my practice for a Maison de Santé Pluridisciplinaire'

GP10 'After all, why not set up something like SOPHIA (a health education program) for diabetes, for chronic renal failure, why not? But afterwards, I'll tell you that I have a set of patients who resemble me, who are fairly well-educated.'

GP11 'it's developing types of coordinated practice with funding for patient education slots... Yes, it's something that already exists, but it needs to be improved, that is to say, made permanent, to really fund it, not with "small measures" sprinkled here and there. [...]'

GP12 'but patient organizations… I imagine that it could be interesting to see people who are going through the same thing. The thing is, we're still at the beginning, so the patient has trouble realizing what's going on, it's just a blood test, but the patient feels fine, doesn't necessarily have any tension. So, it's a bit complicated to set up. But there you go: maybe certain associations could be interesting.'

GP3, GP6, GP8, GP9

The GP claims a central role of anticipation and coordination. This care pathway includes various professionals to manage associated pathologies, but without necessarily requiring the intervention of a nephrologist at the early-to-moderate stage.

GP11 'I think that, in general, we are in the process of identifying and focusing regularly on how things are going and the objective scientific view, and then sharing the educational measures with the team' 'Because we really have a role to play in this. If there's something we can do quickly and easily, it's to modify our prescription, which can have an immediate impact [...] Accompany them on their journey with other specialists for polypathological patients. That is, to be able to explain to the cardiologist that there is renal insufficiency and that such and such an anticoagulant treatment or such and such an antihypertensive treatment cannot be used.'

GP9 'I find that, here too, I have the impression that nephrologists add a little bit more, I've done training on chronic renal failure [...] But in diabetics in particular, apart from trying to balance the diabetes, what can be done for renal failure? With a few ACE inhibitors, but afterwards... Ah, the nephrologist told me: "We have to know them, we have to see them". But what's the point? What you have to do is treat the cause, which is often the etiology, and for that you don't need a nephrologist. To balance diabetes, do you need a nephrologist or an endocrinologist or a cardiologist? It's a general practitioner you need more than anything!'

GP20 'Well, I must admit I rarely send them to the nephrologist at the early stage.'

GP21 'In the early-to-moderate stages, I think we are very central, because these are stages that will rarely go to the nephrologist and there is no point in going to the

nephrologist because it is monitoring and therapeutic education [...], and so the role of the general practitioner is really going to be almost complete accompaniment from A to Z.'

The reasons for referral to the nephrologist are heterogeneous. Although some GPs need a first reassuring contact, all express their limits when CKD becomes worse or more complicated. They then need coaching by the nephrologist to deepen the etiological and prognostic approach and the global management in joint follow-up.

GP1 'I prepare for the nephrological consultation' 'a resource person who is more competent than I am, but who has no involvement in managing the early stages"

GP10 'That if one day I have a disaster, he/she's there and I can call him/her: "You know our patient Mr./Ms. so-and-so has a clearance of 15, with a creatinine that has suddenly risen". So, I can call him/her in a hurry. I like to have a first contact with the nephrologist."

GP9 'Something that seems out of the ordinary. [...] If, on the other hand, there is significant proteinuria, oedema, if there is something that I cannot resolve, a tension that resists.'

GP11 'I expect them to first confirm the etiology, and then guide me to see if my practice is correct, especially in dealing with medication. They can give me a clue about medication management. But, in general, I've taken time beforehand to remove all the nephrotoxic medication and there you are. And, above all, they guides me in preparing for the continuation of the evolution towards the terminal phases, which take a lot of time.'

GP12 'So the nephrologist would have to get to know the patient, explain what it is, be careful, and then that's it. What can happen, what can we do if it gets worse, how far we can go and so on. For the nephrologist it's really her/his specialty. And so, what he tells me, I'm really going to follow his... Well, after that, it's always adapted to the patient. But I'm really going to follow his/her advice. And then I'm reassured that there's someone else who's been able to... That I didn't go completely the wrong way, that I didn't forget something. If I describe everything to her/him, he can tell me what she/he thinks... It's good to have several points of view sometimes in a difficult situation.'

Relationships with nephrologists vary according to personalities, the actions implemented in their area of practice and their previous experiences (feeling of disinterest in the early stages).

GP4 'When we ask questions, we are taken down a bit. I find they are not much of a support. They are not in the business of trying to teach us. You can see it annoys them a bit ....I find that as long as we are not in renal failure that requires dialysis, or at the limit of dialysis or transplantation, I find that they are not very present for us or for our patients.' 'For me it's really to have a second opinion about management, to be sure that we've done everything possible so that it doesn't get worse.'

GP6 'Finally, they don't involve us... The letters don't go into too much detail. Each time it's "Globally, Mrs/Mr. what's-her/his-name's condition is stable or changing, I'll see her/him again at such-and-such a date". 'We have some sort of line of conduct, of care, because it's true that we don't have the same experience as them.'

GP10 'But it's kind of the nephrologist's fault. They don't care. And when you phone them, they tell you 'Oh no, it's nothing, it's not serious, just keep an eye on it. So, you monitor the patient. And when they keep saying 'monitor, monitor, monitor', well, you monitor. Then, the nephrologist reassures us as long as they're not dialyzed, but from then on in the care pathway I no longer exist. I'm lucky if I ever see a return letter from a dialysis patient.'

GP3 'We can have a fairly quick contact for the management, even by phone with the nephrologists, there is proximity.'

GP20 'For the moment it's satisfactory. Before, I found it complicated, because access to the nephrologist was not easy and, I must admit, that since then there's an advanced consultation in the area where I work, it is true it makes things much easier for us, the access and the ease of getting appointments.'

GP19 'But that's what's already happening in fact, we have reports, I have all my patients followed by the nephrologists at the UHC, we have reports that are really exhaustive with things to watch for and complementation to watch as well.' GP12 'tele-expertise. And so there you have it. So, there are several platforms. And it's (platform name). And I get paid too! I don't know if it's 5 or 10 euros, whatever, per consultation. So, it's true it's not so bad. Because it takes time to really, you know, look at the file, and see the values that I send them.'

SUPPLEMENTARY INFORMATION 1

Participant characteristics questionnaire

Age :
Sex :
Exercise :
□ Urban
□ Rural
□ Semi-rural
Department of practice :
Training in nephrology?
- If yes, please specify :
Colleague / nephrologist contact?
Number of years in general practice :
Practice :
□ Private practice
□ Multidisciplinary health center
Number of patients per week :
□ ≤ 100
□ >100
Number of patients with chronic kidney disease per week :
□ < 10
□ 10 - 30
□ > 30
Time devoted to general practice :
□ < 25%
□ 25 - 50%
□ > 50 %
Interest in caring for the elderly :
□ Practice in a home for the elderly? If so, please specify :
□ Experience in geriatrics? If so, please specify:
□ Mostly elderly patients

SUPPLEMENTARY INFORMATION 2 : Interview guide, version 1

1/ What does chronic kidney disease represent for you, as a general practitioner? What does it mean to you?

2/ When you are faced with a patient with CKD before the replacement stage, what is it like? What are your needs?
What sources of information and tools do you use to manage CKD prior to the replacement stage? How do you use them? What do you think of them?

3/ Please take a moment to remember a patient you cared for who presented with early-to-moderate-stage CKD. What happened? What did you do? How did you feel about it? what was complicated and what was easy? ?
-Can you remember another situation that might have happened differently?
-Can you remember a patient with chronic kidney disease before the replacement stage that you managed in collaboration with a nephrologist?

4/ In the light of your experience, what do you think of the CKD patient's care pathway before the suppletion stage?
-What does the need to seek advice from the nephrologist mean to you? How do these exchanges take place in your practice?
-How do you see your place in the discussion and decision about replacement therapy (dialysis or transplantation)?

5/ If you had to sum up your feelings about managing chronic kidney disease before the substitution stage in general medicine, what would you say? What are the main obstacles you may have encountered? How did you overcome them? What improvements would you make?

SUPPLEMENTARY INFORMATION 3: Interview guide, final version

1/ What does early-stage CKD represent for you in practice? (What does it mean to you?)

2/ When you are faced with a patient with early-stage CKD,

- *What happens? What is your attitude? How do you make the diagnosis? How do you integrate the etiology in your diagnostic approach? What do you tell the patient (what words do you use to announce CKD) and when?*
- *What do you think the needs of an early-stage CKD patient are? And how do you respond to them?*
- *What sources of information do you turn to in order to meet these expectations/needs? How do you use them? What role do you give to CKD recommendations in your practice? How do you use them?*

3/ Please take a moment to remember a patient with early-to-moderate-stage CKD whom you've been seeing to. What happened? What did you do? What was a barrier or a facilitator? How did you deal with this complexity...or uncertainty? How do you deal with prognostic uncertainty?

- Can you remember a patient with early-to-moderate chronic kidney disease that you managed in conjunction with a nephrologist? How did it go? How did you coordinate with each other? How did you communicate?

4/ In the light of your experiences, what do you think of the care pathway for the patient with CKD from early-to-moderate stage?

- *What is the role of the GP in this care pathway? Try to prompt discussion of support, education and etiology*
- *What do you expect primarily from the nephrologist?*
- *How do the different protagonists in the care pathway fit together?*
- *What other professionals could be useful? How are you used to working with them for these EMSCKD patients?*
- *How do you see the place of early-stage CKD patients within this care pathway?*
- *What improvements would you like to see to make this care pathway satisfactory?*

5/ Following our exchange, if you had to summarize what you consider to be the essential points in managing early-to-moderate-stage chronic kidney disease in general practice, what would you say?

SUPPLEMENTARY INFORMATION 4

Supplementary information 3 of the main manuscript: Description of Semiopragmatic Analysis

“Semiopragmatic analysis (SPA) is a specific phenomenological approach based on C.S. Peirce’s theories for categorizing real-life experience recorded on interview transcripts. The originality of the method lies in the use of a semiotical formal principle of ordering: Peirce demonstrated mathematically that only three categories of signs (“modes of being”) were sufficient to describe an experiential phenomenon. Signs of law, concepts or generalities, coded [3], signs of fact, experience or action, coded [2], signs of feelings or emotions, coded [1]. These signs, which are to be discovered in the textual elements of the verbatim, are logically dependent on each other: [3] presupposes [2] which presupposes [1].

In practice, SPA is based on two procedures :

- The semiotic characterization of verbatims (or "textual semiotization") consists of recognizing linguistic data with a general mode of being [3], then those with a factual mode of being [2] and finally the feelings that depend on them [1]. This system [3/2/1] enables the data collected to be ordered logically according to their mode of being, by putting the concepts [3] at the helm of meaning. The empirical categories structured in this way depend on a formal logical principle and not on the sensitivity of the researcher.

- Constant comparison is a central process in qualitative research described by Glaser and Strauss in the Grounded Theory Analysis (REF). It consists of a dual continuous comparison: comparison of the data (indices) with each other, emerging as the analysis of a verbatim (the interviewee's experience) progresses in order to develop empirical categories of the phenomenon studied (its dimensions) and then to compare these categories under construction with the categories emerging from the following verbatims. This continuous comparison increases the generality of the categories to the point of theoretical saturation, at which point the analysis no longer provides any new information and the sampling can be stopped."

Like all phenomenological approaches SPA use abductive reasoning to link data from individual interviews within a general category.