

ORIGINAL RESEARCH

What Patients with Mild-to-Moderate Kidney Disease Know, Think, and Feel about Their Disease: An In-Depth Interview Study

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Introduction: It is unknown what patients in primary care with mild-to-moderate chronic kidney disease (CKD) know, think, and feel about their diagnoses and how they value the information provided. The aim of the study was to explore their knowledge, thoughts, and experiences concerning their CKD and the information given to them.

Method: Qualitative interview study with patients with mild-to-moderate CKD who know their diagnoses and are treated mainly by family physicians.

Results: Four themes arose: CKD literacy, coping with anxiety, prerequisites for self-management, and reciprocity in information provision. The participants filled deficiencies in their CKD knowledge with misconceptions and half-truth about causes, symptoms, and treatment. The anxiety about CKD at the time of diagnosis versus the feeling of irrelevance later on was due to the absence of CKD symptoms and their physicians' minimization of the seriousness of CKD. Participants failed to connect lifestyle and cardiovascular disease with CKD. Not all participants were well informed about the consequences that CKD might have. CKD literacy and willingness to change were both necessary to accept lifestyle changes. Further, the participants felt that it would be helpful when information comes with empathy and is tailored to patients' personal needs.

Conclusions: Patients have various perceptions about their CKD. Exploring these perceptions could help match their needs with better-tailored information. Doctors should be aware that they can deliver inaccurate signals about CKD severity, so that patients fail to realize the potential impact of CKD. This makes them less open to lifestyle changes and improving their self-management. (J Am Board Fam Med 2018;31:570–577.)

Keywords: Chronic Kidney Diseases, Family Physicians, Life Style, Primary Health Care, Qualitative Research, Self-Management

Most patients with chronic kidney disease (CKD) in stages 1 to 3 are treated in primary care.¹ The prevalence of CKD is 10% to 12% and is expected to increase due to aging and rising incidences of hypertension and diabetes.² Nearly all interven-

tions for patients with CKD in primary care aim to prevent cardiovascular complications and progression to end-stage renal disease. Not only the treatment of hypertension and diabetes, but also lifestyle changes such as smoking cessation, exercise, weight loss, low salt intake, and medication management are important. These measures rely extensively on patient self-management. The prerequi-

This article was externally peer reviewed.
Submitted 13 December 2017; revised 29 March 2018; accepted 30 March 2018.

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Funding: The Dutch Kidney Foundation funded the study, grant 13A4D302.

Conflict of interest: none declared.

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sites for self-management are patient awareness of the diagnosis and education, and the firm belief that the patient's role and willingness to make lifestyle changes is important.³ Tailored education in primary care is the key to achieving self-management. However, previous research shows that family physicians and practice nurses encounter barriers when informing patients about the diagnosis of CKD,⁴ and quantitative studies confirm the low awareness of the diagnosis among patients with mild-to-moderate CKD.^{5,6} Patients have little specific knowledge about causes, kidney function, treatment, and nephrotoxic medication.^{7,8} Despite research into the information and educational needs of patients with severe CKD, research relating to patients with mild-to-moderate CKD is scarce.^{9,10} To enhance self-management and knowledge, we must first explore what patients know, think, and feel about their disease and about the provided information. Therefore, the aim of this study was to explore patients' knowledge, thoughts, and feelings about CKD, as well as their experiences with the information provision for patients with mild-to-moderate CKD in primary care.

Method

Study Design

We conducted in-depth interviews with patients with CKD. We considered this design appropriate for our exploratory research question. We used the consolidated criteria for reporting qualitative health research checklist as a reporting structure.¹¹

Participant Selection

Physicians from 8 practices, associated with the primary care network of practice-based research in Nijmegen, the Netherlands^{12,13}, recruited patients by phone or e-mail, based on recent consultation or on a sampling from the problem lists, pointing at kidney failure. The inclusion criteria were CKD stages 1 to 3, being informed about the CKD diagnosis, speaking the Dutch language, and CKD management based mainly in primary care. We used a purposive strategy for sampling. After the first 10 patients, we asked the physicians to recruit patients with specific characteristics, characteristics that were not yet represented in the participants who had already been interviewed. We aimed for variety in the categories: age, sex, CKD cause, estimated glomerular filtration rate, duration of the

diagnosis, and education level. The participant sampling, data collection, and analysis were organized in an iterative process. The physicians asked 25 patients to participate. Two patients were excluded because they had been diagnosed with severe CKD (stages 4 and 5). One married couple was recruited. We decided to interview only 1 of them because they likely shared the same knowledge and ideas. One patient refused to participate because he felt misinformed about the type of research. The study population comprised 21 patients (see Table 1 for participants characteristics). Patients were first informed by their family physician by a letter. Further information was provided by the researcher (CvD) before the participants signed for informed consent. The interviews were conducted between December 2015 and August 2016.

Data Collection

We developed an interview guide (Appendix A) based on the literature. This interview guide was pilot-tested on 2 participants who were members of the Dutch Kidney Patient Association. The guide was adjusted after each 3 to 7 interviews, with the use of new insights from the previous interviews and discussion in the research team (for adjustments, see Appendix A). The interviews with the participants took place at their homes or in the practices. The interviewer was an MD and PhD student and trained in qualitative research (CvD, female). She had no connection with the participants. The interviews lasted 30 to 80 minutes. All interviews were audiotaped and transcribed verbatim. The transcripts were returned to the participants for a member check. Three participants reported corrections in the transcripts: 2 nuanced their statements and 1 reported grammatical errors. The analysis of the 21st interview produced no new codes or concepts. We concluded that saturation had been reached.

Data Analysis

We used the technique of constant comparative analysis. This approach is part of the grounded theory in which concepts emerge as theory is formed.¹⁴ Analysis started after the first interview. The analysts (CvD and MD) coded inductively and independently by using Atlas.ti (version 7.1.5). They discussed, merged, and renamed codes after the 3rd, 10th, 16th, and 21st interviews. CD and MD sorted the preliminary findings into categories and themes. The codes,

Table 1. Demographic Information about the Participants

Participant Number	Sex	Age	Marital Status	Level of Education	CKD Since	eGFR	Albuminuria	Comorbidity
1	M	71	Married	Middle	1995	48	No	Hypertension, gout
2	F	64	Married	Middle	2010	43	No	Hypertension, adiposity, hypothyroidism
3	F	66	Married	Low	2015	54	Not measured	Hypertension, psoriasis, arthrosis
4	M	75	Partners	Low	2011	48	Microalbuminuria	Hypertension, diabetes, gout, CVA, angina pectoris
5	M	73	Married	Middle	2014	43	Not measured	Hypertension, arthrosis
6	F	66	Widow	High	2006	48	Microalbuminuria	Hypertension
7	Did not meet the entry criteria							
8	Did not meet the entry criteria							
9	F	62	Divorced	High	Unknown	45	Not measured	Hypertension, arthrosis
10	F	41	Divorced	Middle	1992	56	Microalbuminuria	Nephrectomy, recurrent cystitis
11	F	86	Widow	High	Unknown	55	Microalbuminuria	Hypertension, arthrosis, deep vein thrombosis
12	Felt misinformed about the type of research and quit							
13	M	62	Married	High	2011	38	Microalbuminuria	Hypertension, diabetes, CVA, gout, polyneuropathy
14	F	76	Married	Middle	1996	46	No	Diabetes, CVA, endometrial cancer
15	Married to another participant; excluded because of same ideas							
16	F	78	Married	High	2014	47	Microalbuminuria	Hypertension, hypercholesterolemia
17	M	64	Partners	Low	1995	45	Macroalbuminuria	Hypertension, aortic insufficiency
18	F	78	Widow	Middle	2012	46	No	Hypertension, hypercholesterolemia
19	F	65	Married	Low	2013	48	Microalbuminuria	Asthma, ileostomy for constipation
20	M	71	Married	High	2012	47	No	Hypertension, prostate cancer
21	F	56	Married	Middle	Unknown	50	Microalbuminuria	Asthma, osteoporosis, rheumatoid arthritis
22	M	76	Married	High	2009	39	Not measured	Hypertension, bladder cancer
23	M	64	Married	Middle	2013	41	Microalbuminuria	Hypertension
24	F	62	Unknown	Unknown	Unknown	51	Microalbuminuria	Hypertension, hypercholesterolemia
25	F	73	Married	Low	Unknown	53	No	Hypertension, diabetes, asthma

CKD, chronic kidney disease; CVA, cardiovascular accident; eGFR, estimated glomerular filtration rate

categories, and themes were constantly compared with the transcripts.¹⁵ After saturation, the research team (CvD, MD, WdG, and NS) discussed all codes, categories, and themes. Five consensus meetings were needed to construct the final thematic map (Appendix B). A native-English speaker translated the illustrative quotes.

Results

Overview

Four main themes emerged from the interviews: CKD literacy, coping with anxiety, prerequisites for self-management, and reciprocity in information provision. All themes are illustrated by multiple categories and quotes.

CKD Literacy

We found that patients complete their knowledge gaps with misconceptions, half-truths, and distortion of facts to create their own image about CKD and all what comes with CKD.

Imagining CKD

The information obtained from the interviews showed that CKD is an unclear concept. A broad spectrum of ideas and views appeared when the interviewees were asked for a definition: a shriveled kidney, a number in the computer, blood poisoning, or a shortage of blood substances.

“... that I had a kidney that you could compare with a pottery cup with all kinds of cracks in it. Say just an old cup. That is what my kidney was like.” (participant 5 [P5])

Knowledge Compatible with Professional Standards

Knowledge that corresponded with professional knowledge varied among the interviewed patients. Most patients knew that the kidneys are located in the abdomen and have something to do with the purification of blood. It was less commonly known that CKD is associated with cardiovascular disease. A variety of CKD causes were mentioned: aging, medication, dehydration, and chemotherapy, but despite that, most participants did not link CKD to their hypertension or diabetes. If they knew hypertension or diabetes causes CKD, it was still difficult to imagine how CKD related to vascular damage.

“But at my doctor’s, there was the idea that high blood pressure has an influence, that high blood pressure attacks the organs.” (P6)

The participants rightly linked CKD to pregnancy issues, gout, and problems with contrast agents. Fatigue and itch were mentioned as symptoms. Others experienced no symptoms or were not sure whether their symptoms were related to CKD. It was clear that CKD needs periodic follow-up, including blood and urine examination, to monitor kidney function. Treatment was mainly associated with taking medication. It proved difficult to say which drugs are involved in CKD management and what the effects of the medication should be. However, there was an awareness of medication warnings in case of renal impairment, for example, for nonsteroidal anti-inflammatory drugs, gout medication, and antihypertensive agents.

Misconceptions

Many misconceptions came forward, probably as a result of lack of knowledge. Could kidney damage be caused by stress, narcosis, car accidents, viruses, and bacteria, or was it a side-effect of psoriasis?

“I have an idea that it has something to do with this.” (Points to a psoriasis spot) (P3)

Another source of misconception was speculation about symptoms. Pain, edema, myalgia, infections, and urinary symptoms were considered symptoms of CKD.

“Yes, I know that it can be very painful if something’s wrong with your kidneys; my father had that too. And then it is difficult to urinate, and so on.” (P14)

There were various thoughts about diagnostics. There was the conviction that CKD can only be made visible by a body scan, because a scan was made at diagnosis. Furthermore, there was the idea that the color of the urine reflects health.

“You can see your health in your urine. You just see it yourself – then you have much darker urine.” (P6)

It was reported that cinnamon affects CKD positively. Others were convinced that CKD does not require treatment at all. The patients did not always realize that CKD is a life-long illness, and they thought that CKD was curable.

Gray Area

Some notions were difficult to categorize as true or false. For example, the role of genetics in kidney damage: there might be a genetic predisposition, but that probably did not affect the pathogenesis.

“... and then I have to say that my mother also had a weak kidney. So it is also in the genes.” (P6)

Other unclear items were whether kidney damage is caused by alcohol and organ abnormalities.

“I have always taken a stiff drink, and that can cause kidney damage.” (P23)

Treatment with an infusion of water to flush the kidneys is unnecessary for CKD, but is very important for acute prerenal failure and protection against contrast agents.

Coping with Anxiety

A first reaction of patients being labeled with CKD was fear and doom-thinking about the future. To cope with fear, the participants gathered several signals to minimize seriousness.

Concerns

Some participants were shocked when they received the results of their blood tests. They worried and imagined dialysis or kidney transplantation. Follow-up was stressful to them.

“My kidney function was not good. It was only 60% or so. So yes, that was certainly scary, and I did worry about it for a while.” (P10)

Lack of Relevance

The anxiety at the time of diagnosis contrasted sharply with the perception that CKD is not a serious condition. Doubts about the importance of the diagnosis increased over time. One patient even refused to be labeled as having CKD. Other participants had no symptoms related to the decline of renal function, so it was difficult to imagine that the CKD was serious.

“Yes, I have no trouble with it, so I will not worry about it.” (P11)

The participants’ perceptions were influenced by the fact that the physicians seemed unconcerned about the diagnosis: they trivialized patients’ concerns verbally, judged a referral to a nephrologist unnecessary, or did not explicitly treat the CKD.

“You think that it is not that important. It is stable, so that is good, and now and then it must be checked. Something like that.” (P9)

The interviewees paid little attention to CKD and the physicians’ explanation about it. This led to thoughts of a lack of relevance and priority.

“So then I saw another doctor, who did not talk about kidneys at all. So I assume that they are okay.” (P25)

Some participants recognized their own responsibility regarding CKD. They admitted that they neglected their CKD by not seeking further information.

“And I did not ask anything else about it, because, well, if it does not yet exist, I do not have to know about it!” (P19)

Prerequisites for Self-Management

Participants mentioned 2 factors that are important for living a healthier life: knowledge about the potential effects of lifestyle on CKD and willingness to change. These factors are strongly connected to each other and both are required to actually change lifestyle.

Lifestyle Literacy

Various lifestyle interventions for preventing cardiovascular events and kidney deterioration were mentioned during the interviews: weight control, smoking cessation, sodium restriction, physical exercise, and preventing dehydration. The participants knew about lifestyle in relation to their hypertension or diabetes, but did not realize the positive effects of lifestyle changes on kidney function.

“I do realize that my blood pressure is too high, that I haven’t got my cholesterol right, that I am overweight, that I have to keep working on it and pay attention to it all. But I never made the connection that it affects the kidneys.” (P17)

Willingness to Change

Notions about lifestyle changes differed among the participants. Most were motivated to adjust their lifestyle, but 1 patient argued:

“... it is all very well for them to say that it is this way and you must do such and such. But people do not do it. And I do not either. And that is why I say it does not help.” (P23)

A proactive attitude toward renal decline and medication problems was also discussed. Behavior varied from taking total control to waiting for the doctor to come along.

“As soon as it is under 40 again, I will make it clear that something’s wrong or ask for a consultation.” (P19)

Reciprocity in Information Provision

Patients gathered CKD knowledge from various professionals and had different views on the tasks of professionals involved in CKD care. Patients indicated that it helps when information comes with empathy and is tailored to patients’ personal needs.

Information Sources

Many medical coworkers were involved in informing patients: physicians, their assistants, practice nurses, nephrologists, cardiologists, pharmacists, and even a physiotherapist. Most information was given verbally, although some participants received written information. The internet was the source that was preferred.

Views on Professional Tasks

There was a general satisfaction about the care received from the physicians and nurse practitioners, although doubts about their knowledge were reported.

Empathy

Empathy from the physicians was important. The participants judged a friendly approach as very important. They wanted the physicians to accept their treatment preferences and provide timely information. One patient did not feel free to ask questions:

“I myself know nothing and it scares me a little. He told me that my kidney function was not all that great. Then I am someone who does not open his mouth, yes.” (P10)

Tailored Information

The participants reported knowledge deficits. Not all felt well informed and reported that physicians did not spend enough time on detailed explanation. Other participants could not remember the information.

“The doctor has neither the time nor the energy to explain it that way.” (P16)

“I was informed, but not well informed.” (P20)

A number of questions remained. For example, it was confusing for patients to find that CKD has several synonyms that were used interchangeably: “renal impairment” and “kidney failure.” The interviewees wondered about the difference. Patients expected their physicians to tailor the information.

“We do not want too many medical terms because we do not understand them. It is never been my field of work.” (P1)

Discussion

Summary of Main Findings

Four main themes emerged from the interviews: CKD literacy, coping with anxiety, prerequisites for self-management, and reciprocity in information provision. Patients had deficiencies in their CKD knowledge so that misconceptions arose about causes, symptoms, and prognosis. There was a discrepancy between the anxiety at diagnosis and the later feeling of irrelevance of CKD. Lack of CKD symptoms and physicians’ attitudes reduced the sense of seriousness. The patients failed to associate lifestyle and cardiovascular disease with CKD. Some were willing to make lifestyle changes. Not all were well informed about the consequences that CKD might have. The participants express the need for tailored information.

Comparison with Existing Literature

Several qualitative and quantitative studies^{6,12,13} found that patients have little objective and per-

ceived knowledge in all stages of CKD. This is in line with our study. We were surprised that there were so many misconceptions about CKD—why and when do misconceptions arise? Some studies show the health care professionals’ difficulties with CKD management and education.^{16,17} Limited professional knowledge and lack of prioritization¹⁸ may contribute to knowledge gaps and misconceptions. Furthermore, our study uncovered problems at the level of the doctor-patient communication. The information physicians provide needs improvement. The current literature shows a low baseline understanding of kidneys and CKD¹⁹ among patients. The lack of understandable and uniform CKD information may be a contributing factor.²⁰ Other studies report that patients remember little of what they have been told.²¹

It is questionable whether patients are ready to learn when they receive signals that make them doubt the severity of CKD. The participants stated that physicians not talking much about CKD is one such signal. Other signals were judging a referral to a nephrologist unnecessary and seeming not to actually treat the CKD. The lack of symptoms is another signal for patients that CKD is not a serious condition. These signals form what we call the “relevance discrepancy.” The participants were worried at time of diagnosis, but later they trivialized their disease. Anxious patients avoid information gathering, consciously or unconsciously. Another study described this same phenomenon among patients with progressive renal failure in regard to education about transplantation and donation.²²

Other researchers have identified themes that should be assessed in self-management interventions.²³ We confirm that, from the patients’ perspectives, disease-specific knowledge is one of the crucial themes. Contantini and colleagues²⁴ describe the need for disease-specific information, tailored and focused on the situation of the individual patient. Our findings are consistent with this research. It seems obvious, but given the findings in our study, disease-specific information remains an important point that demands attention.

Strengths and Limitations

It is a strength that CvD and MD established internal validity with independent coding, used Atlas.ti, and conducted mind-mapping sessions with the research team in which additional perspectives

and interpretation of analysis and findings were discussed. The iterative approach of the interviews and the interim data analysis assured the rigor of the data. Another strength is that we included patients with heterogeneous characteristics to collect a broad range of knowledge, feelings, and experiences. These broad outcomes enabled us to take conclusions for this specific population. A limitation is that we did not interview patients with African, Asian, or Latin origin. We cannot comment on how patients with non-white origin experience and understand CKD and the impact on lifestyle. Given the clear outcomes in our white population, we cannot exclude that the problems we found also occur in the non-white population. It is important to do additional research on this. All interviews took place in Dutch. We tried to limit the loss of nuance by having a native-English speaker translate representative quotations. One interviewer did all the interviews; we tried to lower the risk of interview bias by providing feedback on the interview style. We asked physicians to recruit informed patients. The study could be biased toward inclusion of better-informed patients, but the results show that these potentially well-informed patients also have knowledge gaps, misconceptions, or are not able to link CKD to lifestyle changes.

Implications for Practice

The patients lack information about the cause, symptoms, and treatment of CKD. Clear information can reduce the occurrence of misconceptions. The patients do not recognize the link between CKD and cardiovascular risk and lifestyle. It is important to include CKD in cardiovascular information and link lifestyle changes to their positive effects on both cardiovascular disease and CKD. This link might increase patient willingness to make lifestyle changes. Practice nurses can provide important help in this process.²⁵ Repeating the message without dilution helps encourage a healthier lifestyle and makes patients realize how to influence CKD. Patients want tailored information. To deliver tailored information, there is a need for providers to be aware of patients' perspectives about CKD first, not only at diagnosis, but also during treatment. Uniform patient information on the internet or in an article is helpful and useful.

Conclusion

Patients' knowledge of CKD is deficient. There is a discrepancy between the patients' concerned attitude at time of diagnosis and their sense of irrelevance later in the disease. Physicians should be aware that they, often unknowingly, deliver the wrong signals about the severity of CKD, which influences patient behavior toward lifestyle and willingness to enhance self-management. If physicians want to provide tailored and patient-centered information, they need to be aware that misconceptions and perceptions of CKD should be actively identified and addressed.

We thank all the participating CKD patients for their contribution.

To see this article online, please go to: <http://jabfm.org/content/31/4/570.full>.

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Appendix A. Interview guide

(This interview guide was used as memory support for the interviewer, it was not a questionnaire for the participants)

First adjustments in blue

Second adjustments in red

Third adjustments in green

How were you informed about the diagnosis?

- How did you or your doctor find out that you have chronic kidney disease?
- When was it discovered?
- Who discovered it?
- What information did your doctor give you?
- Was the information clear?
- What were your thoughts when you heard that you have chronic kidney disease?
- Are you worried? Why or why not? How can doctors reassure you?

What do you know about chronic kidney disease?

- What do you know about kidney function and anatomy?
- What do you know about your own kidney function?
- What do you know about kidney failure? (Things such as causes, diagnosis, consequences, relation to cardiovascular diseases and diabetes, and prognosis.)
- Do you also have other illnesses? Do you know if there is a relationship between other illnesses and chronic kidney disease?
- Do you lack certain information? What additional information do you need?

What are the consequences of chronic kidney disease for you?

- Physical (any symptoms?)
- Social (does the disease limit you?)
- Psychological (thoughts or anxiety?)
- If you have no symptoms, do you know what symptoms indicate chronic kidney disease? Do you wish to receive this information?

How are you counseled?

- Please describe your treatment for your chronic kidney disease.
- Who advises you? How often? Do you have check-ups at the hospital? With whom?
- What is checked? Why is this important?
- What do you think of the follow-up? Are you satisfied with it? Why of why not?
- What do you need from your family physician for your chronic kidney disease?

What is the effect of chronic kidney disease on your medications?

- Do you use any medication? Which ones? Can any of your medicines can cause kidney damage?
- Are you aware that medications influence kidney function? Does your doctor tell you why your medication needs adjustments?
- What has your family physician (or nephrologist or nurse practitioner) told you about medication in relation to kidney function?
- Was it comprehensible? What did you think then?
- Do you have a need for more information about medication and chronic kidney disease? From whom? In what form – email, printed information, personal explanation, etc.?
- What is the role of the pharmacist in providing information?

What preventive actions are possible?

- What do you do to prevent deterioration to end-stage renal failure?
- Have weight loss, sodium intake, smoking cessation, and other such subjects been discussed with you? If so, who discussed it with you? If not, do you need information about preventive actions?
- What do you think about lifestyle changes? Are they feasible?
- From whom and how would you like to get this information?

Could you provide a summary of the issues discussed? Are there important issues of interest which we have not named?

Information needs

- Do you feel that your family physician informed you well? If not, what do you still need? If you feel well informed: why?
- Imagine you are going to see your family physician tomorrow. What would you ask him/her about chronic kidney disease?
- From whom and when would you like to get what information?

Appendix B. Final thematic map

Category	Code name	Meaning of the code
CKD Literacy		
Knowledge compatible with professional standards	The moment when the patient first knew there was kidney damage	Awareness of the moment when kidney damage was ascertained varies
	Blood pressure treatment	Treating blood pressure is part of the treatment for kidney damage
	Periodic monitoring	Kidney damage is checked periodically
	Treatment with medicines	The treatment of kidney damage is associated with taking medicines
	Policy after diagnosis	There are various degrees of knowledge about the policy for treating kidney damage after it has been diagnosed
	Effect of stress and smoking on blood pressure	Stress and smoking contribute to high blood pressure
	Diagnosis by blood testing	You can determine kidney damage by blood testing
	Diagnosis by urine testing	You can determine kidney damage by urine testing
	Interpretation of lab results	Knowledge about how to interpret lab results varies
	Position of the kidneys	The kidney are localized near the back
	Indications for dialysis	Kidney dialysis is necessary if the kidneys no longer function
	Association of kidney damage and dialysis	An association is made between kidney damage and dialysis
	Sufficiency of one kidney	You can live with only one kidney
	Purpose of kidneys	Kidneys purify your body and blood
	Ignorance of what kidneys do	Some patients do not know what the function of the kidneys is
	Ignorance of consequences of kidney damage	Some patients are unaware of the potential consequences of kidney damage
	Relation of kidney damage to heart disease and death	Kidney damage can lead to earlier death as well as to heart disease
	NSAIDs	You cannot take NSAIDs if you have kidney damage
	Other nephrotoxic medications	Allopurinol, Plaquenil, Sevikar, antihypertensive drugs, prednisone, and lisinopril are bad for the kidneys
	Misconceptions	Necessary medication adjustment and/or assessment
Association of kidney damage and gout		Kidney damage and gout occur together
Association of kidney damage and contrast agents		If you have kidney damage, you must be careful with contrast agents for scans
Association of kidney function and pregnancy		Extra check-ups are necessary during pregnancy if you have kidney damage
Symptoms not connected to kidney damage		Some symptoms have nothing to do with kidney damage
No symptoms for kidney damage		Kidney damage does not cause any symptoms
Itch from kidney damage		Kidney damage can make you itchy
Tiredness from kidney damage		Kidney damage can make you tired
Kidney damage from dehydration		Kidney damage results from a shortage of fluids
Kidney damage from medication		Kidney damage results from the use of certain medications
Kidney damage from cancer or cancer therapy		Cancer or cancer treatment has something to do with kidney damage
Unknown cause		We do not know how kidney damage originates
Kidney damage from high blood pressure		Kidney damage results from high blood pressure
Kidney damage from diabetes		Kidney damage results from diabetes
Kidney damage from old age		Kidney damage can arise from old age
Gray area	Cure for kidney damage	Kidney damage is reversible and therefore can be cured
	Kidneys on the side of the abdomen	The kidney are localized on the abdominal side of the body
	Wandering kidney	The patient was told that he/she has a wandering kidney, but doesn't know what this means
	Diagnosis via diagnostic imaging	You identify kidney damage with scans
	Kidney damage from infectious diseases	Kidney damage arises from infection with a virus or bacteria in the workplace
	Kidney damage from traumas	The physical trauma of an accident can cause kidney damage
	Kidney damage from skin conditions	Psoriasis can cause kidney damage
	Kidney damage from nerves	Stress can cause kidney damage
	Kidney damage from anesthesia	Kidney damage arise from anesthesia in the past
	Infections from kidney damage	If you have kidney damage, you can get infections
	Pain from kidney damage	Kidney damage can be painful
	Symptoms of the musculoskeletal system from kidney damage	Kidney damage can give you back pain and acidify your muscles
	Symptoms in fluid management from kidney damage	You can retain more fluids if you have kidney damage
	Urination problems from kidney damage	If you have kidney damage, it is more difficult to urinate
	Light-colored urine	You can read your health from your urine: a light color means healthy kidneys
Imagining CKD	Cinnamon for kidneys	Cinnamon is good for the kidneys
	Salt and cholesterol	Salt has an effect on cholesterol
	Homeopathy for lowering blood pressure	Alternative medicine is good for kidney function
	Kidney damage and comorbidity	There are various ideas about the association of kidney damage with the intestines and lungs
	Thoughts about the effect of salt	Salt makes the kidneys work harder, and too little salt leads to symptoms
	Infusion for rinsing kidneys	It has been discovered that an infusion (drip) is a necessary treatment once chronic kidney disease has been identified
	Congenital or inherited kidney damage	Kidney damage is congenital or inherited
Imagining CKD	Kidney damage from alcohol	Alcohol causes kidney damage
	Kidney damage from organ abnormalities	Organ abnormalities such as a kink in the ureter or an abnormality of the bladder can cause kidney damage
Imagining CKD	The overall picture of kidney damage	There are different ideas about what kidney damage is: a chipped old cup, a number, a shriveling up, holes in the kidneys, problems with excretion or blood poisoning, a comparison with alveoli, a shortage of certain substances

Appendix B. Continued

Coping with anxiety		
Concerns	Fear of kidney replacement therapies	There is a fear of dialysis and there is a fear of kidney transplantation
	Devastating diagnosis	Receiving a diagnosis of kidney damage is devastating
	Concern about kidney damage	There is concern about having kidney damage
	Tension about check-ups	Patients can be tense about having their kidney function tested
	The picture of kidney-replacing therapy	There are various ideas about what the therapy for replacing kidney function is
	A mind that is, or is not, occupied with kidney damage	A patient may or may not spend time mulling over kidney damage
Lack of relevance	The unimportance of what is not discussed	Some patients conclude that if the doctor does not discuss kidney damage, then it can't be important
	Having kidney damage	Having kidney damage is not so bad
	Doubting the diagnosis	The patient may doubt whether the diagnosis of chronic kidney damage is really applicable
	Influence of symptoms on thinking about kidney damage	Having symptoms related to kidney damage makes you think about kidney damage a lot more
	Low priority for kidney damage	There are more important things to discuss with the doctor than kidney damage
	Limited monitoring: suggestive of limited gravity	Limited monitoring makes the kidney damage seem less serious and vice versa: the more monitoring, the more serious the kidney damage must be
	Kidney damage: treatment only when it is serious	The degree of the kidney damage determines whether it is treated
	Treatment in primary care: suggestive of limited gravity	If the kidney damage is serious, in-hospital treatment is necessary. If the kidney damage is not very serious, the family physician can treat it
	Reassurance through communication	Doctors reassure patients by means of verbal and non-verbal communication
	The physician's and specialist's communication of seriousness	The physician and specialist do not get the message across that kidney damage is a serious problem
	Reassurance via monitoring	Referrals and monitoring affect the concern, anxiety, and reassurance of patients
	Holding kidney damage at bay	If you don't know the ins and outs of kidney damage, you can keep kidney damage at a distance and stick your head in the sand
	Unimpressive information	The information has made no impression, which is why the patient cannot reproduce it
Awareness due to interview	Taking part in the interview makes you reflect about kidney damage	
Information unwanted as long as possible	Sometimes a patient does not want to know until the kidney damage becomes so serious or has such consequences that he/she must know	
Prerequisites for self-management		
Lifestyle literacy	Helplessness	There is nothing you yourself can do to stop the kidney damage from getting worse
	Alcohol moderation	It is advisable to moderate the use of alcohol
	Healthy eating	It is advisable to eat healthful food
	Weight watching	It is advisable to keep your weight at a healthy level
	As few pills as possible	It is preferable to use as few medications as possible
	Smoking	Smoking is bad for your health
	Enough exercise	It is advisable to get enough exercise
	Enough water	It is advisable to drink enough water
	Limited salt	It is advisable to eat as little salt as possible
	Willingness to change	Lifestyle advice
Preparedness to take one's own responsibility		Patients have different ideas about taking their own responsibility in the treatment of chronic kidney damage
Knowledge of the course of one's own kidney function		What patients know about the course of their own kidney function varies
Informing the pharmacist oneself		You can inform the pharmacist yourself about your kidney function
Patient taking over investigation of medication nephrotoxicity		Finding out for yourself whether a medication is dangerous for the kidneys
Do-it-yourself treatment and prevention		After receiving advice, the patient him/herself makes decisions about treatment and prevention
The patient's own plan for taking possibly nephrotoxic medicine		The patient him/herself decides whether or not to take potentially harmful medicine
A wish to involve one's partner in the policy		It's nice to be able to discuss it with each other and make decisions together.
The doctor who knows best	The doctor knows best what should be done; you take that for granted	
Influence of trust in the treating professional	Trusting the treating professional influences the degree to which treatment advice is taken	
Reciprocity in information provision		
Information sources	Information from the pharmacy	Information about kidney damage that the pharmacy gives
	Information from the package insert for the medicine	Information about kidney damage from the package insert for the medicine
	Information from books	Information about kidney damage from books
	Information from the cardiologist	Information about kidney damage received from the cardiologist
	Information from the practice assistant	Information about kidney damage received from the practice assistant
	Information from the internet	Information about kidney damage from the internet
	Information from the internist	Information about kidney damage received from the Internist
	Information from the physiotherapist	Information about kidney damage received from the physiotherapist
	Information from the family physician	Information about kidney damage received from the family physician
	Information from one's surroundings	Information about kidney damage received from people in one's own circles
	Information from the nurse practitioner	Information about kidney damage received from the nurse practitioner
	Information from TV	Information about kidney damage seen on TV
	Information from a printout of lab results	Information that is given with the aid of a printout of lab results
	Verbal information	Information about kidney damage that is given to the patient verbally
	Written information	Information about kidney damage that is given to the patient in writing
	Information transmitted by telephone	Information about kidney damage that is given to the patient by telephone

Appendix B. Continued

Views on professional tasks	Appreciation of the role of the family physician	There are various evaluations of the role of the family physician with regard to the care for kidney damage
	Tasks of the family physician	What is and is not included in the tasks of the family physician concerning kidney damage
	Role of the nurse practitioner	What is and is not included in the tasks of the nurse practitioner concerning kidney damage
	Tasks of the specialist	What is and is not included in the tasks of the specialist concerning kidney damage
	Appreciation of the role of the specialist	There are various evaluations of the role of the specialist concerning the care for kidney damage
	Appreciation of the role of the dietician	There are various evaluations of the role of the dietician concerning the care for kidney damage
	Cooperation of the physician and the pharmacy	Opinions differ about the cooperation of the physician and the pharmacy
	Tasks of the pharmacist	What is and is not included in the tasks of the pharmacist concerning kidney damage
	Added value of the pharmacist's explanations	Opinions differ about the added value of the pharmacist's explanations
	Expertise: specialist versus family physician	Specialists are more expert than family physicians when it comes to kidney damage
	Preference for treatment from the family physician	Sometimes there is a preference to have kidney damage treated by the family physician
	The family physician's pharmacological knowledge	Impressions of the family physician's pharmacological knowledge vary
	Cooperation of healthcare professionals in the chain of care	Patients do not notice much about the cooperation within the chain of care
	Evaluation of the information in package inserts	Opinions differ about the added value of the information in package inserts
	Evaluation of lab printouts	Opinions differ about the value the information provided in lab printouts
Generalized folders	Information in brochures is too general and focuses too little on the individual situation	
Trust in kidney damage care	The degree of trust in kidney damage care varies	
Extra costs	Patients are faced with extra costs when their kidney function must be repeatedly tested	
Empathy	Pleasant healthcare professionals	It is important to the patients that the healthcare professionals interact pleasantly
	Respect for treatment limits	Patients want doctors to respect their treatment limits
	The opportunity to ask questions	Patients like to feel that they can always ask the doctor questions about kidney damage
	Uneasiness about asking for a referral	Patients can feel uncomfortable about asking for a referral to a specialist to have kidney damage assessed
	Timely notification	Some patients have the feeling that they were informed about the kidney damage some time after it had become known
Tailored information	Symptoms taken seriously	Patients want to feel that the doctor takes their symptoms seriously
	Importance of repeating information	Repeating information is important
	Importance of time for explanations	Although they consider it important, patients feel that doctors often have too little time to give explanations
	Adequate and complete information	Adequate and complete information is important
	Verbal information suited to the patient	Patients want the doctor to tailor the verbal information to the needs and ability of the patient
	Feeling well informed	The feeling of being well informed by healthcare professionals varies among the patients
	Difficulty with inconsistent terms for kidney damage	Patients have difficulty with the many differing terms: kidney damage, kidney insufficiency, creatinine, etc.