

## Determinants of Caregiver Burden Among Spouses of Patients With Kidney Failure: A Qualitative Study

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**Rationale & Objective:** Spousal caregivers participate extensively in the care of patients with kidney failure. Although previous studies suggested that these caregivers experience a high burden, a comprehensive understanding of the determinants of this burden and strategies to alleviate it are needed. Therefore, this study sought to explore the contributing and alleviating determinants of burden in spousal caregivers of patients with kidney failure.

**Study Design:** A qualitative interview study with 15 spousal caregivers.

**Setting & Participants:** Dutch-speaking, adult spousal caregivers were recruited and interviewed by the Dutch Kidney Patients Association for the Kidney Decision Aid.

**Analytical Approach:** A directed qualitative content analysis using the stress-appraisal model of caregiver burden as a framework to inform a disease-specific model on spousal caregiver burden for kidney failure that characterizes the impact of care provision on all aspects of spousal caregivers' lives, the burden associated with it, and possible mitigating factors.

**Results:** Providing care for patients with kidney failure is complex and burdensome for spousal

caregivers and results in many lifestyle changes, which are largely caused by kidney failure-specific tasks and the shifting responsibility for daily life tasks. Spouses identified disease-specific determinants of burden including the impact of kidney disease on spouses with the disease as well as the associated caregiver tasks, such as adjusting to dietary restrictions and attending dialysis appointments. Dialysis options (eg, the choice for home or in-center dialysis) were kidney failure-specific moderators of burden. Support of spousal caregivers by health care providers plays a key role in preventing overburdening.

**Limitations:** Potential limited transferability owing to the study of only Dutch-speaking spouses willing to be interviewed and videotaped.

**Conclusions:** This comprehensive overview of the contributing and alleviating determinants of burden experienced by spousal caregivers of patients with kidney failure highlights 4 principal areas: (1) personal and relational, (2) social environment, (3) health care, and (4) work and legislation, in which such burdens occur and may be alleviated.

### Visual Abstract online

Complete author and article information provided before references.

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Informal caregivers, often spouses, are essential to patients with kidney failure because they provide both practical and emotional care.<sup>1</sup> Support from caregivers helps patients with kidney failure adjust to their disease and increase treatment adherence.<sup>2,3</sup> Specifically in kidney failure, informal caregivers often perform disease-specific tasks, including symptom management and home dialysis assistance. This comes on top of daily life tasks, such as cooking and cleaning, which adds weight to their caregiver role.<sup>1,4</sup> While informal care plays an important part in patient well-being, providing care may lead to high levels of caregiver burden, anxiety, depression, and sleep disorders, and it may negatively affect caregivers' quality of life, especially when kidney replacement therapy (KRT) is started.<sup>5-10</sup>

Overburdening is especially seen in spousal caregivers because they are more often older, are coresidents, perform more hours of care, and suffer more from relationship stress compared with other types of care relationships.<sup>11,12</sup> Although previous studies identified a high burden among informal caregivers of patients with kidney failure, research to comprehensively understand the

contributing determinants of spousal caregiver burden and to identify factors that may relieve this burden has been lacking.<sup>4</sup> Qualitative research provides the unique opportunity to gain deeper understanding through the experiences of spousal caregivers themselves.<sup>13</sup> Therefore, this study qualitatively explored the contributing and alleviating determinants of burden in spousal caregivers of patients with kidney failure. Given the high burden especially for spouses, we focused on the need for support in this specific group.

## Methods

### Study Design

A directed qualitative content analysis using a conceptual model of caregiver burden was performed. This is a common method of data analysis in health care research in which a theoretical framework is validated, enhanced, or extended in a new context.<sup>14,15</sup> Previously published stress-appraisal models served as the foundation for the conceptual model.<sup>16-20</sup> This model links caregiving stressors, caregiving appraisals, and moderators to the

**PLAIN-LANGUAGE SUMMARY**

Spousal caregivers are crucial for supporting patients with kidney failure, but they often experience significant stress and challenges. This study explored factors that contribute to spousal caregiver burden and ways to alleviate it. We interviewed 15 spousal caregivers of patients with kidney failure. We found that providing care for patients with kidney failure is complex, burdensome, and has a major impact on caregivers' lives. We identify factors that contribute to caregiver burden but also factors that may ease this burden. This study underlines the need for acknowledgement of spousal caregivers in 4 areas, namely (1) personal and relational, (2) social environment, (3) health care, and (4) work and legislation.

caregiver burden (Fig S1). The model proposes that care demand (primary stressors) leads to actual care provision (primary appraisal). Consequently, care provision leads to consequences for the caregiver's own life (secondary stressors), leading to caregiver burden (secondary appraisal).

Moderators change the effect of stressors (eg, social support may alleviate burden by sharing care tasks). The concept of moderators is that caregivers, even when confronted with similar conditions, respond differently due to different levels of support and resources.<sup>20</sup> Besides these direct relationships between concepts, indirect relationships are also present (eg, primary stressors may also influence secondary appraisals).

The 32-item Consolidated Criteria for Reporting Qualitative research (COREQ) checklist was used to comprehensively report this study.<sup>21</sup> The medical ethical committee of the Amsterdam University Medical Center issued the Medical Research Involving Human Subjects act (WMO) as not applicable, so no ethical approval was required (W22\_406#22.481).

**Data Collection and Procedure**

Informal caregivers were recruited by the Dutch Kidney Patients Association to assist in developing a caregiver module for the Kidney Decision Aid, an educational website to inform and support patients with kidney disease and their caregivers in making future therapy choices.<sup>22</sup> Caregivers were recruited through the patient association's website, digital newsletters, and social media. First, a focus group was organized in which all components and questions of the interviews were discussed, resulting in an interview guide with 20 topics on different aspects of living with a loved one with kidney disease (Table S1).

In total, 29 videotaped, semistructured interviews with informal caregivers of patients with kidney disease were conducted by 2 experienced male interviewers: H.B., the former executive director the Dutch Kidney Patients

Association, a psychologist; and F.vdZ., the managing director of a media company. H.B. had personal connections with some participants through his occupation. In selecting participants (ie, purposive sampling), consideration was given to regional distribution, age distribution, and type of care relationship (ie, spouses, children, and parents). For our aims, all interviews with spouses (n = 15) were analyzed. All participants were adults and able to speak and understand Dutch.

Face-to-face interviews were held between December 2021 and April 2022 at the participants' homes. These interviews lasted approximately 1.0 to 1.5 hours. Video fragments selected from the videotaped interviews for the Kidney Guide were returned to the participants for approval. The Dutch Kidney Patients Association and the interviewed participants provided informed consent for these data to be used for research purposes. Participants could withdraw from the interview at any point, and confidentiality was ensured. There were no incentives for participation.

**Data Analysis**

The videotaped interviews were transcribed verbatim and anonymized. The interviews were analyzed using MAXQDA 2022 (VERBI Software). The data were analyzed according to the steps of Assarroudi et al<sup>23</sup> for directed content analysis. This consists of a preparation phase (eg, transcribing the interviews and getting immersed in the data), an organization phase (eg, developing a formative categorization matrix from existing theory, theoretically defining the main categories, determining coding rules, pretesting the matrix, performing the data analysis), and a reporting phase (ie, reporting all steps of the analysis). A formative categorization matrix with predetermined main categories was created, deductively derived from the stress-appraisal model.<sup>24</sup>

After familiarization with the data, meaning units related to the categorization matrix were identified from the transcripts and given a preliminary code. All transcripts were separately analyzed by 2 researchers (E.D., MSc, PhD candidate, female; and I.D., MD, PhD candidate, male) and were subsequently discussed to ensure coding agreement for the preliminary codes. All preliminary codes were categorized into generic categories according to their meanings, similarities, and differences (ie, inductive abstraction<sup>14</sup>). Generic and main categories were compared, leading to the embedding of generic categories within the main categories (ie, the constant comparison technique<sup>25</sup>). The analysis process was iterative because the steps in analysis were not chronological and codes were revisited and recoded.

**Rigor and Reflexivity**

To establish trustworthiness, strategies for credibility, transferability, dependability, and confirmability were used.<sup>26</sup> Credibility was increased by triangulation: multiple researchers analyzed the transcripts independently and engaged in mutual discussions. The degree to which

results can be transferred to another (comparable) context (ie, transferability) can be determined using the description of caregivers' characteristics. The research team's experience with nephrology, dialysis, informal care, and qualitative research helped secure rich participant descriptions. The purposive sampling strategy helps data transferability. Dependability was ensured through comprehensive documentation and reporting of the research process, and following the COREQ checklist. By including quotes from the participants and a self-reflective approach from the researchers, confirmability was increased (ie, interpretations, findings, and conclusions must be derived from the data).

## Results

### Characteristics

Participating spousal caregivers ranged in age from 34 to 82 years (Table 1). Most caregivers were women (n = 9). Informal caregiving duration ranged from 4 to 37 years. Most patients were on KRT.

### Stress-Appraisal Model in Spousal Caregivers of Patients With Kidney Failure

In Figure 1, generic categories extracted from the 15 interviews are displayed using the modified stress-appraisal model. These generic categories along with the corresponding subcategories are presented in Table 2,

encompassing the contributing and alleviating determinants of burden in spousal caregivers of patients with kidney failure. Box 1 includes quotes of the identified categories.

### Primary Stressors

Care demand of patients with kidney failure is defined by the primary stressors. The first primary stressor, described by several caregivers, is the effect of the kidney disease and its treatment on the patient. This includes the impact of KRT, hospitalizations, and dietary restrictions, as well as the general physical and mental impact on the patient. For example, caregivers explained that dialysis had a huge negative impact on the patients' physical state, resulting in a higher care demand; by contrast, kidney transplantation mostly resulted in a positive change in patients' abilities, leading to a lower care demand. However, 1 caregiver elucidated on how her spouse felt worse and required more care after kidney transplantation. Fatigue and limited energy of the patient were also mentioned by the majority of the caregivers as a cause of increased care demand.

The second primary stressor is patients' comorbidity, including physical, mental, and cognitive comorbidities. Caregivers explained that due to reduced comprehension and cognition as well as reduced physical ability, the patients required more care. A third category of primary stressors, interwoven with the previous categories, was the patients' degree of dependency. Many caregivers spoke about their spouses' inability to remain working, do

**Table 1.** Characteristics of Participants

| R  | Caregiver Characteristics |     |          |                                | Patient Characteristics     |                                |                                      |
|----|---------------------------|-----|----------|--------------------------------|-----------------------------|--------------------------------|--------------------------------------|
|    | Sex                       | Age | Employed | Caregiver Vintage <sup>a</sup> | Kidney Disease <sup>b</sup> | Dialysis Modality <sup>c</sup> | Prior Kidney Transplant <sup>d</sup> |
| 1  | F                         | 34  | Yes      | 6 y                            | IgA nephropathy             | ICHD                           | Yes                                  |
| 2  | M                         | 38  | Yes      | 12 y                           | Hypertensive nephropathy    | ICHD; CAPD; APD                | No                                   |
| 3  | M                         | 49  | Yes      | 7 y                            | ADPKD                       | ICHD                           | Yes                                  |
| 4  | F                         | 51  | Yes      | 1 y                            | Anti-GBM disease            | ICHD; HHD                      | Yes                                  |
| 5  | F                         | 52  | Yes      | 8 y                            | Vasculitis                  | APD                            | Yes                                  |
| 6  | M                         | 55  | Yes      | 1 y                            | Myeloma kidney              | ICHD; APD                      | No                                   |
| 7  | F                         | 55  | Yes      | 4 y                            | Undefined kidney failure    | None                           | No                                   |
| 8  | F                         | 58  | Yes      | 4 y                            | Hypertensive nephropathy    | None                           | Yes                                  |
| 9  | F                         | 59  | Yes      | 16 y                           | Cystic kidney disease       | PD; ICHD; HHD                  | Yes                                  |
| 10 | M                         | 67  | No       | 16 y <sup>e</sup>              | CAKUT                       | ICHD; APD; HHD                 | Yes                                  |
| 11 | M                         | 69  | No       | 8 y                            | MPGN                        | None                           | No                                   |
| 12 | F                         | 71  | No       | 16 y <sup>e</sup>              | Diabetic nephropathy        | None                           | Yes                                  |
| 13 | F                         | 73  | No       | 20 y                           | IgA nephropathy             | APD; CAPD                      | Yes                                  |
| 14 | F                         | 76  | No       | 37 y                           | Cystic kidney disease       | ICHD                           | Yes                                  |
| 15 | M                         | 82  | No       | 6 y                            | Lithium nephropathy         | ICHD                           | No                                   |

Abbreviations: ADPKD, autosomal dominant polycystic kidney disease; anti-GBM disease, anti-glomerular basement membrane disease; APD, automated peritoneal dialysis; CAKUT, congenital anomalies of the kidneys and urinary tracts; CAPD, continuous ambulatory peritoneal dialysis; F, female; HHD, home hemodialysis; ICHD, in-center hemodialysis; IgA, immunoglobulin A; M, male; MPGN, membranoproliferative glomerulonephritis; PD, peritoneal dialysis.

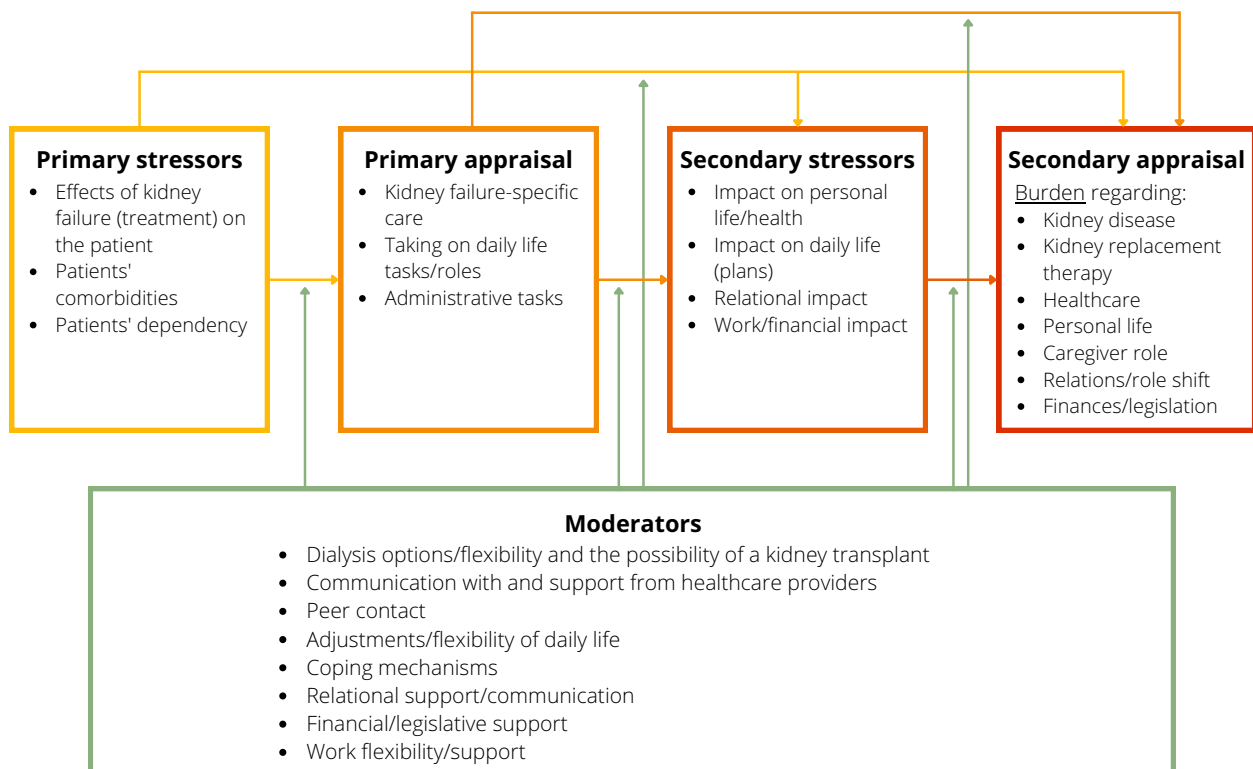
<sup>a</sup>As reported by the caregivers, defined as the moment they felt like they were providing informal care.

<sup>b</sup>As reported by the caregivers.

<sup>c</sup>Dialysis modality/modalities the patient had been treated with or was being treated with at the time of the interview.

<sup>d</sup>The patient has previously received a kidney transplant.

<sup>e</sup>Deceased spouse at time of interview.



**Figure 1.** Contributing and alleviating determinants of burden in spousal caregivers of patients with kidney failure using the modified stress-appraisal model. This model links caregiving stressors, caregiving appraisals, and moderators to caregiver burden. The model proposes that care demand (primary stressors) leads to actual care provision (primary appraisal). Consequently, care provision leads to consequences for the caregiver's own life (secondary stressors), leading to caregiver burden (secondary appraisal). Moderators change the effect of stressors. In addition to the direct relationships between the concepts, indirect relationships are also present.

household chores, and participate in daily life, as well as (for some) their inability to perform home dialysis and the corresponding increased care demand.

### Primary Appraisal

According to the stress-appraisal model, caregivers translate care demand into care provision. Almost all caregivers felt they had to continuously provide care for their spouse. Three categories of care tasks emerged from the interviews: kidney failure-specific care, taking on daily life tasks/roles, and administrative tasks. The kidney failure-specific tasks entailed adjusting to fluid and sodium restriction, attending hospital and dialysis appointments, assisting with medication collection and intake, and performing or supporting home dialysis. Most caregivers described taking on tasks and roles that used to be either their spouses' or a shared responsibility, such as household chores and taking care of the children. Administrative tasks mostly entailed dealing with health care-related administration and tasks regarding (disability) insurance, which caregivers partially or fully took on.

### Secondary Stressors

Care provision conflicts with other activities, impacting caregivers' personal lives on 4 domains: personal life and

health, daily life (plans), relationships, and work/finances. Most caregivers described that providing care reduced their ability to fulfill their personal lives and needs; they were always putting themselves second. A number of caregivers indicated they no longer felt in control of their own lives due to the kidney disease and associated caregiving responsibilities. For many, this was accompanied by a lack of privacy, adverse health outcomes (eg, worse physical condition), disrupted sleep (due to worries or noises of the dialysis machine), and a lack of energy.

Additionally, caregiving impacted the spousal relationship both positively and negatively. Although some spoke of difficulties in their relationships—for example, due to excessive concerns of the caregiver—others talked about how they grew closer to their spouse. One caregiver described that it felt like their spousal relationship had changed into a nurse-patient relationship because of a constant feeling of having to provide care. Furthermore, most caregivers reported being less (physically) intimate with their spouse.

Finally, many caregivers mentioned the negative impact of providing care on their ability to remain working and their financial status, mainly as a result of the reduced ability of both the caregiver and patient to work combined with health care costs.

**Table 2.** Categorization Matrix With Main Categories Derived From the Modified Stress-Appraisal Model

| Generic Categories                                   | Subcategories   |
|--|---|
| <b>Primary Stressors</b>                             |   |
| Effects of kidney failure (treatment) on the patient | <ul style="list-style-type: none"> <li>• KRT</li> <li>• Hospitalizations</li> <li>• Dietary restrictions</li> <li>• Physical/mental impact on patient</li> </ul>  |
| Patients' comorbidities                              | <ul style="list-style-type: none"> <li>• Physical impairments</li> <li>• Mental/cognitive impairments</li> </ul>  |
| Patients' dependency                                 | <ul style="list-style-type: none"> <li>• Inability to participate in daily life</li> <li>• Quitting work/decrease in income</li> <li>• Inability to do household chores</li> <li>• Degree of autonomy</li> <li>• Inability to perform home dialysis</li> </ul>      |
| <b>Primary Appraisal</b>                             |   |
| Kidney failure-specific care                         | <ul style="list-style-type: none"> <li>• Adjustments in daily life (eg, diet)</li> <li>• Attending hospital and dialysis appointments</li> <li>• Assisting with medication collection and intake</li> <li>• Performing/supporting home dialysis</li> </ul>          |
| Taking on daily life tasks/roles                     | <ul style="list-style-type: none"> <li>• Taking on household chores</li> <li>• Taking on care for children</li> </ul>   |
| Administrative tasks                                 | <ul style="list-style-type: none"> <li>• (Support of) administrative tasks</li> </ul>   |
| <b>Secondary Stressors</b>                           |   |
| Impact on personal life/health                       | <ul style="list-style-type: none"> <li>• Adverse health outcomes</li> <li>• Lack of room for personal plans/needs</li> <li>• Disrupted sleep</li> <li>• Lack of energy</li> </ul>   |
| Impact on daily life (plans)                         | <ul style="list-style-type: none"> <li>• Life dominated by kidney disease</li> <li>• Ability to make plans (for the future)</li> <li>• Difficulties maintaining daily/family life</li> <li>• Lack of privacy</li> <li>• Hampering getaways and vacations</li> </ul> |
| Relational impact                                    | <ul style="list-style-type: none"> <li>• Impact on relationship/spousal role-shift</li> <li>• Change in intimacy</li> <li>• Difficulties with (choices regarding) reproduction</li> <li>• Impact relationship with family</li> </ul>                                |
| Work/financial impact                                | <ul style="list-style-type: none"> <li>• Inability to (continue) work</li> <li>• Decrease in income</li> </ul>  |
| <b>Secondary Appraisal</b>                           |   |
| Kidney disease burden                                | <ul style="list-style-type: none"> <li>• Fear of deterioration/death patient</li> <li>• Negative emotions due to diagnosis/effects</li> </ul>   |
| KRT burden   | <ul style="list-style-type: none"> <li>• Intensity and impact of treatment</li> <li>• Fear of KRT (switch)</li> </ul>   |

(Continued)

**Table 2 (Cont'd).** Categorization Matrix With Main Categories Derived From the Modified Stress-Appraisal Model

| Generic Categories  | Subcategories  |
|---|--|
| Health care burden  | <ul style="list-style-type: none"> <li>• Dissatisfaction with health care system</li> <li>• Distrust in health care providers</li> </ul>   |
| Personal life burden  | <ul style="list-style-type: none"> <li>• Discrepancy between expected and actual life</li> <li>• Ability to look forward to something in life</li> </ul>   |
| Caregiver role burden   | <ul style="list-style-type: none"> <li>• Perception of care as difficult/confronting</li> <li>• Feelings of helplessness</li> <li>• Continuous worries</li> </ul>  |
| Relational burden   | <ul style="list-style-type: none"> <li>• Fear of loneliness</li> <li>• Difficulty of not doing things together anymore</li> <li>• Difficulty of adjusting to patient</li> <li>• Difficulty regarding intimacy</li> <li>• Tension regarding heredity of kidney disease</li> </ul>   |
| Financial/legislative burden  | <ul style="list-style-type: none"> <li>• Frustration regarding financial/legislative bodies</li> </ul>   |
| <b>Moderators</b>   |  |
| Dialysis options/flexibility and the possibility of a kidney transplant | <ul style="list-style-type: none"> <li>• Home vs in-center dialysis</li> <li>• Options for dialysis during vacations</li> <li>• Possibility of kidney transplantation</li> </ul>   |
| Contact with and support from health care providers                     | <ul style="list-style-type: none"> <li>• Good communication with health care providers</li> <li>• Understanding of informal caregiver role</li> <li>• Trust in health care providers</li> <li>• Sufficient time of health care providers</li> <li>• Psychological support</li> <li>• Cooperation of the pharmacy</li> </ul>    |
| Peer contact  | <ul style="list-style-type: none"> <li>• Peer support</li> <li>• KRT education tool</li> </ul>   |
| Adjustments/flexibility of daily life                                   | <ul style="list-style-type: none"> <li>• Domestic help</li> <li>• Flexibility with getaways/vacations</li> <li>• Creativity/flexibility with cooking</li> </ul>  |
| Coping mechanisms   | <ul style="list-style-type: none"> <li>• Taking time for oneself (self-care)</li> <li>• Relaxation/energy through hobbies</li> <li>• Habituation/adaptation to the new situation</li> <li>• Distraction/pleasure from activities</li> <li>• Religious coping</li> <li>• Positive personal attitude</li> <li>• Humor</li> </ul> |
| Relational support/communication  | <ul style="list-style-type: none"> <li>• Spousal support</li> <li>• Practical/emotional support from family/friends</li> <li>• Understanding from others</li> </ul>  |
| Financial/legislative support   | <ul style="list-style-type: none"> <li>• Support from financial/legislative bodies</li> <li>• Financial support from friends/family</li> </ul>   |

(Continued)

**Table 2 (Cont'd).** Categorization Matrix With Main Categories Derived From the Modified Stress-Appraisal Model

| Generic Categories       | Subcategories   |
|--------------------------|---|
| Work flexibility/support | <ul style="list-style-type: none"> <li>• Support from/flexibility of work</li> <li>• Maintaining/quitting job</li> <li>• Options for paid care leave</li> </ul> |

Abbreviation: KRT, kidney replacement therapy.

### Secondary Appraisal

All stressors may lead to an increase in experienced burden. Caregivers described different burden types, namely regarding the kidney disease, KRT, health care (providers), personal life, caregiver role, relational, and financial/legislative issues. For example, all caregivers experienced a fear of the deterioration and death of their loved one, often along with feelings of helplessness. Several caregivers explained that their feelings of dissatisfaction with and distrust in the health care providers of their spouse were burdensome. These feelings were most often caused by a lack of communication with and understanding by the health care provider. Most caregivers talked about the burden they experienced with regard to their spousal relationship; for example, they discussed that it was very upsetting to do fewer activities together with their spouse and to completely adjust their lives to their spouses' energy level and schedule. Several caregivers also described their frustration toward financial/legislative bodies because they felt misunderstood and did not receive appropriate support.

### Moderators

Different moderators were identified that altered the impact of stressors on spousal caregiver burden. Regarding KRT, the options and flexibility for dialysis (modalities) as well as the possibility of a kidney transplantation were important moderating factors. Several caregivers described how they felt more relaxed and experienced the normalcy of their old lives after kidney transplantation, although it often still impacted their lives (eg, patients still experienced symptoms such as fatigue and may not be able to work or do chores).

The experiences regarding home or in-center dialysis differed between caregivers. While some described that they preferred that their spouse performed in-center dialysis, others explained that being able to perform dialysis at home created more peace, time, and opportunities for activities. The main reason for preferring in-center dialysis was that it did not add extra caregiving tasks and time, but rather gave more structure and freedom. A few caregivers described they did not want their home to become a piece of the hospital.

Second, communication with and support from health care providers was of importance. Although some caregivers mentioned good communication with health care providers and feeling understood in their role as caregiver,

others explained that they did not feel understood nor that they received any recognition or attention from health care providers. Moreover, the majority of caregivers believed that the support of health care professionals and the potential to discuss issues (eg, regarding intimacy) with them were essential. Other moderators were peer contact, adjustments and flexibility of daily life, coping mechanisms, relational support and communication, financial and legislative support, and work flexibility and support. For example, several caregivers indicated that their employer did not understand what the kidney disease and related care entailed, resulting in difficulties with, for example, application for care leave; others talked about how the support and flexibility provided by their employer helped with adjusting to the disease and easing burden.

### Discussion

We explored the contributing and alleviating determinants of burden in spousal caregivers of patients with kidney failure through interviews. By application of the stress-appraisal model, we provide a comprehensive overview of disease-specific determinants and moderators of burden in spousal caregivers. Disease-specific determinants were identified, including the impact of kidney disease and KRT on the patients themselves as well as the associated caregiver tasks such as adjusting to dietary restrictions and attending dialysis appointments. In addition, dialysis options and flexibility (eg, the choice for home or in-center dialysis) were kidney failure-specific moderators that alleviated burden. Recognition and support of the spousal caregiver role and its accompanying burdens by health care providers play a key role in preventing overburdening.

Although previous studies identified comparable elements of caregiver burden, we provide in-depth information on these elements and how they relate to each other, which can be used to alleviate caregiver burden. For example, our study shows that treatment characteristics, comorbidities, and patients' dependency level influence care demand. Through the model, we provide insight into how these components of care demand affect care provision, caregivers' personal lives, and caregiver burden through various pathways whereas previous research only showed an association between these factors and higher burden levels.<sup>27</sup> Moreover, we add that spousal caregivers especially value specific components of these broad concepts, such as the ability to participate in daily life within the concept of patients' dependency.

With regard to care provision, we conclude that providing care for patients with kidney failure is complex, difficult, and burdensome for caregivers, which is largely caused by kidney failure-specific tasks and the shifting responsibility for daily life tasks. The burden of kidney failure-specific tasks has also been highlighted by previous studies, describing that time spent on caregiving and the difficulty of caregiving tasks were associated with higher levels of caregiver burden, and that dialysis treatment-

**Box 1.** Quotes per Generic Category of the Stress-Appraisal Model for Caregiver Burden Applied to Kidney Failure**Primary Stressors**

Effects of kidney failure (treatment) on the patient

- “In my view, I have a different husband after every hospital admission. Someone new in my home that I have to get to know again.” (R2)
- “When he showers, for example, he is very quickly very tired, and he has to sit on the edge of his bed for at least 15 minutes to recover, that is how tired he is before he can get dressed again. The same is true in the evening after dinner. Eating also takes a lot of energy. And after dinner the same occurs.” (R7)
- “It also still touches me that I see a man who I saw change after the transplantation because of the drugs. So I also suddenly had a very different husband. It was not [spouse name] anymore, who I fell in love with at the time. And I still loved him. And I still love him very much. But he had changed through his medication to the point that he had whole different character traits. And yes, I found that very difficult.” (R8)

Patients' comorbidities

- “For the transplantation we have to wait and see how it goes. First we will see how the cancer progresses and then consult with the nephrologist to see if it is possibly recovering or what other options we have.” (R6)

Patients' dependency

- “[Spouse name] can do very little by himself anymore. [...] Comprehension diminishes, physical quality diminishes, so he cannot pick up ordinary household things.” (R2)
- “[Spouse name] always did a lot in the household, and now everything really came down to me.” (R4)

**Primary Appraisal**

Kidney failure-specific care

- “[Spouse name] is on peritoneal dialysis, and you need bags with fluid for that. I have to build all that up, [spouse name] cannot do that himself. He can connect himself, but you are actually continuously supporting.” (R2)
- “The use of medication and everything around it is quite an arrangement. I have been quite busy with that, especially in the beginning. Acceptance of all those pills that you have to take as a patient is pretty intense, because all of a sudden there is a whole bag of pills that you just have to go and take every day. So I kind of relieved him of that in the beginning.” (R5)
- “I always go with her. Wherever she goes, blood draws, everything. I go with her everywhere.” (R14)
- “Yes, when I look back on that, there are indeed limitations with making food. I know the possibilities and the impossibilities, so I take that into account. I do not have them on my list anymore, but I already have those in my head of what is and is not possible. Yes, it all has influence.” (R15)

Taking on daily life tasks/roles

- “Adjusting to his energy level is quite difficult because you do not feel it yourself. So it is always a bit of an assessment for another person, what they can and cannot keep up with; and, of course, you discuss that. But I do have to take it into account a lot. I do not do much without the children because I know that if I go away without the children, then [spouse name] is at home with 2 children. That is pretty exhausting for him. So that does affect my plans.” (R1)
- “With us it was a completely different situation. I have always been a truck driver abroad, so I was always on the road. And then all of a sudden you are faced with this. Look, I never had to do anything at home because my wife was always at home. And then you are suddenly faced with this, and it just has to be done. It worked out, with the help of the children and everyone. I was more of a stay-at-home husband than a truck driver so to speak.” (R6)
- “During the time that we were both working, the tasks were divided. For example, grocery shopping or household chores. But when [spouse name] could do less, more and more errands came down to me. Household chores kept adding to my plate, and that was not unwillingness on [spouse name]'s part, but it was just he just could not.” (R8)

Administrative tasks

- “Of course, I had to deal with the informal care provision on the administrative side. And I did get involved in that and did have to make decisions.” (R10)

**Secondary Stressors**

Impact on own life/health

- “That I have to adapt to what [spouse name] can do and what we can do together, it is not really grieving for what is possible, but it is feeling a limitation all the time. You would like to do all kinds of things, but because of an external factor you cannot.” (R1)
- “Was there room for me in the whole situation? I felt at that moment I was being carried away by the whim of the day. When I look back at the more than 20 years that we have been dealing with this disease, I get more and more the feeling that there was little for me. I did a bit of that myself as well. And it still revolves a lot around the disease of [spouse name].” (R3)
- “Then at one point we switched to night dialysis, but at one point we had a lot of problems with that, too. Many alarms at night. Sometimes we had nights with 20 alarms, and then I just had to go back to work the next morning. Well, then I felt really broken.” (R4)
- “The disease of [spouse name] really did have an influence on me. You try to sympathize with him, especially in the beginning. In retrospect I actually went a little too far with that. He did not move much. I did not move much either because I wanted to be there. I wanted to support him; I wanted to accompany him. I also wanted to support him when he was psychologically unwell. Be able to talk about it. And yes, my condition also deteriorated fast.” (R7)

(Continued)

**Box 1 (Cont'd).** Quotes per Generic Category of the Stress-Appraisal Model for Caregiver Burden Applied to Kidney Failure

- “Well, the biggest change as an informal caregiver that I have experienced in the last 10 years is actually that step by step it expanded a little bit more each time. And at some point you do not notice that because you are no longer working yourself. So yes, you have whole days, and then at a certain moment it starts with preparing breakfast and then it goes on like that throughout the day until in the late evening hours when the eyedrops have to be administered, medicines have to be prepared. Well, and things like that. And only afterward now that [spouse name] has passed away, then you think back on it, and then you think when did the change come that I started doing more? You cannot really give a date; it just grew slowly. Due to circumstances, I expanded and always did it with love. Only now in hindsight I think I wronged myself in certain ways by not maintaining my social life well enough, so now I am empty handed again and have to build up new friends and acquaintances to fill in my own time again. But all with love.” (R10)

**Impact on daily life (plans)**

- “When we just found out, your whole picture of the future collapses so to speak. You have a certain image; we had just bought a house, and you have a certain picture of your future together. Maybe kids, maybe traveling. You have certain wishes and dreams. And I was very much afraid that all that would no longer work out. I had a lot of doomsday scenarios in my head.” (R1)
- “I find it very difficult to find a good combination of all the roles you have to take on, so to speak, all the responsibilities you have, because you are kind of a nurse, but you also want to be a mother, you also want to be a partner, you also want to be an employee in between. So that does make it very complicated; and because you are trying to do everything in the best possible way and it fails, you feel like you are failing, and that is hard.” (R2)
- “All this time I actually kind of flattened myself out and kind of put myself on the back burner, because this was just important. In addition, of course, I had a family, so I had to be a good mother and a great homemaker and a perfect grandmother. That is just how you go. And then at times when he was in the hospital for a long time, then especially, because then everything had to go on.” (R9)
- “You cannot plan anything anymore. You cannot think tomorrow I am going to do this, or shall we do this together. You cannot, because then one day she can, and the next day she cannot. And that is the same with receiving visitors. Sometimes it is too much, and sometimes it is too little. Then she says I cannot handle it today. And then, then you have to compromise.” (R14)

**Relational impact**

- “Right now, the big part that creates imbalance is the patient–nurse relationship, meaning that the normal spousal relationship does not exist anymore.” (R2)
- “How the sexual relationship, how the development of that was within the course of the disease? Yes, it declines a bit indeed. There is less physical attraction and intimacy; I certainly experienced that. [...] Would I have liked to have had it a bit more? Yes, I would have liked to have had it a little more. Can I wish that? When I look at how the disease has manifested itself in [partner name], I sometimes think I should not complain so much.” (R3)
- “No, intimacy does not happen at all anymore. You can forget that completely. That is completely gone. But that partly also has to do with the diabetes. So that already became less.” (R12)

**Work/financial impact**

- “In terms of long-term and short-term leave, I have made arrangements with my employer that with long-term leave it is really just unpaid leave and with short-term leave my salary goes back to 70%, so financially I then lose out if I want to take care of my partner for an extended period of time. [...] I would have been happy at that time to have had a few months of care leave after the transplantation, for example, just to be able to really support her, to be able to take care of everything at home and be there for her. Driving up and down to [place] or to whatever hospital, without that it would have given me the pressure about the fact that the house also has to be paid, because food also has to be put on the table. It was an oppressive feeling not to have that.” (R3)
- “Financially, it certainly had consequences because we had bought a house here in [place] with the idea that it would be nice. And then [partner name]’s illness progressed quicker than we had thought. So he ended up with occupational disability benefit early, and it was not easy to find work for me that could compensate for that. So that was a quite a problem. There were times when we were really at a loss as to what to do next.” (R9)
- “We actually had a house, a beautiful house in [place]. [Partner name] got ill, of course. She worked at a law firm as a secretary. She could not do that anymore. I always had these short contracts, and we had a large mortgage there, so we did not think we could manage. We cannot go on like this. So then we looked for something else where the mortgage was more affordable. And that is actually how we ended up here. So that did have an impact.” (R11)

**Secondary Appraisal****Kidney disease burden**

- “By now we are a little more free to do things again, except that, of course, there always remains a small fear of kidney function decline. We just assume that the current situation is stable and that we can plan all kinds of things and that we can go on vacation and that we can make further life decisions. And I also think that the assumption that it remains stable is important for us because that allows you to make some future plans as well.” (R1)
- “I have seen how quickly she deteriorated. That did frighten me at times. Also the unknowing, what is the result of the kidneys deteriorating so quickly? That has made me anxious. The fear of having pain and not knowing where it comes from. That has made me anxious at times too, very anxious even. [...] Seeing your wife suffer and not being able to do anything, that is quite frightening.” (R3)

(Continued)



**Box 1 (Cont'd).** Quotes per Generic Category of the Stress-Appraisal Model for Caregiver Burden Applied to Kidney Failure

- “My biggest fears and concerns. So, that is a big question. Of course, I did have a great fear of losing him. And well my worries, they are still there actually. Yes, your life did take a whole different turn.” (R13)
- “It touches me when it comes to life or death, dialysis or dying. Those are the difficult topics to discuss. I think every dialysis patient struggles with that. But as long as the dialysis is going well and you are in the early stages of dialysis, you do not have a lot of additional complaints. But those complaints start coming; they manifest themselves on the most unpleasant topics. All kinds of things come up. She also observes this on the ward where she is lying. She brings home a problem almost every time she comes off dialysis.” (R15)

## Kidney replacement therapy burden

- “My biggest concern for the future is if we have to switch from peritoneal dialysis to hemodialysis. We have tried hemodialysis for a while, and for his fitness it does no good. It affects the physical condition very badly. It also affects the structure of your family very badly, so I hope that we can do peritoneal dialysis for a very long time, that that option still offers sufficient quality. Should that not be the case, I think that our life will go downhill.” (R2)
- “I must say at the time of dialysis, as a partner, I felt that my quality of life was as poor as his. Because you cannot go left, you cannot go right.” (R5)

## Health care burden

- “I am almost always present at appointments with health care providers, especially because [spouse name] actually still felt worse after transplantation. So I go along on all outpatient visits, also because two hear more than one. I am also the one who is very alert; because the other day we were at the outpatient clinic and [spouse name] had to be admitted again because his kidney function had dropped tremendously, and then the doctor who did not know him said that there is not such a good overview in the computer. Well, then I just get really angry. I do not get angry easily, but then I really think, this just cannot be. It cannot be that there is a faulty report in the computer for someone who has had so many complications and setbacks after transplantation.” (R4)
- “I find the pharmacy in particular really quite difficult. If you take a lot of pills like in my partner’s case, 9 times out of 10 it goes wrong. You have to be alert. They give you medication for 3 months, so to speak, or with some pills even for 4 months, and then there’s an expiration date in 2 months. Or they give the wrong ones. I do notice that by now I have a strong relationship with the pharmacy over the phone. Like, be careful, because this is not going well. [Spouse name] also changes medication a lot. Something just changes very quickly with every visit. So there too you have to be alert that the pharmacy gives you the right medication and does not get stuck in an old prescription. So you have to be vigilant yourself.” (R5)
- “One of the things with [spouse name]’s medication use I did find very irritating and troublesome at times is the relationship between the caregiver coming to the pharmacy to pick up medication. Which then went wrong in every way possible. Or half the medication was there and half was not. But then again, you did not get any notice. So you spend the first 45 minutes on hold before you go to the counter to get your partner’s medication, and then you are told that those were not in stock. Then you have to come back next week. As if I have all the time and inclination for that.” (R10)

## Personal life burden

- “Yes, of course, we sometimes look at friends who have kept their income and have been able to buy bigger houses, and then that is mainly a moment of confrontation with the fact that things are slightly different for us. Not so much purely financially but on all sorts of levels that things are just a little different and that can sometimes be quite difficult.” (R1)
- “I think you just lose control of your own life. Because, yes, you cannot do things the way you want to do them and the way you plan, you cannot do that anymore. You cannot. In no way, because you can plan all you want, but you do not know what is going to happen at that time.” (R12)

## Caregiver role burden

- “At times, I found it very difficult because you are just very worried. Especially because all along, both during the dialysis period and after transplantation, there were setbacks and complications every time. And because I know a lot about it myself, I just noticed that every time when I was sitting on the couch next to [partner name], I was thinking is he falling asleep again, has his kidney function deteriorated again, has he taken his medication? You are constantly on guard, and that is difficult. And especially in your mind, I found that very difficult. In your mind you are constantly busy: am I alert enough, am I doing enough, am I not missing things?” (R4)
- “As a patient you know exactly what you are feeling. And as a caregiver, as someone who is on the sideline, then, of course, you do not always have an idea of what someone is really feeling, so I often felt very helpless.” (R8)

## Relational burden

- “In the beginning, I did find it difficult that it was less or almost no more, that we had almost no sex.” (R4)
- “Yes, it is hard because it is ... We used to like to do things together and then it just does not work anymore. And that is hard. But yes, it is part of it.” (R6)

## Financial/legislative burden

- “There have also been things with, for example, arranging the personal budget. Well, that has been quite a hassle. They suddenly started asking for things back. Then I said, do I have to prove it all again? And then sometimes I was like, stop it, because you can ask everything at the hospital. I also told that to the health insurance, for example. And also in the area of taxes, for example. And then I often think, it is the way it is, and yes, then you had to prove it again. Sometimes I got tired of that. I found that an issue sometimes. But other than that, I always say that perseverance wins. So I did a lot of things just ... If it

(Continued)

**Box 1 (Cont'd).** Quotes per Generic Category of the Stress-Appraisal Model for Caregiver Burden Applied to Kidney Failure

did not go left, it went right. But I would get it done if I knew I was right, and that is actually what happened, but sometimes with a lot of effort.” (R9)

- “Well, my husband worked in youth services. He could not do his job anymore. And well, they did not really think along with him, like can we put you in another place? There was no room for that. Actually, he just should not have retired at all. He should have gone on sick leave. And then that bridging period could have been suspended for another 2 years. But the employer did not think that was necessary. And that is very sad. And I probably could have taken over at that time. And my partner did not want that. He said, ‘Oh, never mind. Come on, we can manage.’ But I was like, ‘Well, this is just not right.’ After so many years it still bothers me.” (R13)

**Moderators**

Dialysis options/ flexibility and the possibility of a kidney transplant

- “I liked the fact that he performed dialysis outside the house, that it was just a clearly defined period. He is not at home or he is at home and not that all kinds of medical procedures still have to be done at home.” (R1)
- “The choice of dialysis was very simple. Either she had to go to the hospital 3 times a week or we had the choice of peritoneal dialysis. Which means if you are on dialysis at night you have time to yourself during the day. Now it is still a time of recovery, but soon she will have free time during the day to do things. And not having to go to the hospital mandatory 3 times a week. We had the choice and we jumped at it and we like it, also because you can go away for a longer period of time. As long as you take your stuff with you.” (R6)

Contact with and support from health care providers

- “I do not think there is really much attention for my role. In the beginning, we did ask if there is a social worker in the hospital. Could we talk to one? The doctor himself then said that he did not expect that to be necessary for us. And I think it would be better if it just happened as a standard procedure with everyone, to check up on how people are doing at home. Even if it is not necessary, you just have a pleasant conversation for half an hour, and if you do get something out of it, that is a nice bonus. But even there it was just a little bit about me and a little bit about the whole thing.” (R1)
- “There is also definitely an understanding of my role as a caregiver. We have very good contact with the PD [peritoneal dialysis] team, the nurse, also his nephrologist is also very clearly present, supportive. And the medical social worker also has a very pleasant role in that, by involving the whole family in the situation. So not just focus on the patient, but on everyone.” (R2)
- “I think it would be good if doctors would just be much more considerate of the partner of a dialysis patient or transplanted patient because it just touches the lives of both of them so incredibly. And it would be nice if there was attention for that or maybe they could give tips on how to deal with certain things. And, of course, in the beginning they say if it is difficult you can go to a social worker, but sometimes that step is just a bit too big. While I think that as a doctor or as a social worker you can help a caregiver with small things.” (R4)
- “We have been very lucky with our doctor here, and he actually always has as much time for me as he does for him. So we often do the visits together. And as much as she asks him how he is doing, she does the same with me. And we are also incredibly grateful to her for that.” (R5)
- “I have not yet asked the nephrologist the question about sexuality, and there is a kind of embarrassment. Yes, do we really have to talk about it? Is it not the case with every couple with kidney disease? Those kinds of thoughts go through my head.” (R7)

Peer contact

- “And by now I know a few people in my area who are kind of in the same situation and with whom you can exchange some of your difficulties or your doubts, and that is nice to have. So in that sense a kind of peer group can be very useful, I think. Because I accidentally have found this over the years.” (R1)
- “And we once had a weekend of the kidney patients association for predialysis. We participated in that. That left us with people who lived far away, but we still have contact with them. And these are people who understand. And yes, that is also very difficult ... People just do not understand and ... Or do understand, but then I always think I have to explain. But sometimes there is no explaining.” (R13)

Adjustments/flexibility of daily life

- “I did a lot of things together with the children during the vacations, but we tried to do as much as we could all together as well. Involving [partner name] in everything, looking for things that we can do instead of things we cannot do anymore, and in that way discover other things. Not just visiting that town but taking a moment to visit a museum, which is a little quieter than strolling through a town, so you discover other possibilities. You become more creative with your activities.” (R3)
- “And we also had one of those cookbooks, *Spice Wise*, someone pointed that out to me. I immediately bought it, and it also has fantastic recipes in it where you just do not use salt and compose your own spices, and that is actually delicious.” (R4)

Coping mechanisms

- “And very slowly I learned that nothing in life is certain. So you let go of that. You learn to live with it, it gets a place.” (R5)
- “But we have always had some kind of faith. We are religious, so we hold on to that as well. And in the end, both of us, especially me, think that God is always the main director of our lives and that we ourselves do not always have the full picture of the intention. And often you only see afterwards what lesson He was trying to teach me.” (R7)
- “And then I really had to start working on myself, and that meant just doing fun things and just focusing on the grandchildren again, but in a fun way. Not everything has to be mandatory.” (R9)

(Continued)

**Box 1 (Cont'd).** Quotes per Generic Category of the Stress-Appraisal Model for Caregiver Burden Applied to Kidney Failure

- “I am very social. I like to be around people, so for me even very small things can be very relaxing. Just sitting on a park bench with someone and chatting with them is relaxing. But I also find playing tennis very relaxing. Yes, I really like to be involved with art. I can relax anywhere.” (R12)
- “Well, I like to bike very much. We also like to do that together. But if I really need to clear my head, I go biking alone.” (R13)
- “I get my energy from those things that I can then still do myself on dialysis days. Independently. And that is especially when the weather is nice. As long as I still can bicycle.” (R15)

## Relational support/communication

- “My biggest support is actually my husband. He is always very supportive and knows very well what I find difficult.” (R1)
- “I use my social network. My parents, my brothers, my sisters, they are actually always there for us, and I really like that. And we have a little son, he can always come to them. So that way you are not completely alone.” (R2)
- “We found it very special that at one point we were offered this house and the children said, ‘You go on vacation, we will take care of everything.’ And suddenly there were 20 strong men around us to help us through it. You can only dream about that, and those are very special things. Because you sometimes also hear that that is no longer the case.” (R6)

## Financial/legislative support

- “Whether it is the lack of understanding about kidney disease at the employee insurance agency or ignorance, I dare not say. I think a lack of understanding is more appropriate than ignorance.” (R3)
- “And the other thing I would like to pass along is if you get involved with the employee insurance agency, you should approach people who can help you with that, to bring that to a good end. Do not get confused in all those regulations and everything that has to be done. Seek support in that and get help to solve that.” (R11)

## Work flexibility/support

- “So then I applied for short-term care leave, so that meant I could take one day a week of care leave for 7 weeks. And that just gave just a little bit more space to breathe. Maybe it is for your own sense, but at least it helped me.” (R4)
- “So it was true that my employer was very understanding at the time. And so I did get room to do things, but in between I had to try to combine it, because of course there is no end to it.” (R5)

related tasks were deemed as most difficult.<sup>1,4</sup> Remarkably, we found that the caregiving load was also exacerbated by administrative tasks, and these tasks usually have remained unmentioned in research.

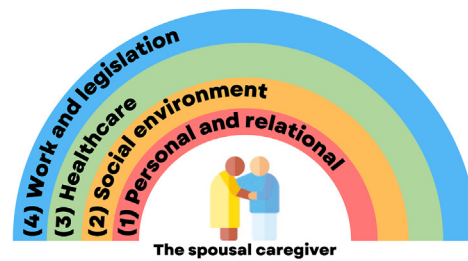
Through the secondary stressors and appraisal, we elucidated the impact of kidney failure and treatment choices on different areas of spousal caregivers' lives (ie, their personal life and health, daily life, relationship, work, and finances). Although treatment choices do not structurally involve spouses, it is important that they are informed of and prepared for the potential impact it may have on their lives. Similar to our findings, studies show that caregivers undergo many lifestyle changes as a result of caring for their loved one, leading to feelings of losing their personal lives and subsequently increasing the caregiver burden.<sup>9,28,29</sup> We found that these lifestyle changes were especially seen at dialysis initiation, and that the impact differed between types of KRT.

In line with a review that described caregivers as “hidden patients” who are frequently ignored by health care providers and who disregard their own health issues,<sup>9</sup> we describe how caregiving impacted spouses' personal life and health, among other aspects, because they put themselves second. Regarding relational impact, we provide an in-depth description from the spouses' point of view, which has not been described before in this context. For example, a role-shift within the relationship was described, from feeling like a partner to a nurse. Difficulties regarding intimacy and reproduction were also highlighted. Last, we describe how providing care

impacted caregivers' ability to continue working (full time), thereby, combined with their spouses' inability to work, impacting their financial status. Similarly, another study reported that most caregivers made at least one job-related choice, most often working fewer hours per week and taking care leave.<sup>30</sup>

The moderators identified in our study provide directions for reducing burden of spousal caregivers through several pathways. Some overlap in moderating factors exists with previous research, but no study has provided such a comprehensive overview of moderating factors for this caregiver group. For instance, previous research has shown improvement in caregiver burden, personal time, and social life after patients' kidney transplantation,<sup>29</sup> but no studies have focused on the impact of dialysis modality on the caregiver. We describe the differences in the preference for home or in-center dialysis between spousal caregivers, depending on different factors (eg, time management and caregiving tasks). Additionally, although previous research on caregivers showed a lack of good communication with the health care provider,<sup>31</sup> we add that feeling understood as a caregiver and trusting the health care provider are important moderators. We described various coping mechanisms, which were partially described in previous research, such as religious coping, pursuing hobbies, and planning for routine.<sup>8,28,32</sup>

A major strength of our study is the disease-specific application of the model, with evidence for all paths of the model, which is important for use in practice. Thorough qualitative research methods were used to validate



### (1) Personal and relational

- **Recognition of caregiver role and need for support**
  - Caregivers should acknowledge the physical and emotional demands of managing their spouses' kidney disease in order to seek appropriate support.
  - Foster an understanding within the relationship about the caregiver's role and associated burden (e.g., discuss tasks that the caregiver takes over, such as performing home dialysis, and how it impacts them).
- **Enhancement of personal strengths and reserves of caregivers**
  - Enhancing personal strengths and reserves aids in building resilience and reducing burden, e.g., through peer contact with other caregivers of patients with kidney failure, enhancing coping strategies (e.g., how to deal with specific stressors), and enhancing relational support (e.g., by improving communication).

### (2) Social environment

- **Acknowledgement of the impact of kidney disease**
  - Raise awareness among family and friends about the (physical and emotional) challenges faced by caregivers of patients with kidney failure through provision of information about the complexity of kidney disease (management).
- **Provision of support**
  - Strengthen the role of social networks in caregiver support (e.g., provide tangible support, such as help with household tasks and transportation to dialysis, and emotional support).

### (3) Healthcare

- **Support and acknowledgement of caregivers by healthcare providers**
  - Healthcare providers, including nephrologists, nurses, and medical social workers, should actively recognize the essential role caregivers play in managing kidney failure, especially in the context of dialysis. This includes acknowledging their emotional and physical burden and providing them with resources and guidance on how to deal with this.
- **Involvement of caregivers in communication between healthcare providers and patients**
  - Caregivers should be considered part of the healthcare team, as they aid kidney disease management. They should be involved in key discussions (e.g., about kidney replacement therapy) and should be able to discuss topics they want to talk about.

### (4) Work and legislation

- **Acknowledgement of the caregiver role by work and government bodies**
  - Employers and government bodies should recognize the unique demands faced by caregivers of patients with kidney failure. This recognition can facilitate informal care through supportive policies, such as providing paid care leave, flexible work arrangements, and assistance with administrative tasks related to caregiving. Such measures can help alleviate the stress and financial burden on caregivers, allowing them to focus more effectively on their role without compromising their employment.

**Figure 2.** Four areas of need for acknowledgement of the spousal caregiver.

the framework in the context of kidney failure. Another strength is the variation in the study population (eg, wide range in age) which contributes to the broad view on spousal care. Experiences with a range of KRT modalities emerged, as well as not receiving or choosing for KRT. In addition, data saturation was achieved after coding 14 interviews (ie, no new concepts were identified), which may also be expected with 15 interviews.<sup>33,34</sup> Relevance and completeness of the interview guide were ensured through development with input from caregivers themselves.

This study also has some limitations. First, transferability of the findings may be impacted by the fact that participating caregivers had to be willing to be interviewed and videotaped for a website (ie, they were likely to be more literate and more engaged, and possibly had a higher socioeconomic status). Additionally, the reasons for declining were unknown, and only Dutch-speaking spouses were included. Transferability to other countries may be impacted by differences in health care systems (eg, dialysis care options, funding, and support) as well as differences with regards to the context of informal care. In the Netherlands, it is regulated by law that the primary responsibility for care

for people living independently is assigned to the social network. Comparable to other European countries, 1 out of 3 Dutch adults provides informal care.<sup>35</sup> Municipalities are responsible for supporting these informal caregivers, for example, through substitute care, housing adjustments, and domestic help. A second limitation is that the participants were not asked about their educational level, cultural background, and health status, which are relevant because previous research has suggested that caregiver burden may be influenced by sociodemographic characteristics and caregivers' comorbidities.<sup>27</sup> Based on what was said in the interviews, we expect a variety of educational levels. Third, 2 caregivers were interviewed after their partner had died. This may have impacted the way they answered the questions. Fourth, no information on patient characteristics, such as age and frailty, were collected.

This study's key implication is the need for acknowledgement of spousal caregivers in 4 areas: (1) personal and relational, (2) social environment, (3) health care, and (4) work and legislation. Recommendations for acknowledgement and support of spousal caregivers in these 4 areas are summarized in Figure 2. Future research should focus on possible differences in the desired support of

caregivers between different types of KRT (such as the difference between home and in-center dialysis<sup>36</sup>), as well as on finding out the best ways to provide support in practice and at what moments in the kidney failure trajectory (eg, the transition to dialysis) to help caregivers stay in control of their lives (ie, enhance self-management).

In conclusion, this study applied the stress-appraisal model of caregiver burden in the context of kidney failure, providing a disease-specific model for practice. Through this model, we describe the impact of care provision on all aspects of spousal caregivers' lives, the burden associated with it, and identify possible modifiable factors to prevent overburdening of caregivers. This study underlines the need for acknowledgement of caregivers in 4 areas to support and facilitate informal care: (1) personal and relational, (2) social environment, (3) health care, and (4) work and legislation.

## Supplementary Material

### Supplementary File (PDF)

**Figure S1:** Modified stress-appraisal model for caregiver burden based on Pearlin et al (1990), Yates et al (1999), Chappell and Reid (2002), Swinkels et al (2017), and Verbakel et al (2018).

**Table S1:** Interview guide.

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## Caregiver Burden Among Spouses of Patients With Kidney Failure

| Study Design   | Results of Qualitative Analysis  |   |
|--|--|---|
| <p> <b>Qualitative study</b></p> <p> <b>The Netherlands</b></p> <p> <b>N = 15 spousal caregivers</b></p> <ul style="list-style-type: none"> <li>• Aged 34-82 years</li> <li>• 60% female</li> </ul> <p> <b>Semi-structured interviews</b></p> <p> <b>Informal caregiving duration: 4-37 years</b></p> | <p> <b>Care demand</b> is defined by effects of kidney failure and its treatment on patients and their comorbidities and dependency</p> <p style="text-align: center;">↓</p> <p> <b>Care provision</b> consists of kidney failure-specific care, taking on daily life tasks and administrative tasks</p> <p style="text-align: center;">↓</p> <p> Care provision conflicts with other activities, <b>impacting caregivers' personal lives</b> on four domains: personal life and health, daily life, relationships, and work/finances</p> <p style="text-align: center;">↓</p> <p> Caregivers described <b>different types of burden</b>, namely regarding kidney disease, therapy, healthcare (providers), personal life, caregiver role, relational, and financial/legislative</p> | <p style="text-align: center;"></p> <p><b>Moderators</b></p> <p>Provide directions for reducing burden through several pathways (e.g., communication with healthcare providers, peer contact, coping mechanisms, and work flexibility/support)</p> |

**CONCLUSION:** This comprehensive overview of the burden experienced by spousal caregivers of patients with kidney failure highlights four principal areas of needed support: personal and relational, social, healthcare, and work and legislation.

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