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## **Towards adequate care for sexual health and fertility in chronic kidney disease: Perspective of patients, partners and care providers**

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### **Citation**

Ek, G. Fvan. (2019, November 7). *Towards adequate care for sexual health and fertility in chronic kidney disease: Perspective of patients, partners and care providers*. Retrieved from <https://hdl.handle.net/1887/80204>

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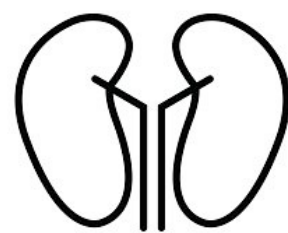
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**Issue Date:** 2019-11-07

## Part IV

# Summaries, Discussion, and Recommendations

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## ***9. Summary***



# ***Part I Sexual care & chronic kidney disease***

## ***The perspective of renal care providers***

### **Chapter 2**

#### **Discussing sexual dysfunction with chronic kidney disease patients; practice patterns in the office of the nephrologist.**

*Introduction* Sexual dysfunction (SD) is a common problem in patients suffering from chronic kidney disease (CKD). Sexual health remains a difficult subject to detect and discuss. Although many studies have been performed on the incidence of SD, little is known about practice patterns when it concerns quality of life (QoL)-related questions such as SD in the nephrologists' practice.

*Aim* The aim of this study was to determine to which extent nephrologists, important renal care providers, discuss SD with their patients and their possible barriers toward discussing this subject.

*Methods* A 50-item questionnaire was sent to all Dutch nephrologists (n = 312).

*Main Outcome Measures* The survey results.

*Results* The response rate of the survey was 34.5%. Almost all responders (96.4%) stated to address SD in less than half of their new patients. The most important barrier not to discuss SD was patients not expressing their concern regarding SD spontaneously (70.8%). Other important barriers were: "the lack of a suitable moment to discuss" (61.9%) and "insufficient time" (46.9%). Eighty-five percent of the nephrologists stated that insufficient attention was paid to SD and treatment options during their training. Sixty-five percent of the respondents stated to be in need of extending their knowledge on the discussing of SD.

*Conclusions* Dutch nephrologists do not discuss problems with sexual function routinely. The lack of knowledge, suitable education, and insufficient time are factors causing undervaluation of SD in CKD patients. Implementation of competent sexual education and raising awareness among nephrologists on the importance of paying attention to SD could improve care and QoL for patients with CKD. More research should be

performed among patients and other renal care providers to develop an adequate method to enhance our current system.

### **Chapter 3**

#### **Evaluated from the perspective of the renal transplant surgeon: the discussion of sexual dysfunction before and after kidney transplantation**

*Background* Sexual dysfunction (SD) is a common problem in chronic kidney disease (CKD) and endures in 50% of patients after kidney transplantation (KTx), diminishing patients' expectations of life after KTx. Unfortunately, SD is often ignored by renal care providers. Research questions as part of a research project among all renal care providers, transplant surgeons' perspectives were obtained on sexual health care for KTx recipients, including their opinion on who should be accountable for this care. In addition, surgeons' practice and knowledge regarding SD were evaluated.

*Design* A 39-item questionnaire was sent to all Dutch surgeons and residents specialized in KTx (n = 47). Results: Response was 63.8%. None of the respondents discussed SD with their patients, before or after surgery. Most important barrier was that surgeons do not feel accountable for it (73.9%); 91.7% thought this accountability should lie with the nephrologist. Another barrier was insufficient knowledge (39.1%). In 75% of the respondents, (almost) no knowledge regarding SD was present and 87.5% noticed education on SD was insufficient during residence training.

*Discussion* Dutch renal transplant surgeons rarely discuss SD with their patients with CKD, as they do not feel accountable for it; this accountability was appointed to the nephrologist. Knowledge and education regarding SD were found insufficient in enabling surgeons and for some it reflects in barriers toward discussing SD. Results emphasize that accountability for providing sexual health care to patients with CKD should lie elsewhere; however, surgeons could briefly provide information on sexual health after KTx, so unfulfilled expectations may be prevented.

## Chapter 4

### **Sexual care for patients receiving dialysis: a cross-sectional study identifying the role of nurses working in the dialysis department**

*Background* Sexual health is not self-evident for patients undergoing dialysis; 70% experience sexual dysfunction. Nevertheless, sexual care is often not provided. The aim was To explore the role of nurses in the dialysis department in providing sexual care to patients receiving dialysis.

*Methods* Questionnaires (n=1211) were sent to employees of 34 dialysis centres from January - May 2016. Descriptive statistics and statistical tests were used to describe and interpret data.

*Results* The response rate was 45.6%. Three-quarter of nurses discussed sexual dysfunction with less than half of their patients. Main barriers for discussing were based on language and ethnicity (57.3%), culture and religion (54.1%) and the older age of the patient (49.7%). Eighteen percent of nurses had sufficient knowledge on sexual dysfunction, competence was present in 51.2% of nurses and 68.3% indicated a need for training. Forty-three percent knew about guidelines on sexual care by renal care providers. Nurses who rated their knowledge or competence higher or who were aware of guidelines, discussed sexuality more often. The accountability for discussing sexuality was appointed to nephrologists (82.8%) and their own group of professionals (66.3%). Nurses referred 1.16% of their patients to sexual care providers.

*Conclusion* Dialysis nurses do not consistently address patients' sexuality, although they feel accountable to do so. This seems due to self-imposed insufficient knowledge, cultural barriers and organizational problems. Study findings imply that current situation could benefit from guidelines, additional training, a private moment to discuss sexual dysfunction and adequate referral systems to specialized care providers.

## Chapter 5

### **Unravelling current sexual care in chronic kidney disease: perspective of social workers**

*Background* Fifty to eighty percent of patients suffering from chronic kidney disease (CKD) experience a form of sexual dysfunction (SD), even after renal transplantation. Despite this, inquiring about SD is often not included in the daily practice of renal care providers. Objectives: This paper explores the perspectives of renal social workers regarding sexual care for patients and evaluates their practice, attitude towards responsibility and knowledge of SD.

*Methods* A cross-sectional study was conducted using a 41-item online survey. Participants: Seventy-nine members of the Dutch Federation of Social Workers Nephrology.

*Results* It was revealed that 60% of respondents discussed SD with a fifth of their patients. Frequency of discussion was associated with experience ( $p=0.049$ ), knowledge ( $p=0.001$ ), supplementary education ( $p=0.006$ ), and the availability of protocols on sexual care ( $p=0.007$ ). Main barriers towards discussing SD consisted of ‘culture and religion’ (51.9%), ‘language and ethnicity’ (49.4%), and ‘presence of a third person’ (45.6%). Sufficient knowledge of SD was present in 28% of respondents. The responsibility for discussion was 96% nephrologists and 81% social workers.

*Conclusion* This study provides evidence that a part of Dutch nephrology social workers do not provide sexual care regularly, due to insufficient experience and sexual knowledge, absence of privacy and protocols and barriers based on cultural diversity. According to the respondents the responsibility for this aspect of care should be multidisciplinary. Recommendations include a need for further education on the topic, private opportunities to discuss SD and multidisciplinary guidelines on sexual care.

## ***Part II Sexual care, relationships & chronic kidney disease***

### ***The perspective of patients and their partners***

#### **Chapter 6**

##### **Exploring sexual care in end-stage renal disease in the Netherlands: a pilot study from the perspective of patients and partners**

*Introduction* During dialysis and after renal transplantation, more than half of patients and their partners are confronted with sexual dysfunction. This explorative cross-sectional multicenter survey was designed to draw up an inventory of the needs and timing for sexual care during dialysis and post renal transplantation in the Netherlands.

*Methods* Between July 2016 and July 2017 320 patients undergoing dialysis and 257 renal transplant recipients plus their partners were invited to complete a questionnaire.

*Results* In the dialysis group, 27 patients (9.0%) and nine partners completed a questionnaire. Of the transplant recipients, 36 (14.4%) participated. Over three-quarter of the responding patients and partners did not receive information about sexuality. A quarter of patients undergoing dialysis and 33.3% of their partners indicated a need for information about the effect of renal disease on sexuality. Among transplant recipients, 76.5% of patients and 57.9% of partners noted that they would like to be informed about sexual dysfunction; most preferably during a consultation with a renal care provider (resp. 76.9% and 54.6%). Offering every patient the opportunity to discuss sexuality was considered important by more than half of patients in the dialysis group (57.1%) and by 78% in the transplantation group.

*Conclusion* Results of this pilot study imply that attention for sexual health is not perceived as adequate in renal care. Although receiving information about sexuality seems to be more of a priority after renal transplantation, offering the opportunity to discuss sexual health is appointed as important both during dialysis and after renal transplantation.

## Chapter 7

### **The implication of end-stage renal disease and sexual dysfunction on relationships; the perspectives of patients and partners.**

*Introduction* End-stage renal disease (ESRD) is associated with challenges within patient-partner relationships, including sexual dysfunction (SD). This pilot study evaluated the self-reported relational impact of ESRD, dialysis or renal transplantation, and SD. Additional focusing on mutual support; all from the perspective of patients and partners.

*Methods* This cross-sectional study invited patients receiving dialysis, renal transplant recipients (n=577) and their partners, from three hospitals.

*Results* Thirty-eight patients (7.0%) and 28 partners were included; 10 patients receiving dialysis participated together with 9 of their partners. The mean relationship-duration was 31.3 years (SD 16.0). Between 22.9-35.7% of patient and partners experienced changed roles within the relationship due to ESRD; partners were more often affected by these changes in the dialysis phase than the transplantation phase (p=0.019). Support from partners in the form of providing care and continuing to participate in fun activities together were considered important. Twenty-five patients (65.8%) experienced SD. Remaining intimate with each other was considered the best support by both patients and partners when experiencing SD (38.5-44.4%), whereas talking about SD was mentioned less often (11.1-20.0%). About 19.5% of patients and 25.1% of partners stated that ESRD, dialysis, renal transplantation or SD had negatively affected their relationship.

*Conclusion* This pilot implies that the impact of ESRD, treatment or SD on the patient-partner relationships is limited. When focusing on support during ESRD and SD, perspectives of mutual support corresponds within most couples.

## ***Part III Fertility care & chronic kidney disease***

### **Chapter 8**

#### **What is the role of nephrologists and nurses of the dialysis department in providing fertility care to CKD patients? A questionnaire study among care providers**

*Background* This study evaluated current fertility care for CKD patients by assessing the perspectives of nephrologists and nurses in the dialysis department.

*Methods* Two different surveys were distributed for this cross-sectional study amongst Dutch nephrologists (N=312) and dialysis nurses (N=1211).

*Results* Response rates were 50.9% (113 nephrologists) and 45.4% (546 nurses). Guidelines on fertility care were present in the departments of 9.0% of the nephrologists and 15.6% of the nurses. 61.7% of the nephrologists and 23.6% of the nurses informed  $\geq 50\%$  of their patients on potential changes in fertility due to a decline in renal function. Fertility subjects discussed by nephrologists included “wish to have children” (91.2%), “risk of pregnancy for patients’ health” (85.8%), and “inheritance of the disease” (81.4%). Barriers withholding nurses from discussing FD were based on “the age of the patient” (62.6%), “insufficient training” (55.2%), and “language and ethnicity” (51.6%). 29.1% of the nurses felt competent in discussing fertility, 8.3% had sufficient knowledge about fertility, and 75.6% needed to expand their knowledge. More knowledge and competence were associated with providing fertility health care ( $p < 0.01$ ).

*Conclusions* In most nephrology departments the guidelines to appoint which care provider should provide fertility care to CKD patients are absent. Fertility counseling is routinely provided by most nephrologists, nurses often skip this part of care mainly due to insufficiencies in self-imposed competence and knowledge and barriers based on cultural diversity. The outcomes identified a need for fertility guidelines in the nephrology department and training and education for nurses on providing fertility care.



## ***10. General discussion and future perspectives***

## General discussion

While sexuality is described by the WHO as a central aspect of human live, it is still under recognized in the current medical world(1, 2). Especially in times of disease, sexuality should be an important topic to discuss as sexual health could be at risk(1). If sexual dysfunction occurs as a result of disease, this could diminish patients' quality of life even further. Little by little the focus in medicine shifts; maintaining patients' quality of life becomes more important than only pursuing increasing survival rates(3). Incorporating the subject sexuality into current medical care would be in line with this shift of focus.

Unfortunately, this thesis shows that an undervaluation of patients' sexuality in times of disease is present in the field of nephrology. Although multiple studies exist focussing on the aetiology and prevalence of sexual dysfunction in patients suffering from end-stage renal disease (ESRD), this information is not yet translated into current clinical practice. As described in **Chapter 1, 2, 3 and 4** of this thesis, renal care providers do not routinely discuss sexuality and/or sexual dysfunction with their ESRD patients. Underlying reasons varied between the different renal care providers.

The main reasons for renal transplant surgeons not to discuss sexuality are: they do not feel responsible for this or they believe this responsibility should lie with the nephrologist. This point of view could be explained considering surgeons' daily practice and because they only get involved in the finale phase of ESRD. This in contrast to the nephrologist, who guide the patient throughout the entire course of disease. Nevertheless, most nephrologist do not assess the subject sexual dysfunction during their consultation because patients do not bring op sexual dysfunction spontaneously. More important, they are often held back by time restraints. Insufficient time and increasing workload are pressing matters in modern medicine and unlikely to be solved in the nearby future.

Seen in this light, nurses of the nephrology department as well as social workers nephrology could fulfil an important part in providing sexual care to patients suffering from ESRD. Both renal care providers feel responsible to do provide care for sexual health and are often regularly in contact with patients during the entire course of disease.

*Are we there yet?*

Unfortunately, most nurses and social workers skip the subject sexuality during their consultation with patients. Often restrained by shortcomings in knowledge and training, but also withheld by an expanding cultural diversity among both care providers and patients. Another obstacle to overcome is the absence of privacy for nurses and social workers. This problem is mainly present during the dialysis phase where consultation often take place in crowded dialysis units where patients are situated closely next to each other.

*How do we get there?*

Before making any alterations, patients' point of view should be considered. **Chapter 6** provides a first glimpse in their wishes and perspectives regarding sexual care in two important stages of ESRD: dialysis and after renal transplantation. Where the first is characterized by sexual dysfunction caused by hormonal disturbances and physiological factors as fatigue and depression, after renal transplantation sexual issues are more induced by immunosuppressive medication or anxiety to damage the renal transplant(4-8). Outcomes suggest the main focus of sexual care during ESRD should be in the transplantation phase, where patients seem to experience the absence of standardized care as an unmet need.

Nevertheless, the results imply that providing an opportunity to discuss sexuality during dialysis is preferred.

Moreover, one important perspective should not be forgotten, that of a party often neglected in current medicine: the partners. They often provide strong support throughout the whole course of disease and also encounter the effects of sexual dysfunction as a result of chronic kidney disease(9, 10). Results of the pilot study in **Chapter 6** imply that especially during the renal transplantation phase, partners would like to be involved when sexual care is provided. It is during this phase that partners could get an even more important role: due to a shortage in organ donors patients are more likely to receive a living donor kidney from their partner(11). One could imagine that such a life-event, besides the possible presence of sexual dysfunction, could be of great impact on the intimate relationship between patient and partner. For example, due to feelings of guilt and the fear of disappointing their partner if they lose the graft(11, 12). Besides, during dialysis the patient-partner relationship could face challenges as well due to changing relationship- roles due to patients' dependency of care and almost daily hospital visit(10, 13). Yet, as is outlined in **Chapter**

7, the actual impact of these life-events, including ESRD, dialysis, renal transplantation and sexual dysfunction, on the intimate relationship between patient and partner seems to be limited.

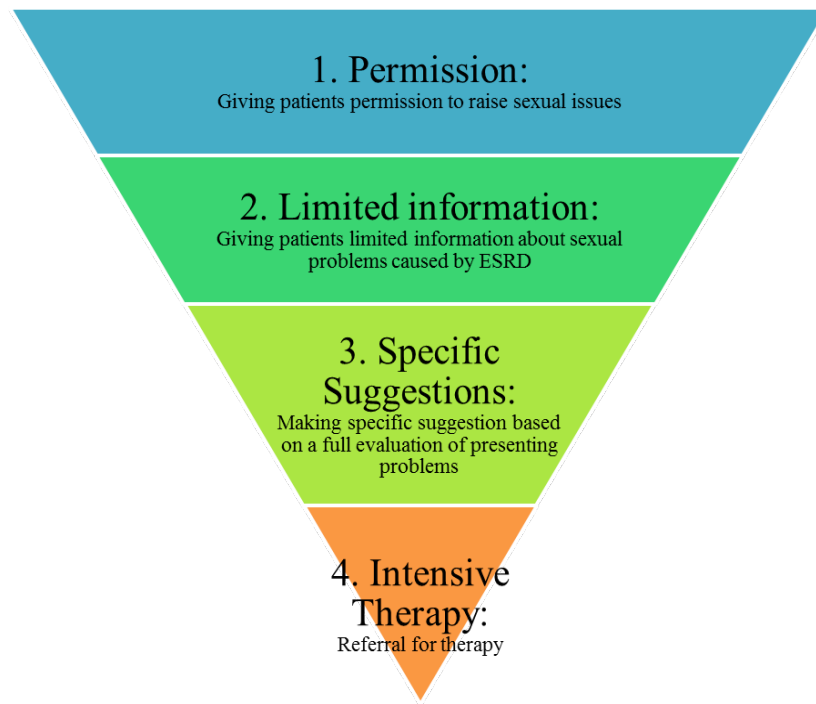
*Where do we begin?*

First, the educational system for nurses and social workers should be improved(2). By implementing the subject sexual healthcare into current educational programs and to provide additional training programs, nurses and social workers' knowledge about sexuality in times of ESRD could be approved(14-16). It will also enable them to provide this part of care in cultural diverse population(17, 18). In addition, their approach in addressing sexuality could be improved by providing them with practical tips and tools(14-16). An example of such a tool is the PLISSIT model developed by Annon in 1974 (See figure 1.)(19). This tool could enable care providers to start a dialogue about sexuality and guide them through the conversation. Some examples for adjusting the tool to the situation of ESRD patients and partners:

- 1) Asking the patients (and their partners) permission to initiate the discussing about sexuality is essential. For instance, by using the sentence "At this point of the consultation, I normally ask some questions about sexuality. Are you okay with that?"(2, 19).
- 2) When proceeding to the next step, brief information about sexuality in context of ESRD could be provided. "A lot of people/couples confronted with ESRD experience sexual dysfunction. This could be caused by ... and express in ...et cetera"(2, 19).
- 3) Every dialogue should be adjusted to the specific situation of the patient (and partner). Patients' age, gender, sexual orientation, but also the stage of disease should be taken into consideration. As described earlier, patients undergoing dialysis face different challenges than those who received a renal transplant.
- 4) The final and most crucial step is the referral for treatment(19). Patients (and their partners) should be referred for treatment to a specialized care provider as one could not expect that nurses and social worker add this to their daily practice. Besides, it is in patients' best interest to be treated by experienced therapist. Fundamental to this last step is constructing clear and easy accessible referral paths within all renal care departments. As mentioned before, besides education and tools, a private and secure location should be provided to nurses and social workers to discuss sexuality(2). Especially in the dialysis phase the absence of privacy could

be challenge as consultation often takes place in a crowded dialysis unit. Maybe a scheduled appointment after dialysis treatment in a separate room could be a solution?

**Figure 1. Annons' PLISST Model adjusted for ESRD**



Nevertheless, sexuality remains a sensitive and difficult subject to address. Besides, nurses and social workers' time is not unlimited either. Seen in this light, informative videos and e-health applications could be welcome tools. This will provide patient- centered health care that is adjusted to a persons' special needs, wishes and disease stage and could guide them through the whole course of disease. On the other hand, it will enable patients and partners to retrieve some self-management in their disease. Even for the elderly, this would be welcome instruments enlarging their independence(20). Easy accesable instruments for elderly will become more important in the near future as their number is increasing in the dialysis as well as in the transplantation group(21). Although some care

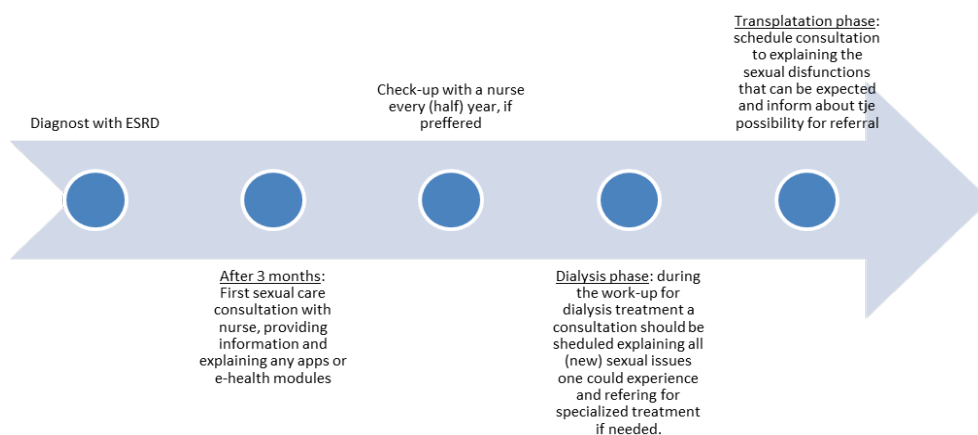
providers are under the impression that sexual dysfunction is not an issue for people of older age literature shows the contrary: about a fifth of the elderly is still sexually active and more than the half still considers sexuality is an important part of life(22).

In the time-linen in figure 2 a proposition is given on how sexual care in ESRD could be constructed.

*But how do we finance these changes?*

The healthcare adjustments mentioned above suggest the need for additional financial resources. However, this might not be the case. By incorporating these adjustment a large part of chronic care will be transferred from the (expensive) medical specialist to (less expensive) paramedics. Besides, the implementation of an educational self-management tool could decline healthcare cost as it could diminish the use of medical services(23, 24).

**Figure 2. Proposition on the structure of sexual care in ESRD**



Therefore attention for sexual health will probably result in a shift of funding, rather than in an increase of healthcare cost.

*A small side-step to fertility*

Although the solutions mentioned above are focused on sexuality, the same could apply to the addressing of fertility. An equally sensitive and difficult

subject that some could find traumatizing to discuss(25, 26). As is enlightened in **Chapter 5**, the most nephrologists include fertility in their consultation. Yet, one can imagine that time restraints and increasing workload may be a problem here as well. Nurses of the nephrology department could also play an important role in addressing this part of renal care. Insufficient knowledge is, however, is a retaining factor in in discussing fertility matters with renal patients. Results outlined in **Chapter 5** as well as literature emphasize the need for training and education to improve nurses' knowledge regarding fertility in renal disease, and to enable them to address this subject in patients and partner with diverse ethnical backgrounds(18, 27). The PLISST model shown in Figure 1 might also be a practical tool for the discussion of fertility although no scientific evidence for this exist. Study findings do suggest that guidelines on fertility care for all renal care departments could be beneficial.

#### *The greater picture*

The most important message of this thesis should not only be that sexual and fertility has to be available to patients and partners confronted with ESRD, but as well that it should be available for patients and partners challenged with any form of disease and disability. If we have a more holistic view and if we collaborate with other medical care departments, an overarching , flexible and adjustable healthcare system can be constructed in which sexual health and fertility care can be accessible throughout medicine.

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