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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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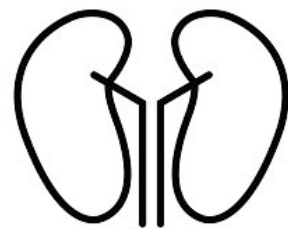
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1. General introduction



Sexual & Reproductive Health; basics human rights

According to WHO guidelines, sexual health is defined as “a state of physical, mental and social well-being in relation to sexuality” (1). The achievement and preservation of sexual health is essential for a persons’ health, well-being and relationships (2). The same applies for fertility; another important component of basic human rights (3). Unfortunately, many factors can influence both sexuality and fertility resulting in dysfunction on several levels. For instance, when focusing on sexual dysfunction, this could be subdivided into disorders on the level of sexual interest, sexual arousal or on orgasmic level (4). Also the etiology of both sexuality and fertility disorders could differ widely; sometimes the presence of one of these disorders could even provoke the arising of the other (5-7). An important component underlying to the existence of both disorders is the presence of disease, especially chronic diseases (1, 3, 4). An example of such a chronic disease causing deterioration of both sexuality and fertility is chronic kidney disease.

Chronic kidney disease in a nutshell

Chronic kidney disease (CKD) is a substantial global health concern and population prevalence exceeds more than 10% in many countries worldwide (8, 9). In the Netherlands, over 1 million people are diagnosed with a form of CKD (10). One speaks of CKD when kidney damage, characterized by reduced glomerular filtration rate and/or increased urinary albumin excretion, is present for 3 months or longer (11). This process is also illustrated in Figure 1, where horizontal arrows indicate the transition within CKD and where the grey areas show the correlations between this transition, the glomerular filtration rate, and damage of the kidney (8). Globally, the most common causes of CKD include diabetes mellitus, hypertension, and glomerulonephritis. In CKD, the process of disease is often complicated by increased mortality, cognitive decline, anemia and mineral and bone disorders. Clinical manifestation can occur in various ways depending on the underlying cause and induced complications; all characterized by a deterioration of patients’ quality of life (9, 11, 12). In terms of treatment in CKD, options varied from lifestyle modifications in patients with a mild form up to renal replacement therapy (hemo- and peritoneal dialysis) in advanced CKD (9, 11). If renal function is irreversibly declined beyond a threshold of clearance, for most CKD patients kidney transplantation could serve as a welcome solution (13).

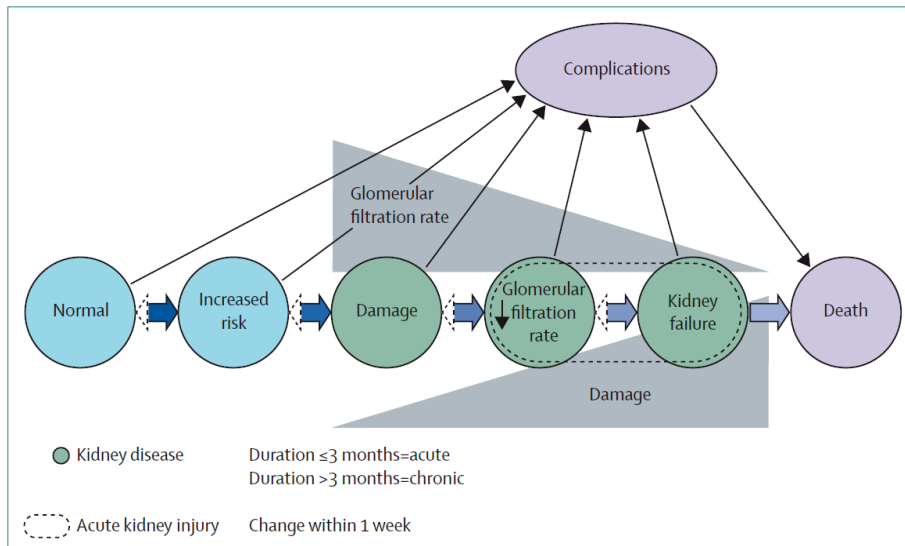


Figure 1. The process of CKD
 Source: Adapted from Eckardt et al Lancet 2013; 382: 158-69

The impact of CKD on sexuality and intimacy

Sexual health does not come naturally for men and women suffering CKD; sexual dysfunction (SD) is a common occurrence throughout all stages of disease (14). Effects of SD can first manifest in the early stage of CKD, often worsening as renal function declines (14-16). The etiology of SD is often multifactorial. Besides the uremic milieu, factors like comorbid illnesses, anemia, and hormone disturbances all contribute to the existence of SD (15, 16). Psychological components contribute as well to the development of SD; depression, anxiety, poor body image and social withdrawal have a negative impact on sexual function (17). Manifestation of SD in male CKD patients often results in erectile dysfunction with a prevalence ranging from 62-77% depending on stage of disease (18-20). Furthermore, when focusing on diabetes, this major and common form of CKD is underlying to 30% of the erectile dysfunction in men as shown in figure 2.

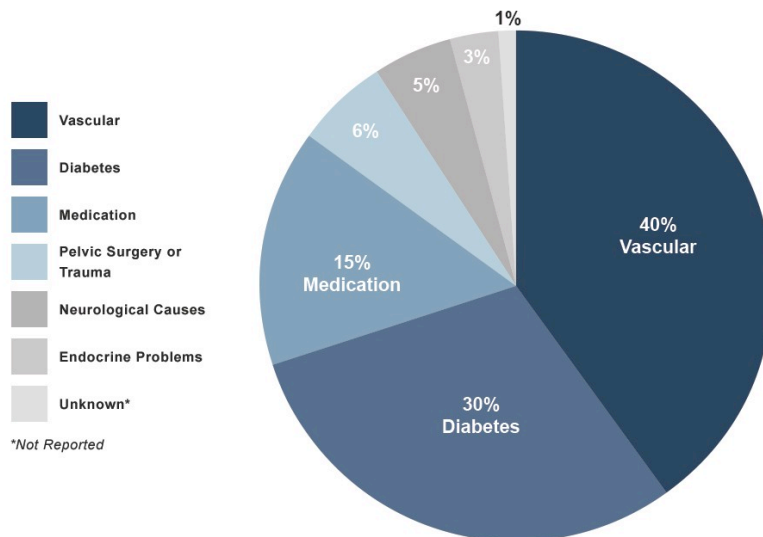


Figure 2. Diabetes: an important cause of erectile dysfunction
 Source: Adapted from Shabsigh R, MD, Lue TF, MD. A Clinician's Guide to ED Management. New York: Haymarket Media Inc.; 2006

Besides, also the vascular, endocrine, and medication components causing erectile dysfunctions are often associated with CKD. Other sexual problems reported by men are anejaculation, reduced libido and difficulty in achieving orgasm (18, 21). Changes in body shape may affect sexual function as well since 30% of male patients on maintenance dialysis develops gynecomastia (15).

Up to 70% of the female patients suffer from SD as a consequence of CKD, with symptoms such as reduced libido and lubrication, difficulty in getting aroused, pain during intercourse, and difficulty in achieving orgasm (14, 19, 22).

Some interventions exist for SD in CKD, however their safety and efficacy are understudied(23). The best treatment for both SD and CKD is receiving a kidney transplant. Renal transplantation (RTx) will improve patients' overall well-being as well as sexual function (24-27). However, even after receiving a donor kidney, the persistence of SD is not uncommon; more than 50% of both male and female transplant recipients still experience sexual complaints (19, 28, 29). Partially induced by the required use of immunosuppressive medication, other factors of influence include for instance changes in body shape and unusual hair growth (30). For example, 65% of male renal transplant recipients experience a level of erectile dysfunction; almost 30% even a severe form (see Figure 3) (29).

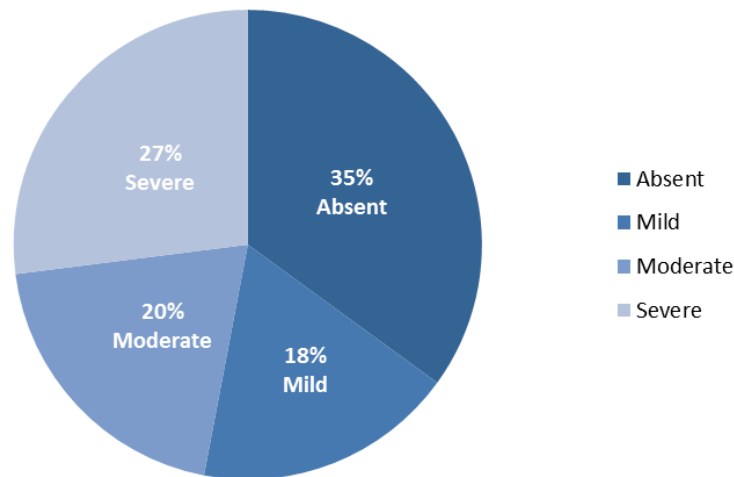


Figure 3 Prevalence of ED after renal transplantation
 Source: Adapted from Antonucci et al. *Archivio Italiano di Urologia e Andrologia* 2015; 87, 4

Relationships in the light of CKD

Chronic diseases, such as CKD, are not only associated with physical impairments; patients will also be psychosocially challenged on multiple levels, especially during dialysis treatment (31). Figure 4 shows these psychological and social difficulties, illustrating the effects of CKD on all levels of patients' well-being. As is displayed, patients social and relation life is often affected by CKD as well. Their partners often fulfill an important and supportive role during intensive treatments or a lingering sickbed (32). As a result, the disease and the accompanying burdens affect also their partners' well-being on several levels (32, 33). The same applies for the relationship between patient and partner; often evolved and shaped by the presence and duration of CKD (32). A strong and stable relationship could provide a good disease coping mechanism for both patient and partner, but a struggling relationship could deteriorate further due to the presence of CKD (32).

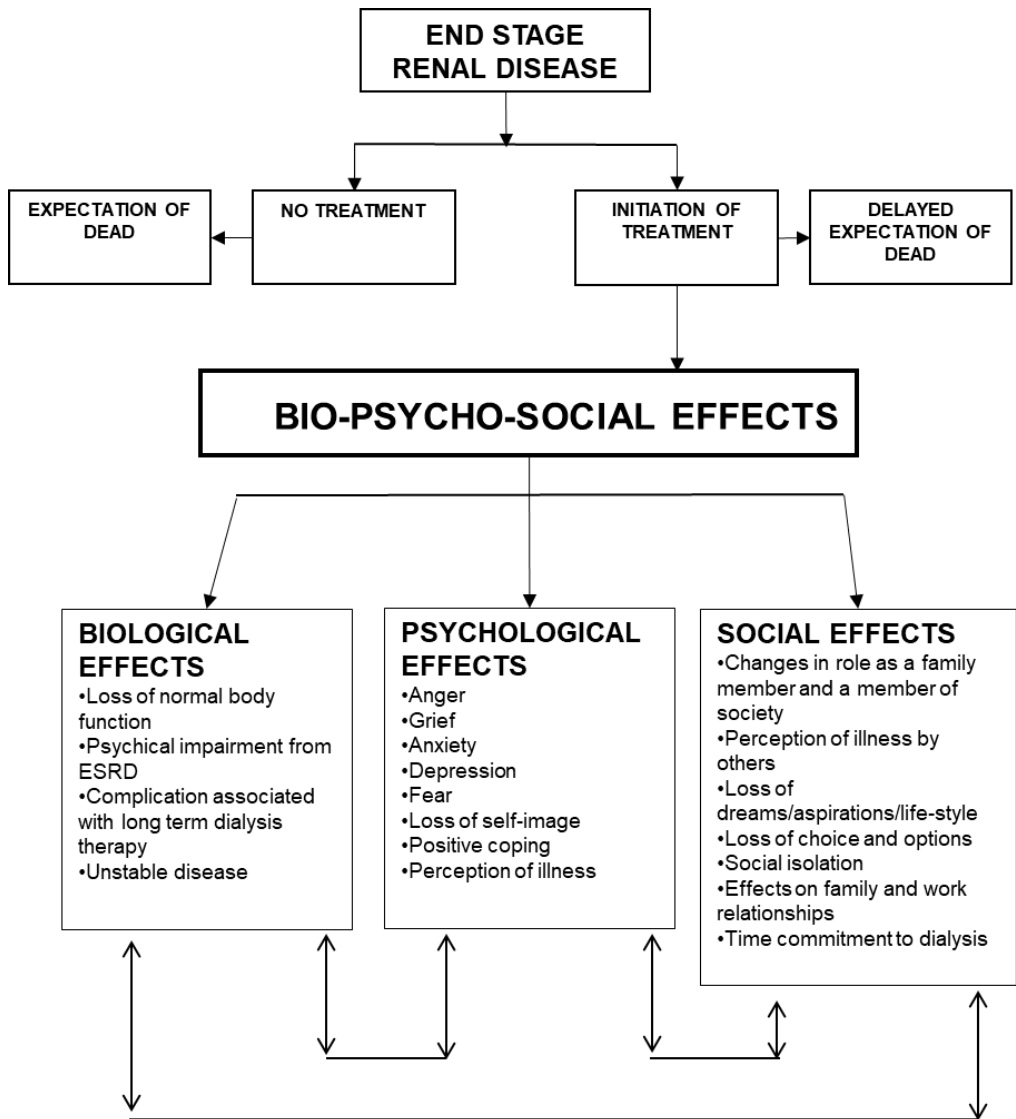


Figure 4. The multiple effects of CKD on patients' well-being Source: Adapted from Y.White and B.F.S. Grenyer Journal of Advanced Nursing 1999

Even when patients and their partners reach the stage of RTx, other complicated challenge within their relationship could occur. Due to a shortage of organ donors, patients are more like to receiving a living donor kidney transplantation from a relative or partner (34). After RTx some relationships might deteriorate as some recipients feel they owe the donor or are afraid to disappoint their partner if they lost the graft (35, 36). Besides RTx also challenges patients and partners to find a new balance and new roles within their relationship. Especially when the patient becomes independent again and is no longer in need of care (37). Spouses could also become more physically effected by the renal disease; their sexuality could also be decreased. Approximately 50% of both male and female partners experience decreased libido as a result of the patients' illness (33).

Fertility in time of CKD

Fertility in men and women suffering from CKD is also not a given, especially during dialysis (38-43). CKD is often associated with a disturbance in reproductive function, however the precise etiology is not yet elucidated. Disturbances in the hypothalamic-pituitary axis contribute significantly to the development of fertility disorders (FD) in both male and female CKD patients (38, 42). FD in female patients reflects in anovulation and menstrual irregularities; experienced by 94% of women who are depended of hemodialysis (38). Due to recent innovations in dialysis, hormonal normalization is induced resulting in an increase of pregnancy rates up to 70% (38). Pregnancy in CKD is complicated by a higher risk for pre-eclampsia and decline in renal function (38). Besides, pregnant women have a higher chance of being in need of blood transfusions, what might complicate future RTx by inducing immunological sensitization (38). The fetus is also more at risks; intrauterine growth restrictions and preterm delivery are common complications (38).

Less is known on fertility in male CKD patients, although disturbances of the hypothalamic-pituitary axe causes, together with oxidative stress and uremia, are associated with a decrease in testicular volume and impairment of spermatogenesis (39, 42).

Current renal health care system

Since CKD patients and their partners face multiple challenges in the area of sexuality, fertility, intimacy and relationships one could assume

awareness about these difficulties exist among their care providers. A range of renal care providers are involved in the treatment and counseling of these patients: nephrologists, renal transplant surgeons, dialysis nurses and nurses specialized in nephrology, and social workers. Some are present during the whole process, others only in a specific stage of disease. The nephrologist is considered as one of the main care providers and fulfills an important role during the whole process of disease by guiding, treating and supporting the patient during all stages of CKD.

Renal transplant surgeons will come insight during the end-stage of CKD when patients have been found eligible for receiving a kidney transplant; a short, however intensive period. Another group of main care providers in CKD are the nurses working in the nephrology department, including dialysis nurses and nurses specialized in nephrology. Especially when patients are in need of renal replacement therapy, such as hemodialysis, they often have intensive contact with nurses during their frequent visitation to the hospital. In addition, social workers working nephrology provide guidance and support on several levels to CKD patients and their families throughout all stages disease.

Unfortunately, a pervasive tendency exists in nephrology: the impact of CKD on sexuality, intimacy, fertility and relationships remains often under-evaluated in renal care as well as in renal research. Patients are often afraid to address sensitive subjects such as sexuality spontaneously due to a sense of embarrassment or because they are concerned that the care provider would dismiss their concerns (44, 45). Although not determined by study, one could imagine similar issues could be present in addressing other sensitive subjects such as fertility and relationships.

At the same time, renal care providers encounter challenges as well when they need to address sensitive subjects and some are hardly aware of the physiological and emotional problems patients have to endure (46). For instance when focusing on sexual and intimacy care; only a few studies have been performed showing that this part of renal care for patients and their partners is often neglected. Various reasons underlie to this problem, ranging from care providers' personal discomfort up to insufficient training (46-48). Nevertheless, the existing studies often only scratch the surface of the omissions present in renal care; more profound and nationwide research is necessary to address the actual difficulties. Do renal care providers inquire about sexuality and intimacy and what are the barriers retaining them from doing so? Do they feel accountable for providing this part of renal care? How do they see their own role and the role of other

renal care providers in providing this part of renal care? And is it even possible for renal care providers to provide sexual and intimacy care in the current organization of their nephrology departments?

The same questions arise when focusing on fertility care. Although some guidelines regarding fertility care in CKD exist, especially for female patients, their main focus is on pregnancy in transplant recipients and not on pre-conceptive counselling during dialysis (49, 50). It is also unclear and understudied if current fertility care is provided in the recommend multidisciplinary approach (38, 51). Adequate information on fertility is especially needed for those patients receiving renal replacement therapy, due to the complexity of fertility during dialysis (38, 52, 53).

Besides, more important information is missing: information of the perspectives of CKD patients and their partners regarding care for sexuality, intimacy, fertility, and relationships. Previous research by Schipper and Abma (2011) (54) showed that patients consider research in these areas as importance, hence no studies have been performed on their needs and preferences regarding care in these fields, let alone of those of their partners.

Purpose of this thesis

The aim of this thesis was to evaluate current health care regarding sexuality, intimacy, fertility and relationships from two perspectives: renal care providers and patients & partners. In addition, the impact of CKD on the relationship between patient and partner will be identified.

The evaluation of the perspectives of the main renal care providers, nephrologist, transplant surgeons, nurses and social workers, on these important elements of renal care will provide an insight on the existing lacunas in current nephrology practice patterns and organization.

Experiences, needs, and perspectives from CKD patients and partners will be obtained by focusing on two specific stages of CKD: post-transplantation and dialysis.

By combining both perspectives, information will be available on how renal care regarding sexuality, fertility and relationship could be improved in a patient & partner-centered way that is practicable and manageable for renal care providers.

Part I will be focusing on the perspective of the major renal care providers, including nephrologists, renal transplant surgeons, nurses of the dialysis

department, and social workers nephrology regarding sexual care for CKD patients.

Part II will assess the perspective and needs of patients and partners regarding care for sexual health in two important disease phases: dialysis and after renal transplantation. In addition, information is provided about relationships in patients and partners who are confronted with CKD, dialysis or renal transplantation, and sometimes even SD.

In part III a first glance is provided in fertility care for CKD patients by evaluating the role of nephrologists and nurses of the dialysis department in providing this important part of care.

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