

## Breaking the Silence; Reproductive and Sexual Health of Women Undergoing Hemodialysis, A Literature Review

Misbah Zafar, Rafat Jan, Salma Rattani, Sajida Chagani  
School of Nursing and Midwifery,  
Aga Khan University Karachi, Pakistan

### Abstract

As the basis for the continued existence of the human race, sexuality is a crucial aspect of human life. If this special aspect of human life is disturbed, it can hurt one's self-confidence and self-esteem and negatively impact social and marital relationships. Given the significance of sexuality, sexual and reproductive health is regarded as a fundamental human right and a crucial element of general health. However, sexual and reproductive health issues appear to be very common in chronic kidney disease (CKD) patients, particularly among women on hemodialysis. The common sexual and reproductive health issues identified among women in literature are hypoactive sexual desire, pain, infertility, menstrual disturbances. These issues impact their marital lives and quality of life. Regardless of the fact that women undergoing hemodialysis face numerous challenges, healthcare professionals often overlook this important aspect of their lives and they are not counselled about the maintenance of their sexual and reproductive health. In Pakistan, there is dearth of literature exploring sexual and reproductive health issues of women undergoing hemodialysis so there is a need to investigate this area of concern.

**Key words:** Sexual Health, Hemodialysis, women health, sexuality, reproductive health.

### Corresponding Author

Misbah Zafar  
Nephro-Urology Nurse, MScN student,  
Aga Khan University Karachi, Pakistan  
Email: [misbahzafar81@hotmail.com](mailto:misbahzafar81@hotmail.com)  
DOI: 10.53778/pjkd81232

Received Sep 06, 2023 and accepted in revised form October 30, 2023

PJKD 20234;(1):3-8

### Introduction

Sexuality is a vital facet of human life which serves as the foundation for the existence of the human race. It impacts several aspects of human life, from conception till death. Sexuality is influenced by the interplay of social, psychological, biological, economic, social, cultural, political, historical, legal, as well as spiritual and religious factors. Whether one has an active sexual life or not, sexuality is part of a person's everyday life. It can also act as the base for fantasies, fear, and anxiety.<sup>1</sup> If this special aspect of human life is disturbed, it could hurt one's self-confidence and self-esteem and negatively impact social and marital relationships.<sup>2</sup> Given the significance of sexuality, sexual related health (SRH) is regarded as a fundamental human right and a crucial element of general health.<sup>1</sup> According to the American Sexual Health Association (ASHA), everyone deserves the support and information that is necessary for preserving their sexuality. A world that ASHA envisions is one in which all people have access to comprehensive information and services related to sexual health, without the fear of coercion, violence, or discrimination at any stage of life.<sup>3</sup>

Moreover, love, respect, and intimacy between partners are thought to be expressed through sexuality. In a qualitative study conducted in Turkey aiming to explore the perspectives of unmarried dialysis patients regarding sexuality, five male and eight female participants expressed sexuality as harmony, love, taking pleasure, sharing, and happiness.<sup>4</sup> Hence, having a satisfying sexual life is crucial to the overall well-being of an individual.<sup>5</sup> However, SRH issues appear to be very common in chronic kidney disease (CKD) patients, particularly among women on hemodialysis.<sup>6</sup>

### Sexual Health Issues among Women Undergoing Hemodialysis

Women undergoing hemodialysis experience sexual dysfunction more commonly in comparison to the overall population and recipients of kidney transplants. Many studies investigating sexual dysfunction among dialysis women have utilized the Female Sexual Function Index Scale (FSFI). This tool consists of six categories comprising pain, lubrication, arousal, desire, orgasm, and overall sexual and relationship satisfaction. Likewise, Kurtulus, Salman, Fazlioglu, and Fazlioglu (2017) conducted a comparative study in Turkey to compare the difference in sexual dysfunction among three groups of women; hemodialysis (n=29); transplant (n=23) and control group (n=30) by using the FSFI scale. It was highlighted that the percentage of sexual dysfunction was significantly higher among women undergoing hemodialysis (89.7%) in comparison to the kidney transplant (73.9%) and control group (56.7%). In the same study, the authors also identified an association between the sexual dysfunction of these women and their age ( $p=.005$ ), educational levels ( $p=.020$ ) and the number of children ( $p=.000$ ).<sup>6</sup>

The majority of women undergoing hemodialysis have SRH issues from the pre-dialysis stage, which worsen over time, as the kidney disease progresses. By using the FSFI scale, a cross-sectional research investigation was carried out including women from three tertiary care hospitals in Lahore, Pakistan to compare the sexual dysfunction among pre-dialysis, hemodialysis, and a control group of healthy women. This study included 60 women of age 22 to 50 years, and 20 women in each group. It was found that women in the pre-dialysis phase experienced more sexual dysfunction than when they initiated hemodialysis therapy. However, significant differences were reported among the three groups: pre-dialysis ( $16.4 \pm 6.8$ ), hemodialysis ( $23.3 \pm 5.0$ ), and healthy women ( $29.9 \pm 1.8$ ).<sup>7</sup>

Another quantitative study with 48 hemodialysis women conducted in Karachi, Pakistan, reported that 33 (63%) of the women were not sexually active after initiating hemodialysis.<sup>8</sup> This indicates that the experiences of these women related to SRH demand an in-depth investigation to study the phenomenon of SRH from their lived experiences.

Besides this, women on hemodialysis find it difficult to remain sexually active due to their own physical and psychological health issues thus they experience hypoactive sexual desire disorder.<sup>9,10</sup> conducted a multicenter, cross-sectional investigation on women undergoing hemodialysis. The data was collected from South America (Argentina) and Europe (France, Hungary, Italy, and Poland). The prevalence of decreased sexual function in women receiving hemodialysis as well as the factors that correlate with it was assessed in this study. The sexual dysfunction was assessed by FSFI. This study revealed that, out of 659 women, only 232 reported that they were sexually active. Moreover, it was reported that the women were also experiencing hypoactive sexual desire, as 382 respondents were identified with low or no sexual desire.

### Reproductive Health Issues among Women Undergoing Hemodialysis

In addition to sexual health issues, reproductive health issues, such as irregular menstrual cycle, heavy bleeding, or amenorrhea, which are caused by hormonal imbalances, may negatively affect the lives of women undergoing hemodialysis. A prospective cohort study was conducted in Mexico, involving 57 young women with chronic kidney disease, 43.9% of whom were receiving hemodialysis as a renal replacement therapy. This study reported that 52.6% of women were experiencing menstrual disturbances. Along with this, 31.5% of the women reported heavy menstrual bleeding, and 21% reported secondary amenorrhea. This study found that menstrual disturbances were considerably more common ( $p=0.01$ ) in women who had hypothyroidism. Moreover, a significant relationship ( $p=0.03$ ) was found between menstrual disturbances and high levels of prolactin levels due to kidney failure.<sup>11</sup>

## Dialysis & Women Health

In another study, 182 premenopausal women with CKD were studied cross-sectionally in China, in four different cohorts: kidney transplants, peritoneal dialysis, non-dialysis, and hemodialysis. The study results highlighted that, in comparison to the other cohorts, the hemodialysis group had the highest rate (76.15%) of menstrual irregularities.<sup>12</sup>

Due to hormonal imbalance and menstrual irregularities, the women undergoing hemodialysis rarely conceive, but if conception occurs there are increased chances of pre-eclampsia, abortion, preterm delivery, and low birth weight. In Cameroon, a cross-sectional study found that only four of the 52 hemodialysis women conceived, and all four (100%) pregnancies were spontaneously aborted within the first four months of pregnancy.<sup>13</sup> Accordingly, another retrospective study, on a large sample of 778 women with kidney disease, was conducted in the United States. For this study, a healthcare system in Utah and Idaho, including 23 healthcare facilities provided the data. The included retrospective data ranged from 2000 to 2013. While comparing women not having kidney disease, the women having kidney disease were 52% more likely to give preterm births, with an odd ratio of 1.52 at a 95% confidence interval and were 33% more likely to deliver by cesarean section. In infants born to kidney disease-affected women, neonatal intensive care facility admissions or infant deaths were 71% higher than those born to healthy kidney women. Similarly, kidney disease also increased the risk of low birth weight twofold.<sup>14</sup>

Regardless of the fact that pregnancy in women undergoing hemodialysis is linked with numerous risk factors, healthcare professionals often overlook this aspect of reproductive health as indicated by the lack of contraceptive use by these women.<sup>15</sup> A research letter to the editor which included data from a retrospective chart review concerning reproductive health documentation of dialysis women at childbearing age indicated the magnitude of the problem. It revealed that only less than two-thirds of women received reproductive health counselling, and evidence of contraception use was less than one-third in a single-centre survey.<sup>16</sup> This retrospective chart review research letter indicated that the reproductive health of women undergoing hemodialysis is an underserved area.

### Impact of SRH on the Quality of Life of Women Undergoing Hemodialysis

These SRH issues of women drastically impact their quality of life and the marital relationship.<sup>17-19</sup> A study was conducted in Brazil, including 58 women of age 18 to 51 years. In this study, the quality of life of women undergoing hemodialysis with and without sexual dysfunction was compared. The instrument employed to measure sexual dysfunction and quality of life were FSFI and Medical Outcomes Study 36-Item Short Form Health Questionnaire. Findings from this research indicated that about 80% of women suffered from decreased sexual function. Additionally, women having sexual dysfunction had lower scores on the quality-of-life questionnaire for vitality ( $p = 0.026$ ), physical function ( $p = 0.007$ ), social function ( $p = 0.034$ ), and bodily pain ( $p = 0.010$ ). In brief, a major problem limiting the quality of life of hemodialysis women is SRH issues.<sup>20</sup>

Furthermore, improved sexual function can result in significant improvement in the quality of life of women undergoing hemodialysis. Accordingly, to determine if nursing guidelines improve sexual function and consequently the quality of life of hemodialysis women, 50 women aged 20 to 50 years old were enrolled in a quasi-experimental study in Iran (intervention group  $n=25$  and control group  $n=25$ ). Researchers trained the interventional group to perform different exercises for strengthening their pelvic muscles to relieve pelvic pain, such as Kegel exercises (which decrease pelvic pain by relaxing the pelvic floor muscles). As a result of the application of the nursing guidelines as an intervention, these women's quality of life score increased to 36.73, from the average pre-intervention score of 28.33.<sup>21</sup>

### Impact of SRH on Marital Relationship of Women Undergoing Hemodialysis

SRH of a woman has a substantial role in marital life to maintain a strong marital relationship and gain marital life satisfaction.<sup>17</sup> Several religious and cultural beliefs regard sexual activity as an essential part of procreation; therefore, a successful marriage is greatly influenced by the quality of the couple's sexual relationship and ability to reproduce.<sup>22</sup> Due to this, failure to recognize or understand a partner's sexual needs can result in distorted marital relationships and family disintegration.<sup>±</sup> Additionally, the menstrual irregularities associated with hemodialysis negatively influence the SRH of women undergoing hemodialysis, and as a consequence, the marital relationships of these women are also adversely affected. In this regard,, conducted a cross-sectional study in Turkey to determine a linkage between quality of sexual life and marital adjustment in women (n=211) with and without menstrual irregularity.<sup>24</sup> This study found a statistically positive relationship ( $r=0.589$ ) between the marital adjustment scale and the quality of sexual life of women having irregular menstrual cycles.

Furthermore, the sexual lives of couples change when one of them is on dialysis therapy, according to a research investigation carried out in the United States for evaluating the strain on the relationship and caregiver burden of partners of transplant and dialysis patients. This study focused on the effect of dialysis therapy on marital relationships. The caregiver partners experienced greater disagreements regarding sexual relations when on dialysis (18.8%) compared to pre-dialysis (9.6%) and their sexual life was also disturbed more in the dialysis group (33.7%), in comparison to the pre-dialysis group (18.3%).<sup>25</sup> Additionally, SRH issues do not only disrupt the marital relationship of a couple but for unmarried women, finding a partner for marriage is also difficult since they feel that due to CKD, the sexual desires of their partners will not be fulfilled after marriage.<sup>4</sup>

### Reluctance of Nephrology Nurses to Discuss the SRH Subject

Nephrology nurses have special opportunities for building an enduring, dependable, and professional relationship with patients receiving hemodialysis, which offers them a great chance to start conversations on SRH topics.<sup>26</sup> However, research indicates that nephrology nurses are hesitant to discuss sexuality issues with hemodialysis patients.<sup>27</sup>

Yodchai in a phenomenological study conducted in Thailand, investigated how nephrology nurses perceive discussing SRH issues with kidney failure patients.<sup>28</sup> In this study, 20 nephrology nurses were interviewed by using a semi-structured interview guide. The themes that evolved to improve knowledge before discussing sexuality with patients for boosting confidence were to gain trust, find an appropriate time, organize suitable settings, and feel gratitude while assisting couples in overcoming their SRH concerns. This analysis revealed that nephrology nurses needed SRH knowledge and adequate time to confidently discuss the SRH subject with kidney disease patients.

The barriers for nurses in talking about sexual health and sexuality were identified by a scoping review of 19 studies, published between 2009 and 2019. Among these work-related issues, fears and personal convictions, as well as ideas and attitudes about age, gender, and sexual orientation, were all identified as barriers.<sup>29</sup>

### Gap Analysis

After reviewing the literature, a research gap was identified in the SRH area of women undergoing hemodialysis globally and in Pakistan. Most studies conducted were quantitative and only a few qualitative studies were found. Quantitative studies cannot investigate the individual experiences of dialysis women because, globally mostly quantitative studies have used the FSFI questionnaire, which only considers the process of coitus, without taking

into consideration other factors that contribute to SRH issues, but there is a need to explore in-depth the lived experiences of phenomenon of interest, in this population.<sup>10</sup> According to the limited knowledge of the researcher, in Pakistan, three quantitative studies have been conducted on the sexual dysfunction of women undergoing hemodialysis, but qualitatively in-depth lived experiences of SRH have apparently not been explored among women undergoing hemodialysis. All three prior research investigations concentrated solely on the sexual dysfunction of women undergoing hemodialysis, rather than their overall sexual and reproductive health experiences.<sup>7,8,30</sup> Among these, two quantitative studies have also included postmenopausal women, who after menopause become infertile and have a hypoactive sexual desire.<sup>31</sup> We conclude that, it is imperative to explore in-depth the phenomenon of interest, which is lived experiences of SRH among women of reproductive age undergoing hemodialysis in Pakistan.

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