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Experiences of sexual and reproductive health among women undergoing haemodialysis in Pakistan: A descriptive phenomenological study

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EXPERIENCES OF SEXUAL AND REPRODUCTIVE HEALTH AMONG WOMEN UNDERGOING HAEMODIALYSIS IN PAKISTAN: A DESCRIPTIVE PHENOMENOLOGICAL STUDY

By

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Dedication

This thesis is dedicated to the two most important people in my life: my mother (Nasim Akhtar) and my spouse (Mr. Muhammad Shafiq). My mother's wisdom, love, support, and motivation have always given me the confidence to believe in myself and the determination to follow the correct road in my personal and professional endeavors. I am also grateful for my husband's continuous support to complete my education; despite the challenges he encountered as a result of my rigorous schedule. I would also like to dedicate this thesis to my children (Imama Shafiq, Abdullah Shafiq, and Hamna Shafiq), who rejuvenated me with their beautiful stories and actions whenever I felt tired during this journey. Furthermore, I cannot forget the women undergoing haemodialysis who participated in this study and shared their experiences honestly by trusting me.

Abstract

Background

Sexual and reproductive health is an essential component of a woman's life that includes respectful and satisfying sexual relationships without coercion and violence, as well as couples' decisions about whether and when to have children. Reproductive-age women undergoing haemodialysis experience numerous sexual and reproductive health challenges as a consequence of their physical and psychological health conditions, negatively impacting their overall well-being. However, they are reluctant to seek assistance from healthcare professionals despite having many sexual and reproductive health issues. Concerning this, it was necessary to explore in-depth, the phenomenon of lived experiences of sexual and reproductive health among reproductive-age women undergoing hemodialysis in Pakistan's socio-cultural and religious contexts.

Purpose

To explore the lived experiences of married reproductive-age women undergoing haemodialysis concerning their sexual and reproductive health and its impact on their quality of life.

Methodology

A descriptive phenomenological study design was used to investigate the sexual and reproductive health experiences of 10 women undergoing haemodialysis. The research was carried out at a tertiary care hospital in District Malir. A semi-structured interview guide was used to gather data. Colaizzi's phenomenological seven-step

approach was employed for data analysis. The data was collected from April 2023 to July 2023.

Findings

Through Colaizzi's data analysis approach, five themes emerged; Intimacy Redefined; Unveiling the Value of Sexuality in Marital Bliss, Stumbling Blocks in Maintaining SRH, Depths of Despair; From Struggle to Strength, Breaking Barriers: A Call for Action by HCPs, Husband's Support: A Beacon of Hope.

Conclusion

In this descriptive phenomenological study, women undergoing haemodialysis valued sexuality in their marital lives. They faced several challenges due to their poor sexual and reproductive health, which impacted their marital life and quality of life, though they strengthened themselves to cope with these challenges. However, raising awareness about sexual and reproductive health education by nephrology nurses and spousal support can play a crucial role in the promotion of the sexual and reproductive health of women undergoing haemodialysis.

List of Abbreviation / Acronyms

AKU	Aga Khan University
ASHA	American Sexual Health Association
CINAHL	Cumulative Index of Nursing and Allied Health Literature
CKD	Chronic Kidney Disease
ERC	Ethical Review Committee
CMH	Combined Military Hospital
FSFI	Female Sexual Function Index
GHQ	General Headquarters (GHQ)
KDIGO	Kidney Disease Improving Global Outcomes
HCPs	Healthcare Professionals
PRISMA	Preferred Reporting Items for Systematic Review and Meta-Analysis
RRT	Renal Replacement Therapy
SRH	Sexual and Reproductive Health
WHO	World Health Organization
UNO	United Nations Organization

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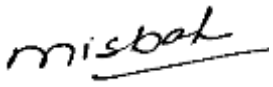
With deepest appreciation,

Declaration

I declare that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university and to the best of my knowledge it does not contain any material previously published or written by another person, except where due reference has been made in the text.

The editorial assistance provided to me has in no way added to the substance of my thesis which is the product of my research endeavors.



(Signature of Candidate)

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Chapter One: Introduction

Sexual and reproductive health (SRH) is an essential part of a woman's life (Bostani Khalesi & Ghanbari Khanghah, 2015). The SRH of women undergoing haemodialysis is severely affected by an array of physical and psychosocial factors, as well as hormonal imbalances. As a consequence of this deterioration in SRH, their quality of life and marital relationship suffer. However, in the Pakistani sociocultural context, no prior research was found that looked into the lived experiences of the phenomenon of SRH among reproductive-age women undergoing haemodialysis. Hence, the current study investigated the lived experiences of SRH among reproductive-age women undergoing haemodialysis in Pakistan.

Background of Study

Chronic Kidney Disease (CKD) is an illness with a multifactorial aetiology. It is characterized by an irreversible decrease in the nephron's function when gradually the kidneys can no longer function adequately (Luyckx et al., 2022). The Kidney Disease Improving Global Outcomes (KDIGO) Foundation defines CKD by using damage markers. These damage markers indicate albuminuria and glomerular filtration rate. Patients are considered as suffering from CKD when these two markers (glomerular filtration rate below 60ml per min and albumin above 30mg/gram of creatinine) are present for more than three months, along with abnormal kidney structure and function (Chertow & Beddhu, 2019; Inker et al., 2014). Based on the Glomerular Filtration Rate (GFR) and albuminuria, there are five stages of CKD (Levey et al., 2020).

Furthermore, globally, the prevalence of CKD has been recognized as a significant public health concern (Sanyaolu et al., 2018). It is estimated that CKD has

affected 13.4% of the global population (11.7-15.1%) and, approximately, 4.902 to 7.083 million patients require Renal Replacement Therapy (RRT) as a result of kidney failure (Coresh, 2017). The main causes of this disease's global rise are the increasing prevalence of diabetes mellitus, hypertension, obesity, and ageing (Lv & Zhang, 2019). Furthermore, South Asians are more vulnerable to kidney impairment due to increasing rates of diabetes and hypertension in this region (Kazmi et al., 2022). A systematic review of studies from Bangladesh, India, Nepal, and Pakistan, reported a high prevalence of kidney diseases affecting from one to four out of 10 individuals in South Asian countries (Hasan et al., 2018). However, in comparison to men, women are at greater risk of suffering from kidney disease and sexual dysfunction is also more prevalent among women (67.9%) as compared to men (44.8%) receiving dialysis therapy (Azevedo et al., 2014; Vos et al., 2016). Moreover, kidney failure due to pre-eclampsia during pregnancy, and the prevalence of autoimmune diseases are some of the challenges women are facing at reproductive age (Piccoli, Alrukhaimi, Liu, Zakharova, Levin, Kam, et al., 2018).

To address the kidney failure issue, the available RRT is either through a renal transplant or in the form of dialysis (a technique that eliminates toxic compounds from a person’s blood circulation to replace kidney function). The dialysis modalities used as RRT are peritoneal dialysis, haemodialysis, hemodiafiltration, and hemofiltration (Kirchhoff, 2018; Levey et al., 2020). However, majority of the patients with kidney failure are left only with haemodialysis as a treatment option, to maintain and replace some of the kidney functions for their survival because of a low number of kidney donors for transplant and the risks associated with peritonitis in peritoneal dialysis (Divyaveer et al., 2021). Moreover, women receive fewer kidney donations than men with kidney

failure, therefore women with kidney failure often select haemodialysis as RRT (Piccoli, Alrukhaimi, Liu, Zakharova, Levin, & Committee, 2018).

Haemodialysis therapy cannot completely replace the renal function such as the endocrine, homeostatic, and regulatory functions of the normal kidney (Romagnani et al., 2017). Therefore, as a result of hormonal imbalance, and homeostatic and regulatory disturbances, women undergoing haemodialysis suffer from both psychological and physical symptoms (Gerogianni & Babatsikou, 2014). As a consequence of these psychological and physical symptoms, and disturbed hormonal function women undergoing haemodialysis face many SRH issues, leading to a diminished quality of life (Balaban et al., 2017; Chou et al., 2021).

Moreover, SRH issues do not only impact women themselves alone but also their social relationships, such as marital relations (Velten & Margraf, 2017). Most of these women are sexually inactive, and the reason for this is a lack of sexual interest (Mor et al., 2014). However, they do not consider their lack of sexual interest as a problem in their sexual lives (Mor et al., 2014). It is obvious that when women are sexually less active, their partners experience decreased sexual satisfaction and loss of libido as a consequence (Velten & Margraf, 2017). The sexual life satisfaction is also related to the marital life satisfaction among couples (Schoenfeld et al., 2017). Therefore, when women are happy in their marital relationships, it improves their overall well-being. In short, sexual health plays a pivotal role in strengthening marital life bonds (Bilal & Rasool, 2020).

Considering this significant impact that SRH has on the lives of women, it has been added to the list of sustainable development goals (SDGs) for the millennium by the

United Nations Organization (UNO). It is emphasized in the SDGs that SRH is a fundamental human right that is key to achieving the 2030 Agenda (Starrs et al., 2018). In this regard, SDG 3.7 describes that sexual and reproductive services should be easily accessible to all reproductive-age women, to prevent unwanted pregnancies (Lozano et al., 2018).

However, reproductive-age women undergoing haemodialysis lack formal reproductive health education in dialysis units and nephrology clinics, since it is unclear to nurses whose role is to provide SRH education to dialysis patients in nephrology units and nurses are also not comfortable in discussing this subject due to cultural and social reasons (Van Ek et al., 2018). Furthermore, when these women undergoing haemodialysis conceive, they are at increased risk of complications related to pregnancy. Commonly these complications are worsening hypertension, risk of pre-eclampsia, polyhydramnios, premature rupture of membranes, and anaemia (Alix et al., 2019; Sachdeva et al., 2017). During the reproductive years, these women with kidney failure also face many complex decisions and significant challenges, because the use of contraceptives can aggravate their kidney problems and, if they conceive, it often results in spontaneous abortion (Attini et al., 2020). Consequently, given SDG 3.7, reproductive-age women undergoing haemodialysis should also be provided with guidance regarding the proper use of contraceptive methods to prevent pregnancy.

Additionally, sexual dysfunction is one of the leading factors that contribute to lowering the quality of life, particularly in the physical and psychological domains of women undergoing haemodialysis (Balaban et al., 2017). Sexual dysfunction is more prevalent in women than in men among those receiving haemodialysis, which has a

negative impact on a couple's ability to enjoy a gratifying marital life (Gerogianni & Babatsikou, 2014; Saedi et al., 2019). Moreover, hormonal imbalance (hypothalamic-pituitary-gonadal axis dysfunction) also causes reduced fertility and menstrual irregularities and disturbances among women undergoing haemodialysis, in addition to sexual dysfunction (Sobolewska et al., 2022). In brief, the SRH of women undergoing haemodialysis at reproductive age is a significant contributor impacting their quality of life and marital relationship.

Problem Statement

SRH issues, such as sexual dysfunction, menstrual problems, infertility, complicated pregnancies, and reduced sexual activity are common among haemodialysis women. However, they rarely seek help from healthcare professionals for their SRH concerns, because they believe it is embarrassing and that there is no treatment for these issues (Elkowessny et al., 2015). Additionally, largely, Pakistan is a Muslim country where more than 96% of the population is Muslim (Pakistan Bureau of Statistics, 2023). It is evident that Muslim women are involved in sexual activity with their spouses due to religious obligation and to satisfy spousal sexual desire, despite having their own reduced sexual desire (Amini & McCormack, 2021).

A few qualitative studies on the experiences of SRH among women suffering from kidney failure have been conducted in other countries (Abarca-Durán et al., 2021; Stewart, 2013). However, there is a need to investigate this aspect of women's health in the religious and socio-cultural context of Pakistan. Hence, this study has provided an in-depth analysis of the phenomenon of interest, that is, the lived experiences related to SRH

of Pakistani reproductive-age women undergoing haemodialysis, and its effects on their marital life and quality of life.

Purpose of Study

The purpose of this study was to explore the lived experiences of reproductive-age women undergoing haemodialysis concerning their SRH. Additionally, this study, by employing a phenomenological approach investigated the phenomena of SRH that may impact the quality of life and marital life of reproductive-age women undergoing haemodialysis.

Study Questions

The following questions were investigated in this study:

1. What are the lived experiences of SRH among reproductive-age women undergoing haemodialysis in Pakistan?
2. What is the impact of SRH experiences on marital life and the quality of life of reproductive-age women undergoing haemodialysis in Pakistan?

Significance of the Study

The study of SRH among women undergoing haemodialysis is underappreciated since nephrology nurses do not consider SRH counselling as essential as other dialysis-related care counselling (Mckie et al., 2021). Additionally, a quantitative study conducted in Lahore, Pakistan, to assess the haemodialysis patients' quality of life, discovered that patients are reluctant to discuss their SRH problems because they are shy and worry that engaging in sexual activity will worsen their condition (Anees et al., 2016). This study, by revealing women's concealed SRH issues, may serve to improve the quality of life of these women. The study outcomes can potentially encourage nephrology nurses to

engage in open communication and offer effective educational consultation to support these women in addressing their SRH issues.

Conceptual Definitions

Sexual Health

"Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled" (World Health Organization, 2023b)

Reproductive Health

"Reproductive health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes. Reproductive health implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so" (World Health Organization, 2023a).

Quality of Life

"A person's perception of his position in life with respect to the culture and value systems in which they live, as well as their objectives, expectations, and concerns all contribute to their overall perceived quality of life" (World Health Organization, 2023d).

Marital Relationship

"It is a public commitment to stay together through "sickness and health" and marriage itself may influence sickness and physical health as well" (Robles, 2014, p. 427).

Haemodialysis

"Haemodialysis is a modality of RRT that utilizes semipermeable membranes to get rid of water and solutes from the plasma using a variety of mass separation techniques, including diffusion, convection, and ultrafiltration" (Zhang et al., 2022, p. 1).

Researcher's Reflection

The researcher is a nephrology nurse having about ten years of work experience in various haemodialysis units of military hospitals. In military settings, there are about more than 15 haemodialysis units across Pakistan. While working in the haemodialysis units, the researcher felt that nephrology nurses educate women about water restriction, dry weight management, dietary regimen, and vascular access care, but SRH has never been a topic of discussion between nephrology nurses and women undergoing haemodialysis. The majority of these reproductive-age women live with their husbands and face numerous challenges that influence their quality of life and relationships with their husbands.

Summary

In brief, SRH issues are more prevalent among reproductive-age women undergoing haemodialysis. Although sexual satisfaction has a vital role in marital life satisfaction, as it improves the quality of life of women undergoing haemodialysis, most research has focused solely on sexual dysfunction, with other facets of sexuality

receiving little attention. Furthermore, nephrology nurses do not regard SRH education as important as other aspects of dialysis patient care. Also, in Pakistan's sociocultural context, the discussion of SRH topics is viewed as embarrassing. Therefore, the need was felt to explore the lived experiences of SRH among women undergoing haemodialysis, in Pakistan. Thus, knowledge generated through this research will add value to contextual-based literature.

Chapter Two: Literature Review

This chapter presents a comprehensive literature review regarding lived experiences of Sexual and Reproductive Health (SRH) among women undergoing haemodialysis. This chapter will begin with the search strategy presented in the form of Preferred Reporting Items for Systematic Review and Meta-analysis (PRISMA). It will be preceded by the significance of SRH in the life of an individual, as well as a transition in the lives of women undergoing haemodialysis and its impact on SRH. The evidence of the association of SRH with various physical and psychological symptoms will then be explained, followed by the SRH issues that women undergoing haemodialysis commonly face and their impact on the quality of life and marital life. Nephrology nurses' reluctance to discuss SRH subjects will also be addressed. At the end of this chapter, the gap analysis in the available literature regarding the experiences of SRH among reproductive-age women undergoing haemodialysis in the Pakistani context will be undertaken.

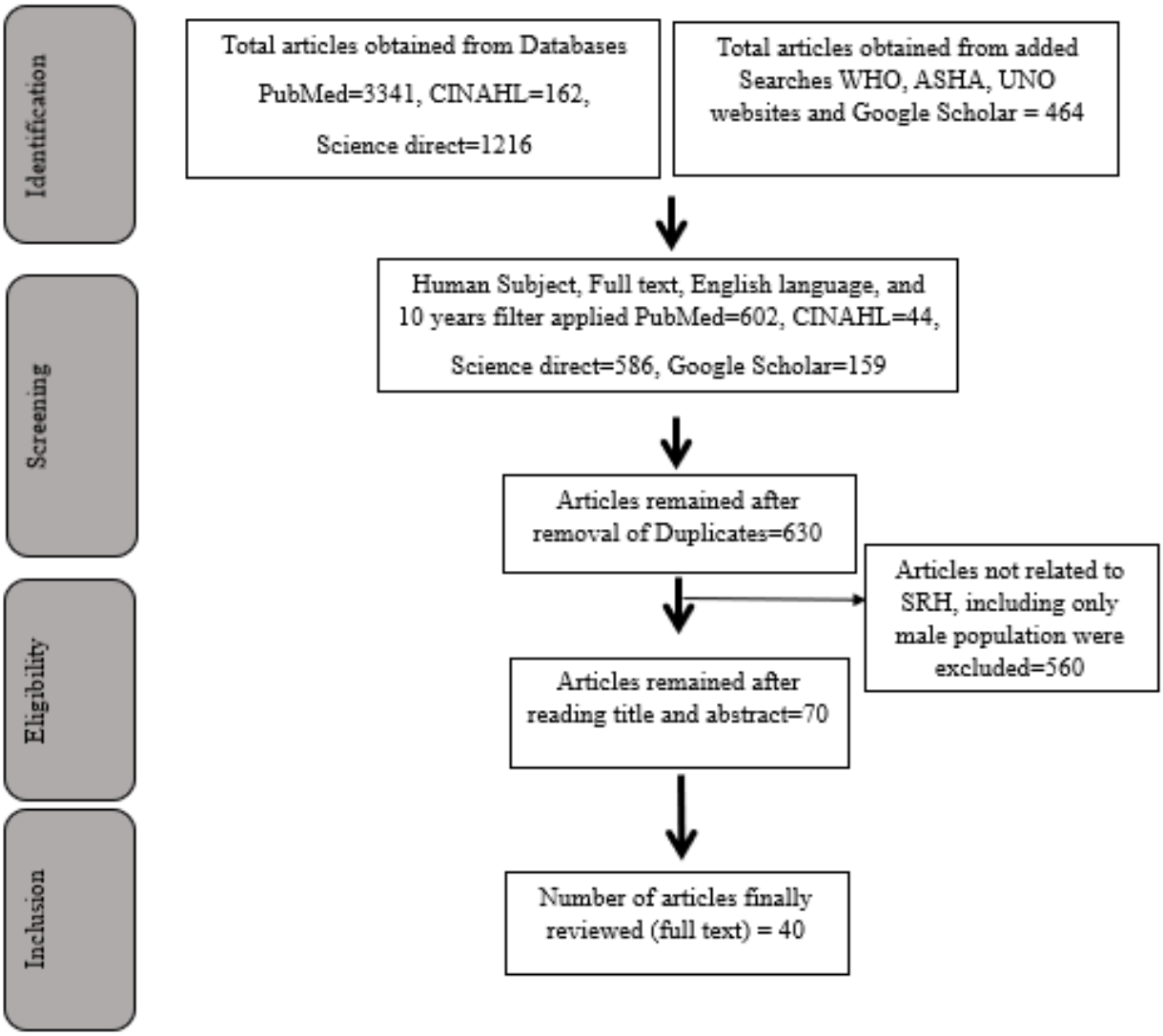
Search Strategy

An organized and comprehensive search of the available literature was carried out to obtain the literature relevant to the SRH of women undergoing haemodialysis, which is the phenomenon of interest and is presented in Fig 1. The searched databases include Google Scholar, PubMed, Cumulative Index of Nursing and Allied Health Literature (CINAHL), and ScienceDirect. A traditional hand search of the selected articles was also undertaken. Boolean operators "OR" and "AND" were employed. The key terms related to the phenomenon of interest, SRH, were used. The search strategy applied for PubMed, CINAHL, and ScienceDirect was (sexual OR sexuality OR "reproductive health" OR "sexual health" OR reproductive) AND (women OR females) AND (dialysis OR

haemodialysis). The search strategy for Google Scholar was modified as (sexual OR sexuality OR "sexual health " OR "reproductive health " OR "sexual health concerns") AND (women OR Females) AND (dialysis OR haemodialysis) AND (“quality of life” OR "life quality") AND (“marital relationship”). In the initial search, 5,183 articles were retrieved from four databases. The filters of 10 years, full text, English language, open access and human subject were then applied. The articles other than in the English language, not available in full text, and only including the male population were excluded. Literature was searched from 2013 to March 2023. The number of articles that appeared after applying the filter was 1,391. The duplicates were removed and the number of articles considered after removing duplication was 630. The researcher read the titles and abstracts of these articles and 70 complete articles were selected for full text reading. Finally, after a careful study of the full text, 40 articles were finalized by the researcher to be included in the literature review. These included 28 quantitative, five qualitative, and seven review articles. The researcher discovered a dearth of qualitative studies related to the phenomenon of interest during the literature search. For the data extraction sheet of included studies refer to Appendix J.

Figure 1

Prisma Diagram



Significance of SRH in an Individual's Life

According to the World Health Organization (2023c), "sexuality is a central aspect of being human throughout life encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors". 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 (Potki et al., 2017).

Given the significance of sexuality, SRH is acknowledged as a fundamental human right and a crucial element of general health (World Health Organization, 2023b). 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 (American Sexual Health Association, 2023).

Acknowledging the fact that one of the most intricate aspects of human behaviour is sexuality, being sexually active can help to reduce anxiety and depression, even in unusual circumstances (Mollaioli et al., 2021). Correspondingly, an Italian study was carried out during COVID-19 to investigate the relational, sexual, and psychological benefits of sexual activity. The findings of this study indicated that subjects who were not

sexually active during lockdown had a significantly greater likelihood of experiencing depression and anxiety, with odd ratios of 1.32 and 1.34 at 95% confidence intervals, when compared to those who did engage in sexual activity (Mollaioli et al., 2021). Hence, having a satisfying sexual life is crucial to the overall well-being of an individual (Sabanciogullari et al., 2015). However, SRH issues appear to be very common in chronic kidney disease (CKD) patients, particularly among women on haemodialysis (Kurtulus et al., 2017).

Transition in the Lives of Haemodialysis Women and its Impact on SRH

Around the world, most kidney failure patients prefer haemodialysis as renal replacement therapy (Jain et al., 2019). After starting haemodialysis their lives undergo transition, as they must adhere to the dialysis schedule, medication compliance, and strict dietary and fluid regimen (Kalantar-Zadeh et al., 2015; Rezaei & Salehi, 2016). Furthermore, the sexual lives of women undergoing haemodialysis are also altered due to the association between dialysis therapy and various physical and psychological factors, adversely impacting these women's sexual functioning (Sabanciogullari et al., 2015). Additionally, literary evidence suggests that the SRH of these women does not improve even after receiving adequate haemodialysis (Kim et al., 2014). Hence, women who undergo haemodialysis may need to modify their sexual and reproductive lives due to the below-mentioned psychological and physical factors.

Impact of Physical Factors on SRH of Women Undergoing Haemodialysis

Fatigue is one of the physical symptoms that patients undergoing maintenance haemodialysis experience the most, and it has a detrimental effect on their sexual arousal (Bossola et al., 2018). The severity of fatigue and its interference with daily activities is

significantly greater on dialysis days in contrast to non-dialysis days. Debnath et al. (2021) conducted a study in the United States of America on 115 dialysis patients and found that fatigue levels were considerably higher on a dialysis day (5.35 ± 2.50) compared to a non-dialysis day (3.47 ± 2.85). These patients were unable to be sexually active because of a lack of energy and the body's need for rest. Accordingly, another study carried out in the Netherlands which investigated 29 dialysis patients cross-sectionally, revealed that a high level of fatigue was one of the factors stopping them from sexual activity (Ek, 2019).

Another physical symptom that haemodialysis patients often experience is restless leg syndrome. It is characterized by pain and discomfort in the legs as well as the compulsive desire for movement of the legs even though they are at rest. In Turkey, Dikici et al. (2014) undertook a cross-sectional inquiry with 246 haemodialysis patients to examine the relationship between sleepiness and sexual dysfunction with restless leg syndrome. It was revealed in this study that sexual dysfunction (24.6 ± 5.7) was more common among patients who experienced restless leg syndrome as compared to the patients who did not experience restless leg syndrome (22.5 ± 6.8). Additionally, according to this study, patients' sexual lives were also adversely affected by daytime sleepiness.

Impact of Psychosocial Factors on SRH of Women Undergoing Haemodialysis

A significant number of women who undergo haemodialysis also experience psychological issues. Psychological symptoms most commonly experienced by women are depression and anxiety, which are often accompanied by conditions that adversely affect their health, such as deteriorating quality of life and difficulties with their sexuality

(Alshelleh et al., 2022; Yaqoob et al., 2020). Shah et al. (2022) conducted a study in the Nishtar Hospital, Multan, Pakistan with 55 women undergoing haemodialysis and an inverse relationship was reported between depression and sexual function. In brief, a key aspect that must be addressed in nephrology nursing practice is SRH, which has a significant relationship with the psychological well-being of women undergoing haemodialysis (Keskin et al., 2019).

The women undergoing haemodialysis have disturbed body image, impacting their sexual relationships. To examine the experiences of change in body image and diminished sexual desire among 18 women receiving haemodialysis, a qualitative phenomenological study was conducted in Spain (Álvarez-Villarreal et al., 2019). This study found that women undergoing haemodialysis had disturbed body image due to their feeling of being deformed and bloated as a result of their oedema. Furthermore, this study also reported that individuals on dialysis were occasionally extremely thin, due to excessive ultra-filtration and weight loss, which also affected their body image. This disturbed body image influenced their self-image and self-esteem. They perceived themselves as less sexually attractive as a result of this disturbed body image, which affected their sexual life (Álvarez-Villarreal et al., 2019).

A qualitative study conducted in the United Kingdom highlighted another important factor influencing haemodialysis women's intimate relationships was their low self-esteem due to a permanent venous catheter or an arteriovenous fistula for haemodialysis. Because these women had a fear that their intimate partners would reject them if they saw the tubes coming out of their bodies (Lewis & Arber, 2015).

Sexual Health Issues among Women Undergoing Haemodialysis

Women undergoing haemodialysis experience sexual dysfunction more commonly in comparison to the overall population and recipients of kidney transplants (Kurtulus et al., 2017). Many studies investigating sexual dysfunction among dialysis women have utilized the Female Sexual Function Index Scale (FSFI) (Saglimbene et al., 2017; Yaqoob et al., 2020). This tool consists of six categories comprising pain, lubrication, arousal, desire, orgasm, and overall sexual and relationship satisfaction (Rahman et al., 2023). Likewise, Kurtulus et al. (2017) carried out a comparative inquiry in Turkey to compare the difference in sexual dysfunction among three groups of women; haemodialysis (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 haemodialysis (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).

The majority of women undergoing haemodialysis 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, haemodialysis, 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 haemodialysis therapy. However, significant differences were reported among

the three groups: pre-dialysis (16.4 ± 6.8), haemodialysis (23.3 ± 5.0), and healthy women (29.9 ± 1.8) (Rahman et al., 2023).

Another quantitative study with 48 haemodialysis women conducted in Karachi, Pakistan, reported that 33 (63%) of the women were not sexually active after initiating haemodialysis (Yaqoob et al., 2020). 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 haemodialysis find it difficult to remain sexually active due to their own physical and psychological health issues thus they experience hypoactive sexual desire disorder (Yılmaz et al., 2017). Saglimbene et al. (2017) conducted a multicenter, cross-sectional investigation on women undergoing haemodialysis. The data was collected from South America (Argentina) and Europe (France, Hungary, Italy, and Poland). The prevalence of decreased sexual function in women receiving haemodialysis 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.

Conversely, despite hypoactive sexual desire in women undergoing haemodialysis, they may become sexually active primarily to maintain marital relationships (Janghorban et al., 2015). A grounded theory study was conducted in Iran by Janghorban et al. (2015), including 35 participants, to examine married women's experiences concerning sexual activities in their intimate relationships. In this study,

women stated that they engaged in sexual activity solely to preserve their marital life or to reduce the likelihood of their spouses having extramarital affairs. In the same study the women also revealed that due to some religious and cultural beliefs, they consider sexual activity as an obligation, to demonstrate devotion to their spouses, and fulfil wifely obligations.

Likewise, women undergoing haemodialysis also avoid sexual activity as many myths exist related to being sexually active while on haemodialysis therapy. There is a common misconception that sexual activity can cause weakness in a person receiving haemodialysis (Georges et al., 2017). Since these women already become weak due to disease complications and the dialysis technique, therefore, the fear of worsening asthenia prevents them from having sexual relations (Georges et al., 2017).

Reproductive Health Issues among Women Undergoing Haemodialysis

In addition to sexual health issues, reproductive health issues, such as irregular periods, heavy bleeding, or amenorrhea, which are caused by hormonal imbalances, may negatively impact the lives of women undergoing haemodialysis. A prospective cohort study was conducted in Mexico, involving 57 young women with chronic kidney disease, 43.9% of whom were receiving haemodialysis 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 due to kidney failure (Serret-Montaya et al., 2020).

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 haemodialysis. The study results highlighted that, in comparison to the other cohorts, the haemodialysis group had the highest rate (76.15%) of menstrual irregularities (Lin et al., 2016).

Due to hormonal imbalance and menstrual irregularities, the women undergoing haemodialysis rarely conceive, but if conception occurs there are increased chances of pre-eclampsia, abortion, preterm delivery, and low birth weight (Georges et al., 2017; Kendrick et al., 2015). In Cameroon, a cross-sectional study found that only four of the 52 haemodialysis women conceived, and all four (100%) pregnancies were spontaneously aborted within the first four months of pregnancy (Georges et al., 2017). 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 the year 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 increases the risk of low birth weight twofold (Kendrick et al., 2015).

Regardless of the fact that pregnancy in women undergoing haemodialysis 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 (Shah et al., 2020). 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 (Okundaye et al., 2022). This retrospective chart review research letter indicated that the reproductive health of women undergoing haemodialysis is an underserved area.

Impact of SRH on the Quality of Life of Women Undergoing Haemodialysis

As previously discussed, physical and psychological symptoms and hormonal imbalance are all independently linked to poor SRH, which drastically impacts the quality of life and the marital relationship of women undergoing haemodialysis (Gerogianni & Babatsikou, 2014; Manjula et al., 2021; Nappi et al., 2016).

Furthermore, improved sexual function can result in significant improvement in the quality of life of women undergoing haemodialysis. Accordingly, to determine if guidelines intervened by nurses improve sexual function and consequently the quality of life of haemodialysis women, 50 women aged 20 to 50 years old were enrolled in a quasi-experimental study in Iran (control group n=25 and intervention 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 (El Monem & Salim, 2020).

Impact of SRH on Marital Relationship of Women Undergoing Haemodialysis

SRH of a woman has a substantial role in marital life to maintain a strong marital relationship and gain marital life satisfaction (Manjula et al., 2021). 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 (Abbott et al., 2016). Due to this, failure to recognize or understand a partner's sexual needs can result in distorted marital relationships and family disintegration (Keskin et al., 2019). Additionally, the menstrual irregularities associated with haemodialysis negatively influence the SRH of these women, and as a consequence, the marital relationships of these women are also adversely affected. In this regard, Soylu (2022), 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. This study found a statistically positive relationship (r=o.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 to evaluate 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%) (Rasmussen et al., 2020).

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 haemodialysis, which offers them a great chance to start conversations on SRH topics (Shahdadi & Rahnama, 2018). However, research indicates that nephrology nurses are hesitant to discuss sexuality issues with haemodialysis patients (Cousins et al., 2020).

Yodchai et al. (2018), in a phenomenological study conducted in Thailand, investigated how nephrology nurses perceive discussing SRH issues with kidney failure patients. 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 to talking about sexuality (Åling et al., 2021).

Gap Analysis

After reviewing the literature, a research gap was identified in the SRH area of women undergoing haemodialysis 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 women undergoing haemodialysis because, most 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, however, it is imperative to explore in-depth the lived experiences of SRH, in this population (Saglimbene et al., 2017). To date, in Pakistan, three quantitative studies have been conducted to investigate the sexual dysfunction of women undergoing haemodialysis, but qualitatively in-depth lived experiences of SRH have apparently not been explored among women undergoing haemodialysis. All three prior research investigations concentrated solely on the sexual dysfunction of women undergoing haemodialysis, rather than their overall SRH experiences (Rahman et al., 2023; Shah et al., 2022; Yaqoob et al., 2020). Among these, two quantitative studies have also included postmenopausal women, who after menopause become infertile and have a hypoactive sexual desire (Worsley et al., 2017). Hence, it is imperative to explore in-depth the phenomenon of interest, which is the lived experiences of SRH among women of reproductive age undergoing haemodialysis.

Summary

This chapter described the significance of sexuality in the life of an individual, considering the significance of how the transition in the life of haemodialysis women impacts their SRH. There are many physical and psychosocial factors which have an association with the SRH of women undergoing haemodialysis. The commonly faced SRH issues are sexual dysfunction, infertility, menstrual irregularities, and complicated pregnancy. These SRH issues negatively impact the quality of life of haemodialysis

women and, consequently, their marital relationships also. Hence, there is a need to qualitatively explore the lived experiences of SRH of women undergoing haemodialysis, for an in-depth investigation of the phenomenon of interest as no qualitative study has apparently been conducted in Pakistan.

Chapter Three: Methodology

This phenomenological study aimed to investigate the lived experiences of Sexual and Reproductive Health (SRH) among women undergoing haemodialysis. This chapter presents the research methodology, which includes a brief explanation of the study's design, the rationale for selecting a specific study design, and the bracketing process required for descriptive phenomenological studies. Furthermore, the recruitment process for participants, data collection tool, data collection process, and data analysis are also discussed. This chapter concludes with a discussion of the study's rigor as well as ethical considerations for the study, followed by a brief summary of the chapter.

Study Design

This study has employed a descriptive phenomenological study design to explore the lived experiences of the phenomenon of interest; the SRH of women undergoing haemodialysis. There are two types of phenomenological study designs; interpretive phenomenology and descriptive phenomenology. Interpretive phenomenology was proposed by Heidegger, and the central idea underpinning the concept is that every piece of knowledge is an interpretation (Burns & Peacock, 2019). Whereas, descriptive phenomenology, proposed by Edmund Husserl, focuses on capturing the true essence of an experience as it unfolds, giving meaning to participants' experiences related to a particular phenomenon and putting aside the researcher's perceptions. As accurately describing a participant's experience is the main goal of phenomenological research therefore researcher brackets his personal perceptions, particularly while collecting and analyzing data (Lee et al., 2019; Willis et al., 2016; Wirihana et al., 2018). Furthermore,

descriptive phenomenology attempts to accurately represent the essential structure of an experience by highlighting what is significant and essential concerning a particular phenomenon (Willis et al., 2016).

This phenomenological study aimed to examine the phenomenon's nature from the viewpoint of women undergoing haemodialysis who had lived through it (Chen & Teherani, 2016). Since a phenomenological study design focuses on what was experienced and how it was experienced in order to explain the meaning of an experience therefore, the descriptive phenomenological design was considered suitable because it facilitated the researcher to better grasp the true essence of lived SRH experiences of women undergoing haemodialysis and to develop a fundamental structure of the phenomenon of SRH.

Study Setting and Population

The research was carried out at the Combined Military Hospital (CMH) situated in the Malir Cantonment which has a 1000-bed capacity. This is a tertiary care teaching hospital providing healthcare services to military personnel and their families. This hospital has a haemodialysis unit with ten dialysis machines and provides haemodialysis in three shifts from seven ‘o’clock in the morning till seven ‘o’clock in the evening and emergency haemodialysis during the night hours. Each month, 350 to 400 haemodialysis sessions are provided, with dialysis care delivered by nephrology nurses and dialysis technicians.

The study population consisted of reproductive-age women (18-50 years) who were undergoing haemodialysis.

Inclusion Criteria

The following women were considered eligible for this study:

- All women of reproductive age living with their spouse, attending haemodialysis
- Between the age of 18 to 50 years
- Having a dialysis duration of more than three months
- Receiving 2 to 3 times weekly dialysis sessions, 3 to 4 hours per session
- Using arteriovenous fistula, arteriovenous graft, and permcath as vascular access for haemodialysis

Exclusion Criteria

The following women were excluded from the study:

- Having temporary vascular access (a double-lumen catheter) were excluded due to the high rate of line sepsis and dysfunction of temporary vascular access, which can impact the general health of the women (Ferreira et al., 2018; Shanmugasundaram et al., 2022)
- Hospitalized for acute illness
- Receiving cancer treatment
- Having any documented cognitive impairments, making it hard for them to share their experiences
- Could not speak ‘Urdu’ or English

Study Duration

The study was started after approval from the regulatory body of all military hospitals across Pakistan i.e., the General Headquarters (GHQ) permission letter is attached (Appendix A), and the Ethical Review Committee (ERC) of the Aga Khan University (Appendix B). The study was conducted from April 2023 to September 2023.

Sampling Strategy

This study applied a purposive sampling strategy, in which participants were chosen based on their characteristics and qualities (Etikan et al., 2016). According to Sandelowski (2000), for qualitative research, purposeful sampling is the most appropriate method for capturing and describing a phenomenon across a range of situations. Moreover, purposive sampling is very useful in situations affecting patient care, to gain knowledge about a specific phenomenon in which the researcher is interested (Palinkas et al., 2015). Furthermore, in previous descriptive phenomenological studies, purposive sampling had been frequently employed (Osei Appiah et al., 2021; Yang et al., 2023; Yılmaz & Karataş, 2018). Additionally, the current research investigation intended to examine the lived experiences of SRH among reproductive-age women undergoing haemodialysis; therefore, the researcher specifically recruited participants purposefully, who could provide maximum information about the sensitive topic of SRH (Ewert et al., 2015).

Sample Size

As for phenomenological studies, the estimated sample size is generally fewer than ten with a minimum sample size of four (Moser & Korstjens, 2018; Shorey & Ng, 2022). In the current study, the data saturation was achieved after the ninth participant,

when no new analytical information was generated and all relevant information related to the study purpose was revealed (Guest et al., 2020; Saunders et al., 2018). A further interview was conducted to confirm data saturation.

Participants' Recruitment Process

After gaining approval from the ERC of the Aga Khan University the researcher visited the haemodialysis unit. The researcher followed the recruitment process as given below:

Step 1: After informing the Matron and Commandant of the hospital about the study purpose and institutional permission letter, the researcher arranged a meeting with the nephrologist and the nurse in charge of the haemodialysis unit. During the meeting, the researcher explained the study's purpose, eligibility criteria, and significance. A printout of the institutional permission letter was also handed over to the nurse in charge of the haemodialysis unit.

Step 2: The nurse in charge introduced the researcher to the nephrology nurses and dialysis technicians working in the haemodialysis unit.

Step 3: The nurse in charge of the haemodialysis unit was requested to provide a list, containing information about eligible participants.

Step 4: The researcher visited the haemodialysis unit regularly, to approach all the potential participants coming on different days according to their haemodialysis schedule.

Step 5: In the first interaction researcher introduced herself to the potential participants to build rapport and gain their trust, which is important when talking about sexuality issues (Yodchai et al., 2018). The researcher explained the study's specifics and purpose in a separate room to each participant, during this first interaction.

Step 6: The researcher gave one week to the potential participants to think and discuss with their spouses about participation in the study. A week after the initial contact, in the second interaction the researcher visited them again according to their hemodialysis schedule, to determine their willingness to participate. In the second interaction after receiving written informed consent and assuring them about the privacy of the data, eligible participants were individually interviewed, in a separate room, in the haemodialysis unit.

Data Collection Procedure

The data collection was started after approval from ERC of AKU from the first week of April 2023 and was completed in the first week of July 2023. In the first interaction which was 15 to 20 minutes duration, details of study were explained individually to each participant in a separate room. After one week of the first interaction, in the second interaction with each participant written informed consent (Refer to Appendices C, D) was taken before the interview upon their willingness to participate. The interviews were conducted one-on-one in a calm, enclosed room to maintain the participants' privacy. Since the subject of SRH is a sensitive topic to discuss, therefore, one-on-one interviews were considered a suitable choice for the in-depth exploration of this delicate subject area (Dempsey et al., 2016). The total duration of the interviews (including written informed consent, sociodemographic questionnaire and semi-structured open-ended questionnaire) was from 50 mins to 70 mins. All the interviews were audio recorded to ensure the accuracy of the data, and field notes and non-verbal clues were also noted. Further, to preserve the meaning of the recordings, the audio

recordings were first transcribed word by word in the Urdu language by the researcher and were then followed by an English translation (Saunders et al., 2018).

Data Collection Tool

Socio-demographic Characteristics Questionnaire

The sociodemographic data was collected before interviewing each participant. The questionnaire included age, education level, years of marriage, years of dialysis therapy, religion, and number of children (Appendix E). The sociodemographic questionnaire was also translated into 'Urdu' (Appendix F).

Semi-structured Interview Guide

A semi-structured interview guide was used to carry out in-depth interviews (Appendix G). This included open-ended questions, which encouraged respondents to offer sincere viewpoints and share personal experiences regarding subjects that may be delicate (Turner III & Hagstrom-Schmidt, 2022). The interview guide for this study explored the difficulties, worries, and concerns about SRH, among women undergoing haemodialysis, and its effect on their quality of life and marital life since starting haemodialysis (Cypress, 2018). The interview guide was also translated into 'Urdu' language (Appendix H). This interview guide was developed based on a literature review and was approved by the supervisor and committee members after discussion.

Pilot Testing

As the first step in data collection, a pilot test with two participants was conducted. This was needed to identify any difficulty related to the interview guide and process. However, no difficulty was identified while conducting the interviews, therefore,

no amendment was required in the interview guide, and only a few probes were added (Turner III & Hagstrom-Schmidt, 2022). The data collected from pilot testing was also included in the study.

Bracketing

In descriptive phenomenology, the researcher serves as a blank slate, using the experiences of participants to gain a deeper understanding of the phenomenon under investigation (Neubauer et al., 2019). Therefore, prior to data collection, and analysis the researcher engaged in "bracketing," by keeping aside the researcher's personal biases, assumptions, and beliefs about the phenomenon of interest i.e., lived experiences of SRH among women undergoing haemodialysis. The bracketing was done by writing critical reflections concerning the SRH of women undergoing haemodialysis (Creswell & Poth, 2016; Yagi et al., 2022). During reflective writing, some of the assumptions, beliefs, and preconceptions related to the SRH of women undergoing haemodialysis, held by the researcher were:

- Women undergoing haemodialysis have distorted SRH due to irregularity in the menstrual cycle and inability to conceive.
- Most married haemodialysis women of reproductive age have no sexual relationship with their spouses. Their marital lives are unsatisfactory.
- Their spouses do not provide any support in order to maintain the sexual and marital relationships.

To avoid introducing assumptions and preconceptions that could negatively influence the analysis, the researchers also used this "reflective technique" prior to collecting and analyzing the data (Lee et al., 2019; Simeone et al., 2022). Moreover, after

every interview reflective journal was also maintained by the researcher. This was also reviewed and discussed with committee members and supervisor during the research process.

Data Analysis by Colaizzi's Phenomenological Approach

The analysis of data was started along with the data collection process. The data was analyzed manually and no software was used for the extraction of themes. Colaizzi's phenomenological approach was employed for the analysis of data. This analysis approach consists of seven steps and is a rigorous and reliable method for analyzing descriptive phenomenological studies (Morrow et al., 2015). Moreover, according to a scoping review, which included phenomenological studies conducted in the year 2021 in nursing research, 53% of the phenomenological studies used Colaizzi's seven-step approach (Shorey & Ng, 2022). This analysis approach enabled the researcher to identify new themes, as well as the interconnectedness of these themes to develop a comprehensive description concerning the lived SRH experiences of women undergoing haemodialysis (Pardell-Dominguez et al., 2021; Wirihana et al., 2018). The steps followed for data analysis are discussed below:

Step 1: Familiarization

As a first step of data analysis, the researcher listened to and re-listened to the audio recordings to get an in-depth comprehension of the participants' feelings and thoughts concerning their SRH experiences. Additionally, the transcripts were read by the researcher several times to familiarize herself with the data.

Step 2: Identifying Significant Statements

The transcripts were read and re-read by the researcher to identify significant statements describing the women's experiences related to their SRH. These significant statements were also checked by committee members and supervisor (Anselmo-Witzel et al., 2017).

Step 3: Formulating Meanings

The researcher has conducted a manual data analysis. The thematic extraction was not done with any software, the researcher constructed meanings through careful consideration of pertinent statements and phrases by reading them several times. These formulated meanings were coded and categorized by the researcher and then reviewed by committee members and supervisor to ensure process accuracy and meaning consistency.

Step 4: Clustering Themes

All noteworthy statements were analyzed and grouped into cluster of themes by the researcher, from which themes relating to SRH experiences of women undergoing haemodialysis emerged.

Step 5: Developing an Exhaustive Description

In this step, an exhaustive description of the phenomenon, i.e., SRH experiences of women undergoing haemodialysis, was developed through the integration of cluster themes, emerging themes, and formulated meaning. This exhaustive description provided a comprehensive picture of the phenomenon being experienced by women.

Step 6: Producing Fundamental Structures

The lengthy description of the SRH phenomenon was condensed to important aspects considered crucial for the organization of fundamental structure, depicting SRH experiences among women undergoing haemodialysis.

Step 7: Verifying Fundamental Structure

The researcher shared an exhaustive description of the lived SRH experiences to the four participants to validate that the findings accurately reflected their lived experiences concerning SRH. During the interview, permission to share the description of the phenomena with the participants was obtained. The description of the phenomenon was also translated into Urdu and shared with the participants for confirmation.

Study Rigor

Rigor is the trustworthiness of the research. A qualitative research study's rigor must be established in order to assess its neutrality (objectivity), consistency (reliability), applicability (external validity), and credibility (internal validity) (Guba, 1981; Singh et al., 2021). Rigor in the current study was ensured by using Lincoln and Guba (1986), trustworthiness framework. It consists of four criteria: credibility, dependability, confirmability, and transferability. However, for this study, the researcher considered credibility and confirmability as follows:

Credibility

Lincoln and Guba (1986), describe credibility as confidence in the veracity of the results obtained. For the purpose of credibility, the researcher ensured that the results accurately reflected what was studied. Credibility was also ensured by audio recordings of the interviews to save every word, and through member check, by returning to the four

of the participants for confirmation and validation of the data in the seventh step of the data analysis process (Kantaporn et al., 2022b). Along with this field notes and non-verbal clues were also noted.

Confirmability

According to Lincoln and Guba (1986), confirmability is the level of neutrality in the study results. The researcher made sure that the results are confirmable by ensuring that they were based on participant data and not influenced by the researcher's interpretations or biases. This was established by bracketing before the data collection and data analysis by writing a critical reflection, to reveal the biases, perceptions, beliefs, and assumptions concerning the phenomenon of SRH among women undergoing haemodialysis (Cypress, 2017). Moreover, after each interview, the researcher expressed personal feelings and emotions by writing in a reflective journal. To ensure the integrity of the findings, the process of extracting statements and identifying themes was discussed with the supervisor and committee members.

Ethical Considerations

Approval was taken, before conducting the study, from the ERC of AKU. A permission letter was also sought from the Medical Directorate General Headquarters. The participants' informed, written consent was taken upon their willingness to study participation. The interview was held in their free time and in a separate room, considering their privacy. In addition, a "Do Not Disturb Label" was displayed outside the room to avoid any disturbance and to prevent hesitancy among the participants. Furthermore, it was explained to them that the interviews would be audio recorded and

that data confidentiality would be maintained. Moreover, their identity would not be disclosed. Codes were assigned to them to ensure their privacy and confidentiality.

The researcher conducted all the interviews herself and the electronic data was secured in the personal laptop of the researcher, in password-protected files. All audio recordings and raw data were stored in lockers for confidentiality. Access to the study data was limited to the primary researcher and the thesis committee members. However, an ethics committee or regulatory body could access the data for monitoring or audit purposes.

The study participants did not directly gain anything from taking part, but they got the opportunity to express and vent their emotions by stating their experiences, which might have helped in improving their overall well-being. Furthermore, because it was possible that participants might experience emotional distress during the interview, a referral mechanism for counselling services in the study setting was also available, and military personnel's families are entitled to free medical treatment at any of Pakistan's military hospitals (Appendix I). However, the researcher had not met a situation that necessitated referral.

Dissemination of Study Findings

The findings of this study will be communicated to the General Headquarters to improve the SRH of women in the reproductive age bracket, who undergo haemodialysis in Military Hospitals. Furthermore, the findings will also be shared through presentations, both within and outside of the institution, at various platforms, such as conferences and research forums. The findings will subsequently be published in a peer-reviewed journal to disseminate findings outside of the military setting, to increase understanding among

renal care providers, particularly nephrologists and nephrology nurses, regarding the SRH concerns of women receiving haemodialysis.

Summary

In brief, the chapter has described the research methodology employed in the study. This study utilized a descriptive phenomenological design to explore the phenomenon of interest. It was carried out in the haemodialysis unit of a tertiary care hospital at Malir Cantt, Pakistan. Through purposive sampling, a total of ten participants were interviewed and their sociodemographic information was completed. Colaizzi's seven-step approach was adopted to analyse data, and rigor was maintained throughout the study process. Lastly, the chapter described the ethical considerations and dissemination plan.

Chapter Four: Study Findings

This section discusses the findings regarding the Sexual and Reproductive Health (SRH) experiences of women undergoing haemodialysis in Pakistan, as well as the impact of these experiences on their overall quality of life and marital life. The study findings revealed women's lived experiences concerning their SRH after commencing haemodialysis. This chapter begins with a discussion of the participants' characteristics, followed by a description of the data analysis in terms of sub-themes and themes derived from the study's findings. Finally, in the end, a summary of this section concludes the chapter.

Participants Characteristics

This study recruited 10 married women of reproductive age (18-50 years) who had been receiving maintenance haemodialysis for two to six years. The women's age ranged from 26 to 43 years, with an average of 34.7 years. More than half of the participants (n=6) had completed primary or secondary school education, and one participant had a bachelor's degree, and three were master's degree holders. Three of the 10 participants had no child, one had more than three children, and six had one to two children. The total marriage duration of the participants ranged from four to twenty-two years. Hence, there was diversity concerning age, number of children, years of marriage, and education. Participants' socio-demographic data is presented in Table 1.

Table 1

Socio-demographic Characteristics of Participants (n=10)

Socio-demographic Characteristics (n=10)	Number of Participants (n=10)	Percentage (%)
Age (Years)		
18-25	0	0
26-30	1	10
31-35	6	60
36-40	1	10
41-45	2	20
Education		
Primary Education	4	40
Secondary Education	2	20
Intermediate	0	0
Bachelors	1	10
Masters	3	30
Religion		
Islam	10	100
Years of Marriage		
<5	1	10
5-10	4	40
11-15	3	30
16-20	1	10
21-25	1	10
Years on Haemodialysis		
1-5	7	70
6-10	3	30
Number of children		
No children	3	30
1-2	6	60
3-4	1	10

Data Analysis

By employing Colaizzi's phenomenological seven step data analysis approach, the researcher extracted significant statements related to the SRH of women undergoing haemodialysis by reading and rereading the transcripts. Following that, meanings were derived from these significant statements. These derived meanings were then coded, and

similar codes were clustered into sub-themes and themes. This method of analysis generated five themes from sub-themes according to the study questions. The researcher has provided narrations of the participants to support the themes and sub-themes. Furthermore, grammatical corrections were made to improve the clarity of the narrations without changing their meanings. Aside from that, important terms and phrases related to the phenomenon in the Urdu language, in italicized form, are also given to help the reader understand the contextual meanings of the SRH phenomenon. Table 2 depicts the five themes as well as the sub-themes.

Table 2

Themes and Sub-themes

Themes	Sub-themes
1. Intimacy Redefined; Unveiling the Value of Sexuality in Marital Bliss	Relationship of trust, love and acknowledging feelings
	Intertwining of SRH and matrimony
	Embracing Divine's will
2. Stumbling Blocks in Maintaining SRH	Poor health and prevailing fatigue diminishing sexual desire
	Fear of pregnancy
	Cultural barriers and inadequate SRH awareness
	Fear of contracting illness
3. Depths of Despair: From Struggle to Strength	Life is not the same
	Remodeling life
4. Breaking Barriers: A Call for Action by HCPs	Women-led SRH education
	Beyond dialysis: prioritizing SRH counselling
5. Husband's Support: A Beacon of Hope	Spousal support to strengthen marital ties
	Without support life could be worse

Theme One: Intimacy Redefined; Unveiling the Value of Sexuality in Marital Bliss

Sexuality was considered important in human life and was perceived in different ways by the participants, with some viewing it as a relationship of love, trust, and understanding of each other's feelings, while others seeing it as a natural need, essential for marital life. Additionally, most participants cited maintaining sexual relationships as obeying Divine's will. A participant explained:

> This (sexual relationship) is important for me because Allah has created humans in this way. Human beings are incomplete without this relationship. Allah has created these systems and these things (sexuality) are included in the nature of human beings. It is important because a human gets inner peace from this when a person gets into an intimate relationship after 'Nikah'. If someone does not experience it that person remains uncomfortable. When we hug each other, we feel that there is someone who is only mine and lives with me and sits with me. It gives a feeling of being complete. (P.08)

This theme comprises three sub-themes; Relationship of trust, love, and acknowledging feelings, intertwining of SRH and matrimony, and embracing Divine's will.

Sub-theme One: Relationship of Trust, Love and Acknowledging Feelings

The participants viewed sexuality as more than just sexual intercourse; they recognized it as a means of expressing love and as a bond that can be upheld through mutual affection. A participant described, "I don't consider it (sexual intercourse) as important. It is a relationship of love and can be maintained by love" (P.06).

Understanding each other's feelings was deemed more important in marital life than sexual intercourse, by the participants, as in a marital relationship, husband and wife come closer and acknowledge each other's feelings. One of the participants shared her views:

> Feelings are more important than sexuality. One must have such a person in life who can understand your feelings; the same is the case with the husband-wife relationship, because life can only be spent if we understand each other's feelings. However, in a good *'Izdwaji Zindagi'* (marital life), reproduction is required. This is the (sexual) relationship in which nothing is hidden from each other and closeness develops. During this closeness, husband and wife can share their emotions with one another. That is why sexuality is so important in life. (P.08)

One of the participants metaphorically described the husband-wife relationship as the wheels of a cart that support each other to keep the cart balanced. She mentioned that a husband and wife have a loving relationship and they conceal each other's flaws. She explained this trusting relationship to cover each other flaws by using the word 'Libas' (clothes to cover the body). She stated:

> I would say that the relationship between the husband and wife is very good thing, just like the two wheels of a cart; if one of them is not in place then the cart will not run. Because they love and trust each other, therefore they are just like '*Libas'* (clothes to cover the body) for each other. (P.04)

The participants highlighted the importance of trust for developing a strong bond in marital life, to maintain a stable household. When there is no trust, this bond weakens, which can be harmful to the entire family. A participants stated:

> If the house is a unit, the husband-wife relationship is where it all begins. Husband and wife should have a high level of trust, but if they do not understand each other, their relationship will deteriorate. It is a trusting relationship that results in bonding, which also leads to nurturing the children. (P.10)

Sub-theme Two: Intertwining of SRH and Matrimony

SRH was regarded as synonymous with marital life by the participants. They believed that sexual relationship is the foundation of a successful marriage and prevent husbands from engaging in extramarital affairs. As stated by a participant, "Married life is another name for this (sexual) relationship. Husband and wife are for each other. When the wife will give time to her husband, he will not go astray and vice versa with the wife" (P.05).

Another participant explained:

> Sexual relationships is very important in marital life. If we do not have this relationship then just living together is not important. If a wife is not capable of this (sexual relationship) then she has no reason to be a wife. Allah has made this relationship for this purpose (sexual relationship). It is to provide peace to a man and woman. However, if one partner is sick, it is not the other's fault. That's why it (sexuality) is necessary and important. (P.02)

Moreover, sexual relationship was considered important for procreation purposes; it was pointed out that even animals have this relationship to breed. A participant, who

had no children stated, “For breeding purposes, sexual relation has to be maintained. In marital life, we have to spend a sexual life as a human being, even animals also have sexual life for breeding” (P.08).

Sub-theme Three: Embracing Divine’s Will

Participants’ religious beliefs also influenced their perceptions of sexuality. Maintaining an intimate relationship, in their opinion, was embracing the Divine's will and obeying one’s husband in all kinds of circumstances was considered Allah's command. A participant explained:

> It is Allah’s order to obey your husband, as Allah almighty says that the husband is ‘Majazi Khuda’ (a word used for husband in South Asian culture, which means earthly god or next to God). If the husband does not allow us to see our parents, we cannot see them. Allah has also said that pious women are for pious men and pious men are for pious women. They are permissible for each other. It (sexual relationship) will enhance love, and domestic matters will also be solved and there will be no disputes. They should understand each other. Allah said that if a woman is preparing a meal and her husband calls for this (sexual intercourse) she should leave the bread, even if it burns. (P.05)

Another participant added that Allah has created this relationship so that husband and wife can provide comfort to each other. She described her experience by saying,

> If the husband is taking care of you and your diet and helping you with the dialysis process, then why not fulfil his sexual desires? Allah has ordered us to do that and HE has chosen our spouses so that we comfort them. (P.04)

The sexual relationship was also acknowledged as a physical and natural need created by Allah, thus indicating the value of fulfillment of these needs in a religious context. Moreover, this need was also considered as being governed by chemicals in the brain, implying that human sexuality has a biological basis. According to one participant,

> These are physical and natural needs. We also read about different chemicals in the brain which play a role in it (sexuality). Yes, since Allah has created this thing (sexual relationship), it is very important. If this need is met at home, there is no need to look elsewhere (extramarital affair), and this is the appropriate way. (P.10)

The participants also narrated that the sexual and reproductive system is created by Allah to fulfil natural human needs and to bring satisfaction in life. She explained:

> Allah has created many systems. One may not be aware of it before marriage but after marriage, one realizes that these (sexual relations) are necessary for life. Many natural needs are fulfilled by this. If you are satisfied with your (sexual) relationship then you will not need anything else. It gives strong satisfaction. When this need is not satisfied then it affects both of them (husband and wife). If you are satisfied with your sexual life then your life routine gets better. (P.03)

Theme Two: Stumbling Blocks in Maintaining SRH

This theme focuses on the barriers in maintaining sexual and reproductive health. Different barriers were identified by the participants concerning their lived experiences which caused reduced sexual activity and hypoactive sexual desire. A participant described her difficulties in maintaining a sexual relationship as follows:

> I did not have the strength and my body became very weak. I didn't even like being touched. Another thing was that I got physically weak gradually. Tiredness was a big issue; the fatigue was too much. Now my sexual needs have diminished because the (sexual) desire has faded away. I became so sick that now I am tired, I am finished (disappointment in voice with slow pace). (P.10)

This theme was derived from three subthemes; poor health and prevailing fatigue diminishing sexual desire, fear of pregnancy, cultural barriers and inadequate SRH awareness, and fear of contracting illness.

Sub-theme One: Poor Health and Prevailing Fatigue Diminishing Sexual Desire

Women undergoing haemodialysis have poor health due to physical symptoms, such as shortness of breath, heart palpitations, or physical restrictions (such as inability to lay flat due to volume overload), hindering their sexual activity. Therefore, sometimes they are unable to meet their husbands' sexual desires. As expressed by a participant, "I faced many difficulties like husband has a desire (sexual) that his wife should sleep with him. But sometimes my health doesn't allow me" (P.09).

These women also suffered from menstrual irregularities; in the current study, the majority of the women were having irregular menstrual cycles. A participant who had menstrual irregularities and heavy bleeding expressed her difficulties in these words:

> I have had no (sexual) relationship after starting haemodialysis. After marriage, this relationship lasted well for almost a year, like happiness and expressing (sexual) desire, and then I fell severely sick. I suffered heavy menstrual bleeding and pain so I was scared. (P.01)

This inability to fulfil their husband's sexual desires also left feelings of regret in these women, as verbalized by a participant,

> Sometimes, I have a problem in my abdomen which causes pain. Many times, I suffer from breathlessness and low blood pressure during this (sexual activity). I feel that when I am unwell, I cannot fulfil my husband's needs. At that time, I feel great regret. (P.05)

Furthermore, due to their poor health, many women felt cold and found it difficult to shower after intercourse (showering after sexual intercourse is obligatory in Islam). A participant shared her experience as, "I feel weakness and pain in the whole body, so it is difficult for me to take a shower after this (sexual intercourse) as I feel cold. Therefore, maintaining the husband-wife relationship seems very difficult to me (smile)" (P.07).

A lack of energy and fatigue were found to be other obstacles in maintaining a sexual relationship. The participants also expressed a discord caused by their health condition with what they viewed as a religious or moral obligation. This distressing experience was expressed by a participant, "Previously it (sexual relationship) was better, now it is just going on. Currently, I don't have stamina and feel fatigued. I know it is a sin to refuse one's husband but it is due to the disease" (P.09).

Sub-Theme Two: Fear of Pregnancy

The fear of getting pregnant was found to be a reason that impacted the sexual relationship of the participants. This fear was triggered, either by past life events or the personal experiences of the participants. A participant having an obstetric history of two intrauterine deaths (IUDs) while on haemodialysis verbalized her concern by saying,

“Now I am not using anything for birth control. My sister says if pregnancy occurs now what will you do, you are weak” (P.06).

One participant's fear stemmed from an emotional reaction to her cousin's death from kidney failure during pregnancy and the subsequent fear of suffering a similar fate if she becomes pregnant while on dialysis. While describing her fear of pregnancy, she said:

> My cousin had renal failure and she died during pregnancy and I couldn’t tolerate that. I was in my third year at that time, it was a huge shock for me. I felt abhorrence after knowing that she had a baby girl in the womb and her kidneys failed. Now, I have a fear that if I get pregnant while on dialysis that would be the end of my life too. (P.10)

Pregnancy-related fears hindering the sexual activity of the participants included worries about their own health and well-being during pregnancy as well as worries about potential complications for the unborn child. One of the participants shared her concern in these words:

> Firstly, I had this fear in my heart that if I got pregnant, the baby would suffer. Then what will I do, it will be a problem. This feeling was in my heart that I am a dialysis patient and I should not have any relationship with my husband, as it can cause problems. Since I underwent dialysis, I have had no (sexual) relation with my husband. (P.01)

Sub-Theme Three: Cultural Barriers and Inadequate SRH Awareness

Participants' narratives revealed inadequate knowledge about SRH, and the majority of participants stated that they had not received any SRH guidance or

counselling since starting haemodialysis. Although they had many questions concerning SRH and the maintenance of their marital lives, they were unable to voice their worries. A participant shared her experience in these words,

> At that time, when the dialysis started, I knew nothing. There were questions in my mind but I thought now there's no such thing (sexual relations). I wanted to ask someone what would happen with our marital life, but couldn't ask. We are not that friendly to ask dialysis nurses about this (SRH), then there was a patient, I would just ask her. (P.05)

One of the participants expressed openness to receiving SRH advice while also expressing sadness about how her disease has impacted her marital life. She admitted being unaware of sexual relationship maintenance while undergoing haemodialysis. She stated,

> Nobody ever guided me. Never in my life did anyone counsel me about this. Obviously, because of my husband, I feel sad as he loves me. If anyone guides me about sexual and reproductive health, I would love to have it. I never had this understanding that in this disease how to keep this (sexual) relation. (P.10)

Another participant, whose renal function had deteriorated during pregnancy added, "No one really talked about it (sexual relationship); however, they did say that pregnancy cannot be continued. When I had my first pregnancy, they (doctors) wanted me to abort before starting the dialysis" (P.06).

Most of the participants were hesitant to ask male healthcare professionals (HCPs) for advice regarding SRH due to cultural or personal reasons. As explained by a

participant, “All of the doctors to whom we go for kidney treatment are males. We never talked to them about this. But if there is any nurse (female), I am comfortable talking to her about it” (P.02).

Another participant described this cultural barrier in these words:

> Yes, because many people do not share their personal life. But there are certain problems that they have to share. I was not sharing this thing (SRH concerns) with them (doctors) though I wanted to conceive at that time. I was hesitant, that he is a male doctor how do I talk to him? (P.08)

One participant voiced about lack of opportunities to try and understand other things such as SRH awareness, because they were already immersed in trying to cope with other aspects of the disease. She said,

> As you have initiated well. I am an educated person, if you talk about it (sexuality), I will understand. If no one talks about it how will anyone understand? We are so immersed in our disease *(Hum to apni bimari men hi dubay hue hen)* that there is no chance to understand anything else. There is nobody or a counsellor who can guide me. (P.10)

Sub-theme Four: Fear of Contracting Illness

Not just for women, but also for their husbands, disease might evoke fears. For instance, a participant who had a viral infection (while recalling her experience) shared that her husband was hesitant to have sexual relationships due to the fear of contracting the illness. She explained,

> My hepatitis was positive and my husband was scared of the disease. At that time, he could have used a condom, if counselled. When he came to know

about my hepatitis being positive, he became reluctant for sexual intercourse. He was scared and I did not force him. Because at that time due to the disease, I was in such a state that I was unable to think about this relationship. (P.03)

Another participant narrated her observations from an earlier life event by saying,

> There was a girl in our village, she had three children. But her dialysis started and her husband stopped approaching her due to the fear of catching this disease (renal failure). So, she took this to heart and would cry. Then she died after two months. (P.06)

Theme Three: Depths of Despair: From Struggle to Strength

This theme refers to the transitions in the lives of women undergoing haemodialysis and their struggle to adapt to these transitions through modification in their lives. One participant talked about her struggle to become strong by saying:

> I think that although I am a patient, I have a daughter and husband so I should give them my time and care. My illness is not their fault so why should they suffer? They have a life, and I shouldn't disrupt it any further. Therefore, I want to keep myself attractive so that he (husband) doesn't indulge anywhere else (extramarital affair). I am not going to make him believe his wife is always sick and in bed. I tried to be strong enough to keep my physical beauty. I reasoned that if I took care of myself, my health would improve and I would look fresh. By Allah's grace, my health is now improving, following dialysis. Initially, I was unstable but, thank God, my health gradually improved. I also have a strong willpower that's why I also coped with having sexual relationship. (P.02)

This theme has two sub-themes; Life is not the same, remodeling life.

Sub-theme One: Life is not the Same

Almost all the participants experienced a change in life, from the role of a healthy person to the role of a diseased person, which had an impact on their marital lives as well as quality of life. While discussing these life changes related to dialysis therapy, one participant mentioned how, despite appearing to be strong, deep inside her she felt diseased. She revealed,

> There are a lot of changes in the marital life of a sick person and that of a healthy person. No matter how strong a person may become, deeper inside one is still diseased. When I was well everything was fine; my thoughts were different. (P.06)

The participants' narrations of their experiences revealed their feelings of despair. They talked about how much life had changed and felt lonely despite the social support of their family. A participant expressed her dismay as follows:

> A lot has changed. Meaning there is no one; a lonely person can only fight by himself. Parents support but a person feels very lonely and there is no pleasure left in life (silence). I used to pray *salat* and find peace but now, due to heavy menstrual bleeding, I cannot do that. (P.01)

The poor sexual health of women receiving haemodialysis not only affected their own lives but also the lives of their spouses, resulting in a significant change in their marital lives. A participant who had no sexual relationship with her husband since the last five years shared her experience in these words:

> The role has changed to a great extent. As a wife, everything goes upside down. I think my husband really understands me but sometimes he gets frustrated.

> He doesn’t say much but I have studied psychology so I understand him well that what he wants (sexual relationship). In that respect, many things get upset after a disease. (P.10)

The SRH issues had detrimental impact on the quality of life of the women undergoing haemodialysis. These issues influenced their energy level, mood, and overall well-being. One participant compared her lack of energy and vitality to “a leaf fallen from a tree” and stated,

> I don’t have enough energy. Like a leaf that has fallen from a tree, I have become like that. My quality of life was affected very badly. I used to sing before but now I get harsh. I used to be soft-spoken but now I have become loud. I can see that this is because of my disturbed sexual and reproductive life. (P.10)

Before the illness, the lives of these women were full of happiness, indicating a sense of normality and contentment before suffering from kidney disease and undergoing haemodialysis. However, they encountered several difficulties following haemodialysis. One specific concern raised was the in-laws' fear that the daughter-in-law's illness would affect her ability to conceive a baby. This concern demonstrates the cultural and social norms that value traditional familial structures, which regard children as necessary for marital fulfillment and happiness. This was explained by a participant having only one daughter:

> There came a great change after dialysis. This is because, before life was full of happiness and then, afterwards, there are some hassles. Firstly, the in-laws have this concern that our daughter-in-law has gotten sick and might not be able to conceive babies. (P.02)

Another participant having no child expressed:

> Sexual and reproductive life is affected largely. These two things (sexual and reproductive health) are important and if your reproductive system is working then you can give birth to babies, and this cannot be without sexual health. These things affect us greatly, particularly in our society, people think that if someone is married and has children then life will be good, it is a fact. When your sexual life is not good then you cannot have a quality life. When you have children, your family is complete, and you understand each other, then, you can have quality time. Yes, these things are important, very important. (P.08)

Sub-theme Two: Remodeling Life

Since dialysis therapy brought many changes in the lives of women, they had to make some adaptations in their lives to maintain their marital lives. Most participants explained that they plan their sexual activity according to their haemodialysis schedule. According to one of the participants "After the dialysis session, when I feel better, at that time we copulate and then I feel pleasure" (P.05).

Participants' statements also revealed, that their vascular access is not interfering with their sexual activity but they and their spouses take care of it by making certain adjustments to avoid complications. As stated, "It does not affect my sexual relationship. Since my arm is swollen, I keep it on one side during that (sexual activity), to avoid any weight on my arm and to prevent bleeding and my husband also knows this thing so he avoids to touch it" (P.04).

The participants further shared that they became strong enough to cope with their daily routine problems, indicating their acceptance of the disease. They accepted that they

had to spend their lives with this disease and had to make certain adjustments in their sexual lives to preserve their marital lives. As stated by one participant:

> Now our routine and life have settled. We know that life will go on in this way. I do not have any problem, as I have accepted that I am already sick but it (sexual relationship) is important for marital life, and if we skip sexual intercourse (*bat kerna*) completely then it will be like the end of our marital life. Then there is no point in living together and being with husband. (P.02)

One participant who was not able to maintain sexual relationship due to her poor physical health expressed her desire to get a second wife to take care of her husband, attributing her decision to Allah's will. According to her,

> I have made up my mind with regard to his second marriage, it is Allah's will, after all. I thought I am sick and I cannot fulfil his sexual desires and he is a male and has some needs. He (husband) is healthy and not very aged. He is not getting peace of mind; no one is there to take care of him (P.07).

Another participant who was not having children fulfilled her desire for children by deciding to get second marriage of her husband, Moreover, she took this decision because she felt that if her husband chose to remarry without her involvement, it would have hurt her even more. Therefore, she, herself, decided to get second wife for her husband. She stated:

> I arranged my husband's second marriage. As he likes children and I had three miscarriages, therefore, the second marriage was arranged so that he could have children. If Allah has not blessed me with children; he may have children from second wife and he will not go away from me. So, I wanted to keep him

with me. If later, he, himself, takes a second wife, it would hurt me more, but now I have arranged his second marriage myself, it hurts less. (P.08)

Theme Four: Breaking Barriers: A Call for Action by HCPs

The lack of awareness about SRH was considered a major barrier among the participants, therefore, they identified the HCPs should raise awareness about SRH. As verbalized by a participant who had therapeutic abortion while on haemodialysis, “They (HCPs) should ask us so there won’t be any loss. They should ask our concerns and if this (sexual relation) is harmful in any way, we should be told. It is easier for us to talk about it with women” (P.09). This narrative indicated a call for action from the HCPs and, additionally, the need for women-led SRH education.

Sub-theme One: Beyond Dialysis: Prioritizing SRH Counselling

It was suggested by the participants that weekly or monthly counselling sessions for both the husband and wife should be scheduled. They also stated that it was essential to address the impact of the disease on marital and sexual relationships, particularly for newlywed couples who may be experiencing difficulties. Moreover, they recommended that SRH education should begin with the basics. As proposed by a participant,

> Both husband and wife should be counselled in a proper room by a counsellor, and weekly or monthly sessions should be scheduled. First, this guidance should be given to newlywed couples, who have kidney problems with their first child; seeing them hurts. When young girls come (for dialysis) with new purses and new shawls, it hurts a lot seeing them that they have just started their lives and it is not known what their destiny would be? So, if they are not aware,

there would be problems. Then, of course, it should be guided; basics should be conveyed, starting from zero. (P.10)

Most participants highlighted the importance of providing women with comprehensive SRH education to avoid negative outcomes, such as abortion and infertility. Such SRH awareness can alleviate the pain and sorrow associated with these negative outcomes. A participant who had a therapeutic abortion expressed her sorrow in these words:

> Everything should be explained in detail. They should tell them, so that the patients do not have this concern that how they should talk to them (doctors and nurses). If we had known these things before, we wouldn't have undergone loss (abortion) and would have borne the sorrow of not having (children). It's really painful. If everything had been conveyed in the beginning none of this (abortion) would have happened. (P.05)

Another participant recommended,

> I think, in the dialysis unit, SRH education should be imparted. This is because, in the dialysis unit one has three to four hours, and everyone can share his/ her opinion. There is spare time during dialysis. They (nurses) are able to communicate openly and offer guidance, which is very valuable. (P.08)

A supportive environment in the dialysis wards, where patients can openly discuss their SRH issues, was considered to be necessary. As suggested by a participant, "The environment in the dialysis wards should be like that; if we have any (SRH) problem, we should be able to discuss it without hesitation" (P.05).

Sub-theme Two: Women Led SRH Education

According to the majority of participants, dialysis nurses can raise SRH awareness more effectively by providing gender-specific SRH education. Also since, all the nurses in military settings are females, women were likely to feel at ease conversing with them. Moreover, they were hesitant to discuss their SRH concerns with male doctors because they did not consider it culturally appropriate to discuss this sensitive topic with male doctors. A participant verbalized, “So, couples should be guided to stabilize their marital and sexual life and this can be possibly done by the dialysis nurses” (P.10).

Another participant added,

> I would say that nurses should go to the patients and ask them if they see their husbands (spend quality time with their husbands) or not and counsel the patients that they should maintain their marital relationship as before, and not think too much about their disease. The nurses should encourage the patients that maintaining healthy sexual relationships with their husbands will bring peace and comfort in their lives. (P.04)

The participants also emphasized that since nephrology nurses receive specialized education and training to care for patients with kidney disease, they are more knowledgeable and capable of addressing their needs than their family members. So, when they guide the patients, it will be more satisfying for the women. One of the participants explained:

> Nurses are trained and they can guide us better, but if we share about it with anyone at home, they will not be aware. They (dialysis nurses) are trained

and a person feels more satisfied that they are qualified and know everything. (P.08)

These women undergoing haemodialysis faced numerous challenges in their marital and sexual relationships due to the impact of the kidney disease, specifically after starting haemodialysis. As their husbands may remarry because of their wives' inability to engage in sexual activity due to inadequate knowledge regarding SRH. Hence, the importance of dialysis nurses guiding patients on this subject matter was revealed by a participant as follows:

> This disease brings with itself so many issues that it’s difficult to manage marital and sexual relationships. The husbands, therefore, remarry on the pretext that their wives are no more able to engage in sexual activity. Therefore, dialysis nurses should counsel patients about this subject. (P.05)

Theme Five: Husband’s Support: A Beacon of Hope

Most of the participants identified their husband’s support as a major contributing factor in the maintenance of their health, and when they were undergoing prolonged haemodialysis treatment, the husband's support served as a beacon of hope. They felt that their lives would have been much more difficult if their spouses had not been supportive during their illness. This theme is derived from two sub-themes: spousal support to strengthen marital ties and without support life could be worse.

Sub-theme one: Spousal Support to Strengthen Marital Ties

The SRH experiences of the participants reflected the difficulties they encountered during intimate relationships and the support that their husbands had provided to continue this relationship, by considering their wives' health. As described by

a participant, “When I don’t feel good, I refuse him (for sexual intercourse) and he understands” (P.04).

Another participant mentioned her husband's supportive attitude as follows:

> Now, when we have (sexual intercourse), my health deteriorates. As a result, my husband does not bother me much; he only requests this (sexual intercourse) once or twice a month. During this time, he asks about my health and whether I am feeling well. When we wake up in the morning (after sexual intercourse), he asks me to drink juice. In short, he is a huge supporter of mine. (P.02)

The husband's assistance in bringing happiness and better health outcomes was also revealed from the narratives of the participants. According to one of the participants,

> Some husbands leave their wives during their sickness but my husband became more caring and concerned about me than before, due to which I did not allow the disease to take me over. In my whole life, my husband has been a great support for me. I am walking and living a life with Allah’s blessing and Allah has made my husband a support for me. (P.04)

Pregnancy in haemodialysis women can be associated with numerous complications, so husbands counselled their wives to avoid having another child by prioritizing their wives' health. A participant who had one child described her husband's caring behaviour as follows:

> My brother-in-law recently had a daughter and asked us to adopt her. Many people have asked me about pregnancy, but I have told them that I cannot have it. My husband, on the other hand, says nothing about having a child. He

says that may Allah Almighty bless you with a healthy life. If you deliver a child and do not stay well then it is pointless. (P.05)

Sub-theme Two: Without Support, Life could be Worse

It was revealed from the experiences of participants that their husbands remained a huge support for them as no one else could give such care and time. As expressed by a participant, "If I would be at my parents' home my brothers would not be able to look after me like this. They (brothers) might be busy in their own lives but my husband left everything for my health. He gives time to his job and also to me" (P.04).

Hence, the participants believed that their lives would have been very different if their husbands had not supported them during their time of illness. Another participant verbalized this experience by saying,

> If I were at my parents' home and I had this problem then my life would end. I would be alone and would be thinking all the time, but here my husband was with me and I never felt alone. I never thought about this problem and didn't take it to heart. I can say that life is so beautiful. If the spouse is supportive then it's like heaven on earth; if the spouse is bad then it's like a living hell. (P.06)

In contrast, a participant who did not have any support from her husband was missing that support, which could have been a huge help to her in dealing with the issues brought on by the disease. She expressed her feelings as,

> However, living together affects both the husband and the wife. You two can be supportive of each other. This implies that you are both aware of each other's positive and negative chemistry. So, if you have stamina, you can support each other. However, my experience was not very positive. We could accomplish

a lot by living together. It's not just the sexual relationship between husband and wife, but I miss a lot of things that I could handle with my husband's support. (P.03)

Description of the Phenomenon

By employing Colaizzi's data analysis approach, a description of the phenomenon under study was developed, which is given below:

The women undergoing haemodialysis valued sexuality in their marital lives, viewing it as a relationship of love, trust, acknowledging feelings, and, above all, as embracing the Divine's will. Furthermore, they viewed SRH and marital life as synonymous. Certain barriers in maintaining sexual relationship experienced by women undergoing haemodialysis were poor health, fatigue, insufficient SRH awareness, and few fears. Because of these barriers, their marital lives suffered greatly, and they modified their lives by strengthening themselves to cope with their disease. However, culturally appropriate SRH awareness by HCPs can improve their marital lives and quality of life. Another important factor that can help to strengthen marital ties and foster intimate relationships is the husband's supportive attitude, without which their lives could be much more difficult.

When this description of the phenomenon was shared with participants for validation in the seventh step of Colaizzi's data analysis approach, one of them commented, “Through the words, I can hear my voice, and I hope it will help at least one soul” (P.02).

Summary

This chapter discussed the study's findings in the form of themes and subthemes, derived from Colaizzi's data analysis approach. Intimacy redefined; value of sexuality in marital bliss, stumbling blocks to maintaining SRH, Breaking Barriers; A call for action by HCPs, depths of despair; from struggle to strength, husband's support; beacon of hope were the five themes that emerged from the data. The following chapter will discuss the study findings in the light of existing literature, and their nursing implications, followed by the study's limitations, strengths, and recommendations.

Chapter Five: Discussion

The findings of the study will be discussed in this chapter. This study explored the lived experiences of sexual and reproductive health (SRH) among reproductive-age women undergoing haemodialysis in Pakistan, as well as the impact of these experiences on their quality of life and marital life. Through Colaizzi's seven-step data analysis approach, five major themes emerged: intimacy redefined; unveiling the value of sexuality in marital bliss, stumbling blocks in maintaining SRH, depths of despair; from struggle to strength, breaking barriers; call to action for HCPs, husband's support; a beacon of hope. These findings are discussed in the light of existing literary evidence. This chapter also discusses the study's strengths, limitations, recommendations, and conclusion, based on the findings.

Perceptions and Beliefs Valuing Sexuality

The current study found that women undergoing haemodialysis valued sexuality through emotional perspectives such as love, trust, and expressing feelings, indicating deeper intimate ties. Furthermore, they valued it as a means for husband and wife to express and validate each other's sentiments, going beyond the specifically physical aspect of the sexual activity. These results are in line with a study conducted by Anam et al. (2020), in Indonesia, involving 12 kidney failure patients, in which the participants reported that they express sexual intimacy with their spouses through loving one another, rather than through sexual activity. Likewise, in a phenomenological study conducted in Spain, by Abarca-Durán et al. (2021), involving 18 kidney transplant recipients, the

participants valued love and understanding feelings more vital in marital life than sexual intercourse.

The word 'Libas' is used euphemistically in a verse, Surah Baqra, of the Holy Quran that says husband and wife are like clothes for one another (Albanon & Abdul-Wahid, 2022). This is in agreement with the results of the current study in which the participants metaphorically referred to the husband-and-wife relationship as *"Libas"* This term captures the emotional bond between a husband and wife, as well as how they meet each other's needs for peace and trust (Ghorashi et al., 2017). Therefore, perceiving sexuality through these emotional prisms encourages a broader understanding of the sexual relationship between husband and wife, by promoting positive and satisfying interactions between them.

Sexuality was regarded as an essential component of marital life to strengthen marital relationships; without sexual interaction, participants considered that there was no reason to live together in matrimony. A study conducted in Turkey found similar results, with participants acknowledging sexuality as a substantial component of their marital lives, as their family life would not exist without sexual interaction (Keskin & Şentürk, 2022).

Furthermore, the significance of a healthy reproductive system was valued in marital life, because having a child was considered an essential aspect of marital life by the women who were childless. These findings are in line with the findings of a study in which the participants from a Pakistani background stated that in the Pakistani culture, married couples are expected to have a child soon after marriage, and having children is

considered a benchmark for a normal marital life (Khokher & Beauregard, 2014). Since Pakistani society is pronatalist in nature, having more children is encouraged, and procreation is considered the main aim of marriage. After a few years of marriage, the couple's inability to have children becomes the subject of scrutiny, especially for the woman, who suffers the most from the social devaluation and lack of status that are connected to childlessness (Qamar, 2018; Slamat et al., 2023). Briefly, SRH is an inextricably linked component of marital life in Pakistani society.

In the current study, women on haemodialysis had decreased sexual desire, related to the gradually deteriorated function of the hypothalamic-pituitary-gonadal axis, which disrupts sex hormones in kidney disease (Dumanski & Ahmed, 2019). The current study findings indicated that although the women undergoing haemodialysis had hypoactive sexual desire, as a result of the disturbed hormonal function, they maintained a sexual relationship with their husbands due to their religious convictions. They believed that it was Allah's command for them to obey their husbands in any situation. They considered it a sin and felt guilty if they refused sexual intercourse, so they maintained this relationship. These findings are congruent with previous empirical literature, indicating the impact of culture and religion on sexual behaviours (Ghorashi et al., 2017; Ussher et al., 2017).

Similar findings were also reported in a phenomenological study conducted in Thailand on Muslim women undergoing dialysis, in which women mentioned that refusing their husband to have sexual intercourse is a sin (Kantaporn et al., 2022a). This

perspective of women stems from religious and spiritual beliefs that consider sexuality as a sacred and meaningful aspect of human existence.

Challenges and Life Modifications to Cope with Challenges

Haemodialysis is a physically exhausting procedure which demands substantial time and energy from patients (Bahgat et al., 2016). Regarding this, the current study findings found that women undergoing haemodialysis experienced fatigue, lack of energy, and tiredness, posing a challenge to their sexual relationships. This disturbed sexual relationship made them feel lonely and forlorn. These women's lack of interest in sexual activity due to fatigue and low energy is consistent with previous empirical studies, where participants reported that fatigue, poor health, and tiredness had affected their overall well-being and marital lives, leaving them feeling lonely and hopeless (Frandsen et al., 2020; Jacobson et al., 2019).

Similar findings have also been reported by women diagnosed with other chronic diseases; such as, in a study of gynaecological cancers, 78.9% of women reported a change in their sexual lives, and 47.4% reported loneliness as a result of the change (Kömürcü et al., 2015). These findings are also in agreement with other studies conducted in Africa and Southeast Asia, in which participants receiving haemodialysis therapy reported that their marital lives had been disturbed due to their inability to maintain sexual relationships (Kantaporn et al., 2022a; Tadesse et al., 2021). Moreover, it was found that this lack of sexual activity also influenced the behaviour of their male spouses, who became frustrated due to the nonfulfillment of sexual desire. These findings are consistent with the findings of a study conducted by Khalil (2016) in Pakistan, which

revealed that males become sexually frustrated when their natural sexual needs are not fulfilled.

Furthermore, taking a shower after sexual intercourse is regarded as obligatory in Islam, but these women found it hard to fulfill the obligation of showering after sexual intercourse, due to a lack of energy and fatigue, therefore they were hesitant for sexual activity. Similar issues were identified in another study including 19 participants receiving haemodialysis in Turkey (Keskin & Şentürk, 2022).

One of the worries held by the women in this study was fear of getting pregnant while on haemodialysis therapy, and the potential threats that pregnancy might pose to their health and the health of their newborn. These findings complement previous studies in which participants mentioned concerns about the health of an unborn child after suffering from kidney disease (Álvarez-Villarreal et al., 2021; Tong et al., 2015). Moreover, the physiological changes that occur during pregnancy can put additional strain on the kidneys, potentially exacerbating the complications associated with kidney disease (ML et al., 2018). This fear of pregnancy-related complications and the potential harm that can arise may lead to a reluctance or avoidance of sexual activity.

There is a high risk of hepatitis infection among haemodialysis patients in Pakistan as a result of poor vascular access, blood transfusions, and emergency dialysis, negatively impacting the quality of their marital relationships (Akhtar et al., 2020; Hussain et al., 2019). In the current study, women who got infected with hepatitis infection faced reluctance from their husbands for sexual intercourse, due to their fear of being infected by hepatitis. This fear of potential transmission of disease significantly

impacted the sexual and emotional well-being of both partners. As there are no SRH counselling services available to help couples to continue their safe intimate relationships. Moreover, these findings are supported by a qualitative study by Jin et al. (2022), conducted in Australia on Chinese immigrants infected with a viral infection. In this study, the participants' experiences revealed that their partners reduced their sexual intimacy due to the fear of being infected. Likewise, a study conducted in Rawalpindi, Islamabad Pakistan reported that 51% of the participants' marital lives had been affected after getting infected by hepatitis and 81 % reported that their spouses avoided sexual intercourse altogether after the hepatitis infection (Rafique et al., 2014). Ultimately, all of these fears and uncertainties can contribute to anxiety and apprehension, resulting in a diminished desire for sexual intimacy.

According to the findings of the present study, women undergoing haemodialysis faced numerous challenges in their sexual lives, resulting in a shift in their daily lives and a lifestyle change. The findings are supported by previous research findings indicating that there are recurring aspects of haemodialysis treatment that an individual finds difficult to deal with and, as a result, adopts a variety of coping mechanisms (Sharma et al., 2019). In this study, participants mentioned coping mechanisms such as focusing on their physical attractiveness and developing acceptance of daily life. A Danish study involving couples, one of whom was receiving haemodialysis, also reported similar findings, in which the participants talked about their mental coping mechanisms by accepting their daily lives, even though their lives had evolved differently than they had anticipated (Frandsen et al., 2020).

After being unable to maintain the sexual relationship or to conceive a child, the participants in this study accepted the change in their marital lives by allowing their spouses to take a second wife to fulfil their sexual needs and to give birth to children. These findings align with the findings of Alinejad Mofrad et al. (2021), who discovered that women having gynecological cancer accepted a second marriage for their husbands due to their own decreased sexual desire. The reason for deciding on a second marriage is that in the Muslim culture sexual expression is considered appropriate only after marriage and extramarital affairs are not considered appropriate (Al-Kawthari, 2020).

Unlike previous studies, most participants in the current study reported no sexual or body image issues related to vascular access (Gucer & Kantarci, 2020; Marki et al., 2023; Silva et al., 2017). They also stated that they only took care of their fistula and kept their arm on one side, but not a single participant mentioned that vascular access interfered with their body image and, consequently, sexual life. This could be because women in the Pakistani culture cover their bodies completely, as a sign of modesty, therefore, vascular access did not interfere with their body image (Mohsin & Syed, 2021).

Vitality of Unwavering Spouse Support

Spousal support during chronic illness was considered vital for maintaining SRH as well as the bonding of married couples. The participants stated that the support and understanding of their spouse had a significant impact on their ability to navigate the challenges and maintain a fulfilling intimate relationship. These findings are consistent with a study conducted on rural women with urinary incontinence (Spring et al., 2011). Moreover, the participants also expressed that their husbands understood their illness and planned sexual relationships according to their health condition. These findings are in

line with a study conducted in Thailand on Muslim women undergoing haemodialysis, in which participants stated that their husbands showed compassion and understanding in maintaining their sexual lives (Kantaporn et al., 2022a).

Similar findings were reported in other chronic health conditions, such as a study conducted in Iran to assess the sexual health needs of women with spinal cord injuries found that (98.7%) of participants required spousal mental and physical support to maintain their SRH (Akhavan Amjadi et al., 2022). Furthermore, the participants believed that their life could be worse if they would not have their husband's support during this time of their illness. In the literature, no findings could be found in which participants expressed such experience of life without husbands as a living hell. However, the reason could be strong couple bonds, as the literature suggests that Muslim women have strong bonds with their husbands and do not feel complete without them (Haghi et al., 2018). In brief, understanding and empathy from a spouse can help women undergoing haemodialysis cope with anxiety, depression, and feelings of inadequacy, which can affect sexual well-being.

Need for Culturally Sensitive SRH Education by HCPs

One of the big challenges for reproductive-age women undergoing haemodialysis in maintaining their SRH, as identified in this study, is a lack of knowledge regarding SRH. An international study also found that a small percentage of HCPs discussed SRH with women undergoing haemodialysis (Ramesh et al., 2017). Due to a lack of knowledge regarding SRH, these women were not aware of the use of contraceptives, which was the reason for unintended pregnancy among these women. These findings corroborate with previous studies (Agarwal & Pavlakis, 2021; Shah et al., 2020).

Another significant cultural barrier identified by participants, as a cause of lack of awareness, was the male doctors with whom the women undergoing haemodialysis were uncomfortable discussing the SRH subject. In many cultures, discussions around sexual health and intimacy are often considered private and sensitive, making it challenging for women to openly address their concerns with male doctors. In the current study, a participant mentioned that SRH was a private matter and they could not discuss it with everyone. These findings are consistent with the findings of an Australian study on young Muslim women, in which they expressed concern about being unable to discuss their SRH concerns with male doctors and this lack of communication, due to cultural barriers, led to inadequate knowledge and understanding of the SRH needs of women undergoing haemodialysis, which further exacerbated the challenges they faced (Meldrum et al., 2016).

Given that participants in the current study were uncomfortable discussing SRH with male doctors, they suggested that nephrology nurses be the appropriate HCPs for SRH counselling, within the dialysis units. They also reasoned that because nephrology nurses are professionally trained and have accurate knowledge about the subject of SRH, they should initiate a discussion with the women about their SRH concerns and advise them on how to maintain sexual relationships in their marital lives, while avoiding unintended pregnancy. These recommendations coincide with those made by participants in an Ecuadorian phenomenological study, in which kidney transplant recipients demanded open communication about their SRH by HCPs, citing the fact that HCPs are trained and can provide better guidance (Abarca-Durán et al., 2021).

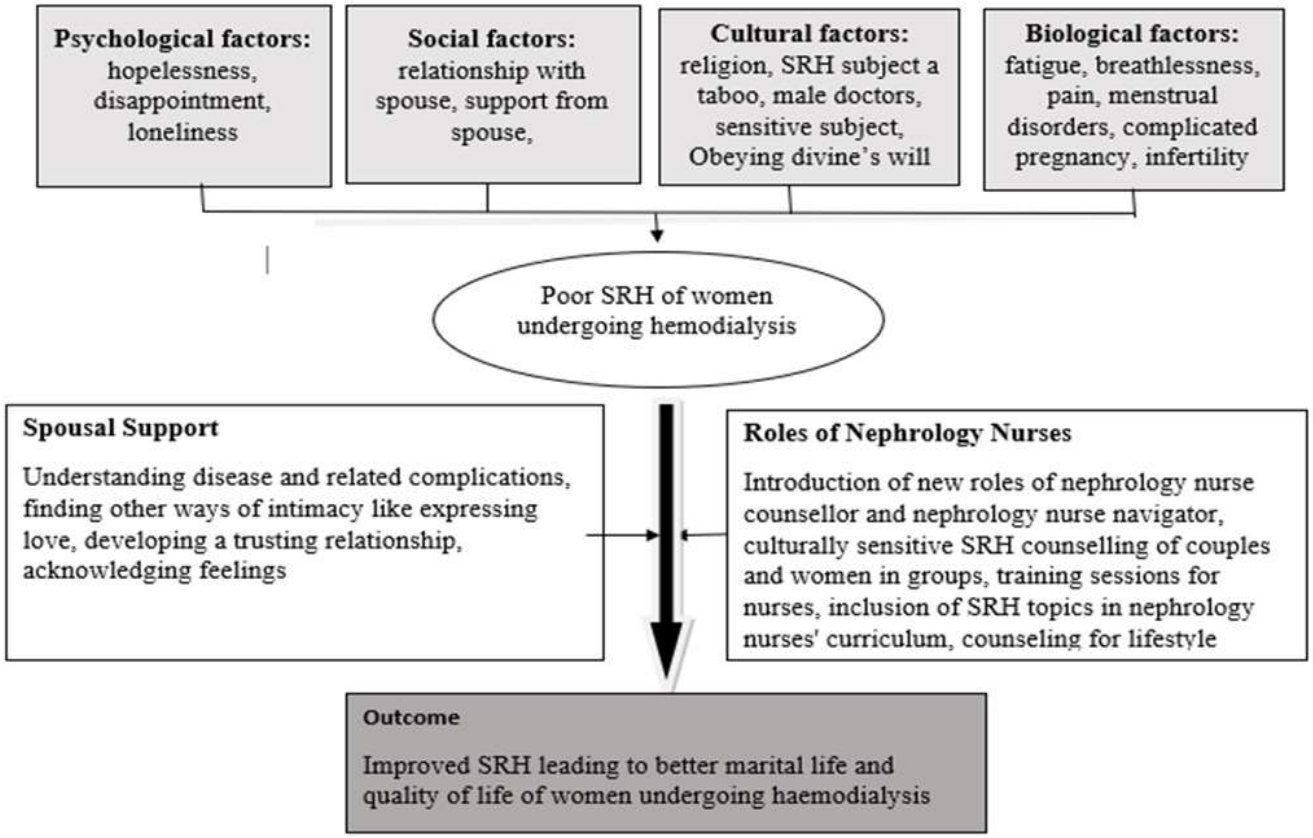
The Bio-psycho-social Model and Fundamental Structure of SRH Phenomenon among Women Undergoing Haemodialysis

According to the study findings, it was found that the phenomenon of SRH among women undergoing haemodialysis is influenced by a combination of bio-psycho-social factors; biological factors include hormonal imbalance, poor health, lack of energy and fatigue, natural needs; psychological factors include hopelessness and disappointment, feelings of guilt; and sociocultural factors include religion, culture, marital relationships, couple dynamics, and reproduction, which are all centred on sexuality (Refer to Fig 2). It is evident in the literature that sexual expressions and manifestations are bio-psycho-social constructs (Rao et al., 2022). Moreover, the findings in this study revealed that the sexual lives of married women undergoing haemodialysis were largely influenced by their religious beliefs, as they considered maintaining sexual relationships with their husbands as Allah's command. When considered collectively, these findings serve as a reminder that the bio-psycho-social approach is essential for comprehending SRH issues in women receiving haemodialysis (Thomas & Thurston, 2016).

The fundamental structure of the phenomenon of SRH has revealed two important factors as playing a critical role in improving SRH in women undergoing haemodialysis. The first is spousal support, which has aided these women's sexual lives, and includes expressing intimacy through love, acknowledging feelings, and building trust. Another factor is the requirement for nephrology nurses to take on new roles in healthcare settings as nephrology nurse navigator and nephrology nurse counsellor.

Figure 2

Fundamental Structure of Phenomenon of SRH among Women Undergoing Haemodialysis



Strengths of the Study

This is the first phenomenological study which has explored the lived experiences regarding SRH of reproductive-age women undergoing haemodialysis in Pakistan as previously three quantitative studies have been conducted in Pakistan to assess the sexual dysfunction among women receiving haemodialysis (Rahman et al., 2023; Shah et al., 2022; Yaqoob et al., 2020). Additionally, this study has revealed that sexuality is considered important in the marital lives of women undergoing haemodialysis, therefore, these findings can inform renal services and healthcare staff about the value of SRH education and support for reproductive age women undergoing haemodialysis. Moreover,

the study has indicated that spousal support is vital in improving the quality of life which indicates the need for couple counselling by the renal team.

Limitations

This study included only women undergoing haemodialysis but for a more thorough examination of the effects of haemodialysis on the SRH of married couples one of whom is receiving haemodialysis, the experiences of both partners could be explored as it is crucial to take the patients' partners' viewpoints into account also. This can be another study in future but the current study has focused only on married reproductive age women. As participants were from a single haemodialysis unit and interviews were conducted in the Urdu, language so participants who spoke other languages like Pushto and Sindhi were not interviewed. Furthermore, because the current study used a descriptive phenomenological approach, and was conducted on a small sample size the findings cannot be generalized to the entire population of women receiving haemodialysis. They are, nevertheless, most likely applicable to other contexts with similar characteristics.

Recommendations

Clinical Practice and Policy

- To address SRH challenges due to a lack of awareness, nephrology nurses can initiate counselling sessions of women both in groups and individual settings, to enable women to openly share their SRH issues.
- The development and implementation of gender and culturally appropriate educational tools and resources for effectively addressing this essential component of women's well-being.

- The fear of pregnancy was hindering sexual relationships, thus guiding these women to proper contraceptive information and exploring alternative ways to maintain intimate relationships can enhance the quality of their marital life.
- Findings of the study suggested that nephrology nurses have to work on additional tasks as nephrology nurse navigator and nephrology nurse counsellor. The nephrology nurses who are already working in the dialysis units can work on these tasks after training.

Education

- Findings of current suggest the conduction of regular training workshops for nephrology nurses and doctors to improve their sexual health communication skills. These workshops will facilitate them to start conversations on the sensitive topic of SRH while respecting the cultural norms and personal preferences of the clients.
- It is important to introduce the sensitive topic of SRH in the Nephro-Urology nursing curriculum to develop competencies of nephrology nurses to address client SRH issues.

Research

- As this study focused on the SRH experiences of women undergoing haemodialysis the experience of their male spouses and males undergoing haemodialysis needs to be explored.

- After introducing the roles of nephrology nurse navigator and nephrology nurse counsellor as a pilot project, the effectiveness of these roles should be determined which can be a randomized control trial afterwards.
- In this study, the experiences of women undergoing haemodialysis revealed a lack of discussion about SRH by HCP, therefore the perspective of renal care team needs to be explored to determine the challenges faced by them while discussing SRH subject.
- As spousal support was found to be an important factor in maintaining marital ties, correlational studies can be carried out to determine the relationship of spousal support with marital and sexual life satisfaction among women undergoing haemodialysis.

Reflection

Before beginning this study, the researcher was very excited to investigate the phenomenon of SRH, which was of particular interest to the researcher. However, while collecting data, the researcher encountered a challenge. It was difficult to get the participants to understand the literary meaning of sexual (Jinsi) and reproductive health (Tolidi). For better understanding of the participants, the researcher used various contextual and culturally appropriate words such as *Milap, humbistri,* and *Mian bivi ka taluq,* which allowed the participants to understand and discuss comfortably. However, it was observed by the researcher that a few participants avoided eye contact while talking about sexuality matters but most women were confident during the interview. They shared their experiences and appreciated that someone talked to them about a health issue that no one had discussed before.

Conclusion of the Study

This descriptive phenomenological study concluded that sexuality was valued by women undergoing haemodialysis as a relationship of love, trust, acknowledging feelings, and embracing the Divine's will. They view SRH and marital life as synonymous. However, insufficient SRH awareness, poor health, fatigue, and a few fears hindered women undergoing haemodialysis from maintaining sexual relationships. In response to these barriers, their marital lives suffered greatly, and they modified their lives by strengthening themselves. SRH awareness by HCPs, particularly nephrology nurses, can however, improve their lives. The husband's supportive attitude can also help to strengthen marital ties and foster intimate relationships.

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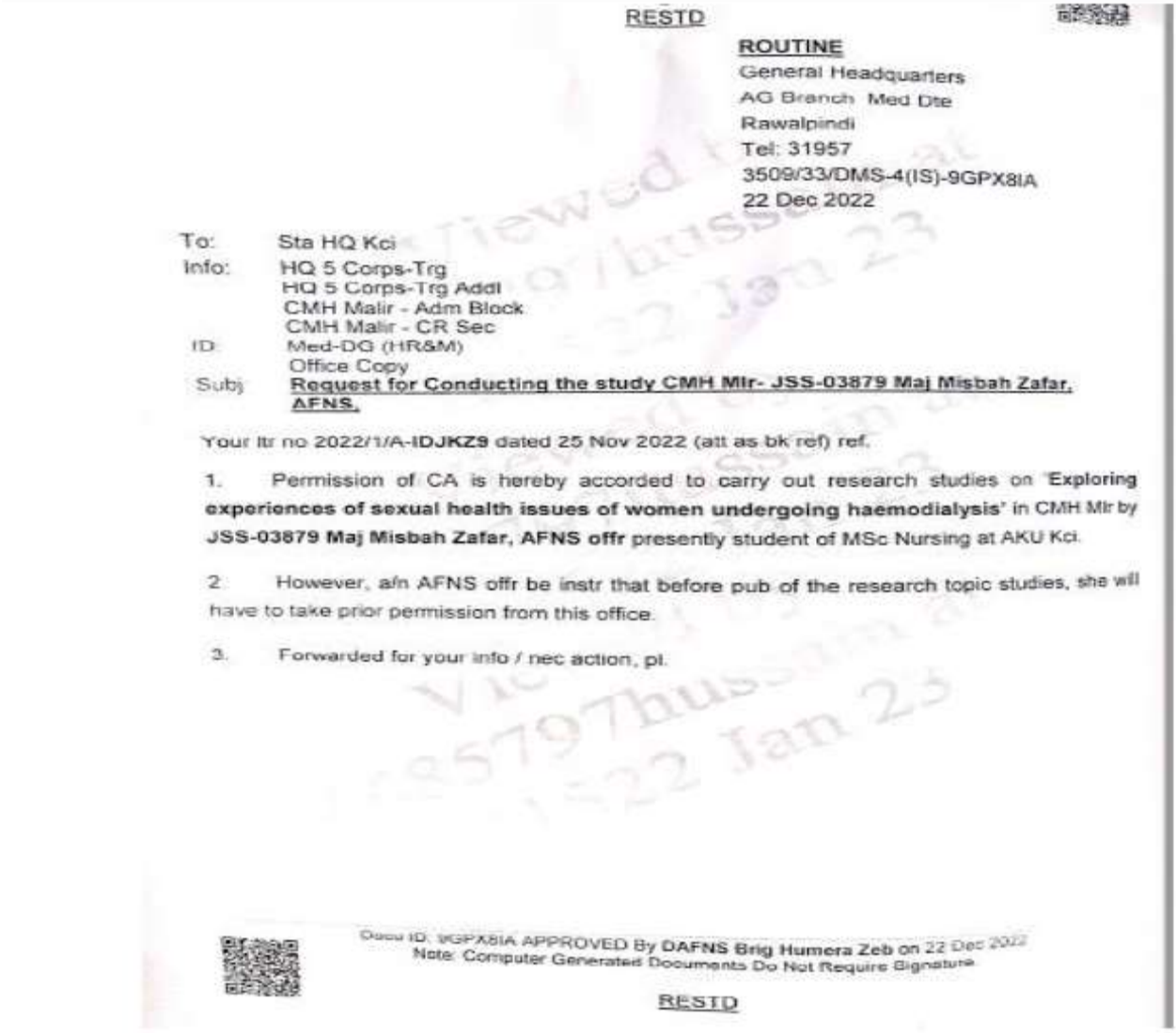
Appendix A

Institutional Permission Letter



RESTD

ROUTINE
General Headquarters
AG Branch Med Dte
Rawalpindi
Tel: 31957
3509/33/DMS-4(IS)-9GPX8IA
22 Dec 2022

To: Sta HQ Kci
Info: HQ 5 Corps-Trg
HQ 5 Corps-Trg Addl
CMH Malir - Adm Block
CMH Malir - CR Sec
ID: Med-DG (HR&M)
Office Copy
Subj: **Request for Conducting the study CMH Mlr- JSS-03879 Maj Misbah Zafar, AFNS.**

Your ltr no 2022/1/A-**IDJKZ9** dated 25 Nov 2022 (att as bk ref) ref.

1. Permission of CA is hereby accorded to carry out research studies on '**Exploring experiences of sexual health issues of women undergoing haemodialysis**' in CMH Mlr by **JSS-03879 Maj Misbah Zafar, AFNS offr** presently student of MSc Nursing at AKU Kci.

2. However, a/n AFNS offr be instr that before pub of the research topic studies, she will have to take prior permission from this office.

3. Forwarded for your info / nec action, pl.

Docu ID: 9GPX8IA APPROVED By **DAFNS Brig Humera Zeb** on 22 Dec 2022
Note: Computer Generated Documents Do Not Require Signature

RESTD

Appendix B

AKU ERC Permission Letter

آغا خان یونیورسٹی
THE AGA KHAN UNIVERSITY

14-Mar-2023

Dr. Rafat Jan
Department of School of Nursing and Midwifery
Aga Khan University
Karachi

Dear Dr. Rafat Jan,

2023-8444-24319, Rafat Jan: Experiences of Sexual and Reproductive Health among Women undergoing Hemodialysis in Pakistan

Thank you for submitting your application for ethical approval regarding the above mentioned study.

Your study was reviewed and discussed in ERC meeting. There were no major ethical issues. The study was given an approval for a period of one year with effect from 14-Mar-2023. For further extension a request must be submitted along with the annual report.

List of document(s) approved with this submission.

Submission Document Name	Submission Document Date	Submission Document Version
NIDA Dr. Rafat Jan	03-Mar-2017	5
CITI Mohsh	28-May-2022	BCR
NIDA Dr. Salma Rathore	03-Mar-2017	5
Sajida certificate	03-Mar-2017	5
Study guide English appendix E	05-Jan-2023	1
Appendix F تحقیقی مطالعے کا عنوان	05-Jan-2023	1
Institutional Approval letter Appendix A	22-Dec-2022	1
Demographic information sheet Appendix D	05-Jan-2023	1
Consent Form ENG Appendix B	05-Jan-2023	1
Affidavit for translation	05-Jan-2023	1.7
Demographic Information Sheet URDU Appendix G	05-Jan-2023	1
Consent Form URDU Appendix C	05-Jan-2023	1
ERC Response Sheet	08-Mar-2023	1
qualitative proposal Version 2	08-Mar-2023	2

Any changes in the protocol or extension in the period of study should be notified to the Committee for prior approval. All informed consents should be retained for future reference.

Please ensure that all the national and institutional requirements are met.

Thank you.

Sincerely,

Appendix C

Informed Consent English

Project Title: Experiences of Sexual and Reproductive Health among Women undergoing Haemodialysis in Pakistan	ERC Num: 2023-8444
Supervisor: Dr. Rafat Jan Professor AKUSONAM	**Contact details**:0321-2422661 Email: rafat.jan@aku.edu
Committee members: Dr. Salma Rattani–Associate Professor at AKUSONAM Email: salma.rattani@aku.edu Miss Sajida Chagani– Senior Instructor AKUSONAM, Pakistan Email: sajida.chagani@aku.edu	
Investigator: Misbah Zafar	**Contact details**: 0302-8494288 misbah.zafar@scholar.aku.edu
Location of study: Combined Military Hospital Malir	**Sponsorship/ Financial benefits:** Nil

"I am Misbah Zafar from the Aga Khan University, Department of Students of Nursing and

Midwifery (SONAM) and researching the “Experiences of Sexual Health Issues of Women undergoing Haemodialysis in Pakistan”. I would like to invite you to this study.

Purpose of this Research Study

You are being asked to participate in a research study designed to explore the “Experiences of Sexual and Reproductive Health among Women undergoing Haemodialysis in Pakistan”. So, keeping in view the impact of the issue, this study will highlight an underappreciated aspect of haemodialysis women and the findings of this study would help to strengthen marital relationships and quality of life by promoting the sexual and reproductive health of women undergoing haemodialysis.

Procedures

This is a one-time study; participants have to give interviews for 30 to 40 minutes which will be tape-recorded. If you are willing to participate, I request that you kindly sign this written consent form. The interview will be carried out as per your preference of language, i.e., English or Urdu, and it will be your wish to answer in English or Urdu. The interview will be carried out at the convenience and comfort level of the participants. It will last approximately 30-40 minutes

Possible Risks or Discomfort

The study is confined to academic purposes. There is no direct benefit to participants. However, participants’ contributions will help to generate knowledge in this area of research. Measures will be taken to ensure participant comfort at every level, although no direct or indirect risks are associated with participation. The interview will be conducted according to the participants' convenience and comfort level.

Financial Considerations

There is no financial compensation for your participation in this research.

Confidentiality

Your identity in this study will be treated as confidential. The results of the study, including other data, may be published for scientific purposes but will not give your name or include any identifiable references to you. “However, any records or data obtained as a result of your participation in this study may be inspected by the ethics review committee of Aga Khan University”.

Right to Refuse or Withdraw

You are free to choose whether to participate in this study. There will be no penalty or loss of benefits to which you are otherwise entitled if you choose not to participate. You will be provided with any significant new findings developed during this study that may relate to or influence your willingness to continue participation. In the event, you decide to discontinue your participation in the study.

Available Sources of Information

In case of further questions or queries about the study, or the consent form, you may contact the research investigator (myself) Misbah Zafar, **Contact details**: 0302-8494288

misbah.zafar@scholar.aku.edu

Authorization

I have read and understand this consent form, and I volunteer to participate in this research study. I understand that I will receive a copy of this form. I voluntarily choose to participate, but I understand that my consent does not take away any legal rights in the case of negligence or another legal fault of anyone who is in or involved in this study.

Name of participant (Printed or Typed): _____

Date: _____

Signature of participant: _____

Date: _____

Signature of Principal Investigator: _____

Date: _____

Name and Signature of the person obtaining consent if other than PI: _____

Date: _____

For Participants unable to read

Witness:

I have witnessed the accurate reading of the consent form to the potential participants, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Witness Name: _____ Participant's Thumb Print: _____

Signature: _____

Date: _____

Appendix D

Consent Form Urdu

ERC نمبر: 8444	**پروجیکٹ کا عنوان:** پاکستان میں ہیموڈائلیسس سے گزرنے والی خواتین میں جنسی اور تولیدی صحت کے تجربات
ڈاکٹر رفعت **سپروائزر:** جان پروفیسر آغا خان یونیورسٹی اور ہسپتال کراچی	**رابطے کی تفصیلات:** 03212422661 Email: rafat.jan@aku.edu
مصباح ظفر **تفتیش کار:**	**رابطے کی تفصیلات:** 03028494288 misbahzafar81@hotmai l.com
کمیٹی کے ارکان:	

ڈاکٹر سلمیٰ رتانی

ایسوسی ایٹ پروفیسرآغا خان یونیورسٹی، کراچی

Email: salma.rattani@aku.edu

ا آغا خان یونیورسٹی، کراچی –مس ساجدہ چغانی، سینئر انسٹرکٹر

Email: Sajida.chagani@aku.edu

اسپانسرشپ/مالی فوائد: کوئی نہیں۔	کمبائنڈ ملٹری ہسپتال **:مطالعہ کا مقام** ملیر

.سے مصباح ظفر ہوں)سونم (میں آغا خان یونیورسٹی، شعبہ نرسنگ اینڈ مڈوائفری

پاکستان میں ہیموڈائلیسس سے گزرنے والی خواتین کی کی جنسی اور تولیدی صحت کے "اور

پر تحقیق کر رہی ہوں۔ میں آپ کو اس مطالعہ میں مدعو کر رہی ہوں "تجربات

اس تحقیقی مطالعہ کا مقصد

پاکستان میں "آپ کو ایک تحقیقی مطالعے میں حصہ لینے کے لئے کہا جا رہا ہے جو

کو تلاش "ہیموڈائلیسس سے گزرنے والی خواتین میں جنسی اور تولیدی صحت کے تجربات

لہٰذا، اس مسئلے کے اثرات کو مدنظر رکھتے ہوئے، یہ .کرنے کے لئے ڈیزائن کیا گیا ہے

مطالعہ ہیموڈائلیسس خواتین کے ایک غیر معمولی پہلو کو اجاگر کرے گا اور اس مطالعے کے نتائج ہیموڈائلیسس سے گزرنے والی خواتین کی جنسی اور تولیدی صحت کو فروغ دے کر ازدواجی تعلقات اور معیار زندگی کو مضبوط بنانے میں مدد کریں گے

طریقہ کار

یہ ایک بار کا مطالعہ ہے؛ شرکاء کو 30 سے 40 منٹ تک انٹرویو دینا ہوگا جو ٹیپ ریکارڈ کیا جائے گا۔ اگر آپ شرکت کرنا چاہتے ہیں، تو میں درخواست کرتا ہوں کہ آپ برائے مہربانی اس تحریری رضامندی کے فارم پر دستخط کریں۔ انٹرویو آپ کی زبان کی ترجیح کے مطابق لیا جائے گا، یعنی انگریزی یا اردو، اور آپ کی مرضی ہوگی کہ آپ انگریزی یا اردو میں جواب دیں۔ انٹرویو آپ کی سہولت کے وقت اور دستیابی پر کیا جائے گا

مطالعہ صرف تعلیمی مقاصد تک محدود ہے۔ شرکاء کو براہ راست کوئی فائدہ نہیں ہے۔ تاہم، شرکاء کے تعاون سے تحقیق کے اس شعبے میں علم پیدا کرنے میں مدد ملے گی۔ ہر ممکن سطح پر شرکاء کے آرام کو یقینی بنانے کے لیے اقدامات کیے جائیں گے، حالانکہ شرکت سے متعلق کوئی براہ راست یا بالواسطہ خطرہ نہیں ہے۔ ڈیٹا اکٹھا کرنے کا کام شرکاء کی سہولت اور آرام کی سطح کے مطابق کیا جائے گا۔

مالی تحفظات

اس تحقیق میں آپ کی شرکت کے لیے کوئی مالی معاوضہ نہیں ہے۔

رازداری

اس مطالعہ میں آپ کی شناخت کو خفیہ تصور کیا جائے گا۔ مطالعہ کے نتائج، بشمول دیگر ڈیٹا، سائنسی مقاصد کے لیے شائع کیے جا سکتے ہیں. لیکن اس میں آپ کا نام یا آپ کے

لیے کوئی قابل شناخت حوالہ شامل نہیں ہوگا۔ "تاہم، اس مطالعہ میں آپ کی شرکت کے نتیجے کا معائنہ AKU ERCمیں حاصل کردہ کسی بھی ریکارڈ یا ڈیٹا کے اراکین کر سکتے ہیں"۔

انکار کا حق

آپ اس مطالعہ میں حصہ لینے کے لیے آزاد ہیں ۔ اگر آپ شرکت نہ کرنے کا انتخاب کرتے ہیں تو اس پر کوئی جرمانہ یا فوائد کا نقصان نہیں ہوگا جس کے آپ بصورت دیگر حقدار ہیں۔ آپ کو اس مطالعے کے دوران پیدا ہونے والی کوئی بھی اہم نئی دریافت فراہم کی جائے گی جو شرکت جاری رکھنے کی آپ کی رضامندی سے متعلق یا متاثر ہو سکتی ہیں۔ اس صورت میں، آپ مطالعہ میں اپنی شرکت بند کرنے کا فیصلہ کرتے ہیں

انکار کرنے یا واپس لینے کا حق

کہ آیا اس مطالعہ میں حصہ لینا ہے یا نہیں۔ .آپ یہ انتخاب کرنے کے لئے آزاد ہیں

اگر آپ حصہ نہ لینے کا انتخاب کرتے ہیں تو کوئی جرمانہ یا فوائد کا نقصان نہیں ہوگا جس کے آپ دوسری صورت میں حقدار ہیں۔ آپ کو اس مطالعہ کے دوران تیار کردہ کسی بھی اہم جو شرکت جاری رکھنے کے لئے آپ کی رضامندی .نئے نتائج کے ساتھ فراہم کیا جائے گا

اس صورت میں، آپ مطالعہ میں اپنی شرکت کو بند کرنے .سے متعلق یا اثر انداز ہوسکتا ہے

کا فیصلہ کرتے ہیں

معلومات کے دستیاب ذرائع

مطالعہ، یا رضامندی فارم کے بارے میں مزید سوالات یا سوالات کی صورت میں، آپ

:مصباح ظفر سے رابطہ کرسکتے ہیں، رابطہ کی تفصیلات (خود)ریسرچ انویسٹی گیٹر

03028494288

misbah.zafar@scholar.aku.edu

اجازت دینا

میں نے رضامندی کے اس فارم کو پڑھ اور سمجھ لیا ہے، اور میں اس تحقیقی مطالعہ میں حصہ لینے کے لیے رضاکارانہ طور پر تیار ہوں۔ میں سمجھتا ہوں کہ مجھے اس فارم کی ایک کاپی مل جائے گی۔ میں رضاکارانہ طور پر حصہ لینے کا انتخاب کرتا ہوں، لیکن میں سمجھتا ہوں کہ میری رضامندی اس مطالعے میں شامل کسی بھی شخص کی غفلت یا کسی اور قانونی غلطی کی صورت میں کوئی قانونی حق نہیں چھینتی ہے۔

حصہ لینے والے کا نام (مطبوعہ یا ٹائپ شدہ):_____

دستخط:_____ تاریخ:_____

پرنسپل تفتیش کار کے دستخط:_____ تاریخ:_____

رضامندی حاصل کرنے والے شخص کا نام اور دستخط:_____

تاریخ:_____

پڑھنے سے قاصر شرکاء کے لیے

گواہ:

میں نے ممکنہ شرکاء کو رضامندی کے فارم کو درست پڑھتے ہوئے دیکھا ہے، اور فرد کو سوالات پوچھنے کا موقع ملا ہے۔ میں تصدیق کرتا ہوں کہ فرد نے آزادانہ طور پر رضامندی دی ہے۔

گواہ کا نام: _____

حصہ لینے والے کے انگوٹھے کا نشان:_____

دستخط: _____ تاریخ:

_____

Appendix E

Demographic Information Sheet English

Title of the Research Study

"Experiences of Sexual and Reproductive Health among women undergoing Haemodialysis in Pakistan"

Date: _____

Demographic Data:

Age: _____

Years of receiving dialysis therapy: _____

Years of marriage: _____ Profession_____

Number of children: _____

Religion: Muslim_____Christian _____Other_____

Education Status:

No Formal Education: _____ Primary: _____

Middle: _____ Matric: _____

Intermediate: _____ Graduation: _____ Master: _____

PhD: _____ Others _____

Appendix F

Demographic Information Sheet Urdu

تحقیقی مطالعے کا عنوان:

پاکستان میں ہیموڈائیلسس سے گزرنے والی خواتین کے جنسی اور تولیدی صحت کے تجربات

شماریاتی معلومات

تاریخ: _____

شماریاتی معلومات:

عمر: _____

ڈائیلسس حاصل کرتےہوئے کتنے سال: _____

شادی کو کتنے سال ہوئے: _____ بچوں کی تعداد: _____

مذہب: _____ مسلمان _____عیسائی _____ کوئی

اور_____

تعلیمی معیار:

ابتدائی: _____ مڈل: _____ میٹرک: _____ انٹرمیڈیٹ: _____

گریجویٹ: _____ ماسٹرز: _____ پی ایچ ڈی: _____ کوئی اور:

_____

Appendix G

Interview Guide English

Title: “Experiences of Sexual and Reproductive Health among Women undergoing Haemodialysis in Pakistan”

1. What is the significance of a husband-and-wife relationship in your perspective based on your marital experience?
2. What is the importance of sexuality in your life?
3. What are your experiences of sexual and reproductive health after starting haemodialysis and what difference have experienced in your sexual life before and after haemodialysis therapy?
4. What is the impact of your sexual and reproductive health experiences on your marital relationship after starting dialysis?
5. What kind of difficulties are you facing in maintaining an intimate relationship with your husband?
6. What kind of difficulties are you facing in your sexual life due to your arteriovenous fistula or permanent catheter?
7. How your sexual and reproductive health experiences are impacting your quality of life?
8. What kind of sexual and reproductive health education have you received from the nephrology department (Doctors and nurses)? and what concerns do you think nephrology nurses should address regarding the sexual and reproductive health of haemodialysis women? Would you like to add something?

Appendix H

Interview Guide Urdu

نیم ساختہ انٹرویو گائیڈ

1	آپ کے ازدواجی تجربے کی بنیاد پر آپ کے نقطہ نظر میں شوہر اور بیوی کے تعلقات کی کیا اہمیت ہے؟
2	آپ کی زندگی میں جنسیت کی کیا اہمیت ہے؟
3	ہیموڈائلیسس شروع کرنے کے بعد آپ کی جنسی اور تولیدی صحت کے تجربات کیا ہیں اور ہیموڈائلیسس تھراپی سے پہلے اور بعد میں آپ کی جنسی زندگی میں کیا فرق پڑا ہے
4	ڈائیلاسز شروع کرنے کے بعد آپ کے ازدواجی تعلقات پر آپ کے جنسی اور تولیدی صحت کے تجربات کا کیا اثر پڑ رہا ہے؟
5	آپ کو اپنے شوہر کے ساتھ قریبی تعلقات برقرار رکھنے میں کس قسم کی مشکلات کا سامنا کرنا پڑ رہا ہے؟
6	آپ کو اپنی جنسی زندگی میں آئیڈیوپیتھک فسٹولا یا مستقل کیتھیٹر کی وجہ سے کس قسم کی مشکلات کا سامنا کرنا پڑ رہا ہے؟
7	آپ کے جنسی اور تولیدی صحت کے تجربات آپ کے معیار زندگی کو کس طرح متاثر کر رہے ہیں؟
8	آپ نے نیفرولوجی ڈپارٹمنٹ)ڈاکٹروں اور نرسوں (سے کس قسم کی جنسی اور تولیدی صحت کی تعلیم حاصل کی ہے؟ اور آپ کے خیال میں نیفرولوجی نرسوں کو ہیموڈائلیسس خواتین کی جنسی اور تولیدی صحت کے بارے میں کون سے خدشات کو دور کرنا چاہئے؟ کیا آپ مزید کچھ کہنا چاہیں گے؟

Appendix I

Entitlement Certificate

ENTITLEMENT CERTIFICATE

Certified that all officer, Junior Commissioned Officer, Soldiers and their families (parents, wife and children) of Pakistan Army are **entitled for free medical treatment in Military Hospitals** according to **Regulation for Medical Services (RMS) 1978 Vol-I, Annex E to Rule 33.**

Major
For Commanding Officer
(Muzaffar Mehdi)

Appendix J

Literature Review Data Extraction Sheet

	Author (s) Name, year of publication, country	Purpose of Study	Sample size	Study Design	Key Findings
1	Abott et al., 2016, USA	Determine whether women's sexual self-esteem is influenced by their religious commitment.	196	Quantitative	Women who were more devoutly religious reported having lower sexual esteem.
2	Aling et al., 2021	Identify barriers for nurses in talking about sexual health and sexuality	NA	Scoping review	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 to discussing sexuality with patients.
3	Alshalleh et al., 2022, Jordan	Determine the prevalence of anxiety, depression, and quality of life perceptions among patients	103	Quantitative, cross-sectional	Depression and anxiety are present in 58.3% and 50.5% of patients with kidney disease, respectively. A negative correlation was reported between anxiety and quality of life.

		with renal disease.			
4	Álvarez-Villarreal et al., 2019, Spain	Analyze the body changes and sexual experiences of female CKD patients at an ambulatory dialysis centre.	18 women	Qualitative phenomenological	Women undergoing hemodialysis had disturbed body image due to their feeling of being deformed and bloated as a result of their oedema. They perceived themselves as less sexually attractive as a result of this disturbed body image, which affected their sexual life. Individuals on dialysis were occasionally extremely thin, due to excessive ultra-filtration and weight loss, which also affected their body image.
5	Bossola et al., 2018, Italy	To examine symptoms severity of hemodialysis patients having fatigue and no fatigue	137	Quantitative	76.6% of fatigued hemodialysis patients reported having trouble getting sexually aroused.
6	Cousin et al., 2020	Investigate how nephrology practitioners develop and sustain a professional rapport with	NA	Review	When working with patients, nephrology clinicians displayed sophisticated communication abilities as well as compassion and empathy, which appeared to be factors in the satisfaction of patients.

		those receiving hemodialysis.			
7	Cruz et al., 2022, Brazil	Examine the relationship between hemodialysis patients' quality of life, sexual function, and depressive symptoms.	54	Quantitative, cross-sectional	It was discovered that women's sexual function and depressive symptoms were correlated negatively. The sexual function of hemodialysis women was positively associated with the quality of life in areas of satisfaction, sleep, and general health.
8	Debnath et al., 2021, United State of America	Describe and contrast the degree to which fatigue interferes with daily activities on dialysis days and non-dialysis days	115	Quantitative	Fatigue levels were considerably higher on a dialysis day (5.35 ± 2.50) in comparison to a non-dialysis day (3.47 ± 2.85). These patients were unable to be sexually active because of a lack of energy and the body's need for rest
9	Dikici et al., 2014, Duzce Turkey	Examine how the sexual function of ESRD patients with RLS is affected by anxiety and sleepiness.	246 (Male 124, females 122)	Quantitative, correlational	The Arizona Sexual Experiences Scale (ASEX) and sociodemographic characteristics showed a significant correlation (P 0.0001). Patients with restless leg syndrome were more likely to have sexual dysfunction (24.6 5.7) than patients without restless leg syndrome (22.5 6.8).

10	EI Monem & Salim, 2020, Turkey	investigate the impact of nursing guidelines on boosting sexual function and quality of life among women undergoing hemodialysis.	50	Quasi-experimental	The researcher trained the interventional group to perform different exercises for strengthening pelvic muscles to relieve pelvic pain, for example, Kegel exercises (helping them to relax their pelvic floor muscles) to improve sexual functioning. After this intervention, it was noticed that the quality of life of these women had increased from an average pre-intervention total quality of life score of 28.33 to 36.73, after the application of the nursing guidelines as an intervention
11	George et al., 2017, Cameroon	Assess the sexual health of Cameroonian hemodialysis patients.	139	Quantitative, Cross-sectional	Since starting dialysis, four women (7.84%) have reported being pregnant, and all of them experienced an early spontaneous abortion. One-third of the women receiving hemodialysis had irregular menstrual cycles. In 43% of women, there was a wish for children. The fear of worsening asthenia prevents them from having sexual relations

12	Jain et al., 2019, USA	Assessment of available data concerning the selection of RRT	NA	Review article	In the United States, hemodialysis (HD) is preferred over peritoneal dialysis (PD) by the majority of kidney failure patients.
13	Janghorban et al., 2015, Iran	Examine married women's experiences concerning sexual activities in their intimate relationships.	35	Grounded theory	Women were engaged in sexual activity solely to preserve their marital life or to reduce the likelihood of their spouses having extramarital affairs. Due to some religious and cultural beliefs, women consider sexual activity as an obligation, to demonstrate devotion to their spouses, fulfil wifely obligations, and prioritize their husband's sexual needs over their condition
14	Kalantar Zadeh et al., 2015	Examine the prevailing dietary practices among dialysis patients and the impact of stringent dietary practices	NA	Review	Hemodialysis patients are facing many dietary restrictions which need to be modified based on individual approaches to enhance the quality of life and satisfaction
15	Kendrick et al., 2015, United State of America	Evaluating the differences between pregnant women having renal	1,556	Retrospective study	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

		disease and pregnant women not having renal disease			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 by twofold
16	Keskin et al., 2019, Turkey	Analyze how the sexual functions of dialysis patients are affected by their personality traits and psychological symptoms.	225	Quantitative, descriptive	A crucial aspect that should be considered by nurses is the sexual wellness and mental well-being of kidney disease patients. When the relationship between marital status and GRISS scores was assessed, it was discovered that there was a significant difference in dissatisfaction and infrequency (F = 5.08, p 0.05; t = 4.98, p 0.05).
17	Kim et al., 2014, South Korea	Determine the effect of dialysis adequacy on the sexual function of hemodialysis women.	73	Quantitative, cross-sectional	No relationship was found between the dialysis adequacy and sexual function of women undergoing hemodialysis
18	Kurtulus et al., 2017, Turkey	Comparing patients receiving	82	Quantitative	The percentages of female sexual dysfunction in the control, hemodialysis, and

		hemodialysis or kidney transplants with the control group in terms of sexual function and depression severity.			transplant groups were 56.7%, 89.7%, and 73.9%, respectively. In comparison to the transplant and control patients, total FSFI scores in the hemodialysis group were significantly lower (p= .05). After the transplant, FSFI scores increased.
19	Lewis & Arber, 2015, United Kingdom	Recognize the impact of physical changes on peer, intimate relationships, and parenting in young adults receiving RRT	40	Qualitative	They had a fear that their intimate partners would reject them if they saw the tubes coming out of their bodies or scars due to renal transplants. Although the women on RRT desired to have children, they were unable to maintain an intimate relationship with their partners.
20	Lin et al., 2016, China	Assess disturbances in menstruation and sex hormones in premenopausal women with impaired kidney function.	184	Quantitative, descriptive	All four treatment modalities (RT: 50%; NHD: 55%; CAPD: 72.1%; and CHD: 76.1%) had a 64.2% overall prevalence of menstrual disturbances. The NHD (25.1 10.9 ng/ml) and RT (13.4 5.1 ng/ml) groups had significantly lower serum prolactin levels than the CHD

					group (55.2 10.8 ng/ml) (p 0.01). In comparison to the CHD group, the serum progesterone levels in the NHD (25.7 8.3 nmol/l) and RT (30.1 5.9 nmol/l) groups were significantly higher (p 0.01) than those in the CHD group. In addition, compared to the other two groups, the hormonal status of the NHD and RT groups was much closer to normal in terms of follicle-stimulating hormone, luteinizing hormone, and testosterone.
21	Manjula et al., 2021, India	Explore how couples with sexual dysfunction, interact, communicate, and maintain marital quality and intimacy.	155	Quantitative, cross-sectional	Intimacy, sexual interaction, and sexual communication are all significantly correlated with marital quality.
22	Mollaioli et al., 2021, Italy	Examine sexual, emotional, and mental health using a web-based questionnaire	6,821 (male 2644, females 4,177)	Quantitative, descriptive	Subjects who were not sexually active during lockdown had a significantly greater likelihood of experiencing depression and anxiety, with odd ratios of 1.32 and 1.34 at 95% confidence intervals, when compared to

					those who did engage in sexual activity.
23	Nappi et al., 2016	Examine the available research on women's sexual dysfunction and talk about the need for further investigations to clarify the connection between sexual function and women's quality of life.	NA	Review	Throughout life, there is an association between the sexual function of women and their quality of life. Women's quality of life is negatively affected by hormonal disorders and hypoactive sexual desire.
24	Okundaye et al., 2022, USA	Review the extent and thoroughness of records of reproductive health guidance provided by nephrologists.	125	Research Letter (Retrospective chart review)	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
25	Potki et al., 2017	Evaluate various variables that affect sexual self-image	NA	Review article	Social, psychological, and biological factors were used to categorize the factors influencing sexual self-concept. Numerous life events can have an impact on an individual's sexual self-concept, so it is

					advised that health policies be implemented in an integrated manner to support sexual self-concept development.
26	Rahman et al., 2023, Lahore, Pakistan	Determine and contrast the results of the Female Sexual Functions of Dialysis (FSFI) assessment in three comparison groups: healthy individuals, those undergoing pre-dialysis, and those undergoing hemodialysis.	60	Quantitative, comparative cross-sectional s	Pre-dialysis, healthy control, and hemodialysis groups all showed a significant statistical difference. The pre-dialysis group's scores were the lowest (16.4 ± 6.8), and the healthy group's scores were the highest (29.9 ± 1.8); the hemodialysis group's scores (23.3 5.0) showed a medium pattern across all sexual domains.
27	Rasmussen et al., 2020, USA	evaluating the relationship strain and caregiver burden of partners of transplant and dialysis patients.	99	Quantitative	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%)
28	Sabanciogul	Find out the	125	Quantitati	Positive correlation between

	lari et al., 2015, Turkey	association between sexual function and "life satisfaction and perception of health" in hemodialysis pat ients		ve correlation al	sexual function and general perception of health
29	Saglimbene et al., 2017, South America, Europe	Assessment of the prevalence of decreased sexual function in women receiving hemodialysis as well as the factors that correlate with it.	659	Quantitati ve, cross-sectional	It was 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.
30	Salehei & Razaei, 2016, Iran	To evaluate the connection between ways of coping and patients undergoing hemodialysis' self-esteem	185	Quantitati ve correlation al	Hemodialysis patients with physical and psychosocial symptoms use different coping styles. Patients with high self-esteem use a problem-oriented coping style and those with low self-esteem use an emotion-oriented coping style
31	Serrat-Montaya et al., 2020, Mexico	Determine the significance of hormonal levels in young women having kidney	57	Prospectiv e cohort	52.6% of women were experiencing menstrual disturbances. Along with this, 31.5% of the women reported heavy menstrual bleeding, and 21% reported secondary

		disease and their relation to menstrual irregularities.			amenorrhea. This study found that menstrual disturbances were significantly high (p=0.01) in the group of women who had hypothyroidism and also a significant relationship (p=0.03) was found between menstrual disturbances and high levels of prolactin levels due to kidney failure
32	Shah et al., 2020, United States of America	Understand the use of contraception by women undergoing dialysis	35,732	Retrospective cohort study	Contraception use is 5.3% among women with kidney disease. There is overall an increase in the use of contraceptive
33	Shah et al., 2022, Multan, Pakistan	Determine the occurrence of sexual dysfunction in female hemodialysis patients, as well as how it relates to depression and anxiety.	55	Quantitative, correlational	Depression and sexual function have been found to have an inverse relationship. Desire and satisfaction with sexual function were both negatively correlated with depression (desire: r= -0.465, p= 0.001) and positively correlated (satisfaction: r= -0.366, p= 0.006). Although there was no discernible link between anxiety and sexual function
34	Shahdadi & Rahnama, 2018, Iran	Explain the nurses' experiences	9	Phenomenological study	The main theme found was challenging care. Then, the facilitators, barriers, results of

		providing dialysis therapy care.			mutual care, and favourable and unfavourable effects of care on patients and nurses, respectively, were also identified.
35	Soylu, 2022, Turkey	Determine the linkage between marital adjustment and quality of sexual life	211	Quantitative, cross-sectional	Statistically positive relationship (r=o.589) between the quality of sexual life and marital adjustment scale of women with irregular menstrual cycles
36	Stavroula et al., 2014	Conduct a literature review and investigate how dialysis affects the quality of life of those with CKD psychologically	NA	Review	Long-term psychological effects of CKD on dialysis patients have been reported. Chronic conditions like failing kidneys are ongoing processes because after starting dialysis patients must adjust to their new identities and lifestyles.
37	Ek, 2019 Netherland	Determining the requirements and preferences of patients and partners for sexual care and knowledge	29	Quantitative	High level of fatigue lowers sexual activity because of a lack of energy and the body's need for rest
38	Yaqoob et al., 2020, Karachi, Pakistan	Evaluate sexual function and investigate the relationship	48	Quantitative, cross-sectional study	The majority of the women (95.6%) were housewives and were postmenopausal (60.4%). About 70 % of women reported

		between sexual dysfunction, anxiety, and depression in hemodialysis women			having no sexual activity. Borderline abnormal depression has been independently linked to sexual dysfunction.
39	Yilmaz et al., 2017, Turkey	Analyze the prevalence of hypoactive sexual desire disorder in women receiving kidney replacement therapy.	192	Quantitative	Women with kidney disease frequently suffer from hypoactive sexual desire disorder, and hemodialysis women are more likely to develop it.
40	Yodchai et al., 2018, Thailand	Investigate nephrology nurses' perceptions regarding discussing SRH issues with kidney failure patients, in a phenomenological study in Thailand	20	Phenomenological study	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.