Assessing sexual dysfunction in people living on dialysis in a New Zealand renal service
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**Abstract**

**Aim:** This study sought to assess for people living in one large dialysis service in New Zealand their level of sexual functioning and also its importance to them.

**Background:** Although there have been a number of international studies showing significant sexual dysfunction (SD) among people living on dialysis, there have been no published studies in Australia or New Zealand.

**Method:** A modified version of the Arizona Sexual Experience (ASEX) questionnaire was used to survey, by post, the dialysis population of the Auckland District Health Board (ADHB) Renal Service. Two new questions, added to the ASEX questionnaire, were asked about their degree of concern over their level of sexual functioning and its impact on their intimate relationships. Responses were analysed as a set of descriptive statistics.

**Results:** This study showed significant levels of SD, 78%, for people living on dialysis in the Renal Service, similar to findings in similar studies elsewhere in the world. Despite these levels of SD, their level of sexual functioning was only of significant concern to 60% of participants and only had a negative impact on their intimate relationship for 42% of participants.

**Conclusion:** The new questions could potentially usefully be used for initial screening to identify whether the person living on dialysis considers they have a problem, in order to determine if a full diagnostic screen for level of sexual functioning was of clinical relevance.

**Keywords**

Dialysis patient, quality of life, sexual dysfunction, Arizona Sexual Experience (ASEX) questionnaire.

**Introduction**

Changed sexual functioning in people with end-stage kidney disease (ESKD) living on dialysis is reported to be common (Palmer, 2003). Sexual dysfunction (SD) is a complication of ESKD which has been identified as an important stressor affecting their quality of life (Lawrence *et al.*, 1997; Dailey, 1998; Soykan, 2004).

Although there have been a number of studies that have sought to assess SD, none have been reported yet in Australia or New Zealand. The aim of this study was to assess the level of SD among people living on dialysis at the Auckland District Health Board (ADHB) Renal Service. The study also sought to discern how important their changed level of sexual functioning was for participants.

**Background**

Several cross-sectional studies have attempted to measure the prevalence of SD among the haemodialysis population, but the number of patients assessed is small (Ayub *et al.*, 2000; Toorians *et al.*, 1997). The prevalence of SD among women is unclear with minimal reported data. This may be due in part to women reporting fewer sexual problems, but also because it is easier to measure SD among the male population. Because of the use of varied definitions and tools in its treatment, assessment of the general prevalence of SD across various populations have ranged from 41% to 93% in various studies (Furlow, 1985; Heiman, 2002).

The pathogenesis of SD due to renal failure is still unknown, in spite of various studies that have revealed multiple disturbances (Utley, 1996). Physiological factors that could affect sexual function include hormonal imbalances, vascular and neurological complications, and medication side effects (Utley, 1996; Oliver, 1999). Studies have shown improved sexual functioning for patients on dialysis after correction of anaemia and maintenance of adequate dialysis treatment (Dailey, 1998; Eknoyan, 2001; Dharmarajan *et al.*, 2003).

Apart from physical impacts due to renal failure, there are a number of psychological impacts that may also contribute to changes in sexual functioning. These include: fear of dying or illness; anger or depression from loss of income, changes in

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social and personal roles, changes in recreational activities; loss of control and independence; and being dependent on a machine (Trudel et al., 2000). Steele et al. (1996), from their study of 68 patients, concluded that it may be that SD is mainly due to the psychosocial impacts experienced by renal patients as a consequence of having a chronic illness.

It is generally agreed that SD reduces the quality of life of people living on dialysis (Lawrence et al., 1997; Dailey, 1998; Soykan, 2004). Steele et al. (1996) found that the renal patients who reported to be sexually inactive, when assessed, had a significantly higher rate of depression, a higher anxiety level and a poorer quality of life. Laumann et al. (1999) make the important point that sexual problems are subjective and depend on the values, wishes and sexual knowledge of the patient and the partner. In particular, there may be a difference between the reported level of SD and the importance of changed sexual functioning as a concern for the person living on dialysis.

**Methods**

**Design**

A cross-sectional descriptive study was designed to identify the level of SD and its importance to people living on dialysis at the ADHB Renal Service. Limited available resources influenced design decisions. A self-report questionnaire was used to measure the level of SD. Questionnaires have been used in other similar studies and this permitted comparison between the results of this study and other studies.

As assessing sexual functioning is a sensitive topic and difficult for some people to discuss, questionnaires were posted out to each patient along with the consent form and an invitation to participate in the study. Both questionnaire and consent forms were coded to ensure confidentiality. De-identified data was used in the analysis. This method of questionnaire distribution enabled the invitee to make his/her decision to participate without outside influence, whilst also enabling each participant to complete the questionnaire in private.

**Participants**

The target population for this study were people with ESKD on dialysis under the care of the Department of Renal Medicine at ADHB. Four hundred and two patients aged 18 and over were invited to participate. All those invited were receiving dialysis treatment and had not been admitted to the hospital in the previous month. Of these 267 (70%) were on haemodialysis and 135 (30%) were receiving peritoneal dialysis. The contact details of the above-mentioned eligible patients were obtained from their medical record notes.

**Ethics**

This study was approved by Northern Regional Ethics Committee (Ref: NTX/06/09/106). The study also received approval from Auckland District Health Board Management Research review committee and the Maori research review committee.

**Instrument**

The questionnaire used a modified version of the Arizona Sexual Experience (ASEX) questionnaire, which is viewed as more relevant and less intrusive than other methods for evaluating sexual functioning (Soykan, 2004). The ASEX scale is a brief, five-item scale designed to assess the core elements of sexual functioning: drive, arousal, penile erection/vaginal lubrication, ability to reach orgasm and satisfaction. For each item the respondent makes a choice from a menu of six options, ranging from extremely strong to nil. Each option has a numerical value which are summed to get a total score. A total ASEX score of 19 or greater, any one item with an individual score of five, or three or more items with individual scores of four, is considered to represent SD. Soykan’s study (2004) has established the validity and reliability of the ASEX questionnaire among haemodialysis patients in Turkey, including Cronbach’s Alpha of 0.94 for females and 0.92 for males.

In the current study, the ASEX questionnaire was modified by adding two further questions (Table 1). These two additional questions were about the patient’s degree of concern about their level of sexual functioning and the impact of their sexual functioning on their intimate relationships. These two questions were rated on a scale of 1 to 4, with one being the least positive response. These two questions were added because the ASEX questionnaire is physiologically oriented, lacking any explicit psychologically oriented components. Apart from their ratings there was provision for participants to provide additional written comments if they so wished. Reliability coefficients were recalculated for the modified scale including the two new questions, being 0.88 for females and 0.84 for males. No specific permission was required to use the ASEX tool.

| 1 | Strength of sexual drive |
| 2 | Ease of sexual arousal |
| 3 | Ease of physical preparedness for intercourse (erection, lubrication) |
| 4 | Ability to reach orgasm |
| 5 | Satisfaction with quality of orgasm |
| 6 | Concern about quality of orgasm |
| 7 | Concern about impact of sexual functioning on intimate relationship |

**Data analysis**

The scores elicited from the questionnaire were translated into values that were then analysed in order to identify the prevalence of SD amongst participants. This included: demographic characteristics; total scores on questions 1–5 providing the percentage of patients recorded as having SD. An analysis of each item on the scale was undertaken and Chi square analysis undertaken on categorical data to determine differences of item and total scores as a function of age and gender. Sexual functioning scores were analysed against dialysis parameters such as dialysis adequacy, inflammatory markers and
anaemia. This data was also analysed against scores on sexual functioning concerns and its impact on intimate relationships. Analysis of variance was undertaken as normal data to determine differences as a function of ethnicity, age and gender. For analysis the threshold for significance was \( P<0.05 \).

**Results**

Of the total of 402 patients invited, 89 (23.4%) patients accepted the invitation to participate. The final study sample comprised of \( n=68 \) male (76%) and \( n=21 \) females (24%). The mean age was 58.6 years, ranging from age 24 to 86 (males \( m=59.4 \) years, female \( m=56.1 \) years). On average, participants had been on dialysis for four years, ranging from six weeks to 27 years. The ethnic mix in the study group was similar to that of the New Zealand renal population with 9% Asian, 43.9% Caucasian, 22.5% Maori and 24.7% Pacific Islander.

A total of sixty-nine (78%) participants were classified as having some degree of SD. Of these, 13 were females, representing 65% of the female participants and 56 were male, representing 81% of the male participants. Sixty participants (68%) were classified as having SD based on the category (noted above) \( >19.5 \) on the basis of \( >4 \) on any 3 items, and 4 on the basis of having any item with a score of \( >5 \). Analysis revealed that the mean scores for European subjects (\( m=23.97, SD 5.47 \)) were significantly higher than those scores of non-Europeans (\( m=20.18, SD 7.54 \)).

The first item on the ASEX questionnaire addressed strength of sexual drive. Sixty per cent of participants reported that they had either no, or a very weak, sexual drive. Only 6% reported their sexual drive was very or extremely strong.

![Figure 1. Strength of sexual drive.](image1)

The second item on the ASEX questionnaire addressed difficulty in sexual arousal. Sixty-two per cent of the study group had some degree of difficulty in sexual arousal; 27.9% of males and 28.6% of females reported they were never aroused.

![Figure 2. Ease of sexual arousal.](image2)

Other specific items in the ASEX questionnaire addressed males’ difficulty in achieving an erection and females’ difficulty in achieving vaginal lubrication, ability to reach orgasm and satisfaction from orgasm. All showed the same pattern of SD. For example, only 31% of the sample had some degree of satisfaction with the orgasms they experienced.

The first new question addressed their degree of concern about their level of sexual functioning. Forty per cent of participants were not at all concerned, but 35% were either very or extremely concerned.

![Figure 3. Concern about sexual functioning.](image3)

The other new question addressed the impact of sexual functioning on their intimate relationship. Forty-eight per cent of participants reported that their sexual functioning was not having a negative impact on their intimate relationships. Twenty per cent of them reported that it had an extremely or very negative impact. Further analysis showed, not surprisingly, a significant positive correlation between concern about their level of sexual functioning and the impact of sexual functioning on intimate relationships, a greater concern about sexual functioning being positively related to an increased negative impact on relationships (Pearson’s \( r=0.62, p=0.01 \)).

![Figure 4. Impact of sexual functioning on intimate relationship.](image4)

Across all questionnaire items the only difference in terms of gender was that which measured degree of concern about level of sexual functioning, with men (45%) being significantly likely to express concern than women (10%) (\( \chi^2=8.16, p=0.003 \)).

Predictably concern about level of sexual functioning varied with age. While there was no evidence of a difference in the impact of sexual function on the intimate relationships of patients as a function of age, those patients under 60 years of age were more likely to be concerned with their sexual functioning than older patients (\( \chi^2=3.06, p=0.06 \)).
One-way analysis of variance showed an association between cause of renal failure and SD ($F_{9,88} = 2.05$, $p = 0.05$). Participants on dialysis as a result of diabetes, polycystic or vascular disease all scored significantly higher on the ASEX scale compared to those whose cause of renal failure was GN. In addition, those on dialysis due to polycystic disease had significantly higher scores than patients with FSGS and reflux nephropathy.

Detailed analysis showed no relationship between a number of potentially significant variables and sexual functioning scores for items in the modified ASEX questionnaires. The length of time a person had been on dialysis showed no correlation with sexual functioning scores. Nor was there any correlation found between haemoglobin (a recognised correlate of general quality of life for people living on dialysis; Valderrábano, 2000) and sexual functioning scores ($r = 0.01$, $p = 0.91$). Despite the wide range of results in the study population for C-Reactive Protein (range from 1–147 mg/L, mean 15.6 mg/L), a reliable measure of inflammation, there was no correlation with the sexual functioning scores ($r = 0.4$, $p = 0.7$). There was also no correlation between adequacy of dialysis therapy, measured by Kt/v, and the modified ASEX scores ($r = 0.009$, $p = 0.93$).

**Discussion**

In this study, 78% of participants reported some degree of SD, despite being medically stable and adequately dialysed, having no significant anaemia and only mild inflammation. This is comparable to international studies in similar population groups, which show prevalence rates as high as 70% to 80% in the dialysis population (Rosas et al., 2001; Turk et al., 2001). The low rate of female participation in the study, only 24%, is interesting, given that another study has found women have specific concerns relating to body image, sexual desire and intimacy with their partner (Castillo et al., 1999). It may be that this form of study does not engage women as effectively as men.

Almost all international studies have concluded that the high rate of SD is a major problem for people living on dialysis, resulting in decreased quality of life and relationship dissatisfaction (Peng et al., 2005; Ayub & Fletcher, 2000; Ali et al., 2005). However, this study showed that the impact of SD was very variable from the individual from their own perspective.

For 40% of participants their level of sexual functioning was of no concern, with only 35% very or extremely concerned about this, despite 78% reporting some degree of SD. For 48% of participants their level of sexual functioning had no impact on their intimate relationship, while for 20% it was very or extremely negative. Understandably, concern about sexual functioning and perceived impact on intimate relationships was strongly correlated.

Earlier studies have sometimes assumed simple relationships, for example between ESKD, depression and SD. However, given the range of variables involved – the syndrome of physical effects caused by ESKD, the psychological and social consequences of this complex, long-term condition, resultant SD, the perceptions of people living on dialysis about their changed sexuality, and their overall quality of life – their relationship is likely to be complex (Rosas et al., 2003; Lew & Piraino, 2005). Depression, a common experience among people living on dialysis, may be both a reflection of and also causative of some of these variables. This study points toward the complexity in the relationship between the range of variables involved, by showing no simple relationship with a number of physiological variables but highlighting the variability in the participants’ own attitudes towards their changed sexuality on dialysis. While the findings of this study showed that for many participants SD does impact negatively on their life, for a significant proportion of them it does not.

**Limitations**

The study had a low response rate (23%), raising questions about the generalisability of these findings. Those who responded may not be representative of the group as a whole. One could speculate that the non-responders were either less concerned or more concerned about SD than the responders. The participants’ views are valid for the respondent group and the response rate is similar to that in other studies. Further studies would be needed to confirm the utility of the modified ASEX questionnaire.

This study makes no distinction between people living on dialysis who have SD related to ESKD itself and those where SD is caused by other comorbid conditions and their management (related or not to ESKD). For instance, there are a number of studies which have concluded that anti-hypertensive medications may affect sexual functioning (Stewart, 2006). Hypertension is one of the major causes for renal failure, and those treated by antihypertensive medicines have to continue using them even after reaching ESKD. This study identified a point prevalence of SD in ESKD patients and does not seek to tease out the specific effect of the original cause of ESKD or comorbid conditions. What was clear was that SD was very common and a significant concern for many people living on dialysis. Whether this is due to ESKD itself is unclear.

**Conclusion**

**Implications for practice and future research**

This study has shown the rates of SD in people with ESKD undergoing dialysis at the ADHB renal service is high, suggesting a similar rate of SD in the ESKD population in New Zealand as has been reported in international studies. It has demonstrated a modified version of the ASEX questionnaire can be effectively used in the New Zealand context to assess SD.

This study has also suggested the importance of ascertaining how concerned people living on dialysis were about their sexual functioning and their view of its impact on their relationships.
The additional questions showed the percentage of people living on dialysis concerned about their level of sexual functioning was not as high as the percentage with SD. Also the percentage of people living on dialysis for whom their level of sexual functioning was having a negative impact on their relationship was lower than the rate of SD.

This study suggests that, rather than simply administering a full diagnostic assessment tool such as the ASEX, a better clinical strategy may be for individuals to be first asked about their view of their own sexuality, in several questions such as those used in this survey, about their degree of concern about their level of sexual functioning and its impact on their relationship. If these questions showed that the individual considered that this was an issue impacting on them negatively, then a full diagnostic assessment tool could be administered. This, in turn, could lead to further assessment, referrals and investigations/interventions. Using these two initial screening questions would not only avoid unnecessary intrusive questioning that is irrelevant to the individual but also prepare those who need further assessment to respond carefully to the objective assessment. In order for such an intervention to be useful and effective staff need to have some training, not only on sexuality and its assessment but also in talking with their patients about this personal and sensitive topic. Such an alternative strategy for identifying SD in people living on dialysis would obviously need to be trialled.

The introduction of these two questions, attempting to gain some insight into the perspective of the person living on dialysis towards their own changed sexuality, points towards further possible studies that could be undertaken to more fully describe the renal client’s view of their sexuality. Such studies, in order to paint a fuller picture, could include the viewpoint of the partner of the person living on dialysis.

While the lens of the SD assessment provides an objective view of sexual functioning, it needs to be complemented by the subjective view of their changed sexuality from the person living on dialysis. Low levels of sexual functioning are only dysfunctional if the person living on dialysis views it that way. This study suggests that, for whatever reasons, a number of people living on dialysis with low levels of sexual functioning do not consider it to be dysfunctional.

References