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## SW-01. THE ROLE OF SOCIAL WORK IN A SPECIALTY ALIGNED KIDNEY PALLIATIVE TEAM

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There is increasing awareness of the unmet palliative care needs among patients living with advanced kidney disease. The KidneyPal (KP) team at Brigham and Women's Hospital attempts to address these gaps by aligning and embedding with the kidney team at their institution. This interprofessional team, composed of physicians, nurse practitioners, and a social worker (SW), addresses complex medical and psychosocial needs, providing comprehensive, longitudinal, goal-concordant care across inpatient and outpatient settings. The case report highlights the role of the KP SW, a core team member providing clinical and systemic support.

The responsibilities of the KP SW include facilitating advance care planning, providing emotional and coping support, guiding patients and families through adjustment to illness, supporting opportunities for legacy planning and meaning making, and bereavement. An important aspect of this role is supporting patients and families through complex medical decision-making across their illness trajectory, including kidney specific decisions about initiating or withdrawing renal replacement therapy.

Working across the inpatient and outpatient setting, the KP SW provides longitudinal support to patients, helping them navigate the evolving challenges of their illness and ensure continuity of care, particularly as they approach end-of-life. The SW perspective and expertise, including emphasis on social justice, trauma-informed care, family systems, cultural humility, social determinants of health, and grief/loss frameworks, is critical when collaborating with patients, families, and the interdisciplinary team to address barriers, support shared decision-making, and ensure care aligns with patient values. Collaboration with dialysis and kidney transplant social workers is vital to align efforts, address psychosocial needs, and connect patients with necessary resources.

SWs are essential to comprehensively addressing the nuanced needs of patients with advanced kidney disease while strengthening inter-professional collaboration. The KP model demonstrates the value of embedding SW expertise in specialty-aligned palliative care programs.

## SW-02. 50 YEARS OF KIDNEY CAMP AND COUNTING

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In 1975, Frost Valley YMCA, in partnership with Montefiore and The Ruth Gottscho Kidney Foundation established the first mainstream camp experience for children with kidney disease. Annually, an interprofessional team collaborates to plan and improve the camp experience, including camper needs, staffing, dialysis supplies, medications, counselor education, and more. Campers meet others with CKD as well as non-affected peers and counselors, while gaining

skills, confidence, and improved management and coping. Dialysis and medication times are arranged to allow maximum participation in activities. To support healthcare transition, older and more stable campers attend with less-intensive medical support.

This year, the partnership has drawn from archived photos and documents to create a 50 year retrospective of this model program, and acquired written and oral narratives from current and former campers, families, and staff.

Over 2000 children with kidney disease have experienced summer camp through this program, with the involvement of 100+ healthcare professionals, over 50 years. While the program served children solely on dialysis when founded, it has adapted to serve those with Stage 3+ CKD and with transplants. Campers and staff unaffected by kidney disease become more knowledgeable about CKD and living with illness. Healthcare professional staff gain insight into life outside the clinic for children with kidney disease. Families note increased confidence, ability to make friends, and improved self-management. Many camp alumni are surviving and thriving in adulthood, with employment in healthcare, education, the arts, the travel industry, and more.

Data collection is ongoing regarding camper and family satisfaction and outcomes. This enduring model of a supported, mainstream camp experience can serve as a template for children living with other chronic conditions and organ transplants. The program will continue to adapt to the changing needs of the pediatric kidney disease community, and to further support the transition to adulthood for campers.

## SW-03. HOUSING INSTABILITY AND HEMODIALYSIS: A SURVEY OF SOCIAL WORKERS

Leah Howitt, Tala Al-Rousan, Pranav Garimella. UC San Diego

Dialysis patients experiencing housing instability face obstacles such as adhering to dietary restrictions, storing medications, and accessing transportation, leading to disrupted care. Mounting evidence suggests that non-clinician led interventions that address social determinants of health are key in achieving better health outcomes for dialysis patients but almost nothing is known in the case of patients facing housing instability.

An anonymous online survey with mixed quantitative and qualitative queries was conducted among SWs in San Diego County dialysis units where patients were cared for by UCSD nephrologists. The survey explored: 1) frequency of contact with patients experiencing housing instability or insecurity; 2) SW knowledge and training on housing placement referrals; and 3) perceived challenges in addressing housing instability among dialysis patients. Thematic analysis was performed on survey responses.

Eighteen SWs from urban dialysis units completed the survey. Dialysis SWs had frequent contact with patients facing housing instability. Thematic analysis revealed: 1) lack of formal training for SWs in addressing homelessness; 2) lack of access centralized resources for housing placement; 3) missed identification of housing insecurity before homelessness; 4) desire for collaboration with housing organizations; and; 5) need for case managers to liaise between housing organizations and dialysis units

Dialysis SWs frequently encounter dialysis patients facing housing instability, resulting in potential adverse health effects and missed treatments. There is a need to provide SWs with resources to help care for patients with housing instability. Our preliminary findings can help inform future studies on policy and public health interventions to enable non-clinician led intervention and improve healthcare outcomes.

### SW-04. WELL-BEING AND SELF-MANAGEMENT OF ESKD PATIENTS IN AN ONLINE HEALTH COMMUNITY

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Online Health Communities (OHC) might positively influence people with kidney disease. This study identifies the sources of support (emotional, informational) patient members find and how the type of support influences patient well-being and self-management.

This study used a cross-sectional survey design. Participants were over 18, English reading, with ESKD, and currently on dialysis. An administrator shared the link to the SurveyMonkey survey. Study measures included the types of online support received, well-being, and self-management.

Forty-eight surveys were included in the analysis. The study sample was mostly white (83%), women (69%), partnered (69%), and living with someone (73%). Most were on home dialysis (98%), had more than a high school education (79%), and were retired or receiving disability benefits (73%) with a mean age of 60 (SD=12.76). Participants found similar amounts of emotional (M=25.46, SD=9.40) and informational (M=29.17, SD=8.73) support. Spearman's rank correlations were computed to assess the relationship between variables, the findings of which are shown in Table 1. Emotional support was significantly positively associated with positive affect and significantly negatively associated with loneliness. Information support was significantly negatively associated with loneliness and perceived stress.

Online emotional and informational support may improve well-being, specifically reducing loneliness and perceived stress while improving positive affect. Kidney disease professionals can encourage people to engage in OHCs to find emotional and informational support, potentially impacting well-being and self-management. Future research that includes a larger sample size, more OHC's, caregivers, and a more racially diverse sample would provide more generalizable recommendations.

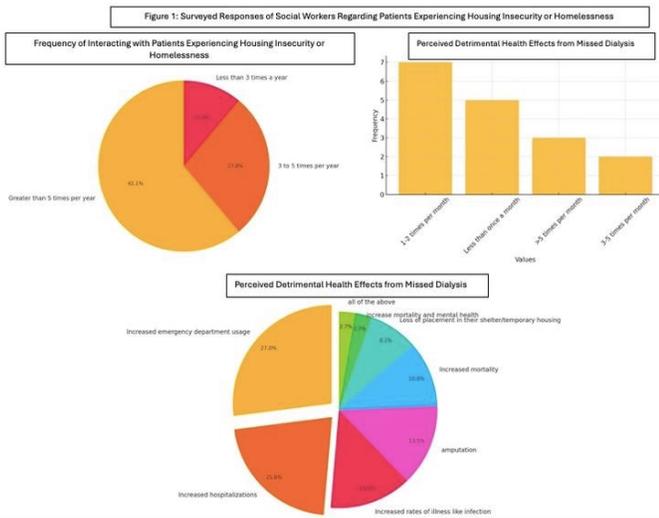


TABLE 1

|                       |                                |                         | Well-Being     |                   |            |                 |                 | Self-Management  |             |            |                     |
|-----------------------|--------------------------------|-------------------------|----------------|-------------------|------------|-----------------|-----------------|------------------|-------------|------------|---------------------|
| Online Social Support |                                |                         | Social Support | Life Satisfaction | Loneliness | Positive Affect | Negative Affect | Perceived Stress | Empowerment | Confidence | Involvement in Care |
| Spearman's Rho        | Emotional Support Subscale     | Correlation Coefficient | .35*           | .33*              | -.51**     | .41**           | -.36*           | -.35*            | .36*        | .29*       | .21                 |
|                       |                                | Sig. (2-tailed)         | .02            | .02               | <.001      | .004            | .012            | .02              | .012        | .05        | .15                 |
|                       |                                | 95% CI (2-tailed)       | .06, .58       | .04, .57          | -.70, -.26 | .13, .63        | -.59, -.08      | -.58, -.06       | .08, .59    | -.00, .54  | -.08, .47           |
|                       | Informational Support Subscale | Correlation Coefficient | .36*           | .29*              | -.54**     | .28             | -.35*           | -.39**           | .21         | .10        | .23                 |
|                       |                                | Sig. (2-tailed)         | .012           | .04               | <.001      | .05             | .014            | .007             | .16         | .51        | .11                 |
|                       |                                | 95% CI (2-tailed)       | .08, .59       | .00, .53          | -.72, -.30 | -.00, .53       | -.59, .07       | -.61, -.11       | .09-.47     | -.20, .38  | .07, .49            |

\*. Correlation is significant at the 0.05 level (2-tailed).  
 \*\*. Correlation is significant at the 0.01 level (2-tailed).

## SW-05. A QUALITY-OF-LIFE ASSESSMENT IN DECEASED DONOR KIDNEY TRANSPLANT CAREGIVER-RECIPIENT DYADS

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Caregiver support can be a significant barrier in access to kidney transplantation. The roles and responsibilities have been unclear contributing to caregiver disparities. This study examines the quality-of-life changes that occur between caregiver and recipients through the continuum of post-transplant care.

A longitudinal, single-center study was performed of 10 adult, DDKT dyads. Over the course of 12 months, recipients and caregivers' mood was measured using the CES-D, financial concerns using the EHQ. Additionally, recipient quality of life and health were measured using KDQOL. Caregivers burden was evaluation using the CSI, health using the SF 12 (PCS and MCS) and quality of life using the CQLQ.

89% of recipients were females. Of those with one caregiver, 6, 50% of the caregivers were female. The remaining dyads consisted of both male and female caregivers. 44% of the dyads were black, 11% Hispanic and 11% Asian. 56% of caregivers were spouses and the remaining were recipient children. 44% were not on dialysis and 33% had engaged in home therapies prior to transplantation. Age range was 31-72 ,mean 58 years. Data exists through month 4. Mean SF-12 physical health composite score was  $40.99 \pm 10.20$  and SF-12 mental health composite  $50.77 \pm 9.87$ , for recipients. Trending improvement in anxiety and depression symptoms indicated by CES-D scores is noted for both recipient ( $7.0 \pm 5.05$ , visit 1 to  $9.11 \pm 6.01$ , visit 3) and caregivers ( $6.92 \pm 4.72$ , visit 1 to  $7.42 \pm 7.95$ , visit 3).

Previous research into caregiving burden and quality of life has been conducted with living donor dyads. This research showed caregiver strain, temporarily worsening in physical and mental QOL at month one measurement and non-significant improvement in caregiver strain at months 6 and 12. Additionally, improvement in economic hardship was reported in both caregiver and recipient in the initial study. This study aims to provide additional insight to better understand the course of caregiver and recipient QOL after kidney transplant.