

Original Article

Symptom burden, quality of life, advance care planning and the potential value of palliative care in severely ill haemodialysis patients

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Abstract

Background. There has been little research on the potential value of palliative care for dialysis patients. In this pilot study, we sought (i) to identify symptom burden, health-related quality of life (HRQoL) and advance directives in extremely ill haemodialysis patients to determine their suitability for palliative care and (ii) to determine the acceptability of palliative care to patients and nephrologists.

Methods. Nineteen haemodialysis patients with modified Charlson co-morbidity scores of ≥ 8 were recruited. Each completed surveys to assess symptom burden, HRQoL and prior advance care planning. Palliative care specialists then visited patients twice and generated recommendations. Patients again completed the surveys, and dialysis charts were reviewed to assess nephrologists' (i) compliance with recommendations and (ii) documentation of symptoms reported by patients on the symptom assessment survey. Patients and nephrologists then completed surveys assessing their satisfaction with palliative care.

Results. Patients reported 10.5 symptoms, 40% of which were noted by nephrologists in patients' charts. HRQoL was significantly impaired. Thirty-two percent of patients had living wills. No differences were observed in symptoms, HRQoL or number of patients establishing advance directives as a result of the intervention. Sixty-eight percent of patients and 76% of nephrologists rated the intervention worthwhile.

Conclusions. Extremely ill dialysis patients have marked symptom burden, considerably impaired HRQoL and frequently lack advance directives, making them

appropriate candidates for palliative care. Patients and nephrologists perceive palliative care favourably despite its lack of effect in this study. A more sustained palliative care intervention with a larger sample size should be attempted to determine its effect on the care of this population.

Keywords: advance care planning; health-related quality of life; palliative care; symptom burden

Introduction

Despite its ability to save life, dialysis is accompanied by significant morbidity [1–4]. A host of physical and psychological symptoms occur in patients on chronic dialysis [3–5]. As many as 87% of these patients have fatigue, up to 75% have pruritis and nearly 20% report suffering from depression [3,4]. Additionally, a dialysis schedule can significantly hamper both professional and personal lifestyle [2–5]. These factors may contribute to the impaired health-related quality of life (HRQoL) reported by patients on maintenance dialysis [1–5]. Unfortunately, most studies assess a limited number of symptoms rather than total symptom burden in this patient population [3,4]. Thus, little is known about the overall prevalence and severity of physical and psychological symptoms and their relationship to HRQoL in patients on dialysis.

Together with morbidity, the annual mortality rate of this patient population is 24%, a rate higher than that seen in prostate cancer (0.2%), breast cancer (2.4%), colorectal cancer (17.4%), ovarian cancer (20.8%) and non-Hodgkin's lymphoma (23.1%) [6,7]. Despite this high rate of mortality, end-of-life care has been neglected in this population [8,9]. Prior studies

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demonstrate that ~50% of these patients fail to complete advance directives, and even fewer discuss their wishes for end-of-life care with their nephrologists [8,9]. Likewise, nephrologists often fail to establish advance directives in dialysis patients and frequently do not follow them once formulated [9].

Given the considerable mortality, debilitating symptoms, impaired HRQoL, and lack of attention paid to advance care planning in this patient population, palliative care could favourably influence the care delivered to patients dependent on dialysis, particularly individuals with significant co-morbidity and poor long-term prognosis. Palliative care is the management of physical, psychological, social and spiritual needs of patients with progressive, life-limiting illnesses. Palliative care consultative services have been established to help address the needs of patients with advanced illness, especially those with cancer, and preliminary data show that such services can reduce symptom burden, favourably impact specific domains of HRQoL and help patients complete advance directives [10,11]. Moreover, patients are open to the assistance palliative care provides when illness reaches advanced stages [11]. Although a few studies have investigated the applicability of palliative care to patients discontinuing dialysis, it is unknown whether chronic dialysis patients or renal providers will find palliative care's emphasis on 'living with a terminal illness' acceptable or whether they will be amenable to discussing topics pertaining to end-of-life care [12].

The aims of this pilot study were to: (i) assess the symptom burden, HRQoL and advance care planning in seriously ill dialysis patients to determine their suitability for palliative care and (ii) assess the acceptability of palliative care to such patients and their nephrologists.

Subjects and methods

Subjects

This was a pilot study designed to assess the acceptability of a palliative care intervention and thus did not contain a control arm. We identified our study population from the Dialysis Clinic Incorporated (DCI) out-patient clinic affiliated with the University of Pittsburgh Medical Center. This clinic cares for ~110 haemodialysis (HD) patients; 34% Caucasian, 66% African-American, 63% female with an average age of 59 years. All patients receiving thrice weekly, in-centre, ambulatory HD were considered for inclusion. To help ensure that patients had acclimated to life on dialysis, they were required to have been on HD for at least 3 months prior to enrolment. The modified Charlson Comorbidity Index (CCI), an instrument designed to quantify co-morbid illness, with higher scores correlating with increased illness, was used to determine co-morbidity scores for all individuals receiving in-centre HD. CCI scores were calculated using the methodology previously described by Beddhu *et al.* [13]. We recruited only patients with CCI scores of ≥ 8 based on our previous findings demonstrating that dialysis patients with these scores had a mortality rate of 49 per 100 dialysis years [13]. The presence of co-morbid medical conditions

was determined by reviewing the patient's dialysis chart and the Medical Archival System (MARS), a computerized database that maintains out-patient and in-patient records, radiology and pharmacy reports, emergency room visits, discharge summaries and financial transactions. Patient recruitment took place from September 2001 to February 2002.

The University Institutional Review Board approved all study procedures. Consent was obtained from all eligible patients and their nephrologists. One patient was randomly selected each week and approached during a routine dialysis session. After obtaining consent, an investigator (S.S.C.) administered a standard Folstein mini-mental status examination to ensure that enrolled patients would understand the nature and details of the study. Subjects who scored ≤ 23 , indicating difficulty comprehending and responding to study questions, were excluded.

Survey instruments

Subjects meeting inclusion criteria completed three pre-intervention surveys; the Memorial Symptom Assessment Scale Short Form (MSAS-SF) to assess physical and psychological symptom burden and severity, the Functional Assessment of Chronic Illness Therapy—Spirituality Scale (FACIT-Sp) to assess HRQoL, and the Dialysis Patient Choices at the End-of-life Questionnaire (DPCELQ) to assess prior advance care planning.

The MSAS-SF consists of 32 questions that assess the presence (Y/N) and severity of 28 physical symptoms (5-point Likert scale, 0 = not bothersome to 4 = very bothersome) and the presence and frequency of four psychological symptoms (4-point Likert scale, 1 = rarely present to 4 = almost constantly present). We eliminated one item pertaining to 'difficulty with urination' because our study population was primarily anuric. In addition to providing an estimate of the overall prevalence of symptoms, the MSAS-SF generates scores on three subscales, the physical symptom subscale (PHYS) which measures physical symptom distress, the psychological subscale (PSYCH) which measures psychological symptom distress, and the global distress index (GDI), an overall assessment of symptom distress [14]. The PHYS score is the mean distress of 12 physical symptoms; the PSYCH score is the mean distress of four psychological and two physical symptoms; and the GDI is the mean distress of six physical symptoms and four psychological symptoms [14]. The range of subscale scores is 0 (minimal distress) to 4 (maximal distress). The MSAS-SF has been utilized most widely in patients with cancer and AIDS, where it has been shown to have good reliability and validity [14,15].

A number of instruments have been used to measure HRQoL in dialysis patients. These include generic questionnaires such as the SF-36, as well as investigator-developed kidney disease-specific measures. We were concerned that the SF-36 would not be appropriate in this very sick population because of the potential for our patients to have scores below the lower limits allowed by the SF-36 instrument (floor effect). We also wanted to include domains, such as spirituality, that might be particularly relevant to palliative care. Hence, we chose to use a FACIT instrument to measure HRQoL in our patients. The FACIT instruments are a family of measures designed to assess the HRQoL of patients with chronic illness [16]. Originally designed for patients with cancer, the core instrument, the FACT-G (Version 4, 27 items), can be supplemented with different subscales to address disease- or symptom-specific domains related to

HRQoL. We combined the FACT-G with a spirituality subscale (Sp) to evaluate HRQoL in our study population. This instrument, the FACIT-Sp, is comprised of 39 items which are scored on a 5-point Likert scale (0 = not at all to 4 = very much), and assesses five domains of HRQoL: physical well being (PWB, seven items), social/family well being (SFWB, seven items), emotional well being (EWB, six items), functional well being (FWB, seven items) and spiritual well being (SWB, 12 items) [16]. Scores for each domain are generated by adding or subtracting (depending on the nature of the question) scores for each item. The total FACIT-Sp score is a sum of the five subscale scores. Higher scores indicate a more favourable perception of HRQoL. Although not previously used in dialysis patients, the reliability and validity of the core instrument have been demonstrated to be high in patients with cancer and other serious illnesses [16,17]. The FACIT-Sp was developed for use in patients with progressive life-limiting illness; its domains address many issues important to palliative care, and it has been widely used in patient populations in whom palliative care plays an important role [14,16,17]. In addition, we chose this measure to allow for a preliminary comparison of HRQoL scores in our severely ill dialysis patients with scores reported by patients with other serious chronic illnesses.

The DPCELQ was developed by the authors based on previous instruments to assess whether patients had discussed advance care planning and end-of-life issues with family members and medical providers. This instrument also collected demographic and other data including marital status, vocational status, ethnicity, religious preference, the importance attached to spiritual beliefs and time on dialysis. All three surveys were read to patients during routine dialysis sessions.

Palliative care intervention

The palliative care programme at the University of Pittsburgh Medical Center consists of a multidisciplinary team composed of physicians, nurses, pharmacists, social workers, spiritual counsellors and behavioural psychologists. After each patient completed the pre-intervention surveys, the palliative care service was notified of the patient's enrolment, as was the patient's nephrologist. Within 14 days, one of three palliative care physicians performed an initial evaluation of the patient during a routine HD session. The intervention consisted of the administration of a standard intake form and performance of a comprehensive history and physical examination. Each patient was then presented at the weekly multidisciplinary palliative care team meeting, and a list of recommendations was generated. Patients and nephrologists were then given both a verbal description of the team's recommendations and a follow-up letter to increase adherence to the recommendations. Recommendations were directed at the treatment of symptoms, the restoration of functional capacity, helping patients cope with illness burden and the establishment of advance directives. The implementation of recommendations was left to the discretion of the patients' nephrologists and was not carried out by the palliative care specialist.

Four weeks later, a follow-up visit by the same palliative care specialist was conducted during a routine HD session. This follow-up consisted of an evaluation of the patient response to the initial recommendations and the generation of further suggestions for improved care. Written and verbal recommendations from this visit were again provided to the patient, nephrologist and, when appropriate, to the patient's primary care provider.

Follow-up evaluation

Two weeks after the second palliative care visit, the MSAS-SF, FACIT-Sp and DPCELQ were re-administered to identify effects of the intervention. Additionally, to assess the patient's opinion of palliative care, a 15-item, investigator-designed Patient Satisfaction Survey was administered. A similar questionnaire, comprised of 18 items and directed toward physicians, was given to each patient's nephrologist to evaluate his/her satisfaction with the intervention. A 5-point Likert scale (1 = strongly disagree to 5 = strongly agree) was used for items on both satisfaction surveys.

Following the completion of the post-intervention surveys, one investigator (S.D.W.) conducted a review of the out-patient dialysis charts of all study participants to determine if the treating nephrologist had documented the presence of the symptoms which had been reported by patients on the MSAS-SF. A symptom was considered documented if, at any time during the 1-year study period, the nephrologist had recorded its presence in the progress notes or had treated the specific symptom as evidenced by review of the orders and medication list. This review also included an assessment of whether recommendations of palliative care had been implemented by treating nephrologists. A recommendation was considered implemented if it was documented in the progress notes, on the order forms or the medication list.

Statistical analysis

To compare the effect of palliative care on symptom burden and HRQoL, pre- and post-intervention summary scores on the MSAS-SF and FACIT-Sp as well as subscale scores were compared using the Wilcoxon sign-rank test for non-parametric data and the paired Student's *t*-test for normally distributed data. The effects of the intervention on patient establishment of living wills and powers of attorney, and the discussion of end-of-life issues were assessed by comparing the pre-intervention and post-intervention item response frequencies on the DPCELQ using the test of proportions. The Jonckheere-Terpstra test, a non-parametric test of association for two ordered variables, was used to correlate symptoms and HRQoL. Data analysis was performed using the STATA 7.0 and StatXact statistical packages.

Results

Patient/nephrologist characteristics

A total of 110 patients were receiving ambulatory HD, 39 (35%) of whom had CCI scores of ≥ 8 . Of these, nine refused (all African-American), five died prior to enrolment, five had advanced dementia and one transferred care prior to enrolment. This left 19 patients who were enrolled. Six of the 19 (32%) had died by the end of the study period. None of the enrolled subjects underwent renal transplantation and all completed the study. Demographic data are summarized in Table 1. Six nephrologists participated in the study. These providers had been practising nephrology for a mean of 21.5 years (range 3–35 years). Nephrologist satisfaction surveys were completed in 18 of 19 cases.

Table 1. Demographic characteristics of study population ($n=19$)

Age (years) (mean \pm SD)	67 \pm 9.6 (range 46–80)
Patients over age 65 (n)	10
Gender (male:female ratio)	12:7
Race (Caucasian:AA ratio)	10:9
Years on dialysis (mean \pm SD)	2.8 \pm 2.2 (range 0.5–10)
Marital status (no. married)	11
Patients with diabetes mellitus (n)	12
CCI score (mean \pm SD)	8.7 \pm 1.0 (range 8–11)
Employment status (no. in work)	1
Patients with failed transplant (n)	1
Patients awaiting transplant (n)	2
Education (no. with bachelors/ further degree)	8

Pre-intervention assessment

Symptoms—MSAS-SF. Results from the MSAS-SF demonstrated a mean number of symptoms of 10.5 (range 1–22). The most frequently reported physical symptoms included lack of energy (74%), feeling drowsy (63%), numbness/tingling (63%), dry mouth (58%), pain (53%) and itching (53%). Seventy-nine percent of patients reported pain and/or numbness/tingling, which many consider to be a manifestation of neuropathic pain, suggesting that pain was the most

prevalent symptom overall. Each of the four psychological symptoms included in the scale—worrying (32%), feeling sad (26%), feeling irritable (26%) and feeling nervous (26%)—was common. The symptoms reported as most severe included constipation, pain, difficulty sleeping, itching and dry mouth (Table 2). There were no differences in symptom prevalence between Caucasians and African-Americans.

HRQoL—FACIT-Sp. Impairments in HRQoL were observed in the five individual domains and in overall HRQoL. Results for the FACIT-Sp are summarized in Table 3. Lower HRQoL scores were correlated with increased symptom prevalence for all FACIT-Sp domains ($P<0.05$) except emotional well being ($P=0.06$). Lower HRQoL scores were correlated with higher MSAS-SF global distress index scores for all FACIT-Sp domains ($P<0.05$) except functional well being ($P=0.09$) and spiritual well being ($P=0.12$). While there were no differences in symptom prevalence by ethnicity, racial differences in HRQoL were significant. A comparison of pre-intervention FACIT-Sp scores between African-Americans and Caucasians is as follows: physical well being 22.1 vs 19.1 ($P=0.19$), social/family well being 19.0 vs 13.7 ($P=0.06$), emotional well being 22.1 vs 16.8 ($P=0.19$), functional well being 18.9 vs 10.4

Table 2. Symptom prevalence and distress by MSAS-SF

Symptoms	Pre-intervention prevalence ^a	Pre-intervention severity ^b	Post-intervention prevalence ^a	Post-intervention severity ^b
Lack of energy	14	1.8	12	2.6
Feeling drowsy	12	0.9	10	0.9
Numbness/tingling in hands/feet	12	1.7	13	2.7
Dry mouth	11	2.4	13	1.7
Pain	10	2.3	7	2.3
Itching	10	2.3	9	1.9
Cough	9	2.1	7	3.1
Shortness of breath	8	2.1	9	2.2
Swelling of arms or legs	8	2.1	6	0.8
Difficulty sleeping	7	2.4	8	1.8
Dizziness	7	1.6	9	2.3
Weight loss	6	0.3	4	2.0
Worrying ^c	6	2.3	8	2.0
Changes in skin	5	1.4	7	1.7
Nausea	5	1.8	4	1.5
Hair loss	5	0.3	5	0
Constipation	5	2.6	4	0.8
'I don't look like myself'	5	1.6	2	3.5
Feeling sad ^c	5	1.6	7	1.7
Feeling irritable ^c	5	1.4	3	3.0
Feeling nervous ^c	5	2.0	4	2.5
Feeling bloated	4	2.3	5	2.6
Vomiting	4	1.8	3	2.3
Diarrhoea	4	1.8	6	2.8
Lack of appetite	4	0.8	6	0.8
Difficulty swallowing	4	2.0	1	3.0
Change in the way food tastes	4	0.5	4	1.0
Difficulty concentrating	3	1.3	6	1.3
Sweats	3	2.0	3	2.7
Problems with sexual interest or activity	3	2.0	4	2.8
Mouth sores	0	0	3	2.0

^aReported as number of patients.^bSeverity scores range from 0 = not severe to 4 = very severe.^cSeverity scores range from 0 = rarely present to 4 = almost constantly present.

Table 3. Quality-of-life scores by FACIT-Sp

FACIT-Sp subscale	Pre-intervention score ^a	Post-intervention score ^a	<i>P</i> -value	Maximum score ^b
Physical well being	20.7	21.3	0.3	28
Social/family well being	16.5	17.5	0.4	28
Emotional well being	19.6	19.8	0.5	24
Functional well being	14.5	13.6	0.7	28
Spiritual well being	2.4	30.1	0.2	48
Total FACIT-Sp	103.7	102.3	0.1	156

^aMean scores.

^bMaximum possible score.

($P=0.01$), spiritual well being 38.6 vs 26.4 ($P=0.04$) and total FACIT-Sp score 120.7 vs 86.4 ($P=0.02$).

Advance care planning—DPCELQ. Twelve patients (63%) had never spoken to their nephrologist about their wishes for care at the end of life, while five (26%) had never spoken to their family or friends about these wishes. Only six (32%) had executed a living will and, of these, four had informed their nephrologist verbally and three had presented a copy of the document to their nephrologist. Seventeen patients (89%) reported having someone they desired to make medical decisions for them at the end of life, yet only six (32%) had formally appointed this person in writing as a surrogate decision maker.

Palliative care recommendations. An average of two recommendations (range 0–4) were made for each patient. Fifty percent of the recommendations were for medications, with 15% of those being for anti-depressants and anti-pruritics, and 85% for analgesics. Approximately 20% of the recommendations were for the nephrologist to discuss advance care planning with the patient and to document patient preferences for end-of-life care in the medical record. The remaining 30% ranged from the work-up of bothersome symptoms such as chronic diarrhoea to the referral to other specialists (neurologists/physical therapists/geriatricians) for ongoing medical conditions.

Post-intervention assessment

Post-intervention MSAS-SF responses demonstrated a mean number of symptoms of 10.1 (Table 2). Pre- and post-intervention MSAS-SF subscale severity scores were similar: GDI (0.91 vs 0.89, $P=0.45$), PHYS (1.12 vs 0.85, $P=0.1$) and PSYCH (0.7 vs 0.8, $P=0.63$). No differences were seen between pre- and post-intervention FACIT-Sp scores (Table 3). Comparison of pre- and post-intervention DPCELQ responses revealed that one additional patient (7/19 vs 6/19, $P=0.6$) had executed a living will, one additional patient (5/19 vs 4/19, $P=0.6$) had informed his/her nephrologist concerning wishes for end-of-life care and four additional patients (7/19 vs 3/19, $P=0.08$) had presented a copy of their living will to their nephrologists.

Patient and nephrologist satisfaction with palliative care

Nine (47%) patients ‘strongly agreed’ and four (21%) ‘somewhat agreed’ that the meetings with palliative care were ‘worthwhile’, while one (5%) ‘disagreed’. Seven (37%) patients ‘strongly agreed’ and five (26%) ‘somewhat agreed’ that it would be useful to continue to meet with the palliative care service, while three (16%) ‘disagreed’ or ‘strongly disagreed’. Six (32%) patients ‘strongly agreed’ and five (26%) ‘somewhat agreed’ that they were able to communicate their preferences for end-of-life care to the palliative care team, while only three (16%) reported being unable to do so.

Nephrologist satisfaction surveys revealed that for 14 (78%) patients, nephrologists ‘strongly agreed’ or ‘agreed’ that palliative care was useful regarding patients’ psychological and physical symptoms, while for the other four patients (22%) the nephrologists ‘neither agreed nor disagreed’. For 11 (62%) patients, nephrologists ‘strongly agreed’ or ‘agreed’ that palliative care supplied them with more information about the patient than they had had prior to the study, while for three (19%) patients nephrologists ‘disagreed’. For seven (39%) patients, nephrologists rated palliative care ‘very useful’, for six (33%) ‘moderately useful’, for four (22%) ‘a little useful’ and for one (6%) ‘not at all useful’. Nephrologists were interested in having palliative care follow-up 12 (67%) of their patients after the conclusion of the study.

Symptom documentation and implementation of recommendations

Chart review revealed that the mean number of MSAS-SF symptoms recorded by treating nephrologists was 4.1. With the exception of pain which was documented in all cases, nephrologists did not document the presence of any of the five most common or six most severe symptoms reported on the MSAS-SF. Sadness was documented in one patient’s chart, while five patients reported this on the MSAS-SF. Irritability, worry and anxiety were not documented in any charts, while each symptom was reported by five or more subjects on the MSAS-SF. Chart review demonstrated that 30% of the recommendations were followed by the treating nephrologists, most of which

were for medications including antidepressants, analgesics and anti-pruritic agents. Recommended referral to a geriatrician for one patient was implemented. Nephrologists did not implement recommendations related to addressing advance directives or to pursuing work-up for ongoing medical problems.

Discussion

Epidemiological studies predict that the dialysis population will double in size over the next decade, with those over the age of 65 representing one of the fastest growing segments [6]. With these trends and the recognition that many patients will not be suitable transplant candidates, continued efforts to improve the quality of life as well as the quality of death of these patients should be of primary importance to renal providers. The results of this pilot study highlight three important issues that underscore the potential value of palliative care to significantly ill dialysis patients.

The first important finding is the marked symptom burden in severely ill dialysis patients. Seventy-nine percent of patients reported pain (either neuropathic pain, e.g. numbness and tingling, or nociceptive pain) and 74% reported fatigue. The mean number of symptoms reported by our patients on the MSAS-SF is higher than described by ambulatory cancer patients (9.7) and is close to the number reported by patients hospitalized with cancer (11.5) (Table 4) [14,15]. Likewise, symptom severity scores on the MSAS-SF are also similar to those reported by hospitalized and ambulatory patients with cancer (Table 4) [14,15]. These findings are important for three reasons. First, patients with cancer frequently have numerous symptoms, many of which can be severe [14]. Secondly, symptoms commonly seen in dialysis patients such as restless legs and muscle cramps are not included on the MSAS-SF, raising the possibility that symptom burden is even higher than observed in this study. Lastly, symptom prevalence and severity correlated with nearly every domain of HRQoL, suggesting their relevance to dialysis patients. Prior studies of symptoms in dialysis patients, although limited in number, support this concept [3]. Merkus *et al.* found that physical symptoms accounted for one-third of the impairment observed in the HRQoL of 226 Dutch dialysis patients [3]. Studies to define further the effect

of symptoms on HRQoL and other patient-related outcomes such as health resource utilization and mortality are clearly needed.

The administration of a symptom assessment scale unmasks symptoms that were not documented, and hence may not be recognized by nephrologists. In studies of other patient populations, such instruments have been shown to capture clinical information often missed by providers [19]. Justice *et al.* [19] found that providers failed to assess the presence and severity of several physical and psychological symptoms that had been reported by 842 AIDS patients on a self-administered symptom instrument. With the exception of pain, the five most common and six most severe symptoms reported on the MSAS-SF by our patients were not documented by nephrologists in patients' charts. Additionally, nephrologists did not record the four psychological symptoms described by patients on the MSAS-SF. Although we assessed only whether nephrologists documented symptoms, this lack of documentation may represent under-recognition of symptoms that could preclude timely treatment and could lead to preventable emergency room visits and hospitalizations. Moreover, given the emerging data on the relationship between depression and mortality in dialysis patients, under-recognition of symptoms suggestive of underlying depression may result in premature death [4]. Future studies should investigate not only whether nephrologists document symptoms, but also whether they recognize symptoms and whether the use of a symptom assessment questionnaire might assist providers in the accurate and timely assessment of symptoms.

The second important finding is the marked impairment in the HRQoL of dialysis patients with significant co-morbid illness. Our patients' FACIT scores are similar to those reported on this instrument by ambulatory and hospitalized cancer patients, populations with well-recognized decrements in HRQoL [14] (Figure 1). Although there are limitations in comparing HRQoL scores across patient populations, the magnitude of the impairment suggested by our results highlights the significant illness in this segment of the dialysis population and reinforces the importance of efforts to affect HRQoL favourably and complete advance directives in this group of patients. We also found significant racial differences on the FACIT-Sp, with African-Americans reporting better HRQoL than

Table 4. Mean (\pm SD) symptom number and distress in dialysis and cancer^a patients

Patient population	No. of symptoms	MSAS-GDI ^b	MSAS-PHYS ^b	MSAS-PSYCH ^b
Dialysis patients with CCI \geq 8	10.2 \pm 5.0	0.9 \pm 0.5	1.1 \pm 0.4	0.7 \pm 0.6
Cancer out-patients ^c	9.7 \pm 6.0	1.0 \pm 0.7	0.7 \pm 0.6	0.9 \pm 0.7
Cancer patients ^d	11.5 \pm 6.0	1.3 \pm 0.87	0.9 \pm 0.8	1.1 \pm 0.8

^aData taken from Vogl *et al.* [15] and Portenoy *et al.* [18].

^bSeverity scores range from 0 = not bothersome to 4 = very bothersome.

^cA total of 123 ambulatory cancer patients.

^dA total of 243 ambulatory and hospitalized cancer patients.

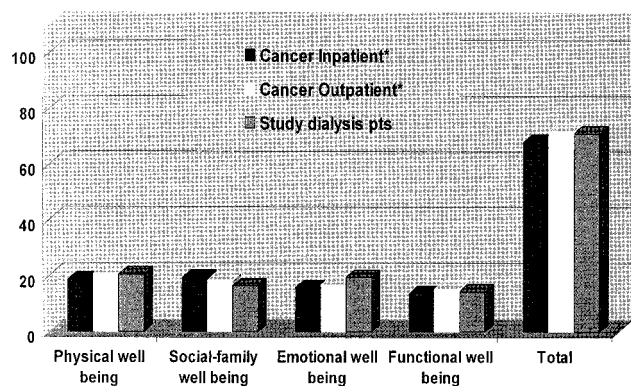


Fig. 1. Quality of life in haemodialysis patients and cancer patients. Data taken from Chang *et al.* [14].

Caucasians. It appears that this variation exists even in extremely ill patients despite the fact that symptom burden and severity are comparable in the two racial groups.

Finally, the present study emphasizes the significant problems with advance care planning in this seriously ill population. Few patients formalize their wishes for care into living wills or formally designate health care proxies. Of those that do complete living wills and assign surrogate decision makers, many do not discuss these decisions with their nephrologists. This is significant given the high mortality rate seen in very ill dialysis patients and because data suggest that advance care planning may have favourable effects in dialysis patients [20]. Swartz and Perry retrospectively compared the nature of death in 182 patients, 74 of whom had previously established advance directives. Those with advance directives were more likely to die in a 'reconciled fashion' than 'suddenly and unexpectedly' [20]. Additionally, discussions with renal staff and family members pointed to a subjective assessment of 'better death' in those who had established their wishes for end-of-life care. Yet, studies conducted in the last decade have continued to demonstrate that advance directives are not completed by a significant percentage of dialysis patients, a finding which has prompted the Renal Physicians Association to publish guidelines for advance care planning in chronic dialysis patients. Unfortunately, there have been few interventions employed to increase the use of advance care planning in this population, highlighting the need for innovative efforts such as palliative care to address this issue.

These three findings, marked symptom burden, impaired HRQoL and failure of nephrologists routinely to address advance care planning, underscore the potential value of palliative care for seriously ill dialysis patients. Fortunately, our results indicate that palliative care is well received by patients and nephrologists. Although our intervention did not result in a measurable change in symptom burden, HRQoL or the number of patients addressing advance directives, this was a short-term pilot study to investigate the suitability and applicability of palliative care. Studies in cancer patients have demonstrated

that carefully applied, more sustained palliative care interventions can reduce symptoms, improve functional capacity and help patients complete advanced directives [10,11]. A recent study by Molloy *et al.* [21] showed how the systematic implementation of a well-designed programme increased advance directive completion and their application in the clinical setting. This programme employed direct patient and proxy education, an advance directive with a range of health care choices and routine provider review of patient preferences. Future studies are needed to determine if such techniques can provide potential benefits in dialysis patients with advanced illness. Moreover, care of the dialysis patient falls not only into the hands of nephrologists, but increasingly involves the expertise of nurses, dietitians and social workers. These providers may interact with patients more frequently than nephrologists, and many patients frequently may discuss issues related to symptoms and HRQoL with such providers. Future studies on the role of palliative care in dialysis patients should be more sustained, include the direct input of patients' family and primary providers and should include dialysis support personnel, as the success of efforts to incorporate palliative care may depend on their valuable input.

This study has several limitations. First, and most importantly, our patient population was of limited size. Although we enrolled all consenting, non-demented HD patients with CCI scores of ≥ 8 , the small sample size may influence the generalizability of our results. Moreover, the disproportionate number of African-Americans and diabetics in our study makes our patient population somewhat unrepresentative of the end-stage renal disease (ESRD) population overall. However, although our findings are limited to ESRD patients with very high co-morbid illness burden, the age, racial background and percentage of diabetics in our study sample are very similar to patients with these high levels of co-morbidity in other studies [13]. This suggests that our results may in fact be generalizable to dialysis patients with this degree of illness. Nonetheless, these findings need to be replicated in larger studies. Secondly, the MSAS-SF, FACIT-Sp and DPCELQ have not been used previously in dialysis patients. Data on their psychometric properties have not been established in this patient population, and such data are needed. We chose to employ the FACIT-Sp because of its perceived applicability to and prior use in severely ill patients such as our study population. The MSAS-SF and FACIT-Sp have been used in tandem in studies of cancer patients, and both instruments have been shown to be responsive to interventions aimed at decreasing symptoms and improving HRQoL in patients with cancer [14]. Moreover, the use of these tools together allowed us to obtain preliminary validity data on both instruments. Thirdly, although our patients' raw scores on the FACIT-Sp and MSAS-SF are similar to those seen in patients with cancer, this does not mean the two populations have comparable HRQoL. Several social,

cultural, ethnic and treatment-related factors must be considered when comparing such scores across disease entities. Nonetheless, our results do show that symptom scores between the two populations are similar, and provide preliminary data regarding the impairments of HRQoL in extremely ill dialysis patients. Future studies should investigate the HRQoL of dialysis patients with various levels of co-morbid illness and whether instruments such as the FACIT-Sp can be used to understand better the issues which impact HRQoL. Fourthly, our review of nephrologist documentation of symptoms was based on chart review during the study period. We did not ask nephrologists directly which symptoms were present nor did we review chart documentation of symptoms before the study period. It is possible that symptoms were recognized yet not documented in the chart or were recorded prior to the initiation of the study and not re-documented. Furthermore, whether palliative care recommendations were instituted was also based on chart review, not on direct questioning of nephrologists. Although chart review may not fully capture the implementation of recommendations, recall bias would almost certainly be a significant problem with direct questioning of nephrologists. Finally, while we enrolled only HD patients, future studies should include patients treated with peritoneal dialysis.

To our knowledge, this is the first study to look at symptom burden, HRQoL and advance care planning in a subgroup of dialysis patients with high levels of co-morbid illness and to assess the acceptability of palliative care to such patients and their nephrologists. Our results suggest that symptoms in these patients are highly prevalent, severe, may be under-assessed by nephrologists, and correlate with HRQoL. Moreover, HRQoL is significantly impaired, and advance care planning is addressed infrequently. These findings provide preliminary evidence that the potential exists for palliative care to make a significant contribution for HD patients with these levels of co-morbid illness. Of equal importance, patient and provider acceptability of such consultations is high. Future studies should incorporate a more sustained, comprehensive, and systematic intervention in a larger sample of patients to define further the role of palliative care in this highly select population of patients, and should determine optimal methods for identifying which patients are most likely to benefit from palliative care.

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