Patient-Centered Advance Care Planning in Dialysis: Phase One

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Due to the high mortality rates and significant symptom burden of dialysis patients, attention to advance care planning (ACP) has grown in the nephrology community. The optimal system for addressing ACP in dialysis units is not known. We report a quality initiative project utilizing a multidisciplinary ACP team, aiming to address ACP in the outpatient dialysis unit setting in a systematic and timely manner. The results suggest that a dedicated ACP program in the dialysis unit setting is a potentially valuable tool for improving advance directive (AD) completion rates in severely ill dialysis patients. Further research of such patient-centered interventions for improving the quality of care of severely ill dialysis patients is warranted.

Background and Significance

Despite significant advances in dialysis technology, endstage renal disease (ESRD) patients have a significant annual mortality rate in excess of 20% (USRDS, 2009). Arnold and Zeidel (2009) noted that, "mortality in this population is so high that it resembles a group of patients with an incurable cancer" (p. 1597). Many ESRD patients experience a significant decline in quality of life as a result of high symptom burden often reported at the end of life (Weisbord, et al., 2005). The dialysis population represents 1% of the Medicare population and accounts for 7% of the Medicare budget; however, many dialysis patients die in hospitals, without hospice services and with significant symptoms of distress and pain (Murray, Arko, Chen, Gilbertson, & Moss, 2006).

In this population, discussions on end of life are often delayed until late in the course of the disease and held in times of crisis, leaving little time for implementing effective end-of-life care (Davison, 2010). Dialysis patients do not receive the end-of-life care they want or need because of either non-existent or poorly designed advance care planning (ACP) interventions (Butcher, 2010). Evidence suggests that patients and family members value early discussions about prognosis, treatment options, and how to prepare for end of life (Holley, 2005; Weisbord et al., 2003). Furthermore, early discussions surrounding end of life and completion of advance directives (AD) in dialysis patients can improve patient quality of life and quality of death (Swartz & Perry, 1993; Weisbord et al., 2003).

Despite fragmentation and inconsistency of ACP in dialysis, guidelines and tools do exist to support successful implementation of programs. Recent parameters for identifying dialysis patients at high risk for dying have been published and can be used as a valuable tool in the ACP intervention process (Cohen, Ruthazer, Moss, & German, 2010). Despite these well-known strategies and interventions aimed at improving quality of life, implementation of ACP programs in dialysis units are not prevalent in the renal community (Moss, 2003). Furthermore, little is known about the effects of in-center patient-focused ACP that utilizes these guidelines and tools.

Although an optimal system for addressing ACP in dialysis units is unknown, we report a quality initiative project utilizing a multidisciplinary ACP team and prognostic indicators to provide effective interventions to patients determined to be at high risk for dying in the dialysis unit. The aims of this initiative involved: 1) creating a framework for addressing ACPs consistently; 2) bridging communication between patients, dialysis staff, the primary care provider (PCP), inpatient providers, and palliative care specialists; 3) creating a multifaceted documentation tool for ACP; and 4) shifting the paradigm of addressing ACP from the inpatient to the outpatient setting.

LITERATURE REVIEW

Patients with ESRD represent a special group of individuals who require comprehensive care that includes planning for end of life. The dialysis population has a shortened life expectancy and symptom burden unlike any other chronically sick population. Growing evidence suggests that the quality of life for dialysis patients at the end of life is less than optimal (Chater, Davison, Germain, & Cohen, 2006; Cohen, Germain, Poppel, Woods, & Kjellstrand, 2000). Researchers have noted the need for more comprehensive approaches to care that improve how practitioners identify patients' end-of-life needs and how they implement endof-life interventions in the dialysis unit setting (Cohen, Germain, Woods, Mirot, & Burleson, 2005; Cohen et al., 2000; Chambers, Germain & Brown, 2004; Emnett, Byock, & Sheils Twohig, 2008). Furthermore, the use of prognostic indicators to identify patients appropriate for palliative care referrals is becoming of more interest to researchers and practitioners as more attention is placed on the significant needs of this population (Cohen et al., 2010).

Note: This study was conducted at the Geisinger Medical Center Outpatient Hemodialysis Unit, 100 Justin Drive, Danville, PA 17822, and the Geisinger Nephrology Clinic, 100 Academy Avenue, Danville, PA 17822.

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Advance Care Planning in Dialysis

Patients with ESRD are often well known to their renal care team due to years of treatment on dialysis and intimate discussions regarding goals of care and symptom management. Ideally, discussions regarding end-of-life care should occur at the beginning stages of dialysis rather than at the end stages of life. Numerous opportunities exist to improve how renal professionals approach end-of-life care planning with dialysis patients at diagnosis and throughout treatment. Furthermore, studies show that patients and families are likely more willing to talk about end-of-life issues than expected (Davison, 2006; Davison, 2010; Moss, 2011). Patients report that they desire more communication and information earlier in their illness about prognosis, how long they can expect to be on dialysis, and what the impact of treatment will be on their daily lives (Russ, Shim, & Kaufman, 2007).

The unique circumstances of this chronically ill population, including the accessibility of patients to staff on a weekly basis in a medical setting, provide extensive opportunities for renal medical teams to develop patient-centered interventions. In the dialysis unit, patients and caregivers have rare opportunities to discuss how patients want to live, what quality of life they want to have, and how they can prepare for the end of life. ESRD patients express much confidence in their renal care team to manage symptoms, address ACP, and provide psychosocial and spiritual support in a timely and effective manner (Davison, 2010). It has been recommended that such planning should emphasize patient and family emotions and focus more on goals of care and less on specific treatments (Tulsky, 2005).

Barriers to Implementation

Despite reports and recommendations for dialysis centers to implement standardized ACP tools, the benchmarks to guide ACP in dialysis units vary among facilities, and are at times non-existent (Davison, 2006; RPA & ASN, 2010). The development and success of ACP for dialysis patients is reported to be challenging because of the sensitive nature of end-of-life issues, coupled with emotional barriers of staff, patients and families. Other challenges include the uncertainty of timing of intervention, inconsistent professional roles, and apprehension among nephrologists about providing early end-of-life interventions without clearly defined prognostic tools (Cohen et al., 2010; Davison & Simpson, 2006; Parascandola, Hawkins, & Danis, 2002). Studies show that the most troubling ethical issues for nephrologists involve starting and stopping dialysis (Cohen, Moss, Weisbord, & Germain, 2006). Furthermore, the postponement of such discussions can lead to urgent decision making, when death seems imminent (Quill, 2000).

Best Practices

Extensive guidelines and recommendations for best practices concerning dialysis patients and ACP are available to renal care providers (Davidson & Torgunrud, 2007; Moss, 2003; RPA & ASN, 2010). However, little research has been done regarding the significance or implementation of ACP pathways in the dialysis unit. Professionals have recommended ACP guidelines that can be used to develop systematic pathways for the dialysis unit setting (Cohen et al., 2010; Davison, 2010; Davison & Torgunrud, 2006; Saini, Murtagh, Dupont, McKinnon, Hatfield, & Saunders, 2006). Despite the diversity in pathways among units, given patient caseload, organizational structure, and staffing, the recommended guidelines provide a framework from which units can develop effective ACP interventions that align with the needs of patients and the agency. Figure 1 represents the Advanced Illness Pathway that was developed for this study and includes both recommended RPA guidelines and goodness of fit for the unit.

Despite existing barriers to implementation of early ACP in dialysis, it is suggested that a multidisciplinary approach to intervention is likely most effective, given the all-encompassing needs of this population (Fasset, Robertson, Mace, Youl, Challenor, & Bull, 2011; Moss, 1997; RPA & ASN, 2010; Young, 2009). Berzoff, Swantkowski, and Cohen (2008) concluded that there needs to be greater education of both patients and families regarding all aspects of the disease process; open communication; ongoing support between patients, families and the staff; continuity of care; pain control; and assistance with ACP. Furthermore, research has indicated that ACP interventions in the dialysis population can lead to desirable outcomes such as a good death, improved sense of hope, and decreased physical suffering (Davison, 2006; Swartz & Perry, 1993; Weisbord et al., 2003).

Emerging evidence suggests that early ACP interventions, guided by validated prognostic indicators and using a multidisciplinary approach, are likely to improve patient quality of life and quality of death (Cohen et al., 2006; Davison, 2010; Holley, 2005; Moss et al., 2008). In order to identify patients with poor prognosis who would benefit from palliative interventions, ACP, and psychosocial, spiritual and bereavement support, there is an increasing demand for more accurate and simple prognostic indicators (Cohen et al., 2006). The mortality calculator is an integrated prognostic model that appears to be a "good fit" for the dialysis population (Cohen et al., 2010). The use of the mortality calculator enables the practitioner to identify more accurately and earlier in the stages of advanced illness a poor prognosis, when referrals to hospice or palliative medicine may be appropriate. The components of the mortality calculator include age, diagnosis of dementia, peripheral vascular disease (PVD), albumin level, and the "surprise question." This prognostic model "lends itself to risk stratification of patients, it is more specific and sensitive than any of its components, and it seems to be a considerable improvement over other existing instruments at predicting survival in the dialysis population" (Cohen et al, 2010, p. 78).

There is existing research that supports the integration of prognostic indicators with early end-of-life planning for

Figure 1. Flow Chart of Advanced Illness Pathway

Advanced Illness Pathway



Key: ACP, advance care planning; AD, advance directive; ESRD, end-stage renal disease; IDT, interdisciplinary team; MD, medical doctor; PCP, primary care physician; RD, registered dietitian; RN, registered nurse; RSW, renal social worker

dialysis patients; however, there are limited studies on the effects of such an approach. The patient-centered approach described in this paper allows for practice that systematically addresses the pervasive needs of both patients and families.

Systematic integration of ACP into dialysis units is a process of sharing information among patients, families, and renal care teams that involves understanding and communication to help patients and family members make end-oflife care decisions (Davison, 2006).

A team approach to intervention ensures effective use of resources in a challenging, always-changing treatment environment. The value of this team approach for dialysis patient care is well documented (Browne, 2012; Porter, 2007; Prescott, 2006; U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, 2008). However, there is scant information regarding its potentially significant benefits for ACP in dialysis settings.

Dialysis professionals provide specialized care throughout the course of a patient's illness, and often until death. Treatment is focused on the medical, nutritional, technical, and psychosocial aspects of care. These significant areas of care are no different in patients with poor prognosis. The lack of a documented multidisciplinary, ACP approach is surprising. The recommended prognostic indicator (i.e., mortality calculator) is multidisciplinary, as its aspects include medical, psychosocial, and nutritional care. Best practice ought to mirror this prognostic tool. This research supports this assertion. Increased attention to this approach to ACP intervention is likely to lead to more positive patient and family outcomes.

STUDY PURPOSES

Given that little research has been conducted on the benefits of ACP in the dialysis unit setting, we conducted a quality improvement (QI) initiative to explore the feasibility of a systematic, multidisciplinary, patient-centered approach to ACP. The purpose of this initiative was to implement a systematic approach to ACP intervention that utilized the expertise of multidisciplinary team members in conjunction with prognostic indicators (i.e., the mortality calculator) to provide a more proactive and patient-focused approach to end-of-life care. At the conclusion of the QI initiative, IRB approval was received to collect data retrospectively in order to evaluate outcomes. Outcomes of interest included: 1) value of prognostic indicator in identifying patients at high risk for dying; 2) frequency of events prior to death such as hospitalizations, referrals to hospice, and referrals to palliative medicine; and 3) AD completion rates.

METHOD

Development of ACP Team

This project started as a quality improvement initiative aimed at several components of ACP in a rural tertiary hospital-affiliated outpatient dialysis unit. An ACP team was assembled in August 2010, consisting of a nephrologist (MD), renal social worker (RSW), unit registered nurse team leader (RN), and a renal dietitian (RD). The team proactively estimated the prognosis of all prevalent dialysis patients, and met quarterly throughout the year to discuss and identify areas of patient need based on their probability of survival. At the monthly dialysis unit's interdisciplinary team (IDT) meetings, attended systematically by a nephrologist and at least two members of the team (RSW and RN), the rounding nephrologists were routinely asked the surprise question, "Would you be surprised if your patient would die in the next 6 months?" Then, specific recommendations on prognosis and ACP were developed. Clinical assessments, combined with prognostic indicator outcomes, were used to identify medical and social needs of patients, and to make appropriate health care and community referrals.

Prognostic Indicators

Rounding nephrologists were each asked systematically during monthly IDT meetings if they would be surprised if their patient would die in 6 months. A "no" answer to the "surprise" question, conferred a 3.5 higher odds of dying within 1 year, in a prospective cohort of 147 patients at 3 hemodialysis units (Moss et al., 2008). The prognosis of prevalent dialysis patients was then estimated monthly using an available prognostic tool endorsed by available guidelines [available at http://touchcalc.com/calculators/ sq] (RPA & ASN, 2010). This online survival estimator tool for dialysis patients was developed, based on the study of Cohen et al. (2010), and uses several simple, readily available parameters (age, serum albumin, presence or absence of dementia and/or peripheral vascular disease, and the answer to the "surprise" question). This prognostic model was developed in a large cohort of prevalent dialysis patients and was prospectively validated with an excellent area under the curve of 0.80 (95% CI 0.73 to 0.88) in another validation cohort of 514 patients from 8 dialysis clinics (Cohen, 2010).

Usual Care in Our Dialysis Unit

All patients in the unit receive standard AD education at admission and yearly thereafter, or with a change of clinical condition. Monthly interdisciplinary team meetings are held as per Centers for Medicare & Medicaid Services (CMS) guidelines. Family conferences and referrals to palliative medicine or hospice are made at the discretion of primary nephrologists. Patients who express their desire to stop dialysis are evaluated and screened for psychosocial interventions by the unit social worker, and appropriate specialty referrals are requested at the discretion of the primary nephrologists.

Advanced Illness Pathway (AIP)

RESULTS

The Advanced Illness Pathway is a biopsychosocial tool that instructs dialysis professionals on how to assess and treat patients who are identified as high risk for dying. Prevalent dialysis patients were selected for the advanced illness pathway (AIP) if nephrologists had a negative answer to the surprise question, or if patients' probability of survival at 18 months was less than 80% per the mortality calculator; if they had more than three admissions to the hospital a period of 30 days; a weight loss of more than 10% body weight; a diagnosis of a terminal illness other than ESRD; poor reported quality of life; or if they requested to withdraw from dialysis treatment.

Patients in the AIP were systematically asked whether they had ADs and were provided with education regarding ACP. When AD were not available or completed, the social worker met individually with the patients and their families and provided additional education and support during dialysis hours with additional phone calls during off hours.

Conferences between patients, families, and staff, including primary nephrologists, were facilitated by the ACP team when conflicts regarding goals of care were perceived or if additional information for decision making was felt necessary.

Documentation

A "template-ed" note entitled, "The Advance Care Planning Social Work Note," was completed in the dialysis unit electronic health record (EpicCareTM) at patient enrollment in the AIP; after each interdisciplinary team meeting; and when patients' conditions changed. The forms contained the dialysis team's assessment and recommendations regarding ADs, referrals to palliative care, or changes in code status (see Figure 2). The notes were submitted for review, edited, and electronically signed by the rounding nephrologists, and then electronically filed and sent by the social worker to primary care physicians and other key subspecialty physicians involved in patients' care.

Data Collection

Demographic and clinical data for estimation of survival was collected prospectively in an MS Excel database accessible to all ACP team members. The ACP team reviewed aggregate results of patient data quarterly.

Patients names were censored at death or at the end of the study, whichever occurred first. Outcomes of interest for our dialysis unit were: AD completion rates, referrals to palliative medicine, number of hospitalizations prior to death, and referrals to hospice. The study was approved by the Geisinger Internal Review Board.

Data was analyzed using descriptive statistics (i.e., means, modes, standard deviations).

Between August 1, 2010, and August 1, 2011, 105 patients received dialysis at the Justin Drive GMC Dialysis unit in Danville, PA. Sixteen patients (15%) died in our unit during the 12 months of followup.

Twenty-eight patients were excluded from the study: 16 transferred to other dialysis centers during the follow up; 4 changed to a home treatment modalities; 3 recovered renal function; 4 received a kidney transplant; and 1 died unexpectedly.

Of the remaining 77 prevalent patients reviewed, 48 met criteria for advanced illness and were included in the AIP group. 29 patients met the criteria for the non-AIP group. Demographic and clinical characteristics of these patients are presented in Table 1. Relevant variables of interest of the prevalent dialysis patients are presented in Table 2.

The mean 18-month estimated survival at enrollment in the AIP group was 56.5% (S.D. 23.8), compared with 90% (S.D. 4.2) in the other patients in our unit. Overall, AD completion rate for prevalent patients in our unit increased from 28.5 % (22 of 77) at baseline to 48% (37 of 77) at 1 year. In the AIP group, AD completion increased from 29% (14 of 48) dialysis patients to 60% (29 of 48) at 1 year.

During the follow-up period, 16 prevalent patients (19.2% of the AIP group) ages 62 to 88, of which 8 were men, died. Of these, 14 (87.5%) were identified to have a survival of less than 80% at 18 months (qualifying for the AIP pathway) and 2 (12.5%) who did not meet the AIP guidelines died unexpectedly. Important patient-centric outcomes in the deceased patients in both groups are presented in Table 3. In the deceased patients in the AIP group, AD completion increased from 5/14 (37.7%) to 11/14 (71.4%) during the year of follow up, 9 (64.2%) were hospitalized within one month prior to death, 7 (50%) were referred to hospice, and 4 (28.5%) were referred to palliative medicine prior to demise.

DISCUSSION

The data from our quality initiative project suggests that a multidisciplinary team approach involving proactive identification of dialysis patients with advanced illness, as well as a systematic persistent approach to ACP, has a positive impact on AD completion rates in a hospital-affiliated dialysis unit. It is evident this study demonstrates that a patient-centered multidisciplinary approach to ACP is of value to the dialysis population. Further integration of palliative medicine into the dialysis unit setting is warranted given these findings.

Given the heterogeneity of dialysis patients, it seems unlikely that renal professionals will be able to provide a single universal ACP protocol that is applicable to all dialysis patients. Still, the value and benefits of early ACP are likely to have a significant impact on overall patient quality of life through early referrals to palliative medicine and

Figure 2. Advance Care Planning Social Work Note

Dialysis Advance Care Planning Social Work Note GMC Outpatient Dialysis Unit Justin Drive			
[Mr./Ms./name] has been seen today for monthly advance care planning.			
Present today were [Mr./Mrs./name, ***], [health care proxy***], [family member***] and [myself***].	, [Dr.***], [Dr.***],		
Patient Condition (include issues that qualify patient for being in the AIP or ACP protoco Albumin < 3.0 mg/dL	1):		
\Box > 3 admissions to the hospital in the past 3 months \Box Weight loss > 10% body weight			
□ Terminal Illness other than ESRD (for reference only) □ Poor reported quality of life. Reason: [***] □ Patient request to withdraw treatment			
<u>Comfort Issues:</u> Patient's perceptions of his/her condition [***] Patient's perceptions of his/her prognosis [***] Patient's perceptions of his/her goals of care [***]			
Advance Care Planning: Living will/5 wishes completed. Y / N			
Health care proxy designated. Y / N Goals of care questionnaire completed. Y / N			
Assessment: The patient has been identified as benefiting from end-of-life counseling.			
Plan: Counseling: [***] Discussed in detail patient's condition/prognosis and options			
Free text: [***]			
Symptom management will be discussed with [Dr.***] (primary attending nephrologist) Referral:			
□Hospice □Palliative Medicine □Other [***]			
Links to the most recent advance care documents [***]			

Demographics	$\mathbf{AIP Group} \\ (n = 48)$	Non-AIP Group $(n = 29)$
Females (%)	23 (47.9)	10 (34.4)
Median Age (S.D.)	76 (9.7)	58.2 (13.6)
Caucasians (%)	100	93
Median time (months) on dialysis (S.D.)	37.7 (39.8)	53.5 (44.4)
Comorbid conditions n (%)		
Congestive heart failure	38 (79.1%)	12 (41.3%)
HTN	39 (81.2%)	27 (93.1%)
Peripheral vascular disease	5 (10.4%)	3 (10.3%)
Diabetes	28 (58.3%)	12 (41.3%)
Cancer	6 (12.5%)	5 (17.2%)
Dementia	4 (8.3%)	0

Table 2. Relevant Variables of Interest of Prevalent Dialysis Patients

	AIP Group (n = 48)	Non-AIP Group $(n = 29)$
Relevant variables of interest as of 8/1/2010		
Advance directives completed	14	8
Relevant variables of interest as of 8/1/2011		
Deaths	14	2
Total number of hospitalizations during 12 months	67	20
Hospitalized within 30 days prior to death	11	2
Palliative care referrals	7	0
Hospice referrals	6	0
Advanced directives completed	29	8

Table 3. Observed Values of End-of-Life Indicators for Deceased Patients

End-of-Life Indicators	AIP Group $(n = 14)$	Non-AIP Group $(n = 2)$
Mean initial predicted survival at 18 months (S.D.)	41.3% (28)	88.5% (7.8)
Mean initial predicted survival at 12 months (S.D.)	55.3% (27.9)	93% (4.2)
Mean initial predicted survival at 6 months (S.D.)	75.4% (21.1)	97.5% (2.1)
Advance directives at start of QI Project	37.7%	50%
Advance directive prior to death	71.4%	100%
Hospitalized at 30 days or < before death	64.2%	100%
Referred to hospice before death	50%	0%
Referred to palliative medicine before death	28.5%	0%

Key: S.D. = standard deviation

hospice, and early discussions surrounding patient goals for end of life. More research is needed to investigate the value of ACP for dialysis patients who are at high risk for dying, particularly as it relates to outcomes for patients, families, and renal care providers. Despite evidence that hospice in ESRD patients leads to decreased reports of pain, improved quality of life and considerable cost savings, research suggests that ESRD patients and family members have end-oflife care preferences and needs that continue to be unmet (Davison, 2010; Davison & Simpson, 2006; Murry, et al., 2006; Thompson, Bhargava, Bachelder, Bova-Collis, & Moss, 2008).

There are also potential benefits associated with early ACP intervention for renal providers, such as improved job satisfaction, and decreased compassion fatigue. However, little information exists regarding the relationship between dialysis staff "burnout" rates and patients' end-of-life care needs. As the dialysis environment continues to evolve in response to the aging population and the changing work environment, awareness of the effects of ACP programs on staff outcomes will likely increase.

Successful future interdisciplinary ACP initiatives will benefit from education and support for all dialysis unit staff. For this ACP project, the primary interdisciplinary care team, along with front-line dialysis nursing and technician staff, were educated regarding the initiative and provided with support and information to ensure consistency regarding end-of-life interventions and care. Overall, staff reported increased comfort knowing that there was an initiative in the unit to address patients' end-of-life needs. During this initiative, staff also responded favorably to the protocol and integrated the ACP initiative into their practices. Although no formal assessment was completed to investigate the responses of patients and family members to the initiative, members of the ACP team, along with dialysis staff, reported that patient and family members appreciated having the opportunity to discuss end-of-life care, including pain control, ADs, and information regarding palliative and hospice care.

As the implementation of ACP programs in dialysis units is increasing, how patients and providers view ACP will greatly depend upon how renal care teams can help patients to overcome misconceptions regarding ACP, end of life, quality of life, and quality of death. The introduction of ACP at the initiation of dialysis, rather than at the "withdrawal stage," offers a more systematic approach in keeping with a continuum of care over time. This is more patient-centered, targeted at reducing symptom burden and increasing of quality of life. The relationship between early ACP, adverse outcomes (e.g., hospitalizations), and a good death is an important aspect of dialysis treatment and requires further exploration to ensure effective interventions and positive outcomes for patients and the health care community.

Renal care teams will continue to play an integral part in developing and implementing patient-centered ACP programs. An interdisciplinary approach, coupled with utilization of recommended prognostic indicators and clinical guidelines, in addition to ongoing comprehensive reviews of patients' needs and the health care environment, will ensure best practices in the dialysis unit setting.

FUTURE GOALS

Desired short- and long-term outcomes for the project include: 1) improved patient/family quality of life; 2) improved communication among health care providers in the Geisinger System; 3) decreased hospitalizations; 4) improved quality of mortality; 5) improved AD completion rates; 6) improved staff coping abilities; 7) introduction of a second phase of the initiative involving the integration of palliative medicine as an adjunct to outpatient dialysis care; and 8) application of the KDQOL-36 as an additional prognostic tool for hospitalization and mortality.

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