

PALLIATIVE CARE EDUCATION IN END-STAGE RENAL DISEASE  
PATIENTS UNDERGOING HEMODIALYSIS

by

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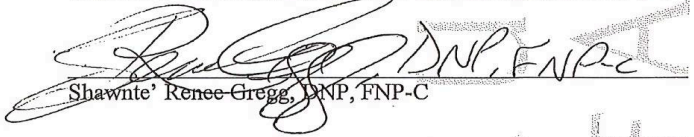
As members of the DNP Project Committee, we certify that we have read the DNP project prepared by Kristian Angelo Dumelod Oarde entitled "Palliative Care Education on End-stage Renal Disease Patients Undergoing Hemodialysis" and recommend that it be accepted as fulfilling the DNP project requirement for the Degree of Doctor of Nursing Practice.

  
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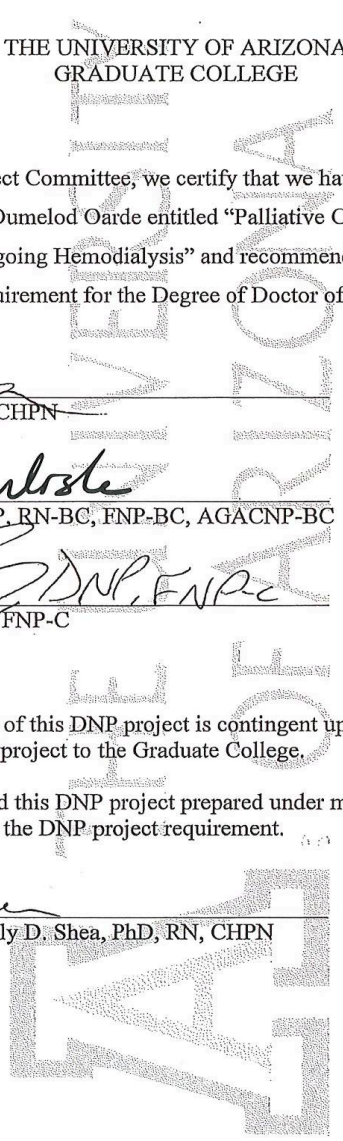
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I hereby certify that I have read this DNP project prepared under my direction and recommend that it be accepted as fulfilling the DNP project requirement.

  
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SIGNED: Kristian Angelo Dumelod Oarde

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## ABSTRACT

**Background:** End-stage renal disease (ESRD) is a chronic medical condition where 90% or more of the kidneys are nonfunctional (Doig & Huether, 2014). The current treatment for ESRD is Hemodialysis [HD] (National Institute of Diabetes and Digestive and Kidney Disease [NIDDK], 2013). Individuals who have ESRD who undergo HD suffer from tremendous symptom and treatment burden that affects various facets of life (Axelsson, Klang, Hagelin, Jacobson, & Gleissman, 2014; Axelsson et al., 2012; Tamura & Cohen, 2010). Unfortunately, the symptom and treatment burden associated with ESRD are underrecognized and undertreated (Feely et al., 2016; Gelfman & Meyer, 2012; Murtagh, Addington-Hall, & Higginson, 2007; Russon & Mooney, 2010; Tamura & Meier, 2013).

**Purpose:** The purpose of this quality improvement project is to explore if ESRD patients in Davita Desert Dialysis are knowledgeable about palliative care and if providing education might change their behavior. The primary aim is to create awareness in patients about PC services in an effort to improve their quality of care through education.

**Design:** A quantitative pre- and post survey approach using qualtrics software was utilized to assess the baseline and post-education knowledge of patients who met the inclusion criteria.

**Setting:** DaVita Desert Dialysis, Sun City, AZ.

**Intervention:** The educational intervention is the viewing of a three-minute voice over presentation about palliative care.

**Limitations:** The sample size was small and exposes this study to marked bias and non-generalizability due to the limited number of recruited individuals.

Results: One hundred percent of the individuals in the posttest had better awareness about and knowledge about PC.

Conclusion: PC can improve the quality of life of patients that suffer from the undertreated and underrecognized symptom and treatment burden (Tamura & Meier, 2013). Further data and studies will be needed to establish PC in the field of nephrology as it relates to the ESRD population undergoing HD. However, the quality improvement focus of increasing PC awareness among ESRD patients undergoing HD has shown great promise as all participants had increased awareness, knowledge availability, and readiness for PC services.

## INTRODUCTION

### Background Knowledge

End-stage renal disease (ESRD) is a chronic medical condition where 90% or more of the kidneys are nonfunctional (Doig & Huether, 2014). It is a debilitating condition affecting millions of patients and their families (Russon & Mooney, 2010; Wasylynuk & Davison, 2015). The current treatment for ESRD is Hemodialysis (HD) (National Institute of Diabetes and Digestive and Kidney Disease [NIDDK], 2013). HD patients are attached to a machine to rid the blood of harmful wastes that is normally carried out by healthy and functioning kidneys (NIDDK, 2013). HD occurs three to four times a week with each session lasting three to four hours at a time (NIDDK, 2013). It requires lifelong adherence to the treatment, medication, and diet regimen that can negatively affect the quality of life of individuals with ESRD (Axelsson, Randers, Jacobson, & Klang, 2012).

Although HD is considered a lifesaving and prolonging measure, it fails to restore health (Tamura & Cohen, 2010; Yong et al., 2009). Individuals who have ESRD who undergo HD suffer from tremendous symptom and treatment burden that affects various facets of life (Axelsson, Klang, Hagelin, Jacobson, & Gleissman, 2014; Axelsson et al., 2012; Tamura & Cohen, 2010). These patients suffer from fatigue/tiredness (71%), pruritus (55%), constipation (53%), anorexia (49%), pain (47%), sleep disturbances (44%), anxiety (38%), dyspnea (35%), nausea (33%), restless legs (30%), and depression (27%) (Murtagh, Addington-Hall, & Higginson, 2007). ESRD and HD carries a considerable burden of disease symptoms and comorbidities (Axelsson et al., 2012; Belasco & Sesso, 2002; Culp et al., 2016; Eneanya et al., 2015; Feeg & Elebiary, 2005; Joshi, 2014; Murtagh, Addington-Hall, & Higginson, 2007;

Tamura & Meier, 2013; Weisbord et al., 2012; Yong et al., 2009) and carries a prognosis similar to cancer (Eneanya et al., 2015; Russon & Mooney, 2010).

Unfortunately, the symptom and treatment burden associated with ESRD are under recognized and undertreated (Feely et al., 2016; Gelfman & Meyer, 2012; Murtagh, Addington-Hall, & Higginson, 2007; Russon & Mooney, 2010; Tamura & Meier, 2013). The Renal Physicians Association (RPA) responded by creating a Clinical Practice Guideline (CPG) that addresses palliative care and symptom management through the shared decision making in the appropriate initiation and withdrawal from dialysis (2010). In order to improve patient-centered outcomes, the RPA recommended that palliative care (PC) services and interventions be offered to all acute kidney injury (AKI), chronic kidney disease (CKD), and ESRD patients who suffer from the disease and treatment burden (RPA, 2010). Regrettably, the underrecognition and undertreatment of symptoms associated with ESRD patients undergoing HD continued. Recent studies reported that symptoms such as weakness (69-79%), poor mobility (44%), drowsiness (44%), pain (64%) persists after the CPG implementation (Lowney et al., 2015; Raj, Ahuja, Frandsen, & Jose, 2017). The poor recognition and undertreatment of symptoms associated with the disease process creates a gap in the care of ESRD patients undergoing HD. This gap in care can be ameliorated by PC utilization.

### **Local Problem**

As an experienced nurse who takes care of patients with ESRD undergoing HD, there is a lack of use and awareness of PC (Tuot & Boulware, 2017). It is not clear whether this is caused by an inadequate exposure to the information or overload of information when they visit their nephrologist or Primary Care Physicians (PCP). As recommended in the CPG, effective PC

should be offered and provided regardless of whether the patient decided to undergo HD, rejected or declined HD, or discontinue HD (RPA, 2010). However, through research and various encounters with patients with ESRD undergoing HD and their families, there is a persistently low level of awareness about PC or its applicability to their disease process and situation (Tuot & Boulware, 2017).

### **Purpose**

The purpose of this quality improvement (QI) project is to explore if ESRD patients in Davita Desert Dialysis are knowledgeable about palliative care and if providing education might change their behavior. The project examined the unmet education needs of ESRD patients undergoing HD at Davita Desert Dialysis in Sun City, AZ. The primary aim is to create awareness in patients about PC services in an effort to improve their quality of care through education. According to the study by Tuot and Boulware (2017), awareness about ESRD only ranges from 6% to 12% while provider recognition rate of kidney disease awareness is at 6% to 50% depending on the severity of the disease. With the creation of patient awareness, patients can strengthen the patient-provider relationship while creating responsibility and accountability with their providers that can improve clinical outcomes and improve their quality of life. Based on literature reviews (Table 1), there have been no studies that employ the approach of PC education for ESRD patients to address the underrecognized and undertreated burdens of the disease and its treatment.

TABLE 1. *Synthesis of Evidence*

| Reference  | Research Question/Hypothesis   | Study Design               | Sample | Methods for Data Collection and Analysis   | Findings  |
|--|--|----------------------------|--------|--|---|
| Axelsson, L., Klang, B., Hagelin, C. L., Jacobson, S. H., & Gleissman. (2014). Meanings of being a close relative of a family member treated with haemodialysis approaching end of life. | To illuminate to what it means to be a relative of a severely ill family member undergoing HD. | Qualitative interpretative | N=14   | Qualitative interviews were utilized and through audio recording which were transcribed verbatim | <ul style="list-style-type: none"> <li>-ESRD patients suffer from multiple complex comorbidities and higher mortality rates.</li> <li>-Patients with ESRD undergoing HD suffers from an impaired quality of life secondary to significant symptom burden associated with the disease process.</li> <li>-Family of patients with ESRD also suffer from the symptom burden associated with ESRD and its treatment.</li> <li>-Assisting in the care of the patient with ESRD undergoing HD can dominate the life of the family member, restrict their freedom, and has been described as taking care of someone at the expense of one's own health.</li> <li>-Symptom burden and the decreased quality of life associated with ESRD creates family strain and burden.</li> <li>-Being a burden is one of the reasons ESRD patients decide to discontinue HD.</li> <li>-Being a family member of a patient with ESRD means living a life that is progressively burdened and heavy, but meaningful.</li> <li>- <i>“Close relatives strive for balance and well-being accompanying their ill family member through the end of life. They are facing dilemmas and growing demands as their responsibilities increase with the deterioration of their family member. Findings show that support and interaction with the healthcare professionals is of significance and that showing a will to understand relatives' perspective is of vital importance for how the situation is perceived. Findings indicate that open communication and acknowledgement may alleviate their suffering.”</i></li> </ul> |

TABLE 1 – *Continued*

| Reference   | Research Question/<br>Hypothesis  | Study Design  | Sample                                   | Methods for Data Collection and Analysis | Findings  |
|---|---|---------------|--|--|---|
| Belasco, A. G., & Sesso, R. (2002). Burden and quality of life of caregivers for hemodialysis patients. | To depict characteristics of caregivers of the HD patients and their perceived burden and factors influencing it and quality of life. | Mixed methods | Caregivers<br>N=100<br>Patients<br>N=100 | Interviews and questionnaires            | <p>-Burden on families has increased to provide care and support for patients of advanced age and comorbid conditions alongside the symptom and treatment burden of ESRD.</p> <p>Chronic caregiver stress results in high physical and mental disturbances—<i>anxiety fatigue, deterioration in family relations, and social isolation</i> occurs when family members assume dialysis care.</p> <p>-Physicians and nurses should be vigilant and should explore the experiences of caregivers and monitor for signs of depression, provide support, and referrals for follow-up care.</p> <p>-Presence of the members of the interprofessional team such as a social worker can help alleviate caregiver burden through counseling and support that would benefit both patients and their families.</p> <p>-Having a family member on HD creates more family burden compared to other chronic medical conditions.</p> <p>-Family/caregiver support should further be explored to improve psychological well-being of family/caregivers.</p> |

TABLE 1 – *Continued*

| Reference  | Research Question/<br>Hypothesis  | Study Design                       | Sample   | Methods for Data Collection and Analysis  | Findings   |
|--|---|------------------------------------|--|---|--|
| Bharadwaj, P., Helfen, K. M., Deleon, L. J., Thompson, D. M., Ward, J. R., Patterson, J., ... Bleznak, A. D. (2016). Making the case for palliative care at the system level: Outcomes data. | To showcase and prove the benefits of PC in a system level  | Quantitative: descriptive          | Study 1<br>N=540<br><br>Study 2<br>Hospital stay<br>N=144<br>ICU LOS<br>N=57<br><br>Five studies total, the other 3 studies utilized monetary counts | Retrospective review of medical records in 7 hospitals measured in LOS, mortality, readmission, saved ICU days, cost avoidance, and hospice referrals.  | -Early use of PC upon admission can decrease LOS (5.08 days), decrease in cost of care by 40% (\$2,362 per day), decreased mortality rate (1.01 vs 1.10), decrease in readmission rate in 30 (61.5%), 60 (47%), and 90 (42.1%) days after PC consultation.<br>-In one pilot study in 2014 with a full-time PC physician in the ICU, reduction in cost was more than \$600,000 and produced 315 saved ICU days, annually.<br>-Early involvement of PC can improve care, decrease cost of care, improve quality, and increase ICU saved days.  |
| Brown, L., Gardner, G., & Bonner, A. (2015). A randomized controlled trial protocol testing a decision support intervention for older patients with advanced kidney disease.                 | To assess the effectiveness of a decision support intervention for older adults when they reach ESRD. | Multisite randomized control trial | N=122  | Data collection tools used are the decision regret scale, the decision conflict scale, a knowledge questionnaire to improve knowledge of options and benefits, quality of life through the KDQOL-SF v1-3 survey | -Healthcare expenditure is expected to rise due to the ageing populations increasing lifespan and the prevalence of chronic diseases.<br>-CKD is one of the most common causes of morbidity and early death (Couser et al., 2011).<br>-ESRD is the most severe form of kidney disease.<br>-The most common cause of death in ESRD worldwide is the withdrawal of HD (Brown et al., 2014).<br>-Most common cause of withdrawal is psychological (McDonald et al., 2010).<br>-There is no discussion of end of life care<br>-50% of ESRD wanted end of life care and with only 10% occurrence rate.<br>-Decision support intervention tool can assist whether to choose dialysis vs non-dialysis - approaches as these decisions have high decisional conflict—high decision regret. |



TABLE 1 – *Continued*

| Reference   | Research Question/<br>Hypothesis  | Study Design                     | Sample   | Methods for Data Collection and Analysis | Findings  |
|---|---|----------------------------------|--|--|---|
| Culp, S., Lupu, D., Arenella, C., Armistead, & Moss, A. H. (2016). Unmet supportive care needs in the U.S. dialysis centers and lack of knowledge of available resources to address them. | To describe the perceptions of adequate supportive care, barriers, suggestions for improvement, and discuss familiarity with EBP resources for supportive care. | Quantitative:<br>survey research | N=487<br>Nephro= 41,<br>NP/PA= 146,<br>Social worker= 199,<br>HD admin= 95 | Online survey                            | <p>-HD patients suffer from high symptom burden from ESRD and comorbidities and are suitable candidates for early and continuous supportive care.</p> <p>-Older patients with multiple comorbidities who are initiated in renal replacement therapy has been associated with poor outcomes, quality of life, and functional status.</p> <p>-Highest incidence rates for initiating dialysis: 75 years old, followed by 65 to 74 age group.</p> <p>-High mortality rates are associated with initiating HD with advanced age and unrelieved symptom and treatment burden.</p> <p>-Supportive care=palliative care</p> <p>-4.5% of respondents believed they were providing adequate supportive and end of life care.</p> <p>-Top 5 barriers to providing high quality supportive care includes:</p> <ol style="list-style-type: none"> <li>1. no formal mechanism (such as a predictive algorithm) for identifying which patients are at high risk of dying within six months</li> <li>2. patient reluctance to discuss</li> <li>3. no specific policy to follow for providing end-of-life care</li> <li>4. no formal assessment of patients who are nearing end of life.</li> <li>5. no formal goal setting and care planning related to end-of-life patient care.</li> </ol> |

TABLE 1 – *Continued*

| Reference   | Research Question/Hypothesis  | Study Design                      | Sample | Methods for Data Collection and Analysis  | Findings   |
|---|---|-----------------------------------|--------|---|--|
| Feely, M. A. Swetz, K., M., Zavaleta, K., Thorsteinsdottir, B., Albright, R. B., & Williams, A. W. (2016). Reengineering dialysis: The role of palliative medicine. | Determining feasibility of incorporating palliative medicine consultation during HD treatments and its impact on the management of symptoms and advanced care planning. | Single center prospective cohort  | N=91   | Review of medical records<br><br>The modified Edmonton Symptom Assessment Scale (MESAS) used to assess symptom burden   | <ul style="list-style-type: none"> <li>-Determining feasibility of incorporating palliative medicine consultation during HD treatments and its impact on the management of symptoms and advanced care planning.</li> <li>-Patients undergoing HD have a shorter life span compared to same aged peers with under recognized symptom burden.</li> <li>-Cognitive impairment in HD patients are three folds more compared to same aged peers</li> <li>-Due to the treatment burden, non-HD becomes too precious to participate in other medical related activities such as referral to outpatient PC consultations.</li> <li>-Palliative care consultation was well received by patients and clinical staff during HD runs</li> <li>-High or greater engagement by clinical staff/team assist in the management of the symptoms creates better QOL for patients</li> </ul> |
| Joshi, V. D. (2014). Quality of life in end stage renal disease patients  | To identify and understand factors related to QOL, instruments, and identification of needs for improvement of QOL  | Quantitative: Retrospective study | N=65   | MEDLINE, PubMed, Google Scholar were utilized with the inclusion criteria of adults >18 with CKD or ESRD, English language, with the keywords quantitative/qualitative studies, reviews, reports, quality of life questionnaire manuals | <ul style="list-style-type: none"> <li>-The treatment burden of ESRD places constraints to the QOL of patients affected by the disease.</li> <li>-The patient's perception is more important than the clinical assessment of QOL.</li> <li>-Most QOL instruments are quantitative, but QOL is qualitative suggesting that further qualitative evidence is needed to be assessed and understood.</li> <li>-Cultural difference affects the shaping or meaning of QOL for each individual</li> <li>-New and up to date QOL instruments are needed to will keep up with the current advancement in healthcare and technology.</li> <li>-Palliative care is underutilized especially in the renal or ESRD population and can assist in improved QOL.</li> </ul>  |

TABLE 1 – *Continued*

| Reference   | Research Question/Hypothesis  | Study Design      | Sample   | Methods for Data Collection and Analysis  | Findings  |
|---|---|-------------------|--|---|---|
| Murtagh, F. E. M., Addington-Hall, J., & Higginson, I. J. (2007). The prevalence of symptoms in end-stage renal disease: A systematic review. | This SR is aimed in the identification and severity of the symptoms experienced by ESRD patients. | Systematic review | 11,695 papers, 61 studies met inclusion criteria | Use of a standardized predesigned form to collate study details and findings on key quality criteria. | <ul style="list-style-type: none"> <li>-Symptoms in ESRD are unrecognized.</li> <li>-Most studies are focused on one symptom and not on the whole experience.</li> <li>-Symptoms include fatigue: 71%, pruritis: 55%, constipation: 53%, anorexia: 49%, pain: 47%, sleep disturbance: 44%, anxiety: 38%, and depression: 27%.-Understanding of survival predictors and disease and treatment burden is imperative.</li> <li>-Good symptom management is identified as a priority of patients.</li> <li>-A patient centered approach is recommended as patients identify recognition, acknowledgement, and alleviation of symptoms as of the highest priority.</li> <li>-Effective symptom management can improve quality of life for ESRD patients.</li> <li>-There is lack of evidence in the end of life care for patients with ESRD.</li> <li>-There is a considerable GAP in the understanding of the disease and treatment symptoms ESRD patients experience.</li> </ul> |

TABLE 1 – *Continued*

| Reference  | Research Question/Hypothesis  | Study Design      | Sample  | Methods for Data Collection and Analysis  | Findings   |
|--|---|-------------------|---|---|--|
| O'Connor, N. R., & Kumar, P. (2012). Conservative management of end-stage renal disease without dialysis: A systematic review. | Summary of evidence on non-HD alternatives regarding prognosis, symptom burden, and QOL | Systematic review | 13 articles<br>-7 cohort studies<br>-5 cross sectional studies<br>-1 obs. study | - MEDLINE, CINAHL, and Cochrane library were searched in any language starting March 2011 with searched keywords of end-stage renal disease or end-stage renal failure or stage 5 CKD or advanced CKD and nondialytic or conservative management or palliative care | <p>-The elderly is the fastest growing dialysis population.</p> <p>-There are more comorbidities associated with the elderly population leading to an increased morbidity and mortality.</p> <p>-In response to the rapidly aging population, non-dialytic alternatives should be considered for patients where the treatment and symptom burden outweighs the benefits.</p> <p>-Alternative (non-HD intervention) management for HD includes careful attention to fluid balance, anemia treatment, correction of acidosis and hyperkalemia, blood pressure management, and individualize symptom management to maximize QOL.</p> <p>-Clinicians are unfamiliar with conservative treatment without HD.</p> <p>-HD can be expected to prolong life, but careful consideration is needed to include cost, infection, vascular access issues, and fluctuating blood pressure.</p> <p>-HD patients spend more time in the hospital versus patients managed conservatively (25 vs 16 days per patient per year).</p> <p>-Patient priorities differ from family in prolonging life vs maximizing time at home.</p> <p>-Patients may live months to years after deciding not to start dialysis, HD withdrawal results in imminent death.</p> |

TABLE 1 – *Continued*

| Reference  | Research Question/Hypothesis                                       | Study Design                      | Sample | Methods for Data Collection and Analysis   | Findings  |
|--|--|-----------------------------------|--------|--|---|
| Yong, D. S. P., Kwok, A. O. L., Wong, D. M. L., Suen, M. H. P., Chen, W. T., & Tse, D. M. W. (2009). Symptom burden and quality of life in end-stage renal disease: A study of 179 patients on dialysis and palliative care. | Exploring the symptom burden and QOL of ESRD patients on HD and PC | Prospective cross-sectional study | N=179  | Demographic data: age, gender, socioeconomic variables<br><br>Data related to clinical status included Charlson comorbidity index (CCI), mode of dialysis, duration, comorbid condition were scored from 1 to 6. QOL assessment utilized the Medical Outcomes Short Form 36 Health Survey (Chinese version). | <p>-HD is life prolonging but has considerable symptom burden that affects a patient's quality of life.</p> <p>-Other comorbidities of patients contribute to the decrease in QOL experienced by ESRD patients.</p> <p>-PC on cancer patients is well established while PC in ESRD is only starting to develop.</p> <p>-Renal PC can assist in the disease management but as well in the management of disease related physical, psychosocial, and spiritual issues/symptoms.</p> |

Key stakeholders that would benefit from this study are the patients, their families, and the organization. With patients, there is a direct correlation with the use of PC and improved quality of life (Bharadwaj et al., 2016; Culp et al., 2016; Gelfman & Meyer, 2012; Joshi, 2014; Murtagh, Addington-Hall, & Higginson, 2007; Tamura & Meier, 2013; Yong, et al., 2009). High family and caregiver burden created by the symptom and treatment burden of ESRD and HD can be alleviated PC (Get Palliative, 2012; Tamura & Meier, 2013). The organization will benefit from PC through the provision of high quality and low cost care with high patient satisfaction (Bharadwaj et al., 2016). Other key stakeholders that may benefit from this study includes the ESRD community, the nephrology/PCP providers, and policymakers.

### **Study Question**

In adult end-stage renal disease patients undergoing hemodialysis, does increased palliative care education increase palliative care awareness and therefore their understanding of palliative care?

## **FRAMEWORK, CONCEPTS AND SYNTHESIS OF EVIDENCE**

### **Theoretical Framework**

The Transtheoretical Model (TTM) is a stage-based theory that proposes behavioral change is through a series of stages (Bridle et al., 2005). The TTM focuses on facilitating intentional change aimed on when, how, and what changes occur when behaviors are modified (Prochaska & DiClemente, 1986). TTM was originally designed through the integration of theories of psychotherapy and behavioral change (Prochaska, 2008). The TTM for this QI served to not limit or control the patient and the “stage” that they are in but rather to guide and encourage patients through education to move forward, increase awareness, and utilize PC

services. The TTM is composed of a series of stages: precontemplation, contemplation, preparation, action, maintenance, and termination (Prochaska, 2008). The stages utilized in this QI project includes the first three stages of the TTM.

### **Precontemplation**

This is the stage where an individual is not intending to take an action in the future or next six months. This may be due to being uninformed, underinformed, or lack of awareness about the significance of a behavior (Prochaska, 2008).

### **Contemplation**

Contemplation is the stage where an individual intends to make changes in the next six months (Prochaska, 2008). This stage is characterized by ambivalence towards a change in behavior and where decisions are weighed heavily with the benefits and drawbacks of the intended change (Prochaska, 2008).

### **Preparation**

In this stage, the patient intends to make changes in the near future (Prochaska, 2008). Individuals prepare to make specific changes based on their decision to move on where small steps are taken towards the behavior/change (Prochaska, 2008).

The advanced practice nurse-patient relationship will play a critical role in the education, problem solving, and in the promotion of effective health management in ESRD patients undergoing HD through PC. Through the TTM model, individuals who were not aware were educated about the use and purposes of palliative care, how it can positively affect their quality of life, and how they can be assisted by APNs through the various stages of TTM.

## Concepts

PC is a specialized medical care utilizing an interprofessional team to provide holistic care to patients and their families (Get Palliative, 2012). It is a team comprised of physicians, advanced practice nurses, registered nurses, psychologists, dietitians, social workers and case managers, nursing assistants, chaplains, bereavement coordinators, physical and occupational therapists, and volunteers (Smith, 2006). PC focuses on care coordination, symptom management, relief of stress, it can decrease cost of care, and improved quality of life of ESRD patients (Get Palliative, 2012).

Symptom and treatment burden refers to the symptoms of fatigue, pruritis, constipation, anorexia, pain, sleep disturbances, anxiety, dyspnea, nausea, restless legs, depression, weakness, poor mobility, drowsiness that patients experience with ESRD and HD (Lowney et al., 2015; Raj, Ahuja, Frandsen, & Jose, 2017; Murtagh, Addington-Hall, & Higginson, 2007).

## Synthesis of Evidence

The recognition and acknowledgement of the symptom and treatment burden of ESRD has been a growing issue (Axelsson et al., 2012). Symptom and treatment burden in patients with ESRD undergoing HD are underrecognized and undertreated (Murtagh, Addington-Hall, & Higginson, 2007). In order to gain a better understanding of how patients are affected by the symptom and treatment burden of ESRD and how palliative care can remedy this gap, a literature search was conducted utilizing CINAHL, PubMed, Clinical Key, Science Direct, and Google Scholar. Combination of keywords used for the search included dialysis, end stage renal disease, renal disease, kidney failure, palliative care symptoms, epidemiology, incidence, prevalence, quality of life, and education. Limitations that were applied in the data collection included the



English language, year 2000 to 2017 (to expand the search results), publication type: peer reviewed, and adults 18 and older (Table 1).

In a systematic review by Murtagh, Addington-Hall, and Higginson (2007), good symptom management was identified as a priority for patients with ESRD undergoing HD. Effective symptom management can improve the quality of life for ESRD patients (Murtagh, Addington-Hall, & Higginson, 2007). Common debilitating symptom and treatment burden experienced by ESRD patients include fatigue, pruritus, constipation, anorexia, pain, sleep disturbances, anxiety, dyspnea, nausea, restless leg syndrome, and depression (Murtagh, Addington-Hall, & Higginson, 2007). According to Belasco and Sesso (2002), family and caregivers also suffer from a decreased quality of life. Chronic caregiver stress results in high physical and mental disturbances that causes anxiety fatigue, deterioration in family relations, and social isolation when family members assume the care of ESRD patients (Axelsson et al., 2014; Belasco & Sesso, 2002).

Based on the literature reviews (Table 1), there are no official guidelines or instrumentation in the assessment of the quality of life of ESRD patients or guidelines in how to treat the symptom and treatment burden experienced by this patient population. Various instruments were used to assess the symptom and treatment burden associated with ESRD and HD (Vandercasteele & Tamura, 2014). There is no gold standard to measure quality of life (QOL) for ESRD patients that was discovered which can be due to the individualized care needed by each situation and patient (Vandercasteele & Tamura, 2014). Additionally, the barriers to the access of care were not discussed and there was the lack of use or direct

identification of a theoretical framework and identification of whether patients became active participants in their care after PC consultation.

Healthcare cost and expenditure are expected to rise due to the aging populations increasing lifespan and continued advancement in healthcare technology (Brown, Gardner, & Bonner, 2015). A benefit of utilizing PC in the ESRD population is its cost-effectiveness (Bharadwaj et al., 2016). In a recent descriptive study by Bharadwaj et al. (2016), early use of palliative care can significantly reduce cost of care through shorter length of stay (\$600,000 with 315 saved ICU days), decreased mortality (1.01 vs. 1.10) in the ICU, decrease readmission after PC consult (30-day readmission decreased by 61.5%, 60-day readmission by 47%, and 90-day readmission by 42.1%), increased referral to hospice (65 to 107) and higher quality of care (Bharadwaj et al., 2016).

PC is progressively developing in the field of nephrology (Yong et al., 2009). In the prospective cohort study by Feely et al. (2016), PC consultation was incorporated while the patient received HD. They discovered that doing PC consultation in a place where the patient is geographically bound provided private and intense discussions about quality of life issues (Feely et al., 2016). This was well received by both the patients and clinicians, which creates high patient and provider engagement that can assist in the improvement of their QOL (Feely et al., 2016). This approach was utilized because the patients' non-HD days "becomes too precious to participate in medical-related activities" (Feely et al., 2016). Symptom management through PC can be achieved by means of an interprofessional approach to provide holistic care, support, and care coordination (Culp et al., 2016; Tamura & Meier, 2013; Yong 2009). Palliative care can improve the quality of care, improve symptom management by addressing the physical and

psychological symptoms, improve care coordination, improve communication, improve patient and family satisfaction, and lowers cost of care (Bharadwaj et al., 2016; Gelfman & Meyer, 2012; Murtagh, Addington-Hall, & Higginson, 2007; Tamura & Meier, 2013).

## **METHODS**

### **Design**

A quantitative pre- and post-survey approach using the qualtrics software was utilized to assess the baseline and post education knowledge of patients who met the inclusion criteria. The questionnaire that was adopted was from the study of Hirai et al. (2011) that quantitatively measured palliative care awareness, knowledge of availability, and readiness for PC services in cancer patients (Appendix A). The modification included the administration of the pretest questionnaire when patient contact was made instead of mailing it to their residences and a professional three-minute educational intervention was utilized prior to the posttest questionnaire.

### **Setting**

The survey was conducted at DaVita Desert Dialysis, an outpatient hemodialysis clinic located at Sun City, AZ. This clinic has 20 hemodialysis chairs and serves the population of Sun City, Sun City West, and the Surprise area with patient ages 20 to 90 years of age. In-center hemodialysis alongside social services and registered dietician consultation is provided at this site.

### **Participants**

A convenience sampling of five or more participants was used for this project. Through this approach, all individuals from an accessible population who met the criteria over a specific

time & interval will qualify (Polit & Beck, 2012). Recruitment involved close collaboration with the clinic staff to ensure selection of appropriate patients that met the inclusion criteria as described below.

Participants included met the following inclusion criteria: adult patients, ages >18 years of age, English speaking, Stage V kidney disease (ESRD) and receiving HD at Davita Desert Dialysis. Patients who declined to be part of the project were excluded. Patients who agreed to take the pre-survey, who listened to the professional educational intervention and who took the post survey will have consented to being part of the QI project. All participants had the option to opt out at any time and not complete the project.

### **Intervention**

The professional educational intervention was the viewing of a three-minute voice over presentation about palliative care on an electronic laptop connected to Wi-Fi (Appendix B). The survey and education presentation were played to the patient or taken on their own depending on their preference. PC education included use and purpose, benefits to patient, services provided by PC, how PC affects symptom management, who pays for it, and how to obtain PC services. The survey and educational intervention were administered individually due to patient placement in the clinic (chairs alongside HD machine), and to provide and protect each individual's privacy. A list of available PC services in the Sun City area were given to the participants after the post-survey.

### **Data Collection**

Participants who have read the disclaimer and who participated were asked for basic information: (1) age range (*in increments of 10 years*), 2) gender, and 3) years living with ESRD,

and 4) years receiving HD. They were asked to respond to five dichotomous ‘yes’/‘no’ questions. These were valid questions that have been tested and are consistent with the three stages of contemplation for behavior change in the Transtheoretical Model (Prochaska, 2008). The stages for this questionnaire are no knowledge, not knowing, precontemplation, contemplation, and preparation.

- (1) Do you know about palliative care? (No knowledge)
- (2) Do you know that palliative care services are available in your living area? (Not knowing)
- (3) Are you interested in using palliative care services? (Precontemplation)
- (4) Do you have any intention of using palliative care services now? (Contemplation)
- (5) Do you think you will use palliative care services in the future? (Preparation)

Responses were entered into an electronic survey specific to each patient who is identified with only a subject ID. When the participants responded “no” to any of the questions, the survey was stopped and the participants were asked to view a three-minute professional educational video on palliative care. The question that receives a “no” response represents the stage of readiness for change that has occurred as a result of palliative care awareness, and knowledge. Following the educational intervention, the same dichotomous questions were asked to be able to compare if the educational intervention created a change in the readiness stage. An additional sixth question was asked.

- (6) Has your understanding of what palliative care can do for you changed? (Post-test only)

The sixth question is to support the hypothesis made on the assumption that after the professional educational intervention, each and every participant will change at least one level and that we were successful in making a change and therefore increasing their awareness. The participants were given the chance to ask about questions or concerns about palliative care prior to closing the encounter. If the participant should ask for contact information for providers of palliative care in the area, a brochure was provided (Appendix C). A minimum of five patients were needed for the survey and once completed, all the information was compiled for data analysis.

### **Process for Data Collection**

The initial patient encounter occurred while the participants were undergoing HD. The survey and the professional educational material were presented to the participants alongside the Davita social worker per Davita policy. The qualtrics software was used in the data collection of both pre-and post-survey. Administration of the survey, professional educational intervention, and data collection were carried out on an individual basis. Once the pre-survey was completed, the professional educational intervention was implemented and the participants were encouraged to ask question or clarifications that they may have prior to proceeding with the post-survey. The survey was closed and all the information were compiled for data analysis after all recruited participants were spoken to.

### **Data Analysis**

The survey questions were compared for change in the stage of readiness as indicated by the dichotomous answers. The data were compared across participants and within participants. The data across participants indicated the level of knowledge that was present in ESRD patients at that clinic. A change within patients will provide support for the professional educational

intervention to assist with improving the quality of care in the clinic by educating patients about their choices. The sample size is too small to complete a large-scale t-test, however the analysis was based on the principles of the t-test (Keller & Kelvin, 2013). For simplicity, we hypothesized that every participant will change at least one level. The change within was analyzed using a one sample binomial test on the mean number of changes in level to test whether the proportion of successes of a dichotomous dependent variable significantly differs from a hypothesized value. A change in one stage will indicate that the professional educational intervention was successful in creating a change. Data is presented using a bar graph with the results of the survey, professional educational intervention, and participant demographics.

### **Ethical Considerations**

#### **Respect for Persons**

Seeing each individual as a unique and respecting their autonomy, treating them with courtesy and respect, and attaining their informed consent constitutes this fundamental principle of ethics (Office for Human Research Protections [OHRP], 1979). Educating each patient that all responses will remain confidential. At any point a participant can withdraw, no questions will be asked. As part of this ethical principle, if the patient is not fully oriented or neurologically competent, he or she will be excluded in order to protect those who have diminished autonomy.

#### **Beneficence**

To do no harm means practicing and providing care and resources the best we can as future providers (OHRP, 1979). Conversations of starting, continuing, or withdrawing HD maybe overwhelming. However, not having a conversation about how PC can improve life at present or in the future means we are not putting our patient's well-being in the front line and not

making decisions “according to the best judgment.” As a future provider, this project will maximize the benefits that can be provided for the patient and their family, reduce the risk of harm by making patients active participant in their care by improving knowledge and social procedures (OHRP, 1979).

**Justice:**

Through experience and conversations with ESRD patients regarding PC, it was evident that conversations between patient and physician regarding PC and their care was either lost in translation or not initiated at all. This can be considered as an injustice because ESRD patients are entitled to benefits that can assist in their quality of life. PC is well established in cancer patients and other chronic terminal diseases, why is not established for ESRD?

## RESULTS

Eight participants were identified by the Davita social worker and facility administrator as individuals who met the inclusion criteria and those who would benefit most from this QI project. Seven of the participants were patients and one was a family member of a patient. The purpose of the project was explained to the potential participants and made aware that participation in the project is voluntary.

Six patients (n=6) completed the pre-survey, watched the professional educational intervention, and then followed up with a post-survey. One participant was hospitalized and unable to complete the survey and one family member was unable to make the appointment. The participant's ages ranged from 61 to 80 years of age, comprised of four males and two females (Figure 1 & Figure 2). The average years of patients with ESRD undergoing HD was from 1-5 years (66.67%) and 6-10 years (33.33%) (Figure 3).



Pre-survey results showed that four participants (66.67%) did not know what PC was and one (16.67%) knew about the availability of PC in their living area and was not interested in using PC services (Table 2). Post-survey results showed six (100%) of the patients knew about PC and its availability in their living area, 5 (83.33%) are interested in utilizing PC, 3 (50%) stating they have the intention of using it now and 5 (83.33%) in the future, and 6 (100%) has better understanding of what PC can do for them (Table 3).

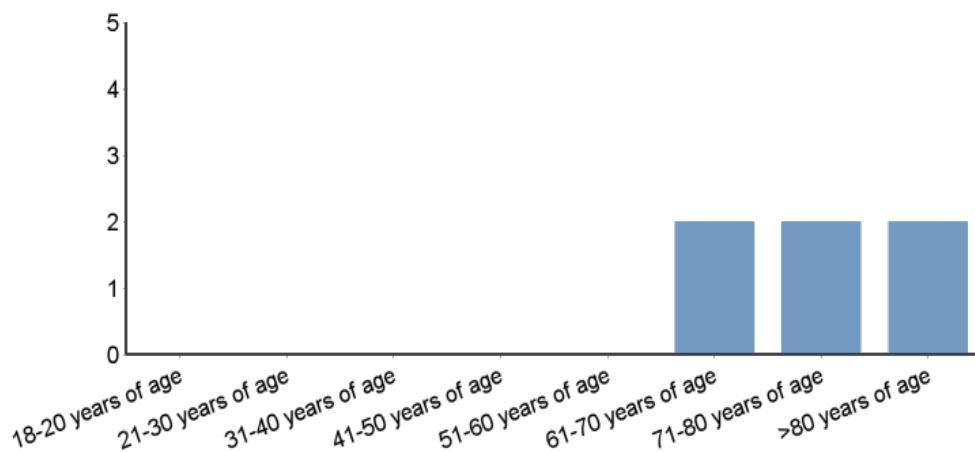


FIGURE 1. Age Range of the Participants.

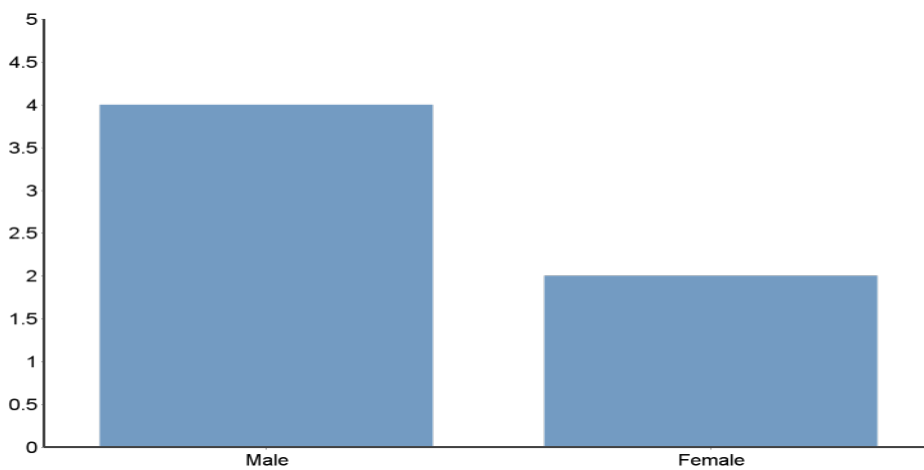


FIGURE 2. Gender of the Participants.

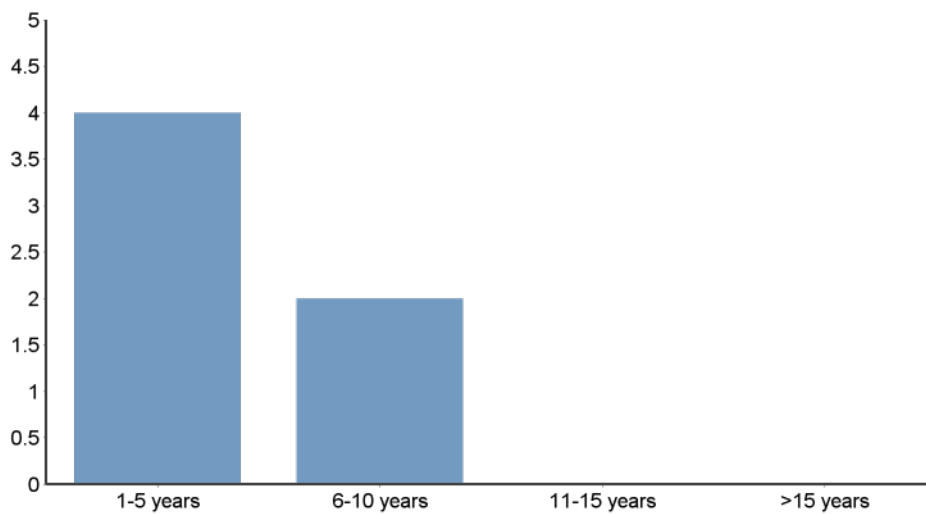






FIGURE 3. The Number of Years the Participants have had ESRD and HD.

TABLE 2. *Pre-test Results*

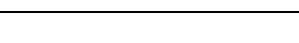

1. Do you know about palliative care?

| Answer | Bar   | Response | %      |
|--------|---|----------|--------|
| Yes    |  | 2        | 33.33% |
| No     |  | 4        | 66.67% |

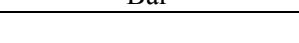
2. Do you know that palliative care services are available in your living area?

| Answer | Bar   | Response | %      |
|--------|---|----------|--------|
| Yes    |  | 1        | 16.67% |
| No     |  | 1        | 16.67% |

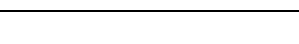
3. Are you interested in using palliative care services?

| Answer | Bar   | Response | %      |
|--------|---|----------|--------|
| Yes    |  | 0        | 0.00%  |
| No     |  | 1        | 16.67% |

4. Do you have any intention of using palliative care services now?

| Answer | Bar  | Response | %     |
|--------|--|----------|-------|
| Yes    |  | 0        | 0.00% |
| No     | **   | 0        | 0.00% |


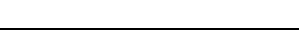
5. Do you think you will use palliative care services in the future?

| Answer | Bar   | Response | %     |
|--------|---|----------|-------|
| Yes    |  | 0        | 0.00% |
| No     | **  | 0        | 0.00% |

\*\*Once the participants answer "no," they move forward with the professional educational intervention and post-survey.

TABLE 3. *Post-test Results*

1. Do you know about palliative care?

| Answer | Bar   | Response | %       |
|--------|---|----------|---------|
| Yes    |  | 6        | 100.00% |
| No     |  | 0        | 0.00%   |

2. Do you know that palliative care services are available in your living area?







| Answer | Bar   | Response | %       |
|--------|---|----------|---------|
| Yes    |  | 6        | 100.00% |
| No     |  | 0        | 0.00%   |

TABLE 3 – *Continued*



3. Are you interested in using palliative care services?

| Answer | Bar   | Response | %      |
|--------|---|----------|--------|
| Yes    |  | 5        | 83.33% |
| No     |  | 1        | 16.67% |


4. Do you have any intention of using palliative care services now?

| Answer | Bar   | Response | %      |
|--------|---|----------|--------|
| Yes    |  | 3        | 50.00% |
| No     |  | 3        | 50.00% |

5. Do you think you will use palliative care services in the future?

| Answer | Bar   | Response | %      |
|--------|---|----------|--------|
| Yes    |  | 5        | 83.33% |
| No     |  | 1        | 16.67% |

6. Has your understanding of what palliative care can do for you changed?

| Answer | Bar   | Response | %       |
|--------|---|----------|---------|
| Yes    |   | 6        | 100.00% |
| No     |  | 0        | 0.00%   |

## DISCUSSION

The intent of this quality improvement project is to understand the public awareness about PC in the ESRD population undergoing HD. Findings in this project will hopefully contribute in the continued increase in awareness and utilization of PC in the ESRD population at Davita Desert Dialysis.

The primary goal of this project is to create awareness and to improve patient quality of life through education. To initiate the efforts in improving awareness of PC in ESRD population, PC education was provided to the staff members at the Davita Desert Dialysis Clinic at the request of their facility administrator prior to patient encounter & project implementation. The PC education that was provided for the staff was the same three-minute professional educational intervention that was presented to the participants in the project. The purpose of the educational

staff presentation was to improve their understanding about PC, its use and purpose, and how it can improve the quality of life of patients. The educational sessions provided the staff the opportunity to learn about PC and answer any questions they had about PC services. The material was presented three various times to the facility administrator, Davita governing board (lead nephrologist, DaVita lawyer, facility administrator, social worker, dietician, and ancillary staff) and to the Davita nurses and HD techs. The overall and unanimous response from the staff was that the education was needed because it increased awareness and understanding about PC in ESRD.

During the course of the investigation, the lack of knowledge, awareness, and the negative connotation or stigma associated with the words “Palliative care” was evident. Initially, individuals were hesitant and uncertain about the project that they were recruited for. The investigator needed to allay their fears of a possible worsening diagnosis that patients were not aware about and explained the reason why they were recruited by the staff for the project.

The theoretical foundation of this project is the Transtheoretical Model (TTM) of behavior change. Table 4 displays the percentages of responses in the pre- and post-surveys and the corresponding stage in the TTM. Comparison between pre- and post-survey shows significant changes in potential for behavior change as a result of PC professional educational intervention. The results of the pretest survey showed low public awareness and understanding of PC. In the pretest survey, only 33.33% knew what PC is and only 16.67% knew PC services were available in their living area. These results indicated that out of the 100% (n=6), 66.67% of the participants did not have any knowledge about PC and were in the no knowledge stage of the TTM. Therefore, the importance of creating awareness by providing education about PC in the ESRD population was evident.

Upon providing education and answering questions about PC services, 100% of the individuals in the posttest had better awareness about PC, knowledge of its availability in their living area, and a better understanding of PC services. The participant's readiness for change was evident in the post survey results. All (100%) of the participants advanced from the 'no knowledge' stage and into the 'not knowing' stage, 83% were able to move further into the contemplation stage (Are you interested in using PC services?), 50% in the contemplation stage (Do you have any intention of using PC services now?), and 83.33% in the preparation stage (Do you think you will use palliative care services in the future?). The readiness for change was also supported by the participant's willingness to continue research on their own to find out more about PC after the intervention and post survey results. A large portion (83.33%) of the participants wanted a brochure regarding PC in which they were directed to the Davita social worker. The change in levels of knowledge and readiness supports the initial hypothesis of the project that every participant will change by at least by one level after the professional educational intervention.

Overall, PC was often confused with hospice. Once the project commenced, additional education was provided to the participants about hospice care to be able to differentiate it from PC. Aside from the confusion, the general image of PC was positive and well-accepted by these participants. They were receptive and were able to receive the new information with ease. After the professional educational intervention was presented and the post-surveys were completed, the conversations centered around how it can benefit their families and the cost of care. Through the discussions with the participants, it became apparent that they were cognizant of the symptom and treatment burden and how it is affecting their families. Most of the participants were interested in PC to be able assist their families with the family burden associated with ESRD and

HD. The other common question associated with the project, by both staff and participants, was the cost of PC services. Prior to the project, the primary investigator was in correspondence with one of the PC companies in the valley in anticipation of this question. Unfortunately, cost cannot be estimated due to the differences in insurance, coverage—whether they have chronic care or PC coverage, copays and deductibles, duration of services if provided, and the individualized care needed by each participant and their family.

TABLE 4. *TTM Survey Results*

|                                | <b>Pre-test</b> | <b>Post-test</b> |
|--------------------------------|-----------------|------------------|
| I. No knowledge                | 33.33%          | 100.00%          |
| II. Not knowing                | 16.67%          | 100.00%          |
| III. Precontemplation          | 0.00%           | 83.33%           |
| IV. Contemplation              | 0.00%           | 50.00%           |
| V. Preparation                 | 0.00%           | 83.33%           |
| VI. Change in PC understanding | ----            | 100.00%          |

### **Limitations**

This study had several limitations. First, the sample size was extremely small and exposes this project to marked bias and non-generalizability due to the limited number of recruited individuals. Secondly, the participants who were recruited by the social worker who met the original inclusion criteria was additionally screened as participants who would benefit most from this QI project and who “needed” PC services at DaVita Desert Dialysis. The additional screening further exposes this QI project to selection bias. Third, geriatric population was the only type of population that was studied in which the average age of participants was from 71-80 years of age. Further research will be needed in the future to study for the age group of <60 years of age to further generalize the effects and benefits of PC education and services.

### **Resources and Timeline**

A total of five days was utilized in the implementation of this QI project due to the varying schedule of each participant. Each participant encounter was 45 minutes in length including the pre-survey, presentation of the professional educational intervention, and the post-survey. The total cost of the QI project was \$57.75 for the professional educational intervention that was professional voiced using a voice-over actor and \$20 for gas and travel, which was financed by the investigator.

### **Lessons Learned**

First, during the implementation of the QI project, compared to the level of awareness in the synthesis of evidence, all the participants were aware of the symptom and treatment burden associated with ESRD and HD. All the participants were interested in PC to be able assist their families with the disease burden associated with ESRD. The decision of whether to utilize PC was cost-dependent due to the unknown costs of services and the limited income of the participants.

And lastly, it became evident that the TTM is not a liner model. The TTM was greatly affected by Maslow's hierarchy of needs, more specifically the basic needs associated with the physiologic and safety needs. The cost of the services was the driving factor in whether the participants would use PC. Due to the limited income of the participants, the demand to fulfill their basic need was far greater than the demand to use PC services.

### **Conclusion**

Quality of life can be improved by PC in patients that suffer from undertreated and underrecognized symptoms and treatment burden (Tamura & Meier, 2013). Palliative care can offer services that can improve care coordination, symptom management, improve



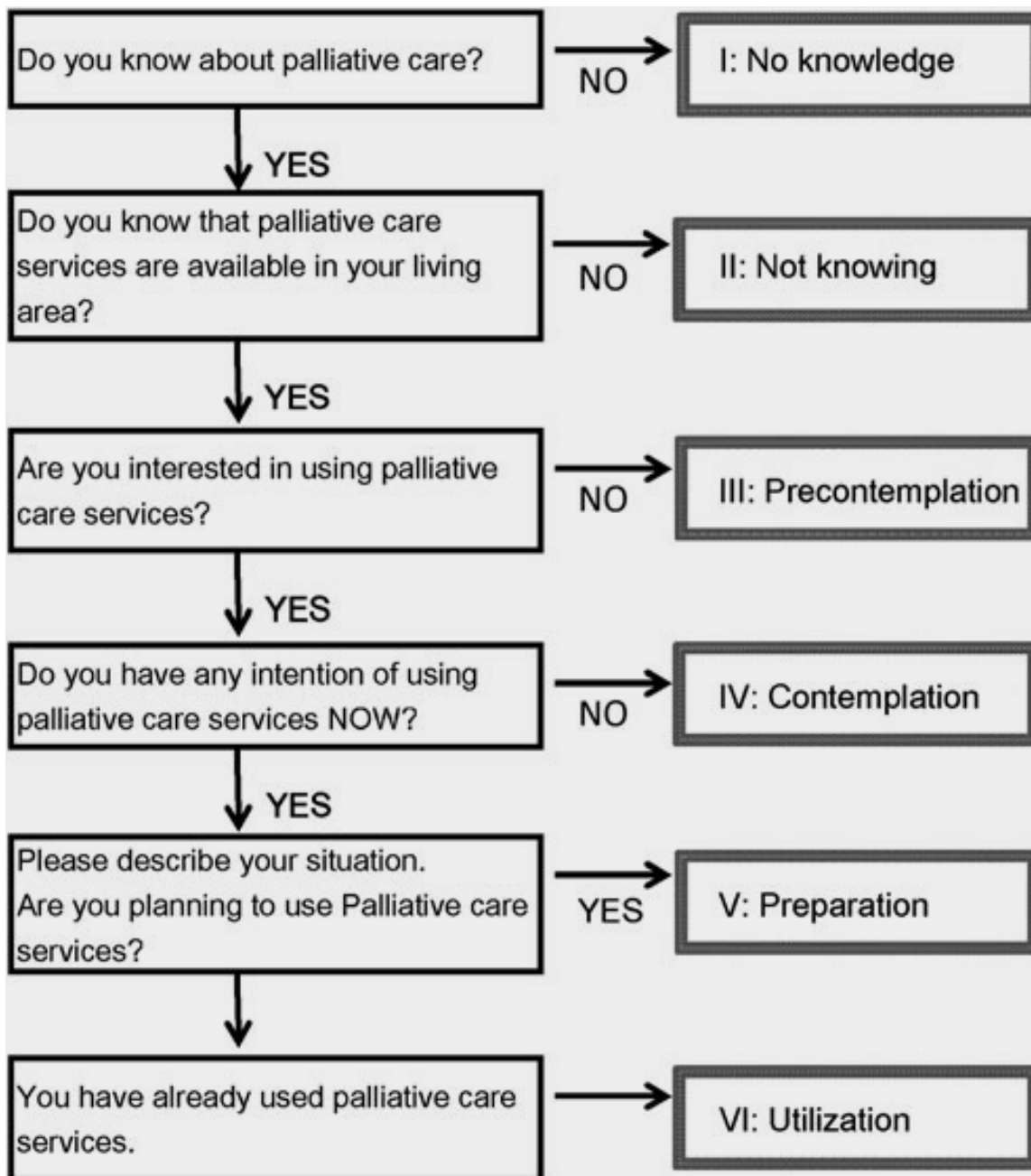
communication, and increase interprofessional support from the PC team (Get Palliative, 2012; Tamura & Meier, 2013) and is cost effective care (Bharadwaj et al., 2016). It can benefit the patients, their families, the community, and the organization through high quality, low cost, and high satisfaction care (Bharadwaj et al., 2016; Feely et al., 2016; Joshi, 2014; Yong et al., 2009).

Using the TTM as a foundational model for change, we can focus on a person's readiness for change. Behavioral change is a process and not a single event. Understanding the different stages and the progression through these stages, we can facilitate intentional change through support and tailored interventions such as awareness through education. By creating awareness about the benefits of PC, we can empower and educate them about services available to patients that can greatly improve their quality of life.

Further data and studies will be needed to establish PC in the field of nephrology as it relates to the ESRD population undergoing HD. However, the quality improvement focus of increasing PC awareness among ESRD patients undergoing HD has shown great promise as all participants had increased awareness, knowledge availability, and readiness for PC services.

APPENDIX A:  
PALLIATIVE CARE QUESTIONNAIRE

## Palliative Care Questionnaire



APPENDIX B:  
PROFESSIONAL EDUCATIONAL INTERVENTION

## PALLIATIVE CARE EDUCATION

Kristian Oarde, BSN, RN  
The University of Arizona  
College of Nursing

### What is Palliative Care?

- Palliative care is a specialized medical care for people with serious illness.



### What is Palliative Care?

- It is appropriate at any stage of the disease, any age, and while receiving curative treatment.



### The focus of Palliative care is to provide relief from...

- Pain
- Nausea
- Itching
- Constipation
- Fatigue
- Anxiety and other symptoms...
- And... to IMPROVE quality of life

### Palliative care can...

- Relieve your symptoms and distress
- Help you better understand your disease and diagnosis
- Help clarify your treatment goals and options
- Understand and support your ability to cope
- Assist with making medical decision
- Coordinate with your other doctors

### How is Palliative Care different from my current care?



### What can I expect from Palliative Care?



- ▶ Palliative care is NOT Hospice care....

- ▶ Palliative care does NOT mean you are giving up.

### Who pays for Palliative Care?

- ▶ Private insurance
- ▶ Medicare
- ▶ Medicaid

### How do I get Palliative Care?

- Outpatient
  - ▶ Hospice of the Valley (Surprise/Thunderbird locations)
- Inpatient
  - ▶ Banner Boswell Medical Center
  - ▶ Banner Del E. Webb Medical Center

APPENDIX C:  
PALLIATIVE CARE SERVICES BROCHURE

## Community Home Based Palliative Care Resources

Updated July 2016

| Name   | Contact Info   | Hours  | Insurance Accepted  |
|--|--|--|---|
| <p><b>Banner Palliative Care &amp; Caring Connections</b></p> <p>MD, NP or SW visits as needed. Telephonic for follow-up. Monthly visits sometimes weekly depending on condition. Assist with symptoms, advanced/goal planning, home safety eval, medication management, hospice transition, partner with current PCP.</p> | <p>480-657-1000 opt 5<br/>Referral fax:<br/>480-655-2527</p> | 8-5 M-F  | <p><b>Palliative:</b> BHN network with the exception of BHN Pioneer</p> <p><b>Caring Connections:</b> Any insurance and no cost program. SW outreach only program</p>   |
| <p><b>Optum Palliative and Hospice Care (Now part of United Health Group)</b></p> <p>Initial completed by physician then transitioned to NP. Can order medications. Visits usually weekly if acute need otherwise vary based on patient need.<br/>*Not taking new palliative patients*</p>                                 | 602-749-5900   | 8-5 M-F (PC visits)<br>24 hour phone triage (PC and hospice) | <p><b>Palliative:</b> Medicare, UHC, APIPA, Life Print, Pacific Care and Secure Horizons. (Under United Health Care umbrella)</p> <p><b>Hospice:</b> All the above plus most AHCCCS. Under Mercy Care contract.<br/>Don't accept BCBS, Banner, Indian &amp; Cigna</p> |
| <p><b>Hospice of the West Palliative Pathways</b></p> <p>Primary telephonic social work outreach and RN assessment. Can coordinate with contracted NP to assist with symptom management services, but there may be an out of pocket cost.</p>  | 602-343-6422   | 8-5 M-F<br>Referral and Triage line for both programs        | <p><b>Palliative:</b> No cost for basic program.</p> <p><b>Hospice:</b> Works with Medicare and all insurance.</p>  |



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| <p><b>Comprehensive Hospice and Palliative Care</b></p> <p>Outpatient palliative care sends out social worker for outreach and support for palliative care program. Assist with community resources and referral along with education on hospice. No providers for symptom management.</p>  | 602-795-9705  | 8-5 M-F                      | <p><b>Hospice:</b> Medicare, BCBS, other insurances they will try to get on time contract</p> <p><b>Palliative:</b> No Cost</p>   |
| <p><b>Arizona Palliative Home Care (Under Hospice of the Valley)</b></p> <p><b>Outreach Palliative Care:</b> Nursing, SW services, volunteer services. Guidance by MD or NP for team. Primarily education based. SW goals: AD, resources, ALTCS. Role in medication reconciliation. Do not write prescription but can talk to PCP. In home visits- every 30 days. If needs arise in between they evaluate phone vs in person. Goal: 60 day program</p> <p>*Any referral from hospital will go to Outreach</p> | 602-212-3000 ph<br>602-212-3002 fax<br>602-636-6319 fax | 7-7 M-F<br>24/7 phone triage | <p><b>Outreach Palliative:</b> No cost</p> <p><b>Contracted:</b> Aetna, AC Foundation, BCBS, Cigna, Healthnet, Humana out of network, Medicare, UHC, Phoenix Healthplan</p> |
| <p><b>AZ Pall Home Care: (contracted plan)</b></p> <p>NP/MD visit patient 1x month in home, frequency of visits higher and length of stay can be longer. Can provide volunteers and</p>   |   |                              |   |

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CNA, RN, Patient assistant. MD/NP able to work with PCP or write prescriptions.  
**\*\* Referrals accepted from insurance case managers ONLY \*\***

**Palliative Dementia Care: 602-636-6363 (private pay only- \$275/month.)** Provides dementia educator (behavior management strategies, medication suggestions, placement options); 24/7 access to RN/SW for questions, MD phone consults, respite by trained volunteer (up to 4 hrs/week) \*for any stage of dementia- for patients not eligible for hospice

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| <p><b>Sage Hospice &amp; Palliative Care</b></p> <p>Social work and NP services for resources, advance directives and symptom management. NP can order labs, diagnostics and will work with PCP</p> | <p>480-777-5117 hospice<br/>480-771-3400 PC</p> | <p>24/7 triage for both</p>    | <p><b>Hospice:</b> Medicare. Call about other insurance</p> <p><b>Palliative:</b> No cost</p>   |
| <p><b>Seasons Hospice &amp; Palliative Care</b></p> <p><b>** Not currently accepting palliative care patients **</b></p>  | <p>480-606-1011</p>                             | <p>24/7 triage for hospice</p> | <p><b>Hospice:</b> Medicare and every insurance except Mercy Care &amp; AHCCCS plans. Will accept charity care patients. Has open access program. Palliative isn't available at this time. The PC will be run by a Palliative Care physician and NPs will assist w/at home or SNF visits.</p> |

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| <p><b>Palliative Care of Arizona (Hospice through their sister company – Infinity Hospice)</b></p> <p>Consultation service with palliative care coordinator (SW) and MD. Will review medication list and goals of care. Can order medications, but prefer to coordinate medication recommendations with PCP. Weekly visits from SW and as needed visits from MD. Length of stay on program is variable.</p> | 602-955-1840                       | 8-5 M-F<br>24/7 triage for hospice & palliative | <p><b>Palliative:</b> Work with most insurance. Call to confirm.</p> <p><b>Infinity Hospice:</b> Medicaid, UHC, Aetna, Some ACCCHS plans (can also work with an out-of-network coverage)</p>   |
| <p><b>Serenity Hospice and Palliative Care</b></p> <p>-SW available to help with community resources, support and advance directives<br/>-NP visits for pain/symptom management-able to do medication reconciliation. Currently work with mobile docs or PCP for scripts<br/>-Visits vary on need. 1x or more frequently.</p>   | 602-216-2273<br>602-265-4663       | 8-5 M-F<br>24/7 Triage calls                    | <p><b>Palliative Care:</b> Not insurance driven. No cost for SW &amp; NP. May be cost for mobile physician. Will alert if co-pay</p> <p><b>Hospice:</b> Medicare, Mercy Care, Bridgeway, Cigna, Health Choice, &amp; BCBS. As long as Hospice benefit is in the patient's insurance plan, they will accept the patient and can bill any insurance.</p> |
| <p><b>Hospice Compassus</b><br/>Point of Contact: Becky Ross</p> <p><b>** Palliative Care offered only in Sedona, Prescott and Flagstaff **</b></p>   | 602-301-1073<br>1-866-326-0864 fax | 8-5 M-F<br>24/7 Triage calls                    | <p>Accept all insurances. Their corporate office will work with any insurance companies for patient coverage. Won't turn away patients.</p>  |

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| <p><b>Prime Care Hospice &amp; Palliative Care</b></p> <p>Only social work and nursing monthly outreach for patients not yet ready for hospice. Offer resources and support. No symptom management.</p>  | 623-847-2323 | 8-5 MF<br>24/7 triage calls                  | <p><b>Hospice:</b> Cigna, Healthnet of AZ, All UHC, University Health plans, All BCBS, HMO &amp; PPOs &amp; Medicare. They don't bill patients for co-pays, out-of-pocket, co-insurance or deductibles.</p> <p><b>Palliative:</b> No cost</p> |
| <p><b>Palliative Care Alliance (PCA)</b></p> <p>MD, NP and social work services. On service as long as clinically appropriate. Help with transition to hospice, but not connected with any agency. Offer symptom management, education and referrals</p>   | 602-269-6011 | 8-5 M-F<br>24 hours for triage calls.        | <p>Work mostly with Medicare and BCBS Medicare Adv. Contract with few plans. Call to confirm. May be out of pocket cost. Does not accept AHCCCS plans.</p>  |
| <p><b>Gap Care Solutions</b></p> <p>Primarily social work case management. MD visits available for symptom management. Frequency determined by clinical need. Provide symptom management, order medications, advance directives and community resources. No maximum length of stay on service. Connect with contracted agencies for home health (Sunrise) and hospice (Reflections), but totally independent from hospice.</p> | 480-268-2675 | 8-5 MF<br>24/7 Triage phone only for hospice | <p><b>Insurance:</b> Work with an extensive array of insurance to include Medicare and AHCCCS. May be out of pocket expenses. Call to confirm</p>   |

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**Thema Palliative Care Services & The Crossings Hospice**

Primarily NP visits. Frequency varies depending on patient need. May see multiple times monthly. Able to adjust medications, write scripts, contact PCP. MD, SW & chaplain available as needed. Long term program- only discharge per patient request or if patient transitions to Hospice. Able to service in home, Group home, Assisted Living setting. \*Willing to do unscheduled visits to help avoid hospitalizations.

**\*\*Palliative only in Phoenix Metro area\*\***

602-889-4400  
(M-F; do have weekend triage for phone calls for hospice only)

Medicare, BCBS, Lifeprint, United Health Care plans, AARP, AHCCCS plans if high need (no current contracts). Call to confirm insurance for palliative care and out of pocket.

Hospice locations in Phoenix/Metro, Miami/Globe & Prescott/Cottonwood

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**Companion Hospice & Palliative Care**

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