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Jerold Cohen
jcohen287@aol.com

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Jerold Cohen

University of San Francisco, School of Nursing and Health Professions

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Earlier Palliative Care Referrals for Nephrology Patients

Section I: Title and Abstract

Acknowledgement

As my time as a DNP student draws to a close, I reflect on the excitement and anticipation of that first intensive in the Spring of 2019. That was the first opportunity to meet face to face with the cohort that would become friends and supporters to help get me through the program. Little did any of us know at that time that by the conclusion of the program the world would have changed, and we would not be able to end as we had started by being together face to face. Instead for the last three terms we have been forced to only meet on Zoom and support each other virtually. Even though it is only virtual the support and colleagueship has been much appreciated.

I am also grateful to the University of San Francisco professors and staff who have guided my way. If it were not for Dr. Wanda Borges who was my faculty advisor and original committee chair, I would have created a project that was so big it would have been undoable. I am only sorry she was not here for the conclusion. However, Dr. Sara Horton-Deutsch went from second reader to chair to bring me down the home stretch. I also need to thank Dr. Jim D'Alfonso for not only becoming the second reader, but also for leading the Kaiser Permanente Nurse Scholars Academy, without which I would never have been able to accomplish this milestone.

I also need to thank my friends and colleagues who have encouraged me as I have gone through the program and have now reached the final hurdle.

Abstract

Palliative care prevents and relieves suffering through the early identification and treatment of pain and other symptoms, which can be physical, psychosocial, or spiritual (World Health Organization, 2018). It is usually considered a service provided to oncology patients and has positively impacted their treatment. However, it is not as common for many other diseases where the patient would benefit from palliative care involvement. Presently, if palliative care is offered to nephrology patients, it is after they have started dialysis and are having second thoughts whether to continue this treatment plan as it has either become less effective or is interfering with the patient's quality of life. It has been demonstrated that elderly patients with co-morbidities might only derive limited survival benefits from dialysis Stopping the dialysis usually leads to imminent death, while those on conservative treatment may live up to an additional 23.4 months (Seccareccia & Downar, 2012). Although Scherer et al. (2018), developed an integrated nephrology and palliative care program, others have been slow to adopt this type of care. The focus of this project was to determine by offering palliative care to patients at earlier stages of Chronic Kidney Disease (CKD), would they accept the intervention and think about what they would like as their goals of care?

The patient panel of one nephrologist from a large urban medical center in the San Francisco Bay Area was used, and those patients who were at CKD stages 3B or 4 were selected for the project. Those patients on the list who already were on dialysis were on the hospital's palliative care registry or life care planning registry or had previously had a palliative or life care planning consult were eliminated. This left 26 patients who were contacted, 14 patients made appointments, ten had consults, and four did not keep their appointment. After the consultation, four of the patients stated they were interested in conservative treatment. The youngest of these was 57, and the oldest was 82. All these patients had low Tangri scores, which predicted that they had time before reaching end stage renal disease (ESRD), the point at which they would need dialysis.

The project demonstrates that with a palliative care consultation early in the disease process the patient can make informed decisions about their goals of care without being in a crisis state. By explaining to the patient that this is normal care that is ordered by their physician, more patients were willing to accept the consultation, and not think they were being handed a death sentence. These patients received palliative care early enough in their illness, so they had time to decide on their own goals of care and have the opportunity to receive ongoing support as their disease progresses. The National Kidney Foundation (NKF) promotes the use of early palliative care for patients with kidney disease, but the medical community is not always willing to accept conservative treatment as they view dialysis as the gold standard ("Starting or stopping dialysis," 2019). As supported by the literature, early palliative care in any life-limiting disease should be a best practice, just as it is for Oncology patients.

Keywords: Earlier palliative care, palliative care and nephrology, dialysis, conservative chronic kidney disease treatment, positive impact of palliative care

Section II: Introduction

Problem Description

Patients who begin having problems with their kidneys generally receive ongoing care from their primary physician with the hope of preventing further deterioration. It is not until they are at Chronic Kidney Disease (CKD) stage 3B, based on their glomerular filtration rate, that they are referred to a Nephrologist for further treatment and potential dialysis or transplant (see Appendix M for stages of chronic kidney disease). Generally, patients are not referred to palliative care, until they reach the level of end stage renal disease, stage 5. Patients referred at this time is because they are often struggling with dialysis, their symptoms, or quality of life, and are trying to determine if they should continue treatment. Some patients might be referred to palliative care earlier than this due to stressors created by co-morbidities, but this is generally the exception, and not the rule.

Patients with advanced chronic kidney disease (CKD) are generally high utilizers of healthcare services due to their increased symptoms. This group usually faces complex medical decisions related to treatment and end-of-life care. These decisions often include starting dialysis or terminating dialysis. To optimize care, nephrology professionals suggest shared decision-making and quality-of-life considerations when determining a treatment plan. However, this has not been integrated into routine nephrology care (Scherer et al., 2019, p. 1).

The number of patients with end stage kidney disease (ESKD) is increasing every year. One reason is better access to care for the aging population, and another is an increase in diabetes and hypertension in this population, which are both risk factors for CKD. In 2015 there were 1.4 million people receiving renal replacement therapy worldwide, which grows approximately 8% a year. These individuals should receive the same level of palliative care services as those with a cancer diagnosis (Noble et al., 2015, p. 1).

With the main care model for patients with CKD and End Stage Renal Disease (ESRD) being dialysis or transplant, little attention has been paid to patient needs beyond the dialysis treatment. This treatment system is ill-equipped to help the patient and family deal with both the emotional issues and illness challenges that come with this disease. Although the ESRD patient receives high-cost, high-intensity care near the end of life, the family generally rates the quality of care received at this time as poor. Palliative care has been suggested to address this issue, but nephrology has been slow to adopt this type of care. (Tamura et al., 2018, p. 866)

Patients are often confused about their ability to choose whether to start or stop dialysis. As pointed out by the National Kidney Foundation (NKF), for many people, dialysis gives them a longer life with quality, while for others, their improvement is much more limited. The recommendation from NKF is that patients and their families seek palliative care to assist them in making this decision as well as to receive ongoing support ("Starting or stopping dialysis," 2019).

The purpose of this project was to provide palliative care consultations to nephrology patients earlier in their disease process, so they can make better decisions about what treatments they should receive and help improve their quality of life. To accomplish this, the project was going to use a training program to educate health care providers, especially renal care managers, on how to identify appropriate patients and refer them to the palliative care team earlier in their disease. Because of the Covid-19 pandemic, and the inclusion of a kidney failure risk equation in the health system's electronic medical record (EMR), the renal care managers, were replaced by a palliative care registered nurse (RN), who reviewed the physician's patient list for the inclusion criteria.

For this project, those patients being followed by a particular nephrologist and having CKD stages 3 to 4 were the identified participants. A model that accurately predicts progression to kidney failure was also used to help determine which patients should receive palliative care sooner than later, so they could make their treatment decisions with time to think, rather than having to make an immediate decision due to crisis. This model uses routinely obtained laboratory tests to accurately predict the progression of the disease (Tangri et al., 2011, p. 1553).

PICO(T) Question

The Problem, Intervention, Comparison, Outcome (Time) (PICO(T)) question for this project was: In patients diagnosed with chronic kidney disease and a score on a kidney failure risk equation(P), do they accept early palliative care intervention, closer to time of stage 3 kidney failure diagnosis (I), compared to accepting palliative care intervention later in the disease, closer to the time of death (C), and does this affect patients' decisions related to their treatment plan (O) after the palliative care consultation(T)?

Available Knowledge

Guided by the PICO(T) question, a systematic search was done in the following electronic databases: Cochrane, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Joanna Briggs, Fusion, Scopus and PubMed. The search keywords used were *kidney palliative care, and early palliative care.* The results of all searches were reviewed, and

34 articles were selected for full review based on their titles and apparent applicability. After this review, the group was narrowed down to 11, which addressed palliative care concerns and met the inclusion criteria. The evidence of these 11 articles was reviewed using the Johns Hopkins Nursing Evidence-Based Practice Appraisal Tools to determine strength and quality (Dang & Dearholt, 2018). This appraisal can be found in Appendix D.

Davison (2011) identified that although palliative care was beginning to be integrated for patients with chronic kidney disease, it still faced many challenges. The first challenge was the ability to identify patients who need supportive and palliative care prospectively. Not all patients need it; since ESRD patients' illness trajectory is heterogeneous it is hard to determine who and when they will need it. Additionally, advance care planning has not been usual care for these patients and needs to be. By developing a combined program between nephrology and palliative care, patients would better manage their symptoms and their needs.

Hussain, Mooney, and Russon (2013) did a retrospective observational study of 441 patients over 70 years old attending a pre-dialysis clinic. Of this group, 172 chose conservative management, while 269 chose renal replacement therapy. They discovered that for patients over the age of 80, with poor performance status or high co-morbidities, there was no survival advantage to renal replacement therapy over conservative management. They also discovered that 76% of the conservative management group accessed community palliative care services, and 47% of this group died in the hospital compared to 0% of the renal replacement therapy patients accessing palliative care and 69% dying in the hospital.

Bull et al. (2014) did a retrospective record review of all patients with CKD who had died on an Australian hospital's renal service from January 1, 2006 to December 31, 2008. She found 45 patients with a mean age of 67 had died during that period. Of that group, 16 had asked to stop dialysis, 13 families asked about withdrawal of dialysis, and it was withdrawn on 20 patients of that group. Although 28 patients experienced significant pain, only eight patients were formally referred to palliative care. It was usually their co-morbidities that would get them referred to palliative care. Bull also surveyed the multidisciplinary team and discovered that only 62% had any experience with palliative care and most had that experience in the acute care setting. This group also found it challenging when a patient asked to withdraw dialysis and be referred to palliative care. With the lack of knowledge, it would be difficult for the team to know when to make a referral.

Bristowe et al. (2015) did a qualitative study of 20 patients at two United Kingdom National Health Service hospitals who were on hemodialysis and were selected based on time on dialysis and symptom burden. The findings demonstrated considerable unmet information and advance care planning needs for people with end-stage kidney disease. The participants described a lack of information or discussion before starting dialysis. This has been found in earlier studies that had been done in Canada and the United States. This study demonstrates the ongoing need for advance care planning and information sharing for this population.

Culp et al. (2016) did an online survey of dialysis professionals to get their perceptions of the adequacy of supportive care services in their dialysis centers, and the barriers to providing it. Of 487 respondents, only 4.5% believed that their centers were providing high-quality supportive care. The rest felt that bereavement support, spiritual support, and end-of-life care discussions were the major unmet needs. If these services are not provided in the dialysis centers, then there is certainly a need to provide them to patients in either the hospital or outpatient setting.

Hoffman et al. (2017) did a study of patients with chronic kidney disease who had chosen conservative treatment and were referred to supportive renal care. They interviewed both patients and carers and found that both groups had the following themes in common: an awareness of what was going on, informed decision making, feeling supported, and waiting for health to decline. The patients also had a need to maintain normalcy in their lives while the carers discussed difficulties in adjusting to their new role. Both groups felt supported by their connection to the supportive renal care. This study supports early palliative care involvement with CKD patients.

Noble et al. (2017) conducted a study of clinician perspectives on patient decisional conflict about deciding on dialysis or conservative management. They found three major themes that were shared by the clinicians, first how frequently patients altered their treatment decisions, second obligatory beneficence, having to help the patient make informed decisions where outcomes were uncertain, and third the intricacy of the decision uncovered the clinicians' view on the brave decision to be made. They discovered that clinicians have great difficulty in assisting patients in making treatment decisions when the clinical outcomes are uncertain. There is a need for an honest and open shared decision—approaching patients with end stage kidney disease to decide what treatment would suit them best.

Scherer et al. (2018) used participatory action research (PAR) methods to develop an integrated nephrology and palliative care program based on a successful program in Australia embedded in a nephrology practice. Using PAR to gather information, investigators and stakeholders worked together to gather the necessary information and develop the program. All involved agreed that there was a lack of palliative care awareness in the renal community and that patients were suffering. The team was able to develop a model that could be embedded in nephrology practice.

Wong et al. (2019) studied of 21 nephrologists who had cared for advanced chronic kidney disease patients who decided not to start dialysis. The participants were mainly from academic practices (n=14) and urban areas (n=15). These nephrologists were practicing person-centered care, which included basing treatment decisions on what mattered most to their patients and found that there was little support for managing these patients conservatively. The study concluded a need for a stronger cultural and health system commitment to providing care models that can support patients who chose not to start dialysis. Early referral to a palliative care program that understands the needs of a CKD patient could help to solve this problem.

Goff et al. (2019) identified that although end-stage kidney disease patients on hemodialysis have a limited life expectancy, their palliative care needs usually go unmet. This study aimed to identify barriers and facilitators to implement a shared decision-making process and renal supportive care for these patients and improve advance care planning. They recruited 29 nephrologists and 24 social workers in 18 dialysis centers in Massachusetts (n=10) and New Mexico (n=8). A total of 102 patients received the intervention, and 40 of them had family members present. The team identified several barriers to successful implementation, which included the complexity of the interventions, inability to meet patients on non-dialysis days, scheduling conflicts of the providers, lack of training for social workers, and lack of leadership engagement. Although advance care planning can positively impact the end-of-life outcomes for the patients and their families it is not routinely done, as demonstrated by this study. More attention to supportive care services to dialysis patients must be provided.

Scherer et al. (2019) began an ambulatory kidney palliative care program and received positive feedback from patients in the first 13 months. Many patients with chronic kidney disease have an elevated symptom burden, high mortality, and a poor quality of life, all issues that palliative care could help alleviate. The team studied 55 patients with a mean age of 72 years. On the initial visit, 87% had an advance care planning discussion, 55.4% had a medication change for symptoms, and 35.5% had a dialysis decision-making conversation. Of the patients who returned satisfaction surveys, 96% viewed the program positively demonstrating the impact of palliative care on this patient group.

Rationale

Patients with end stage renal disease (ESRD) suffer from numerous symptoms, whether they are on dialysis or not on dialysis or receiving conservative treatment. Many of these patients are elderly and have numerous co-morbidities in addition to ESRD that add to their illness burden. These patients have high mortality, approximately 20%, even if on dialysis. When an elderly patient starts dialysis, the one-year survival rate is about 73%, and the five-year rate is 35%. These rates imply that many of these patients are in the last year of their life and need to be discussing their prognosis and end-of- life care to make appropriate decisions (Axelson et al., 2018). These are some of the topics that would be discussed in a palliative care conversation.

Palliative care is a medical subspecialty that started to come into its own during the early 2000's as medical and technological advances increased life expectancy. Unfortunately, this increase in longevity has not changed the way society views death.

The World Health Organization (WHO) emphasizes the importance of palliative care since it improves the quality of life for patients and families dealing with a life-limiting illness. Palliative care prevents and relieves suffering through the early identification and treatment of pain and other symptoms, which can be physical, psychosocial, or spiritual ("WHO," 2018).

Based on the literature search, palliative care has a positive effect on patients, caregivers, healthcare utilization, re-hospitalizations, and provides a feeling of support for the family. The positive impact that has been described leads one to believe that palliative care should be provided to patients as early as possible in their disease trajectory. Why should a patient have physical, psychosocial, or spiritual pain any longer than is necessary?

According to the National Hospice and Palliative Care Organization, in 2017, the average length of stay on hospice was 76.1 days, with the median being 24 days (National Hospice and Palliative Care Organization, 2019). This is a very concise period when the Federal Regulations allow up to 180 days of service, and palliative care would allow unlimited days of service. The late referral to palliative care is often due to the misconception that palliative care is only for the dying, while it should be for any person suffering from a life-threatening illness. It is also often believed that it is a substitute for disease prevention and treatment when it should be used with prevention and treatment.

Patients often reject palliative care because they believe that it is only provided to those who are dying and no longer receiving aggressive treatment. Although this is not true, the perception is such that referrals usually occur late in the illness trajectory. Jean Watson's Unitary Caring Science Theory guides the nurse in how to overcome this obstacle and have greater success in referring and providing patients with earlier palliative care, as has been demonstrated as a best practice in the literature.

In utilizing Watson's theory and her Ten Caritas Processes, there is a relationship formed between the nurse and the patient that supports the development of trust, understanding, and receptiveness to receiving palliative care services. Transpersonal relationships and human-to-human caring moments are the basis of Watson's Human Caring Theory (Wei & Watson, 2019). The transpersonal relationships and human-to-human caring interactions make it possible for the nurse to explain the benefits of palliative care and the reasons that the patient benefits from referral early in their disease.

The core aspects of the theory are Relational Caring, Caring Core, Transpersonal Caring Moment, Caring as Consciousness and Caring-Healing Modalities (Watson, 2008). Originally, Ten Carative Factors described the core aspects, which evolved to include Ten Carative Processes, described in Appendix N, and have further evolved into Caritas-Veritas literacy in Unitary Caring Science. In Caritas-Veritas literacy, the essence of each Caritas Process has been distilled to one word. These keywords are: Embrace, Inspire, Trust, Nurture, Forgive, Deepen, Balance, Co-Create, Minister, and Open (Watson, 2018).

Patient's often refuse palliative care referrals, but if the nurse uses Caritas Processes one, two, five, and eight, this may reduce the number of refusals because of the transpersonal relationship. These processes include practicing loving-kindness and equanimity; being authentically present; being present to and supportive of negative and positive feelings; and creating a healing environment at all levels (Watson, 2008). These processes facilitate the patient's understanding of the importance of an early palliative care referral. Palliative care interventions are associated with improved quality of life and symptom burden, and increased patient and caregiver satisfaction with the care provided (Kavallieratos et al., 2016). To achieve these benefits of palliative care, many of its aspects are applicable early in the patient's illness along with other treatment modalities (Brown, Eggeling, & Chambers, 2007, p. 183). Guided by Watson's theory the project was designed to help patients be open to palliative care and have a more positive response rate when the nurse called to set up the initial consultation. Patients will be able to identify palliative care as an important treatment modality, rather than a lack of treatment and a giving up of all hope.

Aim Statement

By December 2020, the project will increase the number of palliative care referrals for nephrology patients seeking treatment at chronic kidney disease level 3B or four. Patients will be referred to palliative care before they decide to begin dialysis. Key performance indicators will be that patients are willing to set up the appointment and then show up for the appointment instead of waiting until they believe they are close to the end of life.

Section III: Methods

Context

This evidence-based project 's scope was to offer palliative care consultations to a group of patients on the panel of one individual nephrologist early in their disease process.

It took place in a large medical center in the San Francisco Bay Area in the palliative care clinic. The original stakeholders were renal care managers who see the patients coming to the nephrology clinic. With the Covid-19 pandemic, the clinics went virtual, which necessitated changing the project. Instead of using renal care managers to contact the patients, a palliative care RN contacted the patients and set up the appointments. Patients diagnosed with advanced chronic kidney disease face a significant life change for themselves and their families. They often have a high symptom burden, poor quality of life, frequent health care utilization, and end-of-life desires that may not be congruent with their provider or family. Early referral for a palliative care consultation, including goals of care, a life care planning discussion, and a symptom management plan, was available to help the patient and family make sure their goals and values were honored. To accomplish this outcome, it required buy-in from the nephrologist and the palliative care nurse. These key stakeholders are aware there is a problem and anxious to help to solve it. The earlier palliative care consultation is helping the patient inform the physician of the treatment plan they would like to follow.

Interventions

At the present time there are 2,954 patients in the area served by this medical center with chronic kidney disease of stage 3B or above. There are 2,091 at Stage 3B, 739 at Stage 4, and 124 at Stage 5. Of this group, 171 are on the palliative care registry, which is a tool that identifies patients requiring palliative care consults. The criteria for a CKD patient to get on the registry are Advanced CKD (Glomerular Filtration Rate (GFR)<20) and likely to decline, as indicated by an ejection fraction (EF) <30, moderate/severe dementia or residing in a Skilled Nursing Facility (SNF); Dialysis patients who are starting to decline as indicated by high utilization, Chronic Heart Failure (CHF) (EF<30), or diastolic heart failure; Dialysis patients with advanced (Stage IV) Cancer; and CKD and moderate/severe dementia. All these criteria identify the patient late in the disease trajectory. Most have a co-morbidity that would make them a candidate for palliative care even if they did not have CKD, which was identified in the literature. Of the 171 patients on the registry there are 80 patients already on dialysis, and 57 have had a palliative care consult at some time, of the other 91, 58 have had a palliative care consult. Only 58 patients have had the opportunity to have a palliative care consult before going on dialysis and having the opportunity to make an informed decision about their care path. This means 3.9% of the patients with CKD Stage 3B or above have had a palliative care discussion, and 5.8% of this group are on the palliative care registry. This leaves 2,783 members who have not been referred to palliative care. This represents a significant gap that this project began to address.

The current model refers patients when they are already on dialysis, and often trying to decide whether to stop treatment or continue. This is a definite gap since the patient did not have the opportunity at initial diagnosis to determine what course of treatment, they wanted to pursue. By speaking with palliative care, the patient would have the opportunity to discuss all available options with a neutral party.

It is unreasonable to expect, based on current caseload, that the palliative care team could consult with all 2,783 patients, on the registry, in a reasonable period. For this reason, it was decided that 25 patients would be included in the project, starting with the highest Tangri score going down the list until 25 participants were called. Twenty-six patients were ultimately included. Prioritizing those beginning with patients with the highest Tangri score, the nurse was able to see the patients with the highest risk of transitioning to ESRD.

The Tangri predictive model was developed in 2011 (Tangri et al., 2011), and it uses routinely obtained lab tests. It can accurately predict progression to kidney failure for the patients in CKD Stages 3 –4. The organization has embedded this score in the electronic medical record (EMR) to assign every CKD patient a predictive score. This is done using the lab tests that are normally drawn, so there is no effort on the physician or the patient to obtain the score.

Because this scoring system was introduced into the EMR in time for this project, another change that occurred was to no longer use the NECPAL CCOMS-ICO©3.1 (2017) (Gómez-Batiste et al., 2017) to determine the patients who should be referred. The tool consists of thirteen questions and assigns a score according to the needs of the patient. Based on the score, it would identify patients to be referred and determine their basic needs. The tool also identifies the patient early enough so that palliative care could be introduced slowly into the treatment plan if necessary. The tool is available in Appendix O. Utilization and administration of this tool would have been an added burden to the patient and the staff during the Covid-19 pandemic, making the utilization of the Tangri score a streamlined and effective much better and simpler choice for this project.

A GAP analysis was completed and is available in Appendix E. The GAP analysis validates that nephrology patients are either not being getting referred to palliative care or are being referred too late. Usually, at the point of referral the patient is either considering stopping dialysis or approaching end of life decisions and no longer wanting to be tethered to a machine. In Appendix E the table outlines the current practices and what the best practice will be after the project is complete. Appendix F contains a Gantt chart, which outlines the timeline for this project, and a work breakdown structure (see Appendix G) helps demonstrate the various components of the project and in which sequence they will be done. The original plan was to train the renal care managers, but because of Covid-19 and the shift to work with utilization of the palliative care RN, the renal care managers were only informed of the project roll out and its components so they could be supportive of the referral if asked by their patients. This was a simplification of their role in the original project pre-Covid-19. Appendix H is a Responsibility/ Communication plan for the project. It outlines the various roles, and each person's responsibilities. Appendix I is an analysis of strengths, weaknesses, opportunities, and threats (SWOT)of the current state. Appendix J is the cost avoidance from this project. If only 12 patients a year decide they do not wish to have dialysis, and they were only on dialysis for one year, the cost avoidance would be $842,400. Since palliative care consultations to outpatients are already part of the RN's work, there is no change and no additional cost at this time, just a potential change in patients that will be seen. Based on increased numbers of referrals, there could be additional staffing costs at a later time. There could also be additional hospitalization costs, however, these would most likely occur even if the patient were on dialysis.

The project took place via telephone and video visits made by the outpatient palliative care registered nurse. This was a change from the original plan, because of the Covid-19 pandemic. Due to the pandemic, clients were no longer coming to the clinic for routine evaluations, and their contact with the renal care managers who were originally going to introduce palliative care was now limited. The renal care managers were trained to give support for the process if asked by the patient.

Study of the Interventions

A list of patients followed by a single nephrologist was obtained and consisted of 63 patients. Tangri scores were listed for each patient and ranged from a low of eight to a high of 1666. The highest scoring patients were already on dialysis. The list was reviewed, and the following patients were eliminated, those on dialysis, those on the palliative care or life care planning registries, those who had already had a palliative care or life care planning consultation, and those who had expired and had not yet been taken off the list.

The nurse ultimately called 26 patients. The original list of patients, only identified by a number, is in Appendix P. Appendix P has the list of all patients only identified by a number and is the tracking tool for those patients included in the project. It indicates the patients that were called, if they did or did not have a consult, and if they answered the question if they were or were not interested in dialysis. Some of these patients were early in their illness and could change their mind later in the illness. Appendix Q is the guideline that was used by the nurse when calling the patients to get them to schedule a consultation.

Outcome Measures

The measure used to determine the success of this project was that there would be an increase in palliative care referrals of patients at CKD stages 3B and 4, the stages of CKD before ESRD. It was determined 171 patients that had been referred for palliative care out of a total of 2,954 could benefit. This is 5.8% of the total population has been referred. At the end of the project, an additional 14 patients were scheduled for consults, representing 54% of the patients called. Of these ten completed the consults, 38.4%, and four were no-shows, 15.4%. There were 30.7% of the patients called that did not answer the phone, and a message was left. The patients that responded are a higher number of patients than normally respond to the palliative care outreach and schedule appointments. The palliative care consults used the current palliative care template in the EMR, which assures that all the necessary information is conveyed to the patient. The palliative care manager also reviewed the notes for completeness. All information on scheduling and results is in Appendix P.

Because of the easy accessibility of the Tangri score in the electronic medical record (EMR), the NECPAL CCOMS-ICO© 3.1 (2017), which is in Appendix O, was not used. It is included since it can be used to replicate this project if there were not easy access to the Tangri score.

Analysis

The data that was analyzed for this quality improvement project was an increase of palliative care referrals and consults for patients in CKD stages 3B and 4. At the current time, patients at stage 5 are end stage renal disease and are getting ready for dialysis. They are referred to palliative care if they have a high symptom burden or are near the end-of-life. It is demonstrated that by making the referrals earlier in the disease trajectory, the patient can determine without being in crisis whether they would like to go on dialysis when the disease progresses. Wong et al. pointed out, conservative treatment is just beginning to be an alternative to renal replacement therapy, and in the population over 80 there is no data that demonstrates one is better than the other in keeping the patient alive (Wong et al., 2019). By allowing the patient access to earlier palliative care, they can determine the best treatment to have the best quality of life with this chronic disease.

Appendix P provides a table of the final data. During the Plan, Do, Check, Act (PDCA) cycle it was determined that the data gathered was sufficient to demonstrate the project outcome, and its benefits to both the patient and the institution.

Ethical Considerations

This project's ethical considerations are the humanistic values of improving quality of care by using an early palliative care referral approach and how it may benefit patients. These referrals promote equity, universal access, and give the patient the ability to exercise their right to obtain quality care and have a better quality of life. Early referral and careful monitoring of stigmatization and losing the ability to have curative treatments will be avoided (Gómez-Batiste et al., 2017).

The Health Insurance Portability and Accountability Act (HIPAA) privacy rule establishes national standards to protect individuals' medical records and other health care information from being improper use. The rule requires proper safeguards to protect health information and sets limits on its use and disclosure without appropriate authorization from the patient ("HIPAA," 2020). HIPAA provides legal/enforceable regulations that protect patients and their privacy. The professional nurse is ethically bound to ensure and protect patients' rights and privacy which was done in this project. In addition, the organization's Institutional Review Board (IRB) has the responsibility to protect the rights and welfare of human subjects, by assuring that all research and projects involving human subjects is HIPAA compliant. Appendix G is the statement from the IRB that this project was not research and did protect the patients involved. Since there was no data collected that would identify the individual patient, there were no HIPAA issues. The only patient information was the number of patients referred, and if they did or did not have a referral or consult. This was reported by the palliative care RN, and the only people who knew the specific patients were the RN and manager, whom both know all patients that are referred to the program.

This project was consistent with the University of San Francisco Jesuit values, especially *cura personalis* (care of the whole person) (University of San Francisco, 2017). The goal of palliative care is to achieve the best quality of life for the patient and family while controlling symptoms. The provision of psychological, social, and spiritual support is paramount (Brown et al., 2007, p. 183), as it is with the Jesuit value of caring for the whole person. As a holistic approach to care. utilizing physicians, nurses, social workers and chaplains the palliative care team addresses the patient's physical, mental and spiritual needs, while assuring they have the best quality of life throughout their illness.

This project was also consistent with the American Nurses Association Code of Ethics. According to this code, "The nurse practices with compassion and respect for the inherent dignity, worth, and unique attributes of every person. ...and advances the profession through research and scholarly inquiry…" (*Ethics*, 2015, p. v). This project meets those two ethical principles by the theoretical foundation of Caring Science and implementing transpersonal care. As previously outlined, Caring Science helped guide the interviews and follow-up with patients and the palliative care team. The specific processes include practicing loving-kindness and equanimity; being authentically present; being present to and supportive of negative and positive feelings; and creating a healing environment at all levels (Watson, 2008). A demonstration of how the provided care was ethical and compassionate.

This project was also guided by the principles of palliative care which is sensitive to the needs and desires of the patient and family and protects their right to make choices after being given all the necessary information. Although the nurse or other team members may not agree with that choice they are ethically and morally obligated to accept the patient's wishes and provide all the required supportive care as needed. At any time during the illness the patient may change their wishes and the nurse would continue to support them, as was done in this project unrelated to what treatment plan the patient was going to choose.

There were no other ethical concerns identified.

Section IV: Results

Fifty-four percent or 14 of the 26 patients included in this project were scheduled for palliative care consults. Of these ten completed the consults, 38.4%, and four were no-shows, 15.4%. There were 30.7% of the patients called that did not answer the phone, and a message was left. More patients responded affirmatively to a consult and scheduled an appointment than normally respond to the palliative care team outreach. This was the successful learning from the project which resulted in an increased number of palliative care referrals for patients early in their disease trajectory. By consulting with the patients early in their illness they were given the opportunity to assess their options and make decisions about their care goals as the disease progressed.

Utilizing a talking guide and explaining that the consult was a best practice in helping advocate for patient preferences and to help them understand early in their disease process what was available to them resulted in a more positive response rate than when staff approach patients without guidelines for the discussion. Although the physician was supportive of the process, she had not discussed a palliative care referral with the patients prior to the phone call, which is usually the case. Even saying this did not eliminate patients refusing to participate, but 19% is much lower than the usual numbers, which is sometimes as high as 50% of the calls. Based on these findings, the guideline was used for all calls to patients regardless of their underlying or primary medical diagnosis.

Another reason for such a high acceptance rate is because of Covid-19. As a result of the virus, consultations were all virtual, and the patient and family were able to participate from the comfort of their home instead of the inconveniences of transportation to and time required for an in-person clinic appointment. The palliative care team always believed that virtual visits would not work, however, with Covid-19 and families not being able to visit in the hospital or come into clinics circumstances dictated that virtual visits be tried. During the pandemic, the team realized that virtual visits have become a great benefit for both the patient and the provider.

Although this scholarly evidence-based project only dealt with CKD patients, it demonstrates clear advantages of early palliative care intervention and should be considered for spread and implementation for other chronic diseases where quality of life and treatment options are best explored early in a patient's diagnosis.

This project can easily be spread to palliative care programs at other medical centers within the health system. From the evidence, that those individuals on renal replacement therapy increases by eight percent every year, there is a need for alternative treatment options. This project offers other options to those patients who do not want to start on dialysis. In addition, the system is looking at their projections for the next five years and is looking for alternatives to dialysis for some patients. Again, an issue that the spread of this project could help deal with.

Although the focus of the project was on Nephrology patients, there are patients with other diseases that would benefit from early palliative care referrals. Patients with Chronic Obstructive Pulmonary Disease (COPD) would certainly benefit from an early consultation and a better understanding of the disease trajectory. Another group of patients that would benefit from the spread of this project are those with Congestive Heart Failure (CHF). This project can also be spread to patients diagnosed with Covid-19 who also need to be made aware of their treatment options and the choices they can make. Making sure COPD, CHF, and Covid-19 patients are aware of their treatment options and disease trajectory as early in the illness as possible, even at diagnosis, would benefit not only the patient but the health system as well. This project not only has benefits for the individual patient, but the family and health care staff as well. It has demonstrated a win for all involved and should be spread and can be easily with discussion and demonstration to the hospitalists and primary care physicians, as well as to the other palliative care teams.

Section V: Discussion

Summary

This project's success was due to the palliative care nurse's commitment and the primary nephrologist who, for years, has tried to convince colleagues that palliative care and life care planning is beneficial to both the patient, physician and care team. Knowing what a patient wants and then ensuring those choices are honored improves satisfaction for the patient, their family, and the entire care team. As the current movement is to promote high care experience or operational service scores, this project demonstrates that by offering and delivering palliative care early in the disease trajectory that patients are satisfied that their voice is being heard, and they will receive the care that they desire.

With 38.4% of patients contacted accepting the appointments, and only 15.4% not keeping the appointment, this scholarly project demonstrates when patients understand what palliative care truly is they will avail themselves of the service. Starting with the initial phone contact through the consult and follow-up visits when the nurse presents with care, compassion, confidence, and a positive attitude, the patient is much more accepting of what is being offered. They realize they have options, control and decisions to make rather than thinking palliative care is only for the imminently dying or those not wanting any form of treatment. This project demonstrated earlier referral to palliative care benefits patients, their families, health care providers, and the health care system.

Interpretation

During the current global pandemic, palliative care can play an even bigger role in care delivery than it has in the past. As more and more patients want to avoid hospitals, clinics, nursing homes and even home health services, knowing what to expect from their disease can be most beneficial. With palliative care, patients can make better informed decisions about what care they desire. If they are concerned about coming to the hospital, if they know their disease trajectory and what to expect they will have better information to make their decision about hospitalization. Palliative care not only benefits the patient and family but can benefit the health care delivery system by utilizing scarce resources on patients who want them. As an example, with palliative care interventions, patients may decide not to go on a ventilator rather than having to have a family member make a decision at a later time about "pulling the plug" because the treatment was not making the individual better. If patients are not given adequate or appropriate information about their treatment options until after they start dialysis or are put on a ventilator, deciding to end dialysis or withdraw from costly, yet futile treatments can be both traumatic and challenging for patient and family It is considered easier to have early conversations about treatment options versus beginning an invasive and costly treatment simply because the patient lacks information or believes it is their only option. ("Starting or stopping dialysis," 2019).

Early palliative care discussions and engagement is a patient satisfier and a win/win for both the patient and the organization helping to achieve patient service goals and metrics.

This DNP project has demonstrated the benefits of palliative care outside the oncology suite and that patients with other life-threatening illnesses may also benefit. Another potential benefit of promoting, spreading and transferring earlier palliative care consultations could include patients diagnosed with Covid-19, since they have important and critical decisions to consider regarding their care, and often a short period of time to make that decision..

Limitations

Changing existing clinical practices and approaches to patient care involving teams with longstanding care models and pathways can be difficult. Although the one nephrologist involved in this project was supportive of palliative care and life care planning for patients, other nephrologists had not yet bought in. By using the results of this project, could help convince them that there are alternatives, such as conservative treatment, for some patients instead of renal replacement therapy. Total adoption by the entire nephrology team for early palliative care interventions, could still be a slow process. Another potential limitation when the project first began was getting patients to come into the outpatient clinic for a palliative care consultation, which was consistent with findings by Goff et al. (Goff et al., 2019). The original plan to help mitigate for this challenge was to ensure appointments were made on the same day as the patient's nephrology appointments, avoiding any secondary or additional trips to the clinic to receive their palliative care consultation. This plan and need for combining scheduled appointments were eliminated by the arrival of Covid-19, as social distancing and state-wide stay in place orders shifted all in-person patient visits to a virtual appointment format. This virtual appointment option was perceived as more convenient for patients and expanded access options to virtual palliative care consultations One of these two strategies ensure they get their consultation by patients being referred early in their diagnosis.

The project represented a snapshot in time, so it was not possible to determine if the four patients, 15%, who said they did not want dialysis would make that decision when the time came. All that can be determined is that after the consultation, and with the information presented, at that time they did not believe they would start dialysis when the time came.

Conclusions

The literature supports that palliative care is beneficial to patients with advanced chronic kidney disease, and it is a modality that should be provided to this population. Unfortunately, at the current time, health care providers may not think of it until the patient is in the last few weeks of their life, and dialysis is no longer having the anticipated or therapeutic effect. It is certainly beneficial for the patient to receive support for symptom management and spiritual care, and unfortunately many or most patients are not provided essential information on all available care options earlier in their disease process. It has been demonstrated that nephrologists expect their patients to choose renal replacement therapy instead of conservative treatment as soon as they reach stage 5 (Wong et al., 2019). In fact, the nephrologist may often convince the patient to make this choice even if the patient may want a more conservative treatment and care path. Palliative care can help the patient in that decision-making process and support their personal choices. It is their choice to decide how to live the rest of their lives and what quality of life means to them.

By providing palliative care early in their disease trajectory, they can think about their care goals and actively participate in a life care planning conversation and develop an advanced directive. When these discussions occur close to the end-of-life, the patient may not be able to participate in the decision-making process, and others may be forced to decide on behalf of the patient. This project places decision-making where it is most appropriate and rightfully belongs, with the patient.

With success demonstrated by this project, there is a potential to spread to other disease clinics. Chronic Obstructive Pulmonary Disease (COPD) patients are often not referred to palliative care until they are in the intensive care unit (ICU) and/or on a ventilator and decisions need to be made about terminating life-support. The family are then thrust into a crisis that they are not prepared for since they did not have the opportunity to think about what the patient may want, since this anticipated outcome had not been addressed early in the diagnosis.. It is much easier never to put the patient on the ventilator than to ask the family to withdraw it. This is the same situation when a patient on hemodialysis is asking to withdraw. Had they had the benefit of information up front, they might have never chosen to start dialysis. This is a choice they now have because of this project.

The importance of this scholarly project is that when given sufficient information, patients do make choices about the care they wish to receive, especially when dealing with a chronic life-threatening illness. Early palliative care referral allows the patient to think about and decide how he/she wants to spend their last days, and what type of quality of life they desire. The merits and opportunities for spread of this project extend well beyond end stage renal disease and include other chronic diseases with similar challenges and opportunities. At present, the spread of this project is focused on local opportunities to engage more nephrologists on the care team to implement early palliative care consultation as a practice standard for the entire nephology practice group. The positive patient engagement and team support for improved ethical decision making, as well as overwhelming positive business advantages for improved care efficiencies, streamlined implementation of evidence-based practices for quality and safety, as well as minimal investment with measurable cost savings demonstrate that this project is well-suited for further integration across the organization and further spread to other specialty areas. This project gives patients back their choice and ensures their voice is honored in their care decision.

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Appendix A: Signed Statement of Non-Research Determination

DNP Statement of Non-Research Determination Form

Student Name:__Jerold S. Cohen ______________________________

Title of Project: Earlier Palliative Care Referrals

Brief Description of Project:

A) Aim Statement: At least 70% of nephrology patients will be referred for a palliative care consultation at CKD level 3B within 6 months.

B) Description of Intervention: Renal case managers and nephrologists will go through a training to identify which level 3B patients will benefit from a palliative care consultation and make a referral to the palliative care team at that time instead of later in their illness.

C) How will this intervention change practice? It will refer CKD patients earlier in the trajectory of their disease so they can make better decisions about their treatment options and their quality of life. It will make sure that the care provided to patients is the care that they want.

D) Outcome measurements: The number of CKD patients referred at level 3B will increase to 70% of those seen in clinic by the end of this project.

To qualify as an Evidence-based Change in Practice Project, rather than a Research Project, the criteria outlined in federal guidelines will be used: (http://answers.hhs.gov/ohrp/categories/1569)

X This project meets the guidelines for an Evidence-based Change in Practice Project as outlined in the Project Checklist (attached). Student may proceed with implementation.

☐This project involves research with human subjects and must be submitted for IRB approval before project activity can commence.

Comments:

EVIDENCE-BASED CHANGE OF PRACTICE PROJECT CHECKLIST *

Instructions: Answer YES or NO to each of the following statements:

Project Title:	**YES**	**NO**
The aim of the project is to improve the process or delivery of care with established/ accepted standards, or to implement evidence-based change. There is no intention of using the data for research purposes.	**X**	
The specific aim is to improve performance on a specific service or program and **is a part of usual care**. ALL participants will receive standard of care.	**X**	
The project is **NOT** designed to follow a research design, e.g., hypothesis testing or group comparison, randomization, control groups, prospective comparison groups, cross-sectional, case control). The project does **NOT** follow a protocol that overrides clinical decision-making.	**X**	
The project involves implementation of established and tested quality standards and/or systematic monitoring, assessment or evaluation of the organization to ensure that existing quality standards are being met. The project does **NOT** develop paradigms or untested methods or new untested standards.	**X**	
The project involves implementation of care practices and interventions that are consensus-based or evidence-based. The project does **NOT** seek to test an intervention that is beyond current science and experience.	**X**	
The project is conducted by staff where the project will take place and involves staff who are working at an agency that has an agreement with USF SONHP.	**X**	
The project has **NO** funding from federal agencies or research-focused organizations and is not receiving funding for implementation research.	**X**	
The agency or clinical practice unit agrees that this is a project that will be implemented to improve the process or delivery of care, i.e., **not** a personal research project that is dependent upon the voluntary participation of colleagues, students and/ or patients.	**X**	
If there is an intent to, or possibility of publishing your work, you and supervising faculty and the agency oversight committee are comfortable with the following statement in your methods section: *"This project was undertaken as an Evidence-based change of practice project at X hospital or agency and as such was not formally supervised by the Institutional Review Board."*	**X**	

ANSWER KEY: If the answer to **ALL** of these items is yes, the project can be considered an Evidence-based activity that does NOT meet the definition of research. **IRB review is not required. Keep a copy of this checklist in your files.** If the answer to ANY of these questions is **NO**, you must submit for IRB approval.

*Adapted with permission of Elizabeth L. Hohmann, MD, Director and Chair, Partners Human Research Committee, Partners Health System, Boston, MA.

STUDENT NAME (Please print): Jerold S. Cohen

____

Signature of Student: ____DATE 8/13/2019______

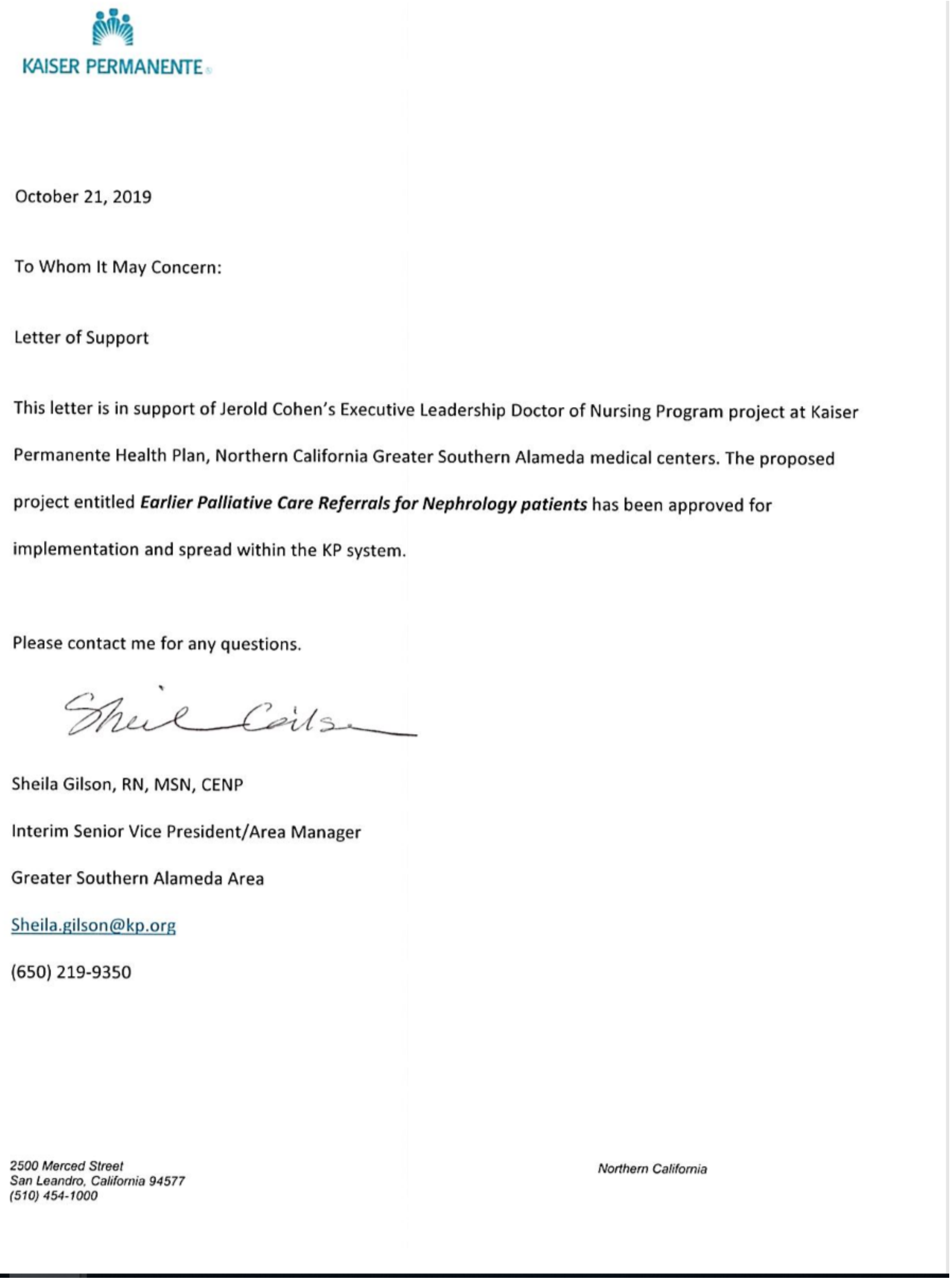
SUPERVISING FACULTY MEMBER (CHAIR) NAME (Please print):

____

Signature of Supervising Faculty Member (Chair):

____DATE__________

Appendix B: Letter of Support from Organization



KAISER PERMANENTE

October 21, 2019

To Whom It May Concern:

Letter of Support

This letter is in support of Jerold Cohen's Executive Leadership Doctor of Nursing Program project at Kaiser Permanente Health Plan, Northern California Greater Southern Alameda medical centers. The proposed project entitled ***Earlier Palliative Care Referrals for Nephrology patients*** has been approved for implementation and spread within the KP system.

Please contact me for any questions.

Sheila Gilson, RN, MSN, CENP

Interim Senior Vice President/Area Manager

Greater Southern Alameda Area

Sheila.gilson@kp.org

(650) 219-9350

2500 Merced Street
San Leandro, California 94577
(510) 454-1000

Northern California

Appendix C: IRB Approval

Kaiser Foundation Research Institute
Kaiser Permanente
Research
Transforming the future of health

December 2, 2019

Subject: RDO KPNC 19 - 149
Title: Earlier Palliative Care Referrals

Dear Mr. Cohen:

As a Research Determination Official (RDO) for the Kaiser Permanente Northern California region, I have reviewed the documents submitted for the above referenced project. The project does not meet the regulatory definition of research involving human subjects as noted here:

[X] Not Research

The activity does not meet the regulatory definition of research at 45 CFR 46.102(d):

Research means a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge.

[X] Not Human Subject

The activity does not meet the regulatory definition of human subjects at 45 CFR 46.102(f):

Human subject means a living individual about whom an investigator conducting research obtains (1) data through intervention or interaction with the individual, or (2) identifiable private information.

Therefore, the project is not required to be reviewed by a KP Institutional Review Board (IRB). This determination is based on the information provided. If the scope or nature of the project changes in a manner that could impact this review, please resubmit for a new determination. Also, you are responsible for keeping a copy of this determination letter in your project files as it may be necessary to demonstrate that your project was properly reviewed.

Provide this approval letter to the Physician in Charge (PIC), your Area Manager, and Chief of Service, to determine whether additional approvals are needed.

Sincerely,

David C. Matesanz

Director
Research Compliance and IRB Administration
Financial Conflict of Interest Officer
Kaiser Permanente
NCAL Regional Compliance, Ethics, & Integrity Office
1800 Harrison St., 10th Floor, Oakland, CA 94612

Appendix D: Evidence Table

Source	Purpose of Article or Review	Design Type	Methodology	Findings	Conclusions	Critical Appraisal Tool and Rating
Davison, S.N.	Review of advances and remaining challenges to integrate palliative care into the care of advanced CKD patients	Professional Commentary	N/A	Patients with advanced CKD can benefit from palliative care These patients have a high symptom burden	Palliative care should be a priority of all dialysis programs Conservative managed patients would benefit from palliative care Advanced CKD patients need advance care planning	N/A (Substantive reference)
Hussain, J.A. et al.	To compare survival, hospital admissions and palliative care access for patients over 70 with CKD stage 5 on renal replacement	Quantitative	Retrospective Observational Study	More RRT patients die in the hospital, Conservative management patients get referred to palliative care RRT patients do not	For patients over 80 with poor performance or high co-morbidities the survival rate is no different for RRT or	Appendix E Level III High Quality

	therapy (RRT) or conservative management				conservative management Conservative management have greater access to palliative care	
Bull, R. et al.	To identify predictors of conservative treatment Determine the perceptions of health professionals on the role of palliative care in CKD management	Quantitative	Retrospective Audit	Loss of function represents a justification to withdraw renal replacement therapy Patient/Family indecision complicates and disrupts end-of-life discussions Professionals support end-of-life discussions, but congruity with patient is necessary	Professional's beliefs, values and knowledge of palliative care influence their end-of-life decisions Professionals support early end-of -life discussions, but don't always do them	Appendix E Level III High Quality
Bristowe, K. et al.	Explore the experiences of people with end-stage	Qualitative	Semi-structured interview	Themes were discovered related to looking back,	Renal patients have unmet advance care	Appendix E Level III A/B High/Good

	kidney disease regarding starting dialysis and their advance care planning needs			current experiences, and looking ahead Lack of opportunity to discuss the future	planning needs There is a need to normalize discussions about preferences and priorities early in the disease trajectory	Quality
Culp, S. et al.	Describe dialysis professionals' perceptions of adequacy of supportive care in their centers, barriers to providing it and suggestions to improve it	Qualitative	Descriptive study	Most participants did not feel their center was providing high-quality supportive care	Dialysis professionals report high unmet supportive care needs in their centers Urgent need for education of dialysis professionals on availability of supportive care	Appendix E Level III A/B High/Good Quality
Hoffman, a. et al.	Gain a greater understanding of the experiences of conservatively managed	Qualitative	Descriptive Study	Themes for patients and carers were awareness of what was going on,	Patients and carers felt renal supportive care gave them peace	Appendix E Level III A/B High/Good Quality

	patients and their satisfaction with renal supportive care			informed decision making, feeling supported and waiting for health to decline Patients also wanted to maintain normalcy, and carers were concerned about their new role	of mind, and they were satisfied with the services	
Noble, H. et al.	To explore clinician views on decisional conflict in patients with end-stage kidney disease	Qualitative	Interpretive	Patients frequently change their mind about treatment Clinicians have to help patients make decisions with uncertain outcomes Clinicians concern about the momentous decisions being made	There is decisional conflict in patient decision-making and a tension between shared decision making and clinical practice Clinicians face conflicts when discussing	Appendix E Level III A/B High/Good Quality

					treatment options due to uncertainty	
Scherer, J.S. et al.	Describes application of participatory action research methods to develop an outpatient kidney palliative care program	Qualitative	Participatory Action Research	Stakeholder needs and challenged to meeting those needs were identified Uncovered a shared understanding of the clinical need for palliative care in nephrology but apprehension toward practice change	There needs to be a development of a new model of care Developed a conceptual model for integrated nephrology and palliative care	Appendix E Level III A/B High/Good Quality
Wong, S.P.Y. et al.	Describe practice approaches of nephrologists who have provided conservative care to chronic kidney	Qualitative	Semi-structured interview Grounded Theory	These nephrologists practiced person-centered care, and adjusted to the needs of their patients Improvised an infrastructure to be able to	Insights from this group demonstrate the need for models of care that will allow patients to forgo dialysis	Appendix E Level III A/B High/Good Quality

	disease patients			provide conservative care in a medical center		
Goff, S.L. et al.	Identify barriers to shared decision making and renal supportive care	Quantitative	Observational	Barriers were meeting with patients on non-dialysis days, scheduling difficulties, perceived need for local policy change on advance care planning, perceived need for additional training, lack of endorsement of the intervention by some staff, and lack of leadership engagement	Advance care planning for dialysis patients has a positive impact, develop policies that routinize advance care planning	Appendix E Level III High Quality
Scherer, J.S. et al (2019)	Describe the patient demographics and clinical activities for	Quantitative	Descriptive	875 of initial visits included advance care planning discussions,	A model of care that integrates palliative care with	Appendix E Level III High Quality

	the first 13 months of a kidney palliative program embedded in a nephrology practice			55.4% included medication changes for symptoms, and 35.5% included dialysis decision-making conversations 96% of returned surveys showed satisfaction with the care received	nephrology care can potentially meet the gaps in care while achieving patient satisfaction	

Appendix E: Gap Analysis

Best Palliative Care Referral Process	**Current Practice**
• Identification of patients in need of a palliative care consultation on first visit to nephrology clinic	• Insufficient knowledge to identify patients currently
• Use the Tangri Predictive Model to predict progression to kidney failure and referral to palliative care	• No tool is in place
• Evaluate the patient utilizing the NECPAL CCOMS-ICO© 3.1 (2017) Tool	• No evaluation tool is in place
• Explain to patient the benefits of meeting with the palliative care team	• Insufficient knowledge to have this discussion
• Arrange for palliative care consultation	• No referral is made at the start of care
• Provide goals of care and care planning conversation	• Only done after patient is on dialysis and near end of life
• Allow patient to determine his treatment whether renal replacement therapy or conservative management	• Patient is advised to start either peritoneal dialysis or hemodialysis depending on ability and living conditions
• Provide ongoing support to patient as symptoms change	• If referred to palliative care only seen when there are symptoms to be addressed

Appendix F: Gantt Chart

Project Timeline		
Start Date	End Date	Task(s)
9/30/2019	10/18/2019	Prospectus Due to advisor
10/7/2019	10/25/2019	Manuscript Due to advisor
10/28/2019	11/24/2019	Prospectus Approval with edits as needed
12/20/2019	1/1/2020	Gather Data on Current Palliative Care Referrals
3/2/2020	6/1/2020	Monitor palliative care referrals and gather data
6/1/2020	8/30/2020	Gather patient list, and identify patients to call
9/1/2020	10/15/2020	Schedule patients and complete palliative care consultations
10/15/2020	11/30/2020	Continue to analyze results and finalize paper and presentation
11/30/2020	12/30/2020	Spread process to other nephrologist’s patients

	2019									2020						
Project Calendar & Important Dates:	Sept	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec
Tasks																
Prospectus Due to advisor (9/30-10/18/2019)	■	■														
Manuscript Due to advisor(10/7-10/25/2019)	■	■														
Prospectus Approval with edits as needed(10/28-11/24/2019)		■	■													
Develop Training Program(11/15-12/15/2019)			■	■												
Gather Data on Current Palliative Care Referrals (12/20/2019-1/1/2020)				■	■											
Identify Renal Case Managers to be trained (1/6-1/31/2020)(Eliminate)					■											
Do initial Renal Case Manager training (2/3-2/28/2020)(Eliminate)						■										
Monitor palliative care referrals and gather data (3/2-6/1/2020)							■	■	■							
Gather patient list, and identify patients to call(6/1-8/30/2020)										■	■					
Schedule patients and complete palliative care consultations (9/1/-10/15/2020)													■	■		
Continue to analyze results and finalize paper and presentation (10/15-11/30/2020)														■	■	
Spread process to other nephrologist's patients 11/30-12/30/20200)																■

Appendix G: Work Breakdown Structure

Level	WBS Code	Element Name	Definition
1	1	Early Palliative Care Referrals	All work to get palliative care referrals earlier in the patient's illness
2	1.1	Initiation	The work to initiate the project
3	1.1.1	Evaluation and Recommendations	Working group to evaluate solution sets and make recommendations (Current referral sources and PC Team)
3	1.1.2	Develop Project Charter	Project Manager develops the charter
3	1.1.3	Deliverable: Submit Project Charter	Project Charter is delivered to the Sponsor
3	1.1.4	Project Sponsor Reviews Charter	Project Sponsor reviews Charter
3	1.1.5	Project Charter Signed and Approved	Sponsor signs the Charter and authorizes Project Manager to move to Planning Process
2	1.2	Planning	The work for the planning process of the Project
3	1.2.1	Create Preliminary Scope Statement	Project Manager creates Preliminary Scope Statement
3	1.2.2	Develop Budget	Project Manager develops Project Budget
3	1.2.3	Determine Project Team	Project Manager determines Project Team and requests them (Members of the Palliative Care Team)
3	1.2.4	Project Team Kickoff Meeting	Planning Process starts with the Project Manager, Project Team and the Sponsor
3	1.2.5	Develop Project Plan	The team develops the project plan under the direction of the Project Manager
3	1.2.6	Submit Project Plan	Project Manager submits plan for approval
3	1.2.7	Milestone: Project Plan Approval	The project plan is approved, and the Project Manager has permission to move forward to execute the project
2	1.3	Development and Training	The work of developing the training program and the training itself
3	1.3.1	Project Kickoff Meeting	Project Manager conducts a formal kickoff meeting with the project

			team, project stakeholders, and the sponsor
3	1.3.2	Verify and Validate User Requirements	The original user requirements are reviewed by the project manager and the team, and then validated with the users/stakeholders (Referrers to Palliative Care – Physicians, Nurses, MSWs) This may necessitate additional clarification
3	1.3.3	Design Script for RN	Project Manager and project team design the training and script to be used by the palliative care RN referrals
3	1.3.4	Develop Renal Care Manager Scripts	Review with Renal Care Managers what to say to patients if they question the palliative referral
3	1.3.5	Training	Review Script with RN
3	1.3.6	Go Live	Have RN begin making calls
3	1.3.7	Gather Data	Project team will gather data on the referrals, and see if the patients are referred earlier than before the training
3	1.3.8	Evaluate Results	Determine if the training was effective, and make changes if necessary
3	1.3.9	Spread	Spread the training to additional staff
2	1.4	Control	The work involved for the control process of the project
3	1.4.1	Project Management	Overall project management for the project
3	1.4.2	Project Status Meetings	Weekly team status meetings
3	1.4.3	Update Project Management Plan	Project Manager updates the Project Management Plan as the project progresses
2	1.5	Closeout	The work to close-out the project
3	1.5.1	Document Lessons Learned	Project Manager and the project team have a “lessons learned meeting” and documents the learnings
3	1.5.2	Update Files/Records	All files and records are updated to show the earlier palliative care referral process

3	1.5.3	Gain Formal Acceptance	Project sponsor accepts the project, signing the document that was in the project plan
3	1.5.4	Archive Files/Documents	All project documents are formally archived

GLOSSARY OF TERMS

Level of Effort:	Level of Effort (LOE) is how much work is required to complete a task.
WBS Code:	A unique identifier assigned to each element in a Work Breakdown Structure for the purpose of designating the elements hierarchical location within the WBS.
Work Package:	A Work Package is a deliverable or work component at the lowest level of its WBS branch.
WBS Component:	A component of a WBS which is located at any level. It can be a Work Package or a WBS Element as there's no restriction on what a WBS Component is.
WBS Element:	A WBS Element is a single WBS component and its associated attributes located anywhere within a WBS. A WBS Element can contain work, or it can contain other WBS Elements or Work Packages.


Early Palliative Care Referrals
1
Initiation
1.1
Planning
1.2
Development and Training
1.3
Control
1.4
Closeout
1.5
Evaluation & Recommendations
1.1.1
Develop Project Charter
1.1.2
Deliverable: Submit Project Charter
1.1.3
Project Sponsor Reviews Project Charter
1.1.4
Project Charter Signed/Approved
1.1.5
Create Preliminary Scope Statement
1.2.1
Develop Budget
1.2.2
Determine Project Team
1.2.3
Project Team Kickoff Meeting
1.2.4
Develop Project Plan
1.2.5
Submit Project Plan
1.2.6
Milestone: Project Plan Approved
1.2.7
Project Kickoff Meeting
1.3.1
Verify and Validate User Requirements
1.3.2
Design Script for RN
1.3.3
Develop Renal Care Manager Script
1.3.4
Training
1.3.5
Go Live
1.3.6
GAther Data
1.3.7
Evaluate Results
1.3.8
Spread
1.3.9
Project Management
1.4.1
Project Status Meetings
1.4.2
Update Project Management Plan
1.4.3
Document Lessons Learned
1.5.1
Update Files/ Records
1.5.2
Gain Formal Acceptance
1.5.3
Archive Files/ Documents
1.5.4

Appendix H: Responsibility/Communication Matrix

Roles	Responsibilities
Chief of Nephrology	• Engage and support new process
Clinic Physician	• Engage and support new process
Renal Manager	• Support the education program • Act as a liaison to nephrologists
Continuum Administrator	• Lead the training • Provide key communications and updates to stakeholders
Renal Case Managers	• Participate in educational program • Complete post-education survey
Palliative Care Manager	• Participate in training • Act as a liaison between nephrology and palliative care
Palliative Care Team	• Provide specialty palliative care to nephrology patients

Appendix I: SWOT Analysis

STRENGTH	WEAKNESS
1. Highly integrated delivery system with the ability to transfer information between teams. 2. Some engaged physicians in nephrology. 3. Engaged Renal Case Managers for successful implementation – supporting consultations 4. Engaged palliative care team.	1. Competing priorities 2. Not in current workflow for nephrology or palliative care. 3. Some nephrologists not supportive of palliative care. 4. Covid-19 5. Lack of knowledge by hospitalists, specialists, and primary care physicians as to what is palliative care and it's benefits. 6. Some palliative care team members are uncomfortable dealing with nephrology diagnoses.
Opportunities	**Threats**
1. Align with best practices. 2. Provide exceptional care to the patient.	1. Adding a new process could upset clinic workflow.

3. Improve patient and family satisfaction with care provided. 4. Other team members besides the RN could perform these consultations. 5. Spread project within the organization and to other organizations.	2. Not the usual standard of care internally or externally. 3. The misunderstanding that palliative care and hospice are the same. 4. This could become the standard of care for other nephrology groups and lose patients internally.

Appendix J: Return on Investment and Cost Avoidance

Proposed Project Cost Avoidance

12 patients a year do not start dialysis

Savings:

Each dialysis session is estimated at $450 a session

Each patient typically requires dialysis 3 times a week

156 sessions per year/per patient

12 patients translate into 1872 sessions

Total Cost Avoidance is estimated at $842,400

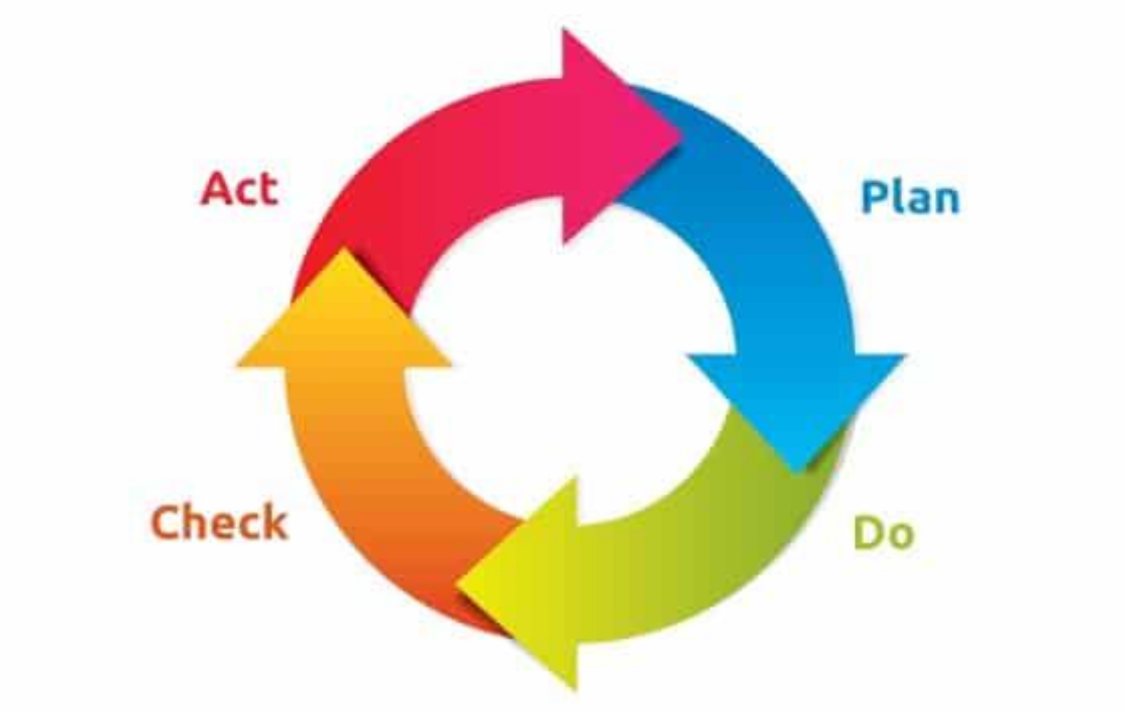
There is no additional FTE cost, since the palliative care RN is already conducting palliative care consultations as part of their current responsibilities. As the number of consultations increase other team members will also conduct these consultations.

Currently the team has capacity, should the number increase substantially there would be a need for added staff, which would add a labor cost. The cost would be directly associated with increase consultations and improved patient care.

Appendix K: Proposed CQI Method and Data Collection Tools

Patient Number	Score	Age	Renal Reg.	Call 1	Call 2	Call 3	Appt. Date and Time	Done	Interest in Dialysis	Comments	PC Reg

Appendix L: PDCA Plan



Plan: Develop training program, select participants

Do: Implement the plan, do training program, select all new patients in Nephrology Clinic to receive palliative care referral

Check: Make sure all new referrals are offered a palliative care consultation, determine if plan is meeting objectives, is there an increase in referrals

Act: Make corrective actions, analyze differences from expectations

Diagram (Taproot, 2020)

Appendix M: Stages of Chronic Kidney Disease

Stages of Chronic Kidney Disease

Below is shown the five stages of CKD and GFR for each stage:

- **Stage 1** with normal or high GFR (GFR > 90 mL/min)
- **Stage 2** Mild CKD (GFR = 60-89 mL/min)
- **Stage 3A** Moderate CKD (GFR = 45-59 mL/min)
- **Stage 3B** Moderate CKD (GFR = 30-44 mL/min)
- **Stage 4** Severe CKD (GFR = 15-29 mL/min)
- **Stage 5** End Stage CKD (GFR <15 mL/min)

("Stages of CKD," 2019)

Appendix N: Carative Factors and Caritas Processes

Carative Factors (1979)	Caritas Processes (2002-2007)
1. Humanistic-altruistic-values	1. Practicing loving-kindness and equanimity for self and others
2. 2. Instilling/enabling faith and hope	2. Being authentically present; enabling/sustaining/honoring deep belief system and subjective world of self/other
3. Cultivating sensitivity to oneself and other	3. Cultivating one's own spiritual practices; deepening self-awareness, going beyond "ego-self"
4. Developing a helping-trusting, human caring relationship	4. Developing and sustaining a helpful-trusting, authentic caring relationship
5. Promoting and accepting expression of positive and negative feelings	5. Being present to, and supportive of, the expression of positive and negative feelings as a connection with deeper spirit of self and the one-being-cared for

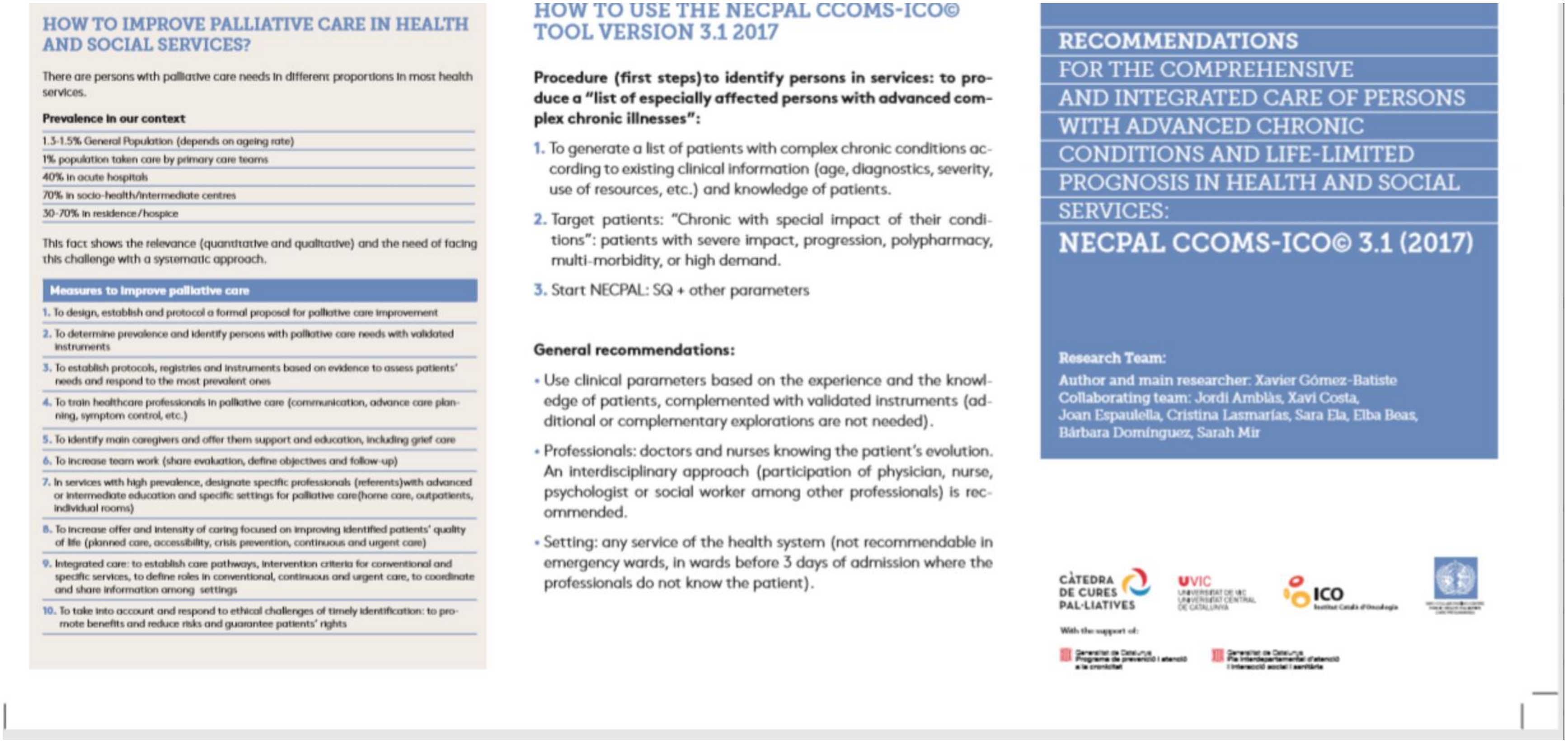
6. Systematic use of scientific (creative) problem-solving caring process	6. Creative use of self and all ways of knowing/being/doing as part of the caring process (engaging in artistry of caring-healing practices)
7. Promoting transpersonal teaching-learning	7. Engaging in genuine teaching-learning experiences within context of caring relationship – attend to whole person and subjective meaning; attempt to stay within other's frame of reference (evolve toward "coaching" role vs. conventional imparting of information)
8. Providing for a supportive, protective, and/or corrective mental, social, spiritual environment	8. Creating a healing environment at all levels (physical, nonphysical, subtle environment of energy and consciousness whereby wholeness, beauty, comfort, dignity, and peace are potentiated (Being/Becoming the environment)

9. Assisting with gratification of human needs	9. Reverentially and respectfully assisting with basic needs; holding an intentional, caring consciousness of touching and working with the embodied spirit of another, honoring unity of Being; allowing for spirit-filled connection
10. Allowing for existential-phenomenological dimensions	10. Opening and attending to spiritual, mysterious, unknown existential dimensions of life-death-suffering; "allowing for a miracle" *

*Interpretation courtesy Resurrection Health, Chicago

(Watson, 2008, p. 31)

Appendix O: NECPAL Tools



HOW TO IMPROVE PALLIATIVE CARE IN HEALTH AND SOCIAL SERVICES?

There are persons with palliative care needs in different proportions in most health services.

Prevalence in our context

1.3-1.5% General Population (depends on ageing rate)
1% population taken care by primary care teams
40% in acute hospitals
70% in socio-health/intermediate centres
30-70% in residence/hospice

This fact shows the relevance (quantitative and qualitative) and the need of facing this challenge with a systematic approach.

Measures to improve palliative care

1. To design, establish and protocol a formal proposal for palliative care improvement
2. To determine prevalence and identify persons with palliative care needs with validated instruments
3. To establish protocols, registries and instruments based on evidence to assess patients' needs and respond to the most prevalent ones
4. To train healthcare professionals in palliative care (communication, advance care planning, symptom control, etc.)
5. To identify main caregivers and offer them support and education, including grief care
6. To increase team work (share evaluation, define objectives and follow-up)
7. In services with high prevalence, designate specific professionals (referents)with advanced or intermediate education and specific settings for palliative care(home care, outpatients, individual rooms)
8. To increase offer and intensity of caring focused on improving identified patients' quality of life (planned care, accessibility, crisis prevention, continuous and urgent care)
9. Integrated care: to establish care pathways, intervention criteria for conventional and specific services, to define roles in conventional, continuous and urgent care, to coordinate and share information among settings
10. To take into account and respond to ethical challenges of timely identification: to promote benefits and reduce risks and guarantee patients' rights

HOW TO USE THE NECPAL CCOMS-ICO© TOOL VERSION 3.1 2017

Procedure (first steps)to identify persons in services: to produce a "list of especially affected persons with advanced complex chronic illnesses":

1. To generate a list of patients with complex chronic conditions according to existing clinical information (age, diagnostics, severity, use of resources, etc.) and knowledge of patients.
2. Target patients: "Chronic with special impact of their conditions": patients with severe impact, progression, polypharmacy, multi-morbidity, or high demand.
3. Start NECPAL: SQ + other parameters

General recommendations:

- Use clinical parameters based on the experience and the knowledge of patients, complemented with validated instruments (additional or complementary explorations are not needed).
- Professionals: doctors and nurses knowing the patient's evolution. An interdisciplinary approach (participation of physician, nurse, psychologist or social worker among other professionals) is recommended.
- Setting: any service of the health system (not recommendable in emergency wards, in wards before 3 days of admission where the professionals do not know the patient).

RECOMMENDATIONS FOR THE COMPREHENSIVE AND INTEGRATED CARE OF PERSONS WITH ADVANCED CHRONIC CONDITIONS AND LIFE-LIMITED PROGNOSIS IN HEALTH AND SOCIAL SERVICES:

NECPAL CCOMS-ICO© 3.1 (2017)

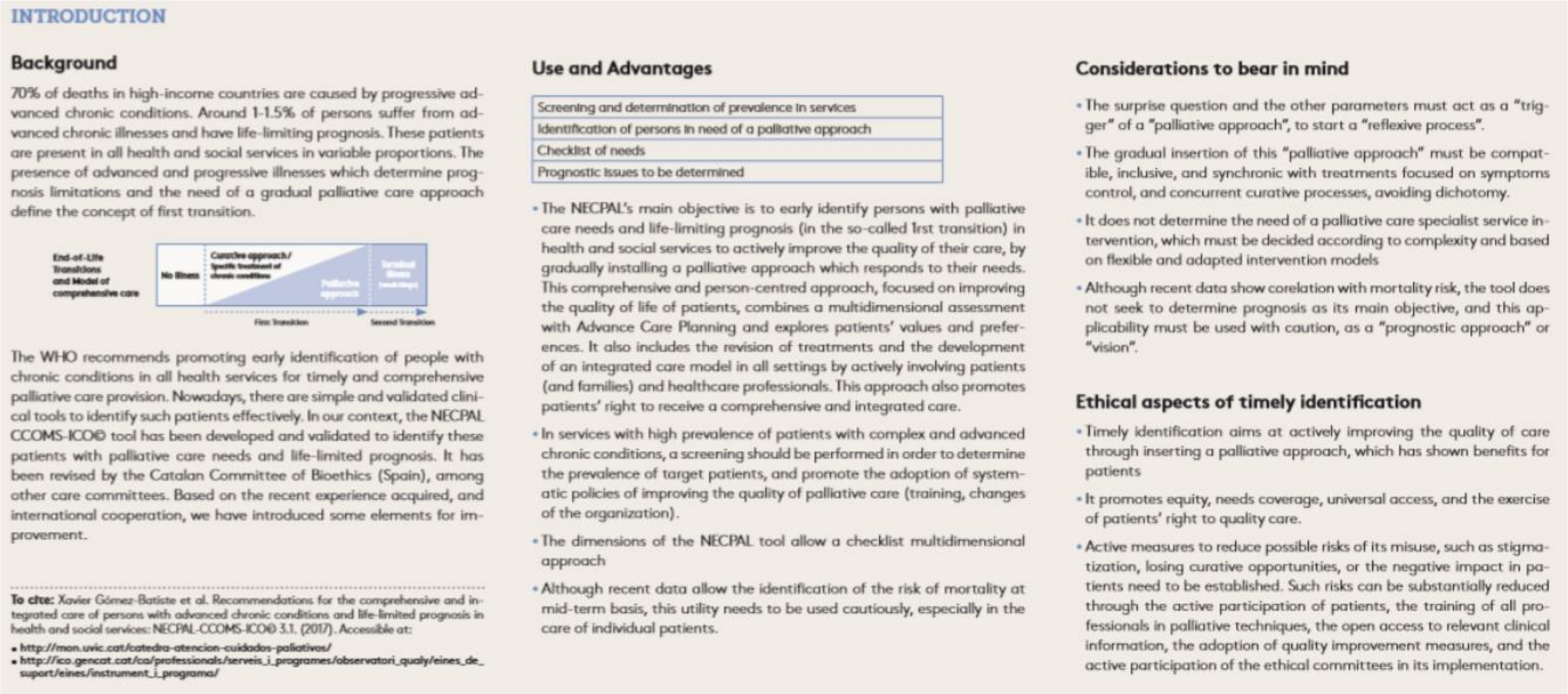
Research Team:

Author and main researcher: Xavier Gómez-Batiste
Collaborating team: Jordi Amblàs, Xavi Costa,
Joan Espaulella, Cristina Lasmarías, Sara Ela, Elba Beas,
Bárbara Domínguez, Sarah Mir

CÀTEDRA DE CURES PAL·LIATIVES
UVIC UNIVERSITAT DE VIC UNIVERSITAT CENTRAL DE CATALUNYA
ICO Institut Català d'Oncologia

With the support of:

Generalitat de Catalunya Programa de prevenció i atenció a la cronicitat
Generalitat de Catalunya Pla interdepartamental d'atenció i interacció social i sanitària



INTRODUCTION

Background

70% of deaths in high-income countries are caused by progressive advanced chronic conditions. Around 1-1.5% of persons suffer from advanced chronic illnesses and have life-limiting prognosis. These patients are present in all health and social services in variable proportions. The presence of advanced and progressive illnesses which determine prognosis limitations and the need of a gradual palliative care approach define the concept of first transition.

The WHO recommends promoting early identification of people with chronic conditions in all health services for timely and comprehensive palliative care provision. Nowadays, there are simple and validated clinical tools to identify such patients effectively. In our context, the NECPAL CCOMS-ICO© tool has been developed and validated to identify these patients with palliative care needs and life-limited prognosis. It has been revised by the Catalan Committee of Bioethics (Spain), among other care committees. Based on the recent experience acquired, and international cooperation, we have introduced some elements for improvement.

To cite: Xavier Gómez-Batiste et al. Recommendations for the comprehensive and integrated care of persons with advanced chronic conditions and life-limited prognosis in health and social services: NECPAL-CCOMS-ICO© 3.1. (2017). Accessible at:

- http://mon.uvic.cat/catedra-atencion-cuidados-paliativos/
- http://ico.gencat.cat/ca/professionals/serveis_i_programes/observatori_qualy/eines_de_suport/eines/instrument_i_programa/

Use and Advantages

Screening and determination of prevalence in services
Identification of persons in need of a palliative approach
Checklist of needs
Prognostic issues to be determined

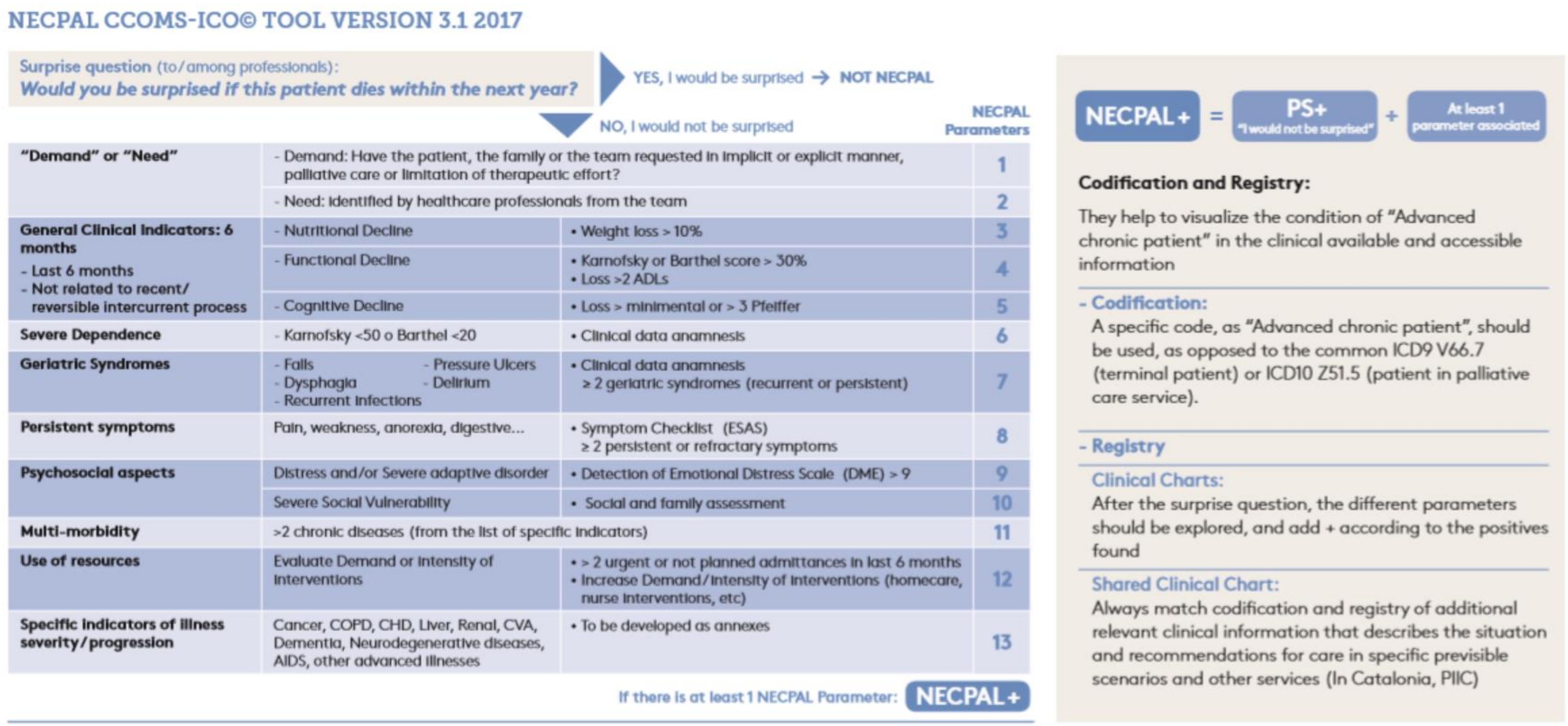
- The NECPAL's main objective is to early identify persons with palliative care needs and life-limiting prognosis (in the so-called 1rst transition) in health and social services to actively improve the quality of their care, by gradually installing a palliative approach which responds to their needs. This comprehensive and person-centred approach, focused on improving the quality of life of patients, combines a multidimensional assessment with Advance Care Planning and explores patients' values and preferences. It also includes the revision of treatments and the development of an integrated care model in all settings by actively involving patients (and families) and healthcare professionals. This approach also promotes patients' right to receive a comprehensive and integrated care.
- In services with high prevalence of patients with complex and advanced chronic conditions, a screening should be performed in order to determine the prevalence of target patients, and promote the adoption of systematic policies of improving the quality of palliative care (training, changes of the organization).
- The dimensions of the NECPAL tool allow a checklist multidimensional approach
- Although recent data allow the identification of the risk of mortality at mid-term basis, this utility needs to be used cautiously, especially in the care of individual patients.

Considerations to bear in mind

- The surprise question and the other parameters must act as a "trigger" of a "palliative approach", to start a "reflexive process".
- The gradual insertion of this "palliative approach" must be compatible, inclusive, and synchronic with treatments focused on symptoms control, and concurrent curative processes, avoiding dichotomy.
- It does not determine the need of a palliative care specialist service intervention, which must be decided according to complexity and based on flexible and adapted intervention models
- Although recent data show corelation with mortality risk, the tool does not seek to determine prognosis as its main objective, and this applicability must be used with caution, as a "prognostic approach" or "vision".

Ethical aspects of timely identification

- Timely identification aims at actively improving the quality of care through inserting a palliative approach, which has shown benefits for patients
- It promotes equity, needs coverage, universal access, and the exercise of patients' right to quality care.
- Active measures to reduce possible risks of its misuse, such as stigmatization, losing curative opportunities, or the negative impact in patients need to be established. Such risks can be substantially reduced through the active participation of patients, the training of all professionals in palliative techniques, the open access to relevant clinical information, the adoption of quality improvement measures, and the active participation of the ethical committees in its implementation.



NECPAL CCOMS-ICO© TOOL VERSION 3.1 2017

Surprise question (to/among professionals):
Would you be surprised if this patient dies within the next year?

YES, I would be surprised → NOT NECPAL

NO, I would not be surprised

			NECPAL Parameters
"Demand" or "Need"	- Demand: Have the patient, the family or the team requested in implicit or explicit manner, palliative care or limitation of therapeutic effort?		1
	- Need: identified by healthcare professionals from the team		2
General Clinical Indicators: 6 months **- Last 6 months** **- Not related to recent/ reversible intercurrent process**	- Nutritional Decline	• Weight loss > 10%	3
	- Functional Decline	• Karnofsky or Barthel score > 30% • Loss >2 ADLs	4
	- Cognitive Decline	• Loss > minimental or > 3 Pfeiffer	5
Severe Dependence	- Karnofsky <50 o Barthel <20	• Clinical data anamnesis	6
Geriatric Syndromes	- Falls - Dysphagia - Recurrent infections - Pressure Ulcers - Delirium	• Clinical data anamnesis ≥ 2 geriatric syndromes (recurrent or persistent)	7
Persistent symptoms	Pain, weakness, anorexia, digestive...	• Symptom Checklist (ESAS) ≥ 2 persistent or refractary symptoms	8
Psychosocial aspects	Distress and/or Severe adaptive disorder	• Detection of Emotional Distress Scale (DME) > 9	9
	Severe Social Vulnerability	• Social and family assessment	10
Multi-morbidity	>2 chronic diseases (from the list of specific indicators)		11
Use of resources	Evaluate Demand or intensity of interventions	• > 2 urgent or not planned admittances in last 6 months • Increase Demand/intensity of interventions (homecare, nurse interventions, etc)	12
Specific indicators of illness severity/progression	Cancer, COPD, CHD, Liver, Renal, CVA, Dementia, Neurodegenerative diseases, AIDS, other advanced illnesses	• To be developed as annexes	13

If there is at least 1 NECPAL Parameter: **NECPAL+**

NECPAL+ = **PS+** "I would not be surprised" + **At least 1 parameter associated**

Codification and Registry:

They help to visualize the condition of "Advanced chronic patient" in the clinical available and accessible information

- Codification:

A specific code, as "Advanced chronic patient", should be used, as opposed to the common ICD9 V66.7 (terminal patient) or ICD10 Z51.5 (patient in palliative care service).

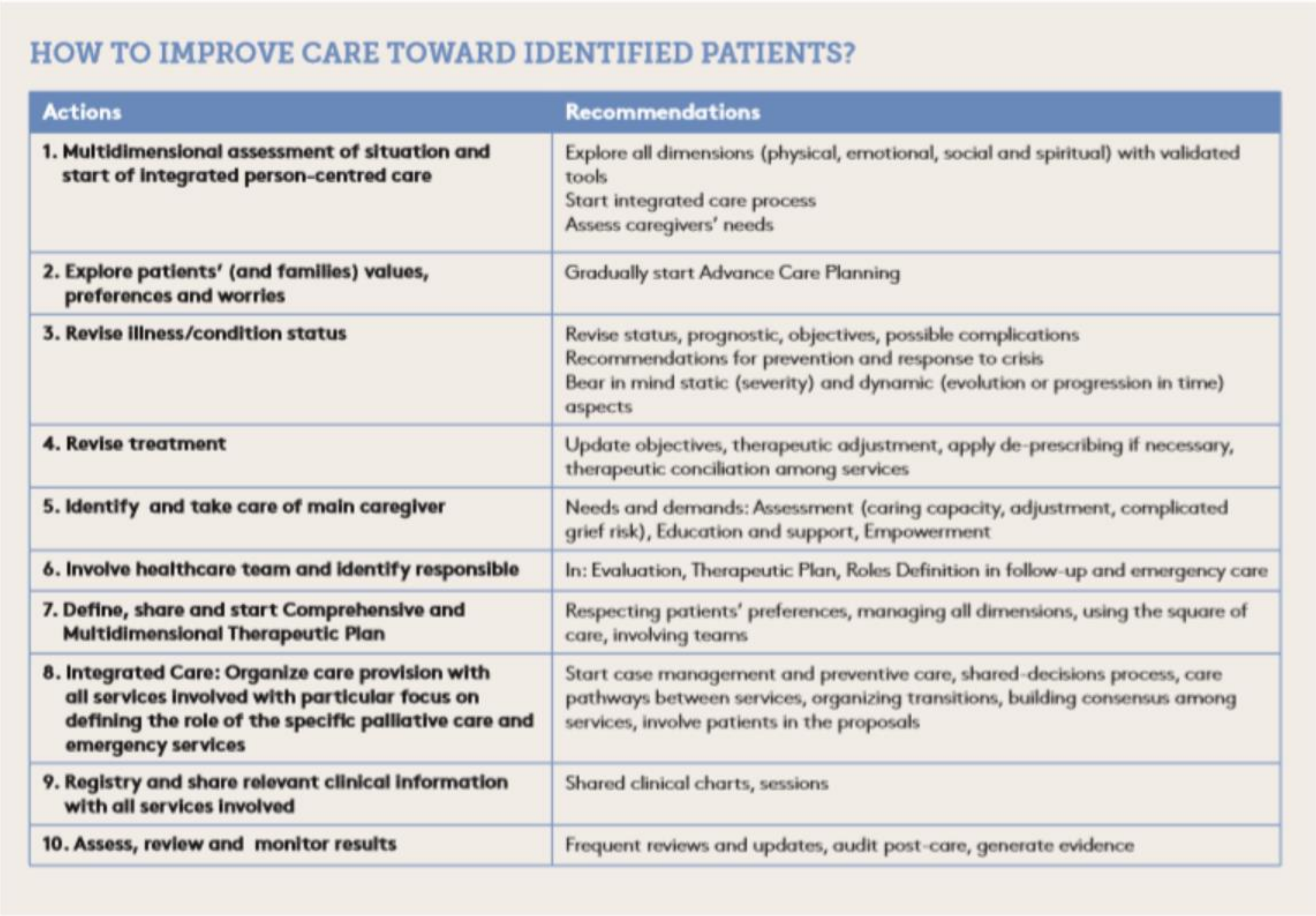
- Registry

Clinical Charts:

After the surprise question, the different parameters should be explored, and add + according to the positives found

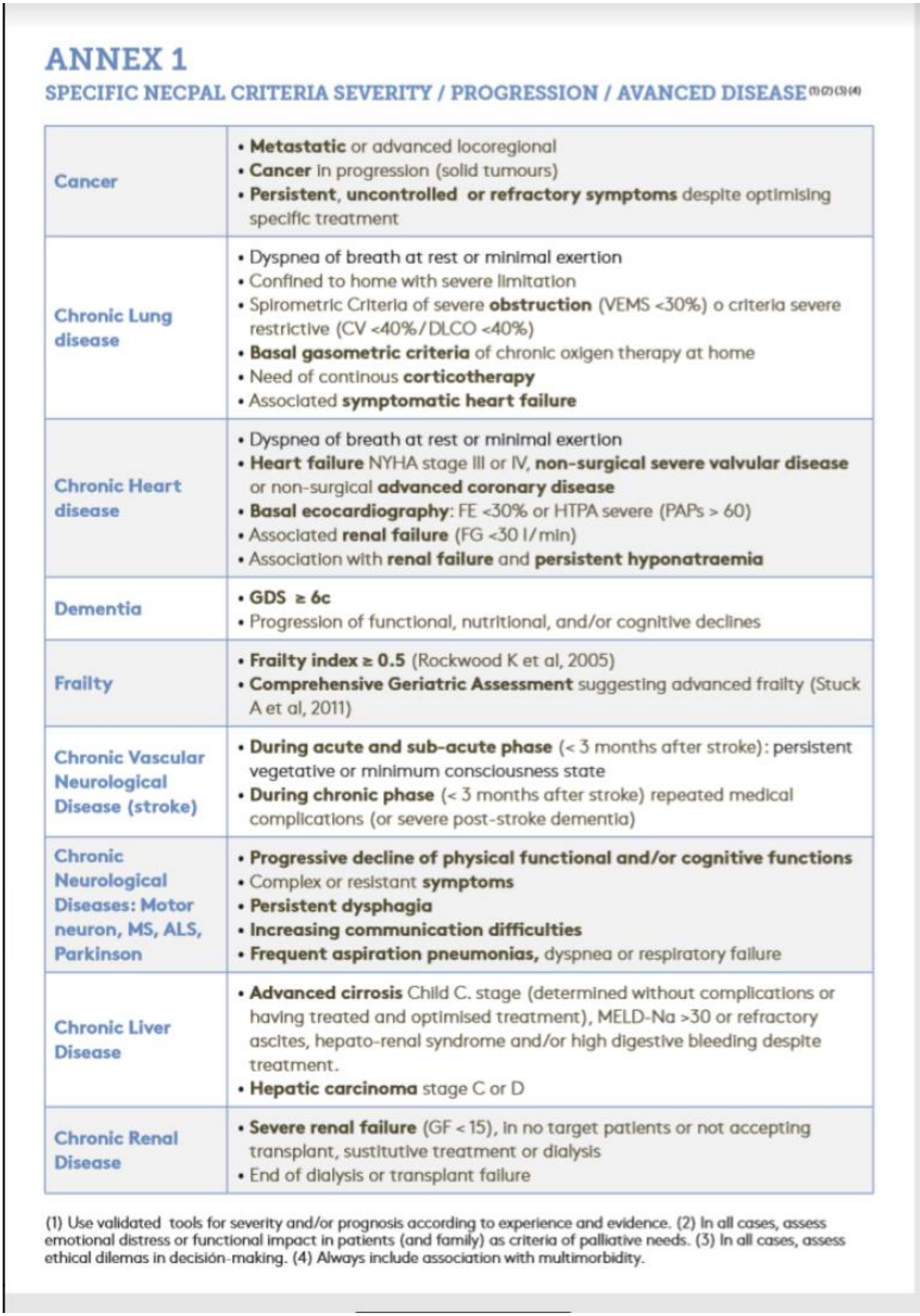
Shared Clinical Chart:

Always match codification and registry of additional relevant clinical information that describes the situation and recommendations for care in specific previsible scenarios and other services (In Catalonia, PIIC)



HOW TO IMPROVE CARE TOWARD IDENTIFIED PATIENTS?

Actions	Recommendations
1. Multidimensional assessment of situation and start of integrated person-centred care	Explore all dimensions (physical, emotional, social and spiritual) with validated tools Start integrated care process Assess caregivers' needs
2. Explore patients' (and families) values, preferences and worries	Gradually start Advance Care Planning
3. Revise illness/condition status	Revise status, prognostic, objectives, possible complications Recommendations for prevention and response to crisis Bear in mind static (severity) and dynamic (evolution or progression in time) aspects
4. Revise treatment	Update objectives, therapeutic adjustment, apply de-prescribing if necessary, therapeutic conciliation among services
5. Identify and take care of main caregiver	Needs and demands: Assessment (caring capacity, adjustment, complicated grief risk), Education and support, Empowerment
6. Involve healthcare team and identify responsible	In: Evaluation, Therapeutic Plan, Roles Definition in follow-up and emergency care
7. Define, share and start Comprehensive and Multidimensional Therapeutic Plan	Respecting patients' preferences, managing all dimensions, using the square of care, involving teams
8. Integrated Care: Organize care provision with all services involved with particular focus on defining the role of the specific palliative care and emergency services	Start case management and preventive care, shared-decisions process, care pathways between services, organizing transitions, building consensus among services, involve patients in the proposals
9. Registry and share relevant clinical information with all services involved	Shared clinical charts, sessions
10. Assess, review and monitor results	Frequent reviews and updates, audit post-care, generate evidence

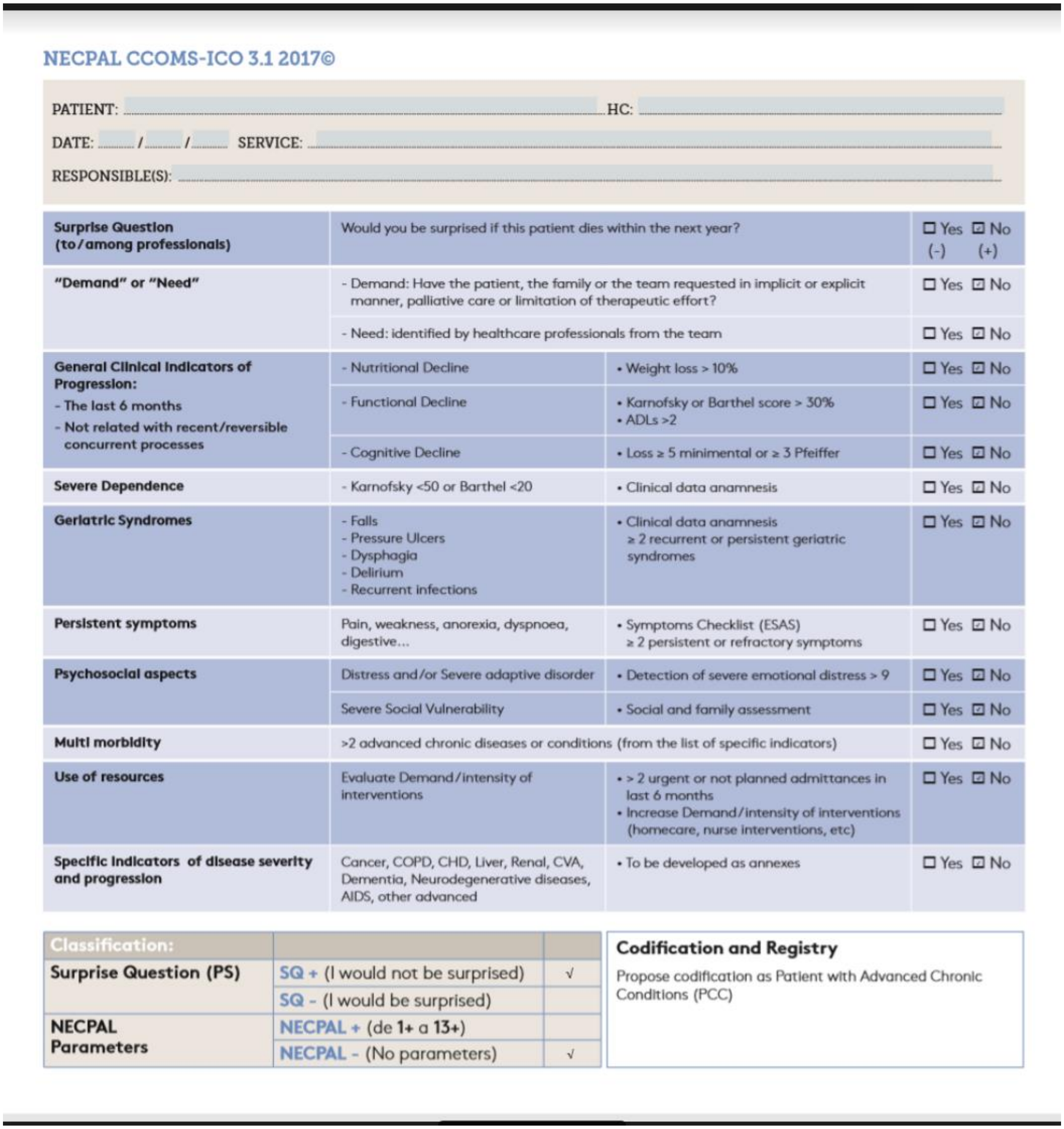


ANNEX 1

SPECIFIC NECPAL CRITERIA SEVERITY / PROGRESSION / AVANCED DISEASE(1)(2)(3)(4)

Cancer	• **Metastatic** or advanced locoregional • **Cancer** in progression (solid tumours) • **Persistent, uncontrolled or refractory symptoms** despite optimising specific treatment
Chronic Lung disease	• Dyspnea of breath at rest or minimal exertion • Confined to home with severe limitation • Spirometric Criteria of severe **obstruction** (VEMS <30%) o criteria severe restrictive (CV <40%/DLCO <40%) • **Basal gasometric criteria** of chronic oxigen therapy at home • Need of continous **corticotherapy** • Associated **symptomatic heart failure**
Chronic Heart disease	• Dyspnea of breath at rest or minimal exertion • **Heart failure** NYHA stage III or IV, **non-surgical severe valvular disease** or non-surgical **advanced coronary disease** • **Basal ecocardiography**: FE <30% or HTPA severe (PAPs > 60) • Associated **renal failure** (FG <30 l/min) • Association with **renal failure** and **persistent hyponatraemia**
Dementia	• **GDS ≥ 6c** • Progression of functional, nutritional, and/or cognitive declines
Frailty	• **Frailty index ≥ 0.5** (Rockwood K et al, 2005) • **Comprehensive Geriatric Assessment** suggesting advanced frailty (Stuck A et al, 2011)
Chronic Vascular Neurological Disease (stroke)	• **During acute and sub-acute phase** (< 3 months after stroke): persistent vegetative or minimum consciousness state • **During chronic phase** (< 3 months after stroke) repeated medical complications (or severe post-stroke dementia)
Chronic Neurological Diseases: Motor neuron, MS, ALS, Parkinson	• **Progressive decline of physical functional and/or cognitive functions** • Complex or resistant **symptoms** • **Persistent dysphagia** • **Increasing communication difficulties** • **Frequent aspiration pneumonias,** dyspnea or respiratory failure
Chronic Liver Disease	• **Advanced cirrosis** Child C. stage (determined without complications or having treated and optimised treatment), MELD-Na >30 or refractory ascites, hepato-renal syndrome and/or high digestive bleeding despite treatment. • **Hepatic carcinoma** stage C or D
Chronic Renal Disease	• **Severe renal failure** (GF < 15), in no target patients or not accepting transplant, sustitutive treatment or dialysis • End of dialysis or transplant failure

(1) Use validated tools for severity and/or prognosis according to experience and evidence. (2) In all cases, assess emotional distress or functional impact in patients (and family) as criteria of palliative needs. (3) In all cases, assess ethical dilemas in decisión-making. (4) Always include association with multimorbidity.



NECPAL CCOMS-ICO 3.1 2017©

PATIENT: .... HC: ....
DATE: ....../....../...... SERVICE: ....
RESPONSIBLE(S): ....

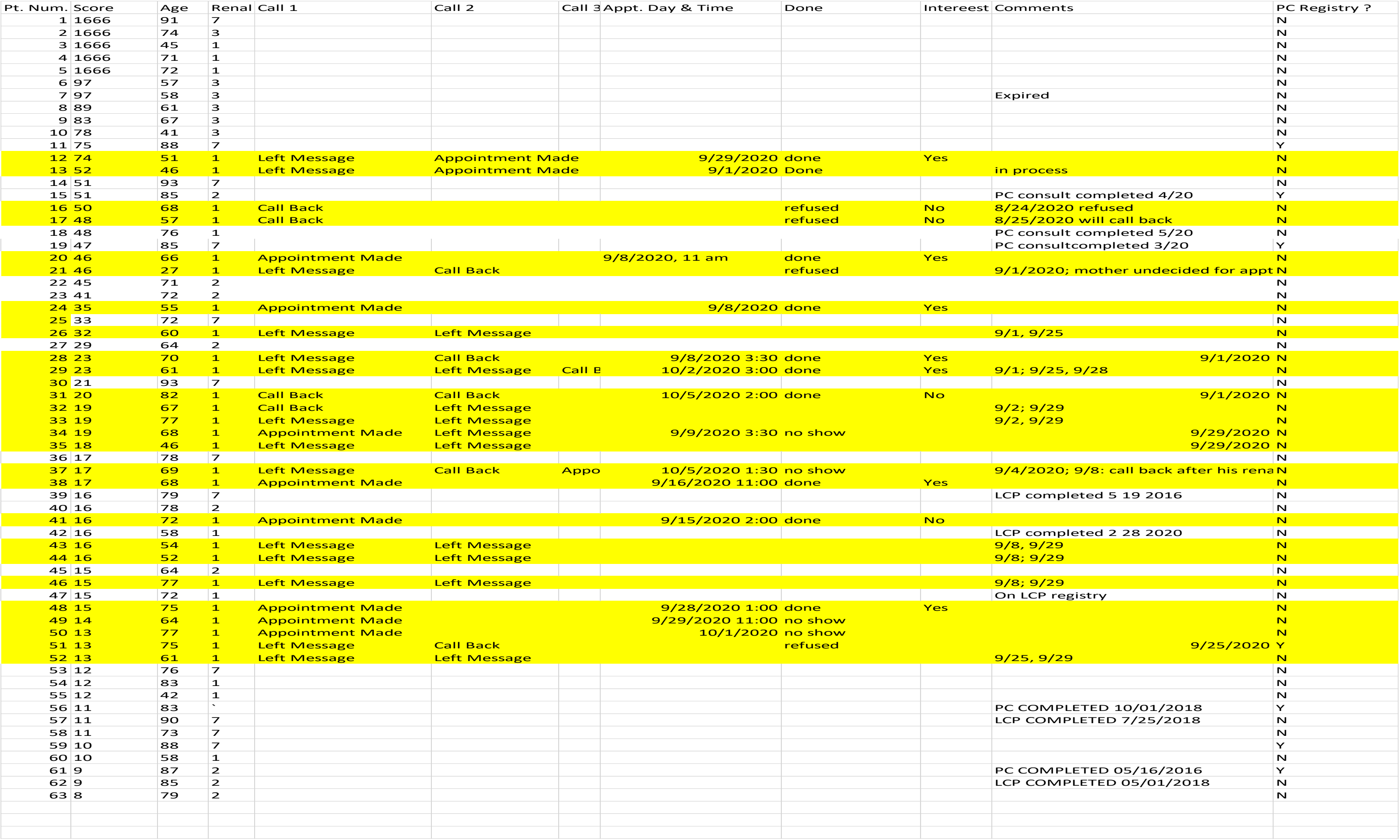
Surprise Question (to/among professionals)	Would you be surprised if this patient dies within the next year?		☐ Yes ☑ No (-) (+)
"Demand" or "Need"	- Demand: Have the patient, the family or the team requested in implicit or explicit manner, palliative care or limitation of therapeutic effort?		☐ Yes ☑ No
	- Need: identified by healthcare professionals from the team		☐ Yes ☑ No
General Clinical Indicators of Progression: - The last 6 months - Not related with recent/reversible concurrent processes	- Nutritional Decline	• Weight loss > 10%	☐ Yes ☑ No
	- Functional Decline	• Karnofsky or Barthel score > 30% • ADLs >2	☐ Yes ☑ No
	- Cognitive Decline	• Loss ≥ 5 minimental or ≥ 3 Pfeiffer	☐ Yes ☑ No
Severe Dependence	- Karnofsky <50 or Barthel <20	• Clinical data anamnesis	☐ Yes ☑ No
Geriatric Syndromes	- Falls - Pressure Ulcers - Dysphagia - Delirium - Recurrent infections	• Clinical data anamnesis ≥ 2 recurrent or persistent geriatric syndromes	☐ Yes ☑ No
Persistent symptoms	Pain, weakness, anorexia, dyspnoea, digestive...	• Symptoms Checklist (ESAS) ≥ 2 persistent or refractory symptoms	☐ Yes ☑ No
Psychosocial aspects	Distress and/or Severe adaptive disorder	• Detection of severe emotional distress > 9	☐ Yes ☑ No
	Severe Social Vulnerability	• Social and family assessment	☐ Yes ☑ No
Multi morbidity	>2 advanced chronic diseases or conditions (from the list of specific indicators)		☐ Yes ☑ No
Use of resources	Evaluate Demand/intensity of interventions	• > 2 urgent or not planned admittances in last 6 months • Increase Demand/intensity of interventions (homecare, nurse interventions, etc)	☐ Yes ☑ No
Specific indicators of disease severity and progression	Cancer, COPD, CHD, Liver, Renal, CVA, Dementia, Neurodegenerative diseases, AIDS, other advanced	• To be developed as annexes	☐ Yes ☑ No

Classification:		
Surprise Question (PS)	SQ + (I would not be surprised)	√
	SQ - (I would be surprised)	
NECPAL Parameters	NECPAL + (de 1+ a 13+)	
	NECPAL - (No parameters)	√

Codification and Registry

Propose codification as Patient with Advanced Chronic Conditions (PCC)

Appendix P: Evaluation Table



Pt. Num.	Score	Age	Renal	Call 1	Call 2	Call 3	Appt. Day & Time	Done	Intereest	Comments	PC Registry ?
1	1666	91	7								N
2	1666	74	3								N
3	1666	45	1								N
4	1666	71	1								N
5	1666	72	1								N
6	97	57	3								N
7	97	58	3							Expired	N
8	89	61	3								N
9	83	67	3								N
10	78	41	3								N
11	75	88	7								Y
12	74	51	1	Left Message	Appointment Made		9/29/2020	done	Yes		N
13	52	46	1	Left Message	Appointment Made		9/1/2020	Done		in process	N
14	51	93	7								N
15	51	85	2							PC consult completed 4/20	Y
16	50	68	1	Call Back				refused	No	8/24/2020 refused	N
17	48	57	1	Call Back				refused	No	8/25/2020 will call back	N
18	48	76	1							PC consult completed 5/20	N
19	47	85	7							PC consultcompleted 3/20	Y
20	46	66	1	Appointment Made			9/8/2020, 11 am	done	Yes		N
21	46	27	1	Left Message	Call Back			refused		9/1/2020; mother undecided for appt	N
22	45	71	2								N
23	41	72	2								N
24	35	55	1	Appointment Made			9/8/2020	done	Yes		N
25	33	72	7								N
26	32	60	1	Left Message	Left Message					9/1, 9/25	N
27	29	64	2								N
28	23	70	1	Left Message	Call Back		9/8/2020 3:30	done	Yes	9/1/2020	N
29	23	61	1	Left Message	Left Message	Call B	10/2/2020 3:00	done	Yes	9/1; 9/25, 9/28	N
30	21	93	7								N
31	20	82	1	Call Back	Call Back		10/5/2020 2:00	done	No	9/1/2020	N
32	19	67	1	Call Back	Left Message					9/2; 9/29	N
33	19	77	1	Left Message	Left Message					9/2, 9/29	N
34	19	68	1	Appointment Made	Left Message		9/9/2020 3:30	no show		9/29/2020	N
35	18	46	1	Left Message	Left Message					9/29/2020	N
36	17	78	7								N
37	17	69	1	Left Message	Call Back	Appo	10/5/2020 1:30	no show		9/4/2020; 9/8: call back after his rena	N
38	17	68	1	Appointment Made			9/16/2020 11:00	done	Yes		N
39	16	79	7							LCP completed 5 19 2016	N
40	16	78	2								N
41	16	72	1	Appointment Made			9/15/2020 2:00	done	No		N
42	16	58	1							LCP completed 2 28 2020	N
43	16	54	1	Left Message	Left Message					9/8, 9/29	N
44	16	52	1	Left Message	Left Message					9/8; 9/29	N
45	15	64	2								N
46	15	77	1	Left Message	Left Message					9/8; 9/29	N
47	15	72	1							On LCP registry	N
48	15	75	1	Appointment Made			9/28/2020 1:00	done	Yes		N
49	14	64	1	Appointment Made			9/29/2020 11:00	no show			N
50	13	77	1	Appointment Made			10/1/2020	no show			N
51	13	75	1	Left Message	Call Back			refused		9/25/2020	Y
52	13	61	1	Left Message	Left Message					9/25, 9/29	N
53	12	76	7								N
54	12	83	1								N
55	12	42	1								N
56	11	83	`							PC COMPLETED 10/01/2018	Y
57	11	90	7							LCP COMPLETED 7/25/2018	N
58	11	73	7								N
59	10	88	7								Y
60	10	58	1								N
61	9	87	2							PC COMPLETED 05/16/2016	Y
62	9	85	2							LCP COMPLETED 05/01/2018	N
63	8	79	2								N

Appendix Q: RN Talking Guideline

Hello, Mr./Ms.______________. My name is _____________, and I am an RN from the supportive care team. Your kidney doctor asks us to talk with all of her patients who have kidney disease, so we can provide extra support to you and discuss your illness. Part of our discussion is for you to decide what your goals of care should be, and your treatment plan. Although, you and your doctor will make that decision, I am available to give you information to help with your decision making. I would like to set up a call with you and your family to have this discussion. Would that be all right with you?

Appendix R: Renal Care Manager Guideline

Hello, Mr./Ms.______________. I am _______________ your care manager. Your doctor did ask supportive care services to talk with you, as she does with all of her patients who have kidney disease. They will provide extra support to you and discuss your illness. Part of their discussion is for you to decide what your goals of care should be, and your treatment plan. Although, you and your doctor will make that decision, they will give you some additional information. It is a good idea for you to talk with them and listen to what they have to say.