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PALLIATIVE CARE

Establishing a Palliative Care Program in a Research Center: Evolution of a Model

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“It’s not about death, it’s really about living with a disease that’s going to kill you, about good living on the way to death.” —Joanne Lynn^[1]

To cure sometimes, To relieve often, To comfort always. —Anonymous physician, 15th century.

INTRODUCTION

Just as health is more than absence of illness, so too is palliative care much more than the absence of disturbing symptoms. The two quotes above demonstrate Pain and Palliative Care team’s philosophy that supports our patients’ search for normalcy, comfort, and balance as patients pursue novel experimental treatments for advanced disease. In this paper we describe the necessity of and facilitation of integrating palliative care into a research model of practice at the National Institutes of Health.

The National Institutes of Health (NIH) is an agency of the United States Department of Health and Human Services with initiatives that are funded by an approved congressional budget. The NIH has an organizational

mission which is accomplished through conducting research, supporting research of non-federal scientists, training research investigators, and fostering communication of medical information. The goal of the NIH is to uncover new knowledge that will lead to better health, to prevent, detect, diagnose, and treat disease and disability, from the rarest genetic disorder to the common cold.

The NIH is comprised of 23 Institutes and Centers, including the National Cancer Institute. The Warren Grant Magnuson Clinical Center, the hospital which supports the intramural research mission of the institutes, is where the Pain and Palliative Care Service (PPCS) is housed. The Clinical Center has an annual census of 7,000 inpatients and 68,000 outpatients. All patients have consented to participate in clinical trials.

The goal of science and research is to generate reproducible and objective knowledge which can be applied in any clinical setting. Clearly, this is critical in helping cure disease. However, the primary focus of research and science is not necessarily to meet individual patient needs. It is also clear that in order to relieve suffering, the essence of palliative care, one must tailor care to meet the individual’s needs. In recognition of this mission the PPCS at the NIH was developed in August 2000. Since its creation, this service and its interdisciplinary team members

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has successfully been able to combine empirical, technical and clinical knowledge with humanism in a research environment.

Paramount to the development of the PPCS was the ability to define palliative care in the institution. According to Taber's Cyclopedic Medical Dictionary, palliative care is defined as "serving to relieve or alleviate, without curing."^[2] Palliative care is further refined at the NIH as the following:

- not time-limited to end-of-life
- optimized through early initiation and comprehensive implementation throughout the disease trajectory
- parallels aggressive research and treatment modalities
- a combination of active and compassionate therapies that is primarily focused on the physical, psychological, social, and spiritual "suffering" of the patient, family, and caregiver
- not limited to pain management
- comprehensive management of any symptom which affects the quality of life

The PPCS at the NIH has thrived through its ability to balance a rigorous scientific environment that supports good research with a holistic approach.

FORMULATING A PAIN AND PALLIATIVE CARE SERVICE

Institutional Vision

Organizational commitment is one of the cornerstones in providing an environment that fosters excellence in research of human subjects. What does the clinical participant expect of the organization's commitment? The patient wants ready access to the health care team for monitoring and care, consultative advice and support through completion of the protocol when consenting to enter a clinical trial. Furthermore, participants come to the NIH with great expectations and hope for the "cure" of their chronic and often terminal disease. In fact "Hope is central to the human experience of living and dying, and is integrally entwined with spiritual and psychosocial well-being."^[3]

The research patient requires both "high tech and high touch" care. This multi dimensional approach meets both the clinical, scientific and functional needs with compassion. Clinical care for symptom management is critical, with the necessary facets of education to patient,

family and clinicians, and attention to research support. The Institute of Medicine Report on *Improving Palliative Care for Cancer* identifies and outlines deficits and potential improvement for professional education, clinical practice guidelines, and cross-cutting research issues.^[4] Creating a collaborative Pain and Palliative Care Service boldly supports a vision that encourages progressive quality care and research integrity.

Through a performance improvement process, a review of clinical issues and gaps within the categories of the current NIH 1) system structure, 2) clinical practitioners and 3) patient needs was the basis for formulating this PPCS. Several clinical departments and research institutes with a vested interest in promoting a program were asked by the Clinical Center administration to evaluate what key concepts needed to be addressed through an assessment process such as a white paper format. These core departments included nursing, anesthesiology, rehabilitation, social work, pharmacy, National Cancer Institute, National Institute of Dental and Craniofacial Research and the National Institute of Allergy and Infectious Disease.

Benchmarking three East coast hospitals with identified or emerging programs gave insight into potential models, common clinical foci and developmental guidelines, and space requirements. Interestingly, all three large centers focused predominantly on pain only and were eager to glean information from this new program.

Moreover, Research patient input was derived from customer feedback to clinicians, patient representatives and through patient satisfaction surveys. Protocols are new and unfamiliar territory for patients, therefore, they want a plan of care and to feel comfort with informed choices. Key improvement processes identified were to 1) increase continuity of care across settings including discharge plan, 2) address symptoms that may be secondary to the protocol pathway, and 3) review national research indicating under-treatment of pain in hospital settings.

Three expert clinicians were invited to attend a review of the current issues and gaps in the field with the vested departments and benchmark results. The discussion then expanded into future growth and national needs in this domain of care. This group meeting solidified the need to be interdisciplinary and consultative in format and to broaden the scope to "Pain & Palliative Care" where the emphasis originally was predominantly on pain.

The last critical component in the planning phase was clinical leadership. Selection of the new Chief position was a pivotal step in setting the direction and



Establishing a Palliative Care Program

315

tone of the program. It is important that the candidates' values and abilities mirror the Institutes' direction and vision and the clinical research agendas. After embarking on a national search, a committee was formed to interview and select a Chief.

Lessons Learned: The Third Time Is a Charm for New Leadership

In August of 2000 the Chief of the PPCS arrived and started the team with one nurse practitioner that had been assigned from within the Clinical Center. The new Chief used her prior experience of creating services in two other large academic institutions to identify barriers and beneficial components to aid in the development of a successful team. One of the most important lessons learned was that institutional support was critical in developing a successful service. It was clear from the beginning that the NIH had made such a commitment. From a practical point of view, this support was dramatically demonstrated as the administrative staff initially rounded with the PPCS on the different units in order to introduce the new service to the different research teams.

It was clear that ultimately the needs of the service would grow and more staff would be needed, however it was prudent to begin slowly and assess the needs of the institution as well as the team. This deliberate organic growth of the team fostered a unified and cohesive team with a singular sense of mission and a deep sense of community.

From past experiences it was judged that a consultative format would facilitate its growth and acceptance within the academic environment, while also educating and influencing the staff more broadly. By communicating directly with the primary care physician one was teaching the concepts of pain and palliative care, while being viewed a valued extension of the research team. With continuous communication between the consult service and the research team, the patient is cognizant that all are contributing to the plan of care.

The most critical piece to assure success was the ability to integrate pain and palliative care into the functioning of the research team. This collaborative relationship prevents any adversarial or competitive feelings between the consultative and treating teams. This attitude also discouraged the "cure versus palliative approach" to care. Rather, it fostered a sense of weaving palliative strategies into curative-intent and blending approaches for the betterment of patients throughout their course of treatment. Palliative care, or the relief of

suffering, is appropriate during a time one is focused on cure as when one is dealing with end of life. A patient with a serious illness such as cancer wants to hope and live as long as possible and are often very open to aggressive, experimental therapies. However, the patient also needs to be focused on living each day with quality of life. It is necessary to fully appreciate that it is not an "either/or" phenomenon of "cure versus palliative care," but both working in unison to promote the best possible care.

Another component to success was returning to the basics of "bedside caring" and teaching by example. One cannot initiate a palliative care service in an institution and expect consults if one does not teach others what palliative care is. Bedside rounds each day provides the physical presence and engagement of the team to the unit staff and patient. The research team witnesses benefits to their patient and support to their staff first-hand. This style of practice quickly generated an abundance of referrals from such positive outcomes.

Sensitivity and the ability to recognize the clinical staff's need for their palliative care is essential in the role of the PPCS. Again, teaching by example to care for ourselves as caregivers, as well as caring for the patient. Caring for seriously ill patients on a continuous basis leads to the depletion of emotional and physical energy. Therefore, our PPCS office is open to all clinical staff for respite. The office then becomes a safe haven for a compassionate ear, emotional support or often just a cup tea. To keep our core team replenished, we consciously take the time to eat lunch together, discuss morning cases and regroup for the afternoon schedule.

NECESSARY ELEMENTS FOR A PAIN AND PALLIATIVE CARE CONSULT SERVICE

During the inception of developing new programs or services, it is imperative to avoid the labor intensive task of "reinventing the wheel" by reviewing and integrating elements from existing systems. The fundamental structure of the NIH Pain and Palliative Care Service is based on an extension of the foundation, philosophy and goals of Hospice care as it has existed in the United States since 1974. Hospice and Palliative Care in the United States has been typically defined and practiced as end-of-life care, restricted to a limited prognosis and by an "either, or" choice for comfort care in lieu of aggressive curative treatment modalities.^[5] The meaning of our extended model of care was to eliminate the barriers of limitations of end-of-life care, thereby integrating physical, emotional and spiritual palliative



symptom management from the onset of chronic, life-disabling or terminal disease entities within a research environment of aggressive treatment. Our mission is defined as, "a consult service that incorporates empirical, technical and clinical knowledge with humanism in a research environment."

The philosophy of care practiced by the NIH PPCS adapted the model of quality of life (insert quality of life diagram) from the perspective of identifying how physical symptoms, along with emotional and spiritual suffering issues impact the patient's total quality of life. Assessment of the physical symptoms may relate to the natural course of the disease process and any comorbidity and concomitant entities. Clinical research studies can add symptoms from potential adverse effects from treatment modalities such as chemotherapy, radiation therapy or surgery. Allogeneic bone marrow transplant is an example of aggressive therapy often causing multiple symptoms from graft versus host disease. Suffering issues include those emotional, social or spiritual symptoms which affect the integrity of the personhood of the patient.^[6] Symptoms which could impact suffering include the pre-existing psychological state and traits, coping skills, changes in social and personal role, physical or emotional limitations, financial concerns, spirituality, social or family functioning and fear of death.^[7]

It is essential during the assessment and evaluation process to expand your professional scope beyond the science and look at, talk to and hear the patient. Our belief is that palliative care should be practiced as "the art and science of patient focused, family-oriented, relationship-centered medical care aimed at enhancing quality of life and minimizing suffering."^[8]

Within the scope of the PPCS mission and goals lies the task of developing an interdisciplinary team to deliver the philosophy of care. The building of a nurturing interdisciplinary team for a PPCS does not require the arduous delay of waiting for a large financial funding, grant or endowment. During the first year of the PPCS, the initial budget was allocated for the positions chief physician, a palliative care advanced practice nurse and an administrative coordinator. The adult nurse practitioner and doctorally prepared nurse thanatologist were reassigned by the nursing department to complete the core team. Commitment from the administration's support for inter-institutional team development and the subsequent cooperation of established departments led to designation of liaisons to collaborate with the core team. (insert diagram of interdisciplinary team) Departments benefit by demonstrating increased referrals and utilization of services.

ROLES OF THE INTERDISCIPLINARY TEAM

The primary role of the core team member is to perform a comprehensive assessment to evaluate how the summation of symptoms and suffering impact the patient's quality of life. Impaired quality of life could ultimately influence how a patient responds to and endures the research protocol. Focused and timely symptom management of pain, nausea, anxiety, and/or ineffective coping, has supported the patient to begin or continue on a clinical trial.

The plan of care is communicated and coordinated by the core team member through the primary investigator, clinical staff and interdisciplinary liaison team members. The core team is also responsible for assisting with discharge planning and communicating with physicians in the patient's home environment, to insure continuity of care.

The interdisciplinary liaisons have a commitment of approximately eight hours per week, to be divided between two half day clinics and a weekly interdisciplinary team meeting. Their role is to provide a more in depth assessment of their designated specialty, recommend a treatment modality and implement their intervention into the plan of care. Initially the core team, along with the interdisciplinary liaisons, made weekly rounds on the unit to establish a visual reinforcement of cohesiveness. The plans of care are then reviewed and revised during the weekly interdisciplinary team meetings. Liaisons are resources in palliative care within their individual departments and facilitate patient care communication.

PROCESS OF INTRODUCING A NEW SERVICE

The process of introducing a new clinical service resembles that of the real-estate adage of "location, location, location." Accessibility is brought to the patient who needs the service; clinical presence at the bedside is paramount. The interdisciplinary team involvement early on in the study engages the multilevel concerns of the patient. Respecting the common goals in the context of the protocol is to seek cure, maximize quality of life and restore hope within the realism of the patients situation. When introduced early in the protocol the PPCS can continuously reassess the physiologic and suffering dimensions of care in real time. Clear and concise communication with the primary researcher avails them of the rationale for suggested care interventions.

Three essential steps were taken to introduce the PPCS to the various clinical institutes and patient care



Establishing a Palliative Care Program

317

units. The first was attending daily rounds with the protocol teams on the inpatient units. This opportunity allowed the core team to suggest potential symptom management interventions that had not been previously considered. The second critical step was in daily follow-up visits; this level of presence anchors the patient's symptom management in a protocol centered approach to care. Lastly, documentation in a consult format provided a logical rationale for interventions written in the progress note.

Several research teams at the NIH embraced the importance of the PPCS in benefiting their patients and families. The National Cancer Institute's bone marrow transplant division is an example of a research team who has requested consults during the screening for each new transplant candidate. Early involvement of the PPCS has proved invaluable to the patient, family and clinical research team. Although patients initially present with few physical symptoms, this affords an opportunity to establish a rapport and determine their baseline of function. Early entrance yields acceptance, therefore easing symptom burden throughout the research pathway.

Some research teams had confidence in managing patient needs and were speculative in the additional benefit of the PPCS. "Go Where He Lives," is a value we follow meaning, identify the clinical investigator perception and work from there. Everyone has a different perspective; and as a new team it is important to respect and appreciate these differences through negotiation. If not applied, team impact will be diminished.

Similarly, the patient perceives that pursuing a clinical trial if not for a cure, but minimally an extension of survival. A qualitative study exploring factors that result in "false optimism about recovery" was observed in patients with small cell lung cancer. It was determined that "false optimism about recovery" was the result of an association between the doctors' activism and the patients' adherence to the treatment plan. Furthermore, selective criteria and information was used defining fragments of disease recovery, avoiding the acknowledgment of the complete scenario. There was mutual denial between the clinician's ability to impart negative information and the patient wanting to hear, thus resulting in collusion. In the conclusion of the study, "treatment brokers" as clinical mediators were recommended.^[9] The pain and palliative care team can act as a treatment broker, assisting with difficult communication. Successful outcomes are not to decrease hospitalized deaths, length of stay, or diminish hope but to support the patient and family who have made an educated decision to try new clinical frontiers.

PROVOCATIVE STRUCTURE

The corporate concept of "out of the box" creativity can be recycled as a provocative structure to follow in a new program. Recent advances in complementary, behavioral and pharmacologic therapies call for a renaissance in pain and palliative care medicine. Algorithms are necessary in protocol pathways, but palliative care can approach from a very holistic view with the research agenda still in the forefront. Serving "High Tea," typifying tea for royalty, creates a comfortable milieu for the patient to share with family, friends and health care givers. This offers a non-clinical setting to converse, verbalize wishes, concerns or reminisce.

To evoke a positive attitude, the PPCS has the flexibility to provide hospitality for customers (patient, family and clinicians) with the goal of breaking down the sterile barriers and lightening the intensity level. Team theme days such as "sun-fun," "mardi gras," signature hats and boas are a diversion from white lab coat attire. Spontaneous celebrations such as sending a patient to his favorite football team have reminded patients that they can have a little of their home while they are hospitalized.

Core staff retreats have nurtured the team's effectiveness and preservation. By six months into the program, there were four members and growth required visioning and operational issues. Designing a brochure that accurately described our customer focused service was worthy of group team think. Logistics such as closing out patient cases were also addressed in a retreat setting. The larger weekly interdisciplinary meeting provides a venue team enrichment. The last meeting of each month is reserved for team member palliation which has included massage, music and humor therapy.

CLINICAL

The PPCS functions in an inpatient and out patient arena. The initial assessment is completed by a core team member within 24 hours of the consultation request. This assessment includes objective and subjective data of pain and symptoms encompassing medical, family, psychosocial and spiritual history. Determination is then made on which of the other team disciplines would benefit the patient. Daily follow-up bedside visits are made for inpatients and bi-weekly clinic visits are offered for outpatients. The entire interdisciplinary team is present during clinic hours. Clearly, the most important element



of our clinical care is human touch with an integrative medicine model.

ADDRESSING SUFFERING

“Care more particularly about the patient than for the special features of the disease” Sir William Osler^[10]

It is well recognized that people dealing with a chronic medical condition which may eventually lead to their death, experience various degrees of pain which is mostly influenced by personality, coping styles and cultural background. While pain has been described in the literature for centuries, and has been one of medicine’s greatest mysteries, it still remains a challenge for professionals trained in providing palliative care to patients, their families and significant others.^[11]

Woodson in discussing the hospice concept identified four components of pain: physical, psychological, social, and spiritual.^[12] More recently, Welk developed a model which designated suffering as the central concept connecting these components.^[13] Consequently, a major focus of palliative care is addressing suffering by the person as it impacts total pain and symptom management.

In order to alleviate suffering, there are several approaches that will facilitate intervention. First, acknowledge that “effective caring and support imply a recognition of human sameness rather than difference.”^[14] That is to say dropping the barriers of our respective roles, the professionals versus the patient. This means to relate at the human level with our own fears, hope, and desire to make a difference in dealing with serious illness. Second, any sound intervention cannot be implemented without making oneself “emotionally accessible”^[14] to patients and families, a very difficult task, but necessary, as it is a reminder of personal vulnerability. This implies entering the patient and family systems so that suffering can be understood and taken in the right context. Thirdly, it is essential to validate the feelings and emotions experienced by patients and families as normal reactions when facing a life-challenging illness. The clinician is able to establish a therapeutic alliance by emphasizing normalcy rather than conveying that something is wrong psychologically. Of course, this position does not exclude further psychosocial/psychiatric assessment and modified intervention when faced with poor coping or in the presence of a psychiatric diagnosis. In such a case, a referral to the psychiatrist is most appropriate.

It easily becomes a challenge for the emotional integrity of the pain and palliative care team when addressing suffering issues. Interdisciplinary team management can often result in an overlapping interventions, which can lead to role confusion and duplication in services. Therefore, it is important for team members to identify situations during weekly team meetings that require an internal referral for an alternative liaison intervention. For example, if the Nurse Thanatologist (counselor) on the team identifies that spiritual pain is the primary issue, it is wise to refer to the chaplain on the team for further expert intervention.

Finally, being exposed to suffering on a daily basis can be emotionally taxing for team members. Therefore, a climate of safety and non-judgmental approach needs to be maintained so that the team members become a source of support to each other in coping with their own pain on a daily basis. This is particularly crucial when members may be at risks for crossing professional boundaries, a potential consequence of working with chronic illness. In conclusion, addressing suffering in palliative care allows to deal with the whole person and contribute to maximal quality of life. However, it can only be done with an intact and well-balanced team.

EDUCATION

Education has been executed in formal and informal forums. Initially it is essential to address the myths that palliative care was just for end-of-life care. Therefore the mission, philosophy and goals must be presented at the onset. Concerns that end-of-life or hospice care is the focus of the PPCS should be dispelled, and the clarification that the team is there to function in partnership to maintain the integrity of the research goal.

The initial mass introduction to the Pain and Palliative Care Service at NIH was presented at Grand Rounds, “Palliative Care: It’s not just for pain or end-of-life any more.” Palliative Care as it was to be implemented at the institution was clearly defined, with the scope of practice and means by which to make referrals.

Following Grand Rounds, brief informal education and input was offered during daily unit rounds. The concept of “back to the basics of bedside care” became part of routine practice. Within a few weeks individual units requested short in-services relating to our role in the Clinical Center and how our service would impact the research environment. Equally, it was important to



Establishing a Palliative Care Program

319

understand the culture and goals of each unit in order to maintain a welcoming and open relationship.

Clinical staff are offered a brief informal educational overview after each new and follow-up assessment is made. It was decided from the onset that PPCS would maintain the status of a consult service, making recommendations but not writing or imputing orders. This process necessitates speaking directly with an attending or fellow each time a change in intervention or progress updates are made. By doing so, instruction is imparted to clinicians that may not be otherwise obtained formally.

Within four months an attempt was made to evaluate the nurses' knowledge base of palliative care to use for future performance improvement. A 36 multiple-choice palliative care knowledge exam was administered to 366 nurses through the clinical center, 36% of which identified themselves as having a specialty in oncology. The results indicated that oncology nurses demonstrated a better knowledge of pain and palliative care than nurses in other specialties and that nurses who had contact with the PPCS, in the previous four months, had higher scores than nurses who indicated that they had not had contact with the team.^[15] This has given direction for internal, professional education.

Individual unit inservices were offered in the format of a 30-minute presentation with a supporting hand-out followed by a 15–20 minute interactive discussion. As the requests for education became a time-consuming issue it was determined that unit nursing liaison representation was needed to meet the ongoing demands for educational support. By working with the nurse educator electronic interdepartmental communication was sent to all clinical nurse specialists announcing the development of the nursing liaison educational program. They were invited to attend and asked to select one representative from their units who would also attend the 8-hour seminar session, communicate, educate and become a palliative care resource person for their unit colleagues. Topics of the day included the definition, philosophy and goals of the PPSC, the assessment and integrative interventions for physical, emotional, and spiritual symptom management. The follow-up to this program will be monthly 1-hour brown-bag luncheon sessions to share literature reviews and discuss topics of mutual interest in palliative care.

In addition to providing palliative care to our patients and their family members, it is imperative to provide palliative care to the clinical staff. Staff development has taken many unique forms of structured lectures, bedside practice by example and the informality within our office. While offering refreshments and

a sympathetic ear within the comforts of our office with clinical staff, there is a professional exchange of ideas and information.

There are an abundance of opportunities to share the success of the NIH, PPCS through community education to special interest groups, skilled nursing and acute care facilities, nursing schools and health care organizations. Professional visitors may apply to attend an observership program whereby participants from all over the country are provided clinical experience in this unique setting.

INCORPORATING RESEARCH AND PERFORMANCE IMPROVEMENT

Biomedical research is supported by the PPCS beyond the consultative purpose of symptom management. There is also partnering on protocols to discover interventions directly for symptoms. Current studies underway for the outcome of alleviating problematic symptoms are for example: an oral intervention for preventing mucocitis from chemotherapy and another is the use of radiofrequency ablation therapy for pain relief. Other institutes conducting studies have requested a palliative assessment to seek out subtle changes or symptoms that present with a disease, such as depression and bone density levels, and the genetic disorders of McCune Albright Syndrome. Internally, the PPCS is embarking on a three year randomized study to evaluate the process and outcomes of the team intervention in patients with advanced malignancies who are surgically treated by the National Cancer Institute. This research will be pivotal in opening the door to future studies in the science of managing symptoms and emotional suffering. Two other studies will be looking at personality and coping skills in bone marrow transplant patients, as well as a study of a fatigue treatment algorithm.

Institutional assessment of structures that support pain relief has come to the forefront from the new standards put forth by the Joint Commission for Hospital Accreditation. The PPCS team has been instrumental in the design and measurement of the hospitals approach to meeting the standard.

BRIDGING SERVICE TO THE BROADER COMMUNITY—FUTURE GROWTH

In one year the PPCS provided service to 550 new patients. This active service has integrated palliative care into a curative research model. The PPCS has become part of the fabric of the institution by humanizing research.



We have also compiled a working group from throughout the United States to help us maintain excellence in pain and palliative care as well as work with others nationally so that a cohesive model can be taken to each institution.

As is sung in the “Sound of Music,” music is brought back into the home. We feel we have done this at the NIH Clinical Center. Our goal at this time is to help change things nationally and be able to have others replicate what we have done.

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