AN EDUCATIONAL LEARNING MODULE TO ENHANCE COMMUNICATION SKILLS
of NURSE PRACTITIONERS CARING FOR SERIOUSLY ILL PATIENTS AND THEIR
FAMILY CAREGIVERS

By

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Statement of Author

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APPROVAL BY PROJECT DIRECTOR

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Dedication

I would like to thank the Professors in the College of Nursing at University of Arizona for their patience, assistance, and guidance throughout this project. I would like to express my appreciation to Dr. Ki Moore, DNSc, RN, FAAN, my Master's Project Chair, and Virginia LeBaron, RN, MS, ACNP-BC, AOCN, ACHPN who served as Co-Chair. You have given me the confidence to complete this endeavor. Thank you for your time and participation in making this project progress to completion.

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Abstract

Healthcare providers have proven to be very technically and medically competent. One area needing attention is the education of healthcare providers in effective communication. This is particularly needed when caring for patients coping with serious illness and facing the difficult transition from curative to comfort focused care. The ability of the healthcare provider to appropriately address and treat terminal medical conditions is impacted by how they communicate and partner with their patients and families. The end-of-life experience can be either positively and/or negatively impacted by how the healthcare provider communicates with their patients and families.

The purpose of this scholarly project is to review literature on present academic education on communication for health care providers and provide an educational module to teach health care providers, especially nurse practitioners how to effectively communicate to families. This paper will discuss how to implement and participate in a family conference, discuss ethical dilemmas when working with families, when to review prognosis and when to initiate end of life discussions.
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CHAPTER ONE - INTRODUCTION

Patients go to a health care provider because of their need for the knowledge about disease management and/or health restoration. The health care provider obtains the signs and symptoms of the illness from the patient for which he/she has presented for treatment. The health care provider completes a physical assessment and provides a treatment plan for the patient to follow. This treatment plan, by its own design, is usually a process the compliant patient is able to follow to maintain health wellness or prevent disease progression. When the patient is diagnosed with a potentially life threatening illness, the health care provider must often communicate a different treatment plan, which relays the information honestly and compassionately while meeting the emotional and psychosocial needs of the patient (de Haes, 2005).

Most healthcare providers receive no formal education on how to effectively communicate with a patient or family with a poor prognosis (Campbell, 2002). A patient who is dealing with severe illness will usually want information about prognosis. The United States is a nation with a diverse population. Healthcare providers will meet individuals from a variety of cultures may want varying degrees of information about their illness. In this case, a patient may appoint an assigned surrogate to assist or make health care decisions for them (Glass, 2004). A conversation initiated by the health care provider discussing prognosis, plan of care and death/dying can be complex and challenging (Lang, 2004). Healthcare providers need to be honest with patients while providing information on all possible scenarios that may occur in the
disease process, so the patients and families have a knowledge base to move forward with on the plan of care (de Haes, 2005).

Communication should be part of the treatment plan given to the patient and family by the health care provider (HCP). HCP caring for the seriously ill must be able to assess the patient’s and caregivers’ expectations, ask what they wish to know, explain prognoses in general and statistical terms, use graphs, diagrams and numbers when appropriate, and know when to defer or reinitiate discussions, while assessing for level of comprehension (Epstein, 2009). Effective communication will provide the basis for a relationship between the patient and family which is crucial for effective collaboration between the patient and their health care provider. The plan for communication explores families’ emotions while providing emotional support. The health care provider must transfer the information to the patient in a calming and caring way, while providing a positive environment for communication for the patient and family (Morita, 2004). With therapeutic effective communication the family can start to process the “what if’s” and move forward on how this disease has affected their family member. By getting the communication process initiated effectively, all members of the health care team can be honest in their attempts to answer the most difficult questions a patient may ever ask, as they plan how their patient’s disease will be treated (Liao, 2007).

Acute Care Nurse Practitioners (ACNP’s) provide care for the sickest individuals in the healthcare system. The American Association of Colleges of Nursing (AACN), (2004) states the ACNP is educationally prepared to provide advanced nursing care to patients with complex acute, critical and chronic health conditions. Acute myocardial infarction, stroke, and trauma
are examples of diagnoses the ACNP may care for in the acute setting. The ACNP is able to promote and improve the quality of life for the patients in critical care and palliative care (Byock, 2006).

Effective communication is important for all ACNP’s. ACNP’s provide communication that is based on knowledge about treatment of the disease process, current research and evidence based practice. An ACNP utilizes theoretical frameworks, acknowledges legal and ethical implications and most importantly, follows a high standard of communication to incorporate all elements of a patient’s needs. ACNP’s need to be adequately educated in providing information on a medical assessment, giving both positive and negative prognosis, talking about goals of care, and dealing with spiritual and existential issues that arise when talking to families of critically ill patients (Liao, 2007).

For communication by health care providers to be effective, education for the health care provider on how to provide patient education is needed in the academic setting (Holley, 2007). Registered nurses are well educated on the communication process provided in a general nursing role. But as a nurse practitioner (NP) the communication relationship has changed from nurse to patient to a new role of nurse health care provider to patient. This places the NP in a gray area between the role of nurse and the physician; hence the need for education for the NP on providing patient centered communication (Berry, 2009).

Communication should be inclusive of the holistic needs of the patient (and the family of the patient if the patient designates they may be present): from defining the disease process in laymen’s terms, expanding on potential treatment options in pain control, providing psychosocial
support, acknowledging cultural preferences, and spiritual needs. To extend a relationship between the ACNP and patient, the approach to care involves meeting the social, psychosocial, spiritual and physical needs of the patient. By introducing the prognosis and stages of the disease early in the relationship, the health care provider helps the patient identify their physical and emotional needs while supporting families in the plan of care and acceptance of the disease process (Ragan, 2003).

**Purpose**

The purpose of this paper is to provide an educational guide for ACNP’s on what is considered by the literature as effective communication provided by a health care provider when working with patients and families on difficult issues, terminal prognosis and end of life issues. This paper will identify how to implement an educational program for nurse practitioners on how to communicate provider-patient education, how to provide a setting for positive communication, identifying/reducing barriers of communication, identifying ethical and cultural factors that affect communication, and the steps to complete a family conference.

**Definitions**

*Acute Care Nurse Practitioner (ACNP).* Acute Care Nurse Practitioner cares for adults with complex, acute illnesses that are in intensive care units, emergency departments, trauma units or specialty practices. The ACNP utilizes critical thinking, disease process analysis, evidence based practice and the research process in collaboration with other health care professionals.
**Communication.** Communication is the process of transferring information from one entity to another. Communication is a learned skill, to speak well and communicate effectively. Speaking, listening, and our ability to understand verbal and nonverbal meanings are skills developed by observing other people and modeling our behaviors based on what is seen. Communication skills are learned thru education, practice, culture, and reflect our personal, academic and professional career.

**ELNEC.** End of Life Nursing Educational Consortium (ELNEC) project is a national education initiative to improve palliative care. During a seminar, undergraduate, graduate, CE providers, staff development educators, and specialty nurses complete core curriculum on: Nursing care at the end of life, Pain management, Symptom management, Ethical/Legal issues, Cultural considerations in End-of-Life Care, Communication, Loss, Grief, Bereavement; and Preparation for and Care at the time of Death. The ELNEC curriculum was developed through the work of nationally recognized palliative care experts (ELNEC, 2009).

**EPEC.** Education for physicians on end of life is a project devoted to “equipping clinicians with the attitudes, knowledge, and skills to provide the best possible palliative care to their patients. The ultimate goal is to relieve suffering and improve the quality of life for all who are living with, or dying of, life-threatening illnesses (EPEC, 2009).

**Health Care Provider (HCP).** Health care provider is an individual who provides healthcare in a systematic way professionally to individuals in need of health care services.

**Hospice.** Hospice is a special concept of care designed to provide comfort and support to patients and their families when a life-limiting illness no longer responds to cure oriented
treatment; it involves a team oriented approach to expert medical care, pain management, emotional and spiritual support, tailored to the patient’s needs and wishes to improve the quality of a patient’s last days by offering comfort and dignity. Life expectancy is usually six months or less (NHPCO, 2009).

*Nurse Practitioner (NP).* A nurse practitioner is a registered nurse with specific advanced nursing education and training in the diagnosis and management of common medical problems. NP’s can treat both acute and chronic conditions through comprehensive history taking, physical exams, physical therapy, ordering laboratory tests, radiologic films, and providing therapy for patients within their scope of practice.

*Palliative Care.* Palliative care is the medical subspecialty focused on the relief of pain, symptoms and stress of a serious illness. The goal is to ensure the highest quality of life possible for patients and their families. Palliative medicine programs address serious illness regardless of prognosis and patients can receive assistance from palliative care at any stage in their illness without curative treatment. Palliative care programs generally address the physical, psychosocial, spiritual needs, and expectations of a patient with a life-threatening illness, at any time during that illness, even if life expectancy extends to years (CAPC, 2009).
CHAPTER TWO

According to Fallowfield (2002), healthcare professionals censor the information they provide patients and families in an attempt “to protect them from potentially hurtful, sad or bad news” (p. 297). A HCP has an ethical obligation to tell patients and families the truth about their illness, prognosis, and available treatment options. A censorship of information by a HCP may actually cause increased anxiety and fear to the patient, exactly what the HCP was hoping to alleviate. Patients who have discussions with their HCP about prognosis have increased satisfaction with care, decreased depression, less anxiety and hope to sustain them through the illness (Epstein, 2009). Hope evolves over time, and can be present without a cure. Hope requires a HCP to believe in the spiritual nature of hope, and embrace how a plan of care can embrace a person’s hope. This can be a cure, not going back to the hospital, or seeing their grandchildren smile (Glass, 2004). It’s better to give truthful information in a tactful manner than to sugar-coat and give false hope to patients and families (Buckman, 2001; Glass, 2004).

Medical professionals do not receive formal structured information on effective ways to communicate with patients and families about poor prognosis associated with illness or when serious medical decisions need to be made (Buckman, 2001; Epstein, 2009; Berry, 2009). Recently, education to improve end of life care is being improved through organizations such as, End-of-Life Education Consortium (ELNEC) and Education for Physicians on End-of-Life (EPEC). These organizations assist clinicians with the attitudes, knowledge, and skills to provide quality palliative care to their patients. As HCP begin to be exposed to the resources of ELNEC and EPEC in the form of educational materials, lectures, and core skills in the area of
palliative care their knowledge base will increase. The information these organizations provide equip HCP’s with tools so they can have a more effective communication process with their patients and families. People in the United States deny death, believing that medicine can cure any disease. Death is seen as a failure of the modern health care system rather than the natural life cycle (ELNEC, 2009; EPEC, 2009).

In a study by Morita (2004), a multi-center questionnaire patient survey stated “considerable or much improvement was necessary in the communication methods” (p. 1551). Patients associated the need for improvement when the physician is stating he/she could do nothing for the patient, not explaining treatment goals in specific terms, not pacing the explanation to the family, lack of knowledge about treatment regimen, and an environment not conducive for a family meeting (Morita, 2004). Epstein and Quill (2009) discussed to a group of medical professionals in New York how “discussions about prognosis frequently do not occur, and when they do, communication is often problematic” (p. 1). In addition, many clinicians feel uncomfortable dealing with the emotional issues patients and families during discussions of prognosis (Epstein, 2009). WHO, 2004 Health Evidence Network (HEN) synthesis report recommended investment in “quality improvement methods, rewarding health care organizations for their involvement, and expanding education and training for staff providing palliative care” (p. 4). There needs to be a formal education process that allows practitioners to identify and practice different scenarios that would assist with communication strategies (Field, 2009). Some of these scenarios may include: identification of a “good” death versus a “bad” death; acknowledgement of past experiences with death; ethical and cultural issues associated with
death; and personal/professional experiences with illness/death so the provider can learn new responses to provide effective and compassionate care (Field, 2009). Communication by HCP's can be improved with education, but professionals "need help to sustain new skills in everyday practice (p. 8).

ACNP’s and physicians have received education on how to save a life, resuscitate a patient with Advanced Cardiac Life Support, and document care, to prevent legal or ethical events in the clinical arena. Few ACNP’s have received education on communication with families related to end of life issues. In the late 1970’s and early 1980’s it was widely believed that communication skills were “intuitive, almost inherited” (Buckman, 2001, p.2). Although, on the job training as an NP, prior experience as a nurse, and learning from mistakes have guided NP knowledge on how to approach patients with end of life issues and chronic disease management, further education needs to be completed. Recently, researchers have found that communication skills can be taught, retained over years of practice, and acquired like many other clinical skills (Buckman, 2001). There is evidence to suggest that communication skills training can have a beneficial effect on health care providers and communication with cancer patients. Further research is needed to assess efficacy of compulsory education for all HCP’s (Moore, 2003).

Research also shows that there may be a financial implication for organizations to have a regular process in place to adequately inform patients of their disease process and plan of care. Hospitals may not directly see the costs that occur by miscommunication, redundant care, and frustration from families but those costs do exist. Morrison (2009) found hospitals that utilize
palliative care consultant teams are associated with significant hospital cost savings. As population demographics show unprecedented gains in life expectancy with the aging of the “baby boomers” the number of people over age 85 will double to over 10 million in 2030, just over 3% of the population (Morrison, 2009). Having a carefully planned, effective approach to communicate with patients and/or families, helps keep the care in a positive and effective direction. When this does not occur, there are associated costs that will be incurred because of poor communication, and increased family frustration (Moore, 2009).

The World Health Organization (WHO) has defined palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with a life threatening illness, through the prevention and relief of suffering by means of early identification, impeccable assessment, treatment of pain and other problems, physical, psychosocial and spiritual” (WHO, 2002, p. 1). Palliative care is a comprehensive, interdisciplinary service for patients with life threatening or terminal disease and should be offered throughout the health care spectrum when the primary focus on care is comfort and quality of life. It is an emerging specialty that is developing from the need for care that still provides options, is provided in the acute care setting, and compliment to hospice.

Hospice began in the United States in the 1960’s to improve the quality of the dying experience for patients and their families. Hospice patients pursue treatments meant to promote comfort, not cure the illness. Hospice involves a team oriented approach to expert medical care, pain management, emotional and spiritual support, tailored to the patient’s needs and wishes. Hospice believes that “each patient should be able to live and die free of pain, with dignity, and
that our families should receive the necessary support to allow us to do so” (NHPCO, 2009, p.1).

The Medicare Hospice Benefit (MHB) was designed to provide professional and material support for dying individuals during their last 6 months of life. Hospice can best be described as an intensification of palliative care at the end of life.

Hospice and palliative care share the philosophy of maintaining and managing the patient’s quality of life. Hospice provides for patients who can no longer benefit from regular medical treatment, per a doctor’s determination, and are in the last stages of a terminal illness. Palliative care programs generally address the physical, psychosocial, and spiritual needs and expectations of a patient with a life-threatening illness, at any time during that illness, even if life expectancy extends to years. Palliative care does not preclude aggressive treatment of an illness, provides comfort to patients, and their loved ones (Icaberry, 2009).

Summary

Patients have a need to be informed of their disease process, options for treatment, and prognosis for recovery. Options should be explained to the patient and family so that they can decide how they want to proceed with their plan of care. Due to Health Insurance Portability and Accountability Act (HIPPA), the patient may want to hear this information alone, and this request should be respected and honored. A healthcare provider must be knowledgeable and feel comfortable communicating with the patient and family about end of life issues. This communication is especially important for all ACNP’s in the acute care setting who are taking care of patients often faced with serious illness. The patient and family must have an open relationship with the ACNP in which questions can be answered as the severity of the illness is
understood. An ongoing communication process that is supportive of the needs of the patient and family will help the family process the new diagnosis and ongoing physical changes the patient is experiencing. Communication is the primary relationship through which interpersonal interaction based on respect and trust occurs between an ACNP and patient.

Providing good communication can be rewarding to the practitioner. It assists the patient and families in resolving conflict related to an illness. Effective communication helps achieves closure, once a patient/family knows what disease they are dealing with, they can move forward on what treatments they prefer and how the plan of care should progress according to options given. Reinforcement of the plan of care and options presented maybe reiterated by ancillary staff such as the chaplain, bedside nurse, case manager, social worker or palliative care nurse.

Communication, especially in a crisis, is a very private opening into an individual’s most vulnerable experiences as a human being. The ACNP needs to understand that this is a private and personal experience for the patient, and whatever choice the patient makes, it must be respected. The healthcare provider needs to be aware of the importance of the opportunity given to them in sharing this very important time with the patient and family (Buckman, 2001).
CHAPTER THREE

Patients and families value accurate information related to a clinical diagnosis, however many feel they receive inadequate, insufficient explanation and that doctors and nurses currently have limited ability to detect a patient's need for education. Many studies of people diagnosed with chronic illnesses reveal that the way in which they are told information and interact with HCP’s for decision making are important determining factors for satisfaction of care. This is also important for the families. An educational seminar, targeting HCP’s, especially nurse practitioners would be initiated to expand on the present knowledge base for communication of chronic illness.

Initially a target audience would be obtained in the rural area of Yuma, Arizona. An educational brochure advertising a 4 hour educational seminar would be sent out to all physicians, physician assistants, nurse practitioners, clinics, urgent cares, etc to obtain a target audience of 25 attendees. This timeframe would allow clinicians the flexibility to complete hospital rounds and/or maintain a partial office appointment schedule during the hours surrounding the conference. The clinical education department associated with Yuma Regional Medical Center would also be contacted to obtain necessary authorization for CME/CEU credit for attendees.

A pre survey would be done prior to the start of the seminar to assess the knowledge of the participants. Educational content for the seminar would be presented by palliative care physician and nurse; chaplaincy, and nurses educated in ELNEC philosophy and palliative care. The content of the seminar would follow a power point presentation in the form of a didactic
presentation, lasting less than 1 hour, that reviews the current lack of formal education for health care providers in the academic arena, basics of communication (appendix A), how to plan and participate in a family conference (appendix B), how to communicate with patients, families, and other professionals (appendix C), ethical issues in clinical practice (Appendix D), discussing prognosis, and potential triggers that indicate a discussion of prognosis for a serious illness is warranted. Educators would need to be knowledgeable on the information to be provided, educated in the scope of information to be presented, and provide evidence based information. The educational team needs to show consensus, work together, show professional conduct, respect each individual role, create an atmosphere where communication occurs without fear of reprisal or embarrassment, and have a common goal to increase the communication by practitioners to families. Short presentations (15-20 minutes) would also be provided by chaplaincy, palliative care, and case management on how their specific departments could assist with families' transition to a serious illness. A didactic presentation will provide a large quantity of information to a large group in a short period of time and at a lower cost to an organization (Satterlee, 2008).

Multiple interactive case studies representative of the top chronic diseases admitted to the community hospital and cultural issues related to the geographical area close to Mexico, large indigent/transient population would be divided amongst small group for discussion. Each group would propose how to best handle the situation with the seminar information provided and the seminar leader will summarize and offer additional “tips” to assist with further learning.
A role playing exercise would be completed by small groups of 3-4 participants. Participants would play the role of physician, patient, family member, and bedside nurse. After the role play exercise participants would be asked to comment on professional concerns and emotions felt during the exercise. After the role play, the group with a facilitator would document on a dry erase board the consensus of the participants. This would allow the participants to summarize the different attributes each member of a health care team and family unit may express during a communication of serious illness. A study by Cochrane Library showed that professionals achieved the most effective continuing education from interactive communication seminars (Satterlee, 2008).

At the end of the seminar time would be left for questions and comments. A post survey to assess what participants learned in the seminar and what further educational seminars are needed to assist practitioners when communicating a serious illness to a family unit. Participants would be given a handout with a list of resources within the community to assist with complex patients who need assistance with pain, symptom management, psychosocial support, and physical restrictions. These resources could be provided inside the hospital or outside of the hospital within the community. Further resources may include: nutritionist, case management, palliative care, chaplaincy, oncology, pharmacists, nurses, and community support agencies (Hospice and home health agencies).

After the seminar is complete, the educators who have given the seminar would also provide input on areas requiring improvement. Survey's (pre and post) would be reviewed for
participants response to educational materials/methods provided. A quality improvement plan would be initiated to improve the seminar.
CHAPTER FOUR

NP's and physicians complete a standardized curriculum to obtain a degree in nursing or medicine. Credentialing, continuing education, and on the job training all contribute to the success of a HCP, however, there is no examination or review board for the process of communication with patients and families with chronic or end of life issues present to the HCP. Patient communication at the end of life, when everything should be strategically planned with a person's intimate wishes followed, is often inadequately addressed in the academic world. The education deficit is being acknowledged with programs such as ELNEC and EPEC, but this is just a beginning. For HCP's to meet the needs of the aging population, cost reduction for services provided, and a shortage of HCP's the education for patient communication needs to improve dramatically.

As articles address the lack of education a balance in educational programs to increase the knowledge base of HCP on communication of seriously ill patients should start to appear such as ELNEC, EPEC, and hospital continuing education. For the classes to be successful, a continuing awareness of the deficit, benefits to be obtained by attending classes and ultimately showing improved patient care. In addition, cost reduction benefits attract hospitals to provide more educational services on communication. The motivated HCP will reap the benefits of attending a seminar.

The lack of education on communication is becoming evident in the literature, but at a tempo too slow to meet the rising crisis in medical care. Educational seminars are costly due to remote locations, few classes throughout the year, time prohibitive, budgets not flexible for
elective classes and not available for everyone in today's economy. Instructors and qualified presenters may not be available. Research in this area is new, and data may not be available to support endeavors.

Communication on end of life issues will affect many NP's in the near future as the health care industry changes, NP's become the primary patient care provider, and discussions relating to plan of care are completed by the NP versus the physician. Academic classrooms will need to add to the curriculum of how, when, and why a patient is approached for end of life issues or serious illness. Further research will be warranted to determine the effect of education on providers' communication and family units understating of serious illness.
APPENDIX A
Basics of communication

*Communication*—is the exchange of information—a message sent is received and interpreted by the intended person.

- Introduce yourself; tell the patient why you are there, your role and what part of their care you provide. Find out the relationship of everyone in the room before the discussion begins. Take a seat approximately two feet from the patient.

- Provide a quiet, uninterrupted environment for the discussion. If possible, hold the discussion in a room away from the patient’s bedside, such as a conference room, or closed lounge where privacy can be maintained. Make sure everyone is seated.

- Use words that mean the same thing to the sender and the receiver of the message. In healthcare, different meanings can cause serious problems. Avoid words with more than one meaning.

- Use familiar words. If you use medical terms, paraphrase them with words in laymen terms. Make sure the patient and family understand all medical terms used.

- Be brief and concise. Communicate in a logical and orderly manner. Stay on target with the conversation. Give thoughts step by step.

- Understand and respect the patient. Acknowledge one’s regrets that the patient has the illness.

- View the patient as a physical, psychocological, social, and spiritual human being.

- Appreciate the patient’s problems and frustrations.
-Respect the patient’s rights.

-Facilitate communication between the patient and the family. Assess the patient’s and close family members reactions to the news and give them time to comment, express their emotions, and recover composure.

*Nonverbal communication*—does not use words; messages are sent with gestures, facial expressions, posture, body movements, touch and smell.

*Body language*

- Face the patient as you talk to them; sit on a chair-on the edge of a chair and lean in towards the patient to show interest
- Keep feet flat on the floor
- Undo your coat if you are wearing one
- Rest your hands on your knees; try not to stand so you are at the same eye level as the patient
- Actively listen to patient and turn towards family members as they contribute to the conversation
- Try to look relaxed and unhurried

*Eye contact*

- Monitor the patient for eye contact; understand not everyone will maintain eye contact; some patients will not make eye contact due to shyness, lack of interest, humility, low self esteem, or to show respect to the healthcare provider
-Maintain eye contact for most of the time the patient is talking—especially if the interview becomes intense or emotionally charged, and if the patient is crying or is angry, it is helpful to the patient if you look away (to break eye contact) at that point.

**Touch**

- Can be an important form of nonverbal communication; touch can mean comfort, caring, trust, concern, reassurance; A healthcare provider may ask a patient if it is “OK” to touch them;

**Verbal communication**

- Face the person

- Control the loudness and tone of your voice

- Speak clearly, slowly and distinctly

- Do not use slang or vulgar words

- Repeat information as needed

- Answer one question at a time

- Clarify and repeat the question as needed.

**Art of listening:** Active listening requires full observation of the events within the care conference

- Listening to words and observing non verbal gestures
-Utilizing silence and encouraging the patient to talk allows the patient to process the information provided

-Nodding, smiling, saying “hmmm”

_Cultural sensitivity:_ Cultural competence includes issues related to religion, spiritual needs, cultural, ethnic, racial, gender and language. If the patient does not speak English, use a medical interpreter that is not a family member to provide the knowledge to the patient. Ask each individual what he/she wants to know.

Note: As a caregiver-verify your personal cultural background will not be a barrier in providing care for the patient.

_Empathetic Response:_ A technique of acknowledgement, showing the patient that you have observed the emotion the patient is experiencing, identifying the origin of that emotion, responding in a way that tells the patient that you have made the connection with the above

Plan ahead for the bad new conversation and tell the patient, so he/she can invite whomever he/she wishes to be present during the conversation. Let the patient know that you do not mind if he/she records the conversation for those who cannot be there or to listen to again to enhance understanding.

Expect tears, and prepare yourself to sit through them. Have tissues available.

Based on your assessment of the patient’s and family’s reaction, continue with further information on the illness and treatment options.

Give the patient and family time to formulate questions.
If the patient and family are too emotionally distraught to handle any more information, arrange another time when you all can meet to discuss the disease and treatment plan further.

If the patient is ready to make the treatment decision, ask the patient to summarize what you have told them to ensure his/her understanding.

End the conversation on a positive note. Reinforce your availability to the patient and family, your empathy that they are faced with this illness, and your commitment to helping them cope with the illness in whatever way they choose.


Appendix B

Family Conference

The family conference allows the health care team to communicate information to the family and patient. Increased satisfaction with care provided, and molding of the end of life experience has been noted by family members who have been allowed to participate in care conferences. The meetings should be scheduled routinely, with input from the patient on whom they would like to attend and who is allowed to have information on their healthcare information. A team of healthcare providers should be present for the meeting, including physician and physician consults, ACNP, social worker, care coordination, chaplain, primary nurse, and palliative care nurse, Medical social worker, etc… One individual should be in charge of documenting the content of the meeting for the medical record. The more complete this team of caregivers is, the more effective it will be in providing the total view of the disease process and what alternatives there may be for the patient and/or family.

Preparing for the conference

-Schedule the date and time of care conference keeping in mind that there may be some negotiation necessary so that the meeting allows family members of the patient to be present if that is the patient and/or family’s desires.

-Obtain results of all lab, radiology, pathology and medical consults opinion for conference

-Advise all healthcare professionals of planned agenda for conference

-Identify any new issues that need to be addressed

-Agree on time-frames, and boundaries for behaviors during the conference
- Resolve conflicts between physicians and within the healthcare team
- Identify location for family conference; Allow adequate space for all members of family and healthcare team
- Provide quiet room where no interruptions will occur
- Position all members of healthcare team at a table, same level
- Acknowledge caregivers discomfort related to discussing death and dying

Plan for the family conference

- Prior to conference prepare agenda and setting
- Introduce everyone to be sure that everyone knows each other and each person’s role
- Make family as comfortable as possible about discussing death and dying
- Identify gaps in knowledge and update as needed
- Avoid technical jargon and use layman’s terms
- Avoid pathophysiology
- Provide honest, meaningful information about prognosis
- Assess family knowledge of situation
- Stress the specific care provided and goals of care

Ending the conference

- Repeat what the patients and clinicians have said to summarize the conference
- Spend time exploring the family’s reaction to what was discussed
- Acknowledge strong emotions (anger, anxiety, and sadness)
- Use reflection to show empathy
-Ensure that there is a follow up plan of care

APPENDIX C
Communication with families

**Breaking bad news**-Give in a sensitive manner and at an individual’s pace; assess patient’s perception of situation (may need to confirm bad news); allow time to absorb bad news before exploring patient’s feelings and identifying concerns

**Denial**-maybe a valid coping mechanism for those who are unable or not ready to adapt to the reality of a terminal illness; Relatives may encourage; may be ambivalent, and level may change over time; Most patients move towards reality

**Collusion**-generally an act of love or a need to protect from pain, “Please don’t tell him that he has cancer.” explore reasons for collusion

**Difficult Questions**-when the reality of bad news is accepted, difficult questions--in that the answers are tenuous or constitute further bad news may soon follow; Many of these questions are rhetorical and have no clear answers; Examples-Is there a cure? Why me? How long have I got? What happens after this? (end of life) What complimentary therapies help?

**Emotional reactions**-when people accept that they or someone they love will die in the near future, there are often strong emotional reactions which need to be expressed and diffused.

  Anger-often misdirected towards HCP; should establish if it is justified & where anger focused

  Guilt-feelings that the illness is a punishment for past sins

  Blame-belief that current situation is the fault of others

**Health professionals**-costs to professionals of dealing with dying patients and their families
-identifying patients’ concerns brings professional close to patients’ pain, feelings of failure when patient dies, imbalance between work and relaxation, risk of emotional burnout

APPENDIX D

Ethical Issues in Clinical Practice

**Autonomy**—requires that a person be adequately informed to make his own decisions

People want to know the truth about their illness and prognosis, even when the news is not good. HCP’s need to ask how much information people want to know; Individuals may refuse to be told medical information even though they are mentally capable of making their own decision; If the patient refuses to hear the information, he/she must direct someone to receive the information in their behalf; This is a culturally sensitive alternative, and legally acceptable as long as documented in the medical record.

**Healthcare Professionals’ Ethical Obligation to Tell the Truth**

1) **Respect for autonomy**

2) **Beneficence/Nonmaleficence**—HCP have the duty to do good by facilitating patients’ and families adaptation to the illness; make decisions consistent with their personal goals and offers patients the chance to participate fully in their treatment plan; discuss their financial plans; end of life plans; adaptation both spiritual and emotional; acknowledging a patient is a peace helps survivors in their grief; make meaning out of life circumstances—including illness, suffering, and dying

Not do anything to harm a patient or family—if HCP fail to become skilled in giving bad news honestly and sensitively, they may severely impede patients’ and families’ ability to deal with serious illness and/or prepare for death

3) **Justice**—general rule of human conduct to treat others fairly
4) **Ethic of care**- doing the right thing stems from the HCP relationship or connection with the patient

**Outcome of not telling the truth: Inadequate information to make informed choices**-
Recognizing the dying process of a patient brings with it the duty of having the appropriate reverence; the way the patient is treated as a human being.

1) Explicitly and compassionately informing the patient that he or she is in the process of dying
2) Initiating a discussion of the patient’s own understanding of his or her impending death

***The failure to do these two things perpetuates a lie in the presence of a dying patient***

- not disclosing all the available information about the diagnosis, prognosis, and available treatment options; If the patient’s prognosis is less than 6 months, hospice may be discussed as a choice
- emphasizing one or two positive aspects of the information while “glossing” over the negative aspects
- not answering patients’ or families’ questions directly and not giving the specific information they are requesting
- presenting the information with a bias that reflects the presenter’s preferences

**Reasons Healthcare Professionals Do Not Tell the Truth**
- failing to acknowledge one’s own mortality
- having an unrealistic perception of their own ability to stop the dying process
- denying the reality of the terminal situation and believing the only way to help the patient is to remain focused on the cure
- being unable to grieve the loss of patients to illness
- lacking the opportunity to overcome personal fears in order to have honest conversations with patients and families
- believing that patients really do not want to know the truth or making assumptions about people’s wishes for information
- believing that it is best to follow the wishes of the family and to not tell the patient the truth
- a diffusion of responsibility
- not wanting to “take away the patients hope”

**Truth-telling without taking away hope: Bebeficence without maleficence**-HCP tend to think of hope in terms of the possibility of a physical cure. Hope is not static, evolves over time, although disease and suffering can assault hope, hope can be present even when a cure is unlikely. Hope involves the spirituality and resiliency of the human spirit.

References


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