Autonomy at The End of Life: What do elders want when faced with a terminal illness?

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Premise

- Studies have shown that many patients and caregivers feel that end-of life communications are often inadequate.
- They have questions that cut across a wide variety of issues:
  - Medical, practical, psychosocial and religious.
- Everyone in the team assumes someone else has addressed these questions.
- Preparing patients and caregivers for final journey involves more than just giving factual information about the process.

Goals

- Discuss what people want at the end of life.
- Identify barriers to open dialogue at the end of life.
- Discuss a few simple steps to facilitate conversations about the dying process.

What is Autonomy?

- **Definition:** Autonomy is the "personal rule of the self that is free from both controlling interferences by others and from personal limitations that prevent meaningful choice." Autonomous individuals act intentionally, with understanding, and without controlling influences.

Why is Autonomy important in medicine?

- Autonomy in medicine is not simply allowing patients to make their own decisions
- For a physician, respect for autonomy includes acknowledging an individual's right to self-determination as well as creating the conditions necessary for autonomous choice.

Respect for autonomy also includes

- Seeking informed consent for medical treatment and procedures
  - General Information
  - Alternatives
  - Risk
- Disclosing information about their medical condition to patients
  - Not assuming they cannot handle it
- Maintaining privacy

Death as Failure

“What tormented Ivan Illych most was the deception, the lie, which for some reason they all accepted, that he was not dying but was simply ill, and that he only need keep quiet and undergo a treatment and then something very good would result…”

Leo Tolstoy

The Death of Ivan Illych, 1886

Some Things still Ring True Today

“I would define medicine as the complete removal of the distress of the sick, the alleviation of the more violent disease, and the refusal to undertake to cure cases in which the disease has already won the mastery, knowing that everything is not possible to medicine…”

Hippocrates, 460-370 BC.

Experiences of Cancer Patients

- Only 66% recalled being given a prognosis related to their malignancy while 61% had asked to discuss prognosis.
- 8% felt that physicians should not communicate bad news to patients and 14% that clinicians should only communicate good news to patients.
- Information was sourced from the internet by 31% of the patients and 7% sought information from other patients.

Alifrangis C, Koizia L, Rozario A, Rodney S, Harrington M, Somerville C, Peplow T, Waxman J. The experiences of cancer patients. QJM (Monthly journal of the Association of Physicians). 2011 Dec;104(12):1075-81.

Experiences of Cancer Patients

When patients were asked: Worst aspect of illness

- Pain
- Sickness
- Hair loss
- Mood changes
- Loss of dignity
- Fear of death
- Breakdown of family
- Loss income
- Time spent in hospital
- Getting to hospital
- Parking
- Miscellaneous

Alifrangis C, Koizia L, Rozario A, Rodney S, Harrington M, Somerville C, Peplow T, Waxman J. The experiences of cancer patients. QJM. 2011 Dec;104(12):1075-81.

Important factors associated with good death

- Being in control and mentally alert until death, involved in decisions about care
- Being comfortable (pain and other symptoms controlled)
- Recognition of impending death and sense of closure
- Affirmation/value of the self, with beliefs and values honored
- Trust in care providers, including a strong patient-physician therapeutic alliance

Important factors associated with good death

- Relationships optimized with family and friends, burden minimized to family
- Family cared for, including bereavement support
- Death in preferred place of care
- Religious prayer or meditation
- Personal affairs in order
- Leaving a legacy

Khan SA, Gomes B, Higginson IJ. End-of-life care: what do cancer patients want? Nat Rev Clin Oncol. 2013 Nov 26.

What People Want at the End of Life:

- Truth
- Touch
- Time

Kuhl D, et al., What people want at the end of life; E-published 09/13/2010: ww.cmja.Ca

What People Want…

- Truth:
  - Facts about the disease, but not to have hope taken away.
  - Hope is not limited to escaping death.
    - They want to be reassured that their symptoms will be managed; that they will not be alone; that they may be able to spend time with loved ones.

Truth

- Beware of the patient or family member who asks that you “give it to me straight.”
  - They want to know, but are hoping for something positive.
    - They often see themselves as the exception that will pull through.
  - When conversations about end of life occur at the point of care(ward, ICU, etc.), people tend to be over-optimistic about prognosis.

Allen LA, et al. Discordance Between Patient-Predicted and Model-Predicted Life Expectancy Among ambulatory heart Failure Patients; JAMA. 2008 June 4.

Sharot T, et al. How Unrealistic Optimism is Maintained in the Face of Reality; Nat Neurosci. 2012

What People Want…

- Touch:
  - Physically, spiritually, and emotionally.
  - Often times, people are afraid to touch sick relatives or loved ones.
    - The patient feels like a leper. This adds insult to injury.
  - Family members often distance themselves.
    - This leaves an emotional void.
    - There is a profound sense of abandonment at a critical time.

Addressing Spiritual Suffering in Terminally ill Patients:

- A national survey of 2016 practicing U.S. physicians aged 65 years or younger (2015):
  - Most U.S. physicians believe that patients with unresolved spiritual struggles tend to have worse physical pain and that physicians should seek to relieve patients’ spiritual suffering just as much as patients’ physical pain.

Smyre CL, Yoon JD, Rasinski KA, Curlin FA. Limits and responsibilities of physicians addressing spiritual suffering in terminally ill patients. J Pain Symptom Manage. 2015 Mar;49(3):562-9.

What People Want…

- Time:
  - To process, to plan, and to deal with unresolved issues.
  - This is key for patients to come to terms with their illness, losses and unresolved issues.

Top 5 sources of spiritual distress

- Findings from the 2013 Spiritual Care survey states top 5 sources of spiritual distress that is encountered by chaplains.
  - Guilt or shame or forgiveness issues (54%)
  - Broken or damaged relationship with faith tradition or community (53%)
  - Lack of a sense of meaning (45%)
  - Loss of usual source of religious or spiritual coping or well-being (44%)
  - One or more life events that are unresolved (44%)

National Hospice and Palliative Care Organization (NHPCO) Newsline January 2014

What People Want…

- Often times, as death approaches, elders will have a variety of questions,
  - Medical.
  - Practical.
  - Psychosocial.
  - Religious or spiritual.
- However, just as often, many won’t know what to ask.
  - That is where ***WE ALL*** come in.

Barriers to Open Dialogue…

- Health care providers:
  - Unresolved personal issues or negative emotions associated with such discussions.
    - Fear of death.
    - Previous bad experience; Unhealed wounds.
  - May not know how to broach topic.
  - Lack of experience or familiarity with topic.

Barriers to Open Dialogue

- Healthcare providers….
  - Failure to check what the patient or family already know.
  - Provide too much information at once or cover too many topics.
  - Use jargon not familiar to lay people.

Barriers to Open Dialogue

- Patients and families:
  - Often don’t know what to ask.
  - May feel overwhelmed.
  - May not want to appear ignorant.
  - Previous bad experience with health care providers.
    - Leads to mistrust.
    - Afraid of being dismissed.

Steps for Giving Bad News

- Do your homework
  - Make sure you have all the facts.
- Make time.
  - Minimize interruptions.
- Find appropriate location.
  - Not the hallway or in front of strangers.
- What do they know?
  - What have you been told?

Buckman, R. (1992). How to Break Bad News: A Guide for Health Care Professionals. Baltimore: Johns Hopkins University Press.

Steps for Giving Bad News

- How much do they want to know?
  - Autonomy gives a patient the right not to know.
  - In some instances, a patient may delegate this function to a surrogate.
- Pause.
  - Give the patient, family, a chance to absorb information.
- What next?
  - Follow up.

Actions That Fall Short of Standard of Care…

- Avoiding discussion and simply giving patients and families a resource handout.
  - A handout is not a substitute for conversation.
  - A handout or resource should serve to supplement the conversation.

Actions That Fall Short of the Standard of Care

- Communicating information without validating the other person’s emotions.
  - “This must be very difficult to hear.”
  - “It is OK to cry.”
  - “It is OK to be angry.”
- Acknowledging the emotions creates a connection. It is a form of touch .

Steps That Can Be Taken to Improve Dialogue…

- Script out a brief introduction:
  - At times like this, people often feel overwhelmed and don’t know what to ask. Do you feel that way?
  - Do you have any questions regarding what is happening to your loved one?
  - People often worry that the medications may speed up the dying process. Do you feel that way? Would you like to talk about it?

Steps That Can Be Taken to Improve Dialogue…

- Educate ahead of time.
  - Explain what signs or symptoms they may observe as the disease progresses.
    - Assure that there are therapies available to manage them.

Steps That Can Be Taken to Improve Dialogue

- Educate ahead of time:
  - Talk about the benefits of advanced directives.
    - Reduced stress level.
    - Proper communication of patient’s wishes.
    - Assists in grasping reality of patient's condition.
- Discuss medications and talk about how they will affect patient later on.
  - More sleep.
  - Less pain.
  - Less restlessness.

Once You Have Started the Conversation and Answered Some Questions

- Offer educational resources.
  - We have talked about a lot of things. It may be difficult to remember everything later.
    - Do not hesitate to ask me more questions .
    - I would be happy to repeat myself. I am sure this is an overwhelming time and sometimes we use technical terms that can be confusing.
  - We have a booklet that reviews some of the things we talked about. I would like to give you a copy. Is that OK?
    - After you read it, if you have any questions, do not hesitate to ask me.

Be Careful!!

- Some people are not fully literate!!
- Most people today are embarrassed to admit they can’t read or write. However, studies show that as many as 20% of people may have some difficulty with reading medical materials.

Be Careful!!

- Here are a couple of questions that may indicate the person has problems with literacy:

1. How confident are you about filling medical forms?
    - Very: literate.
    - A little: high likelihood of illiteracy.
    - Not at all: illiterate.

2. Do you usually ask someone to help you read instructions or printed materials?
    - Yes.
    - No.

If the Person Is Suspected of Having a Low Literacy Level…

- Offer to assist with reading.
  - Sometimes these materials are a little difficult to read. Would you like me to read it with you?
  - Would you like me to give it to someone in your family, to go through it with you?

Do Not Ask…

- Do you understand???
  - That assumes you are communicating well and the patient , family member or caregiver has a problem understanding.
  - People may not want you to think they are "dumb."
  - They may be overwhelmed but do not want to be perceived as being trouble makers.

Ask….

- Did I explain myself?

- Would you like me to go over this again?

Assess Understanding

- It is not enough to give information. We must ascertain that it was absorbed.
- One must be careful not to appear like this is a pop quiz.
- Again, scripting is very helpful.
  - Tell me what you are taking away from this conversation.
  - Tell me what you will tell your(spouse, friend, family, etc.) about our conversation.

Assess Understanding…

- Eliciting feedback might be less stressful if we make it sound like we are making sure we didn’t overlook anything, rather than making sure the patient understood.
  - “So I can make sure that I have done a good job of explaining things to you, can you tell me what you are taking away from this discussion?”
  - “I know I have given you a lot of information at once. Can you tell me what you are taking away from this discussion?”

Don’t Forget……

- Make sure you have read any resource that you will be providing your patients and can talk about it
- All of your staff who have contact with your patients need to know what the booklet describes.

Why Do You Get Sick?

Most communicable diseases are caused by viruses and bacteria that spread easily through direct and indirect contact. Direct contact involves touching someone who is sick. Indirect contact results from coming into contact with germs a sick person has left behind. These germs can be in the air from coughs and sneezes; on eating utensils, drinking glasses, and personal items; and on doorknobs, telephones, and other contaminated surfaces.

Flu and cold germs live about 12–48 hours once they have left the human body. To avoid getting sick, wash your hands often and stand at least three feet away from someone who is ill. Staying home when you are sick greatly reduces both types of contact and protects others from your germs.

How to Treat Colds and Flu

- Stay home and rest.
- Take pain relievers for fever and body aches. (No aspirin for children and teens.)
- Drink lots of liquids (water, clear broth, diluted juices).
- Try hot drinks to soothe a sore throat.
- Wash hands often to avoid spreading germs. Also, don't share cups or eating utensils, such as forks and spoons, with anyone.

Most people get over colds or flu within two weeks. However, if you don't get better within a couple of weeks, seek medical care. This may be a sign of infection with another virus or bacteria (called secondary infection), which may lead to complications such as bronchitis and pneumonia.

Seek early medical care for flu if your symptoms are severe (very high fever, trouble breathing, confusion, etc.). Your doctor may prescribe antiviral medication to treat flu. Antiviral treatment must be started within two days of becoming ill; the treatment takes five days.

For more information about preventing colds or flu, visit the U.S. Centers for Disease Control and Prevention (CDC) Website: www.cdc.gov/flu/

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If You Are Sick…

It’s easy to spread cold and flu germs. If you are sick, stay home!

2 more points……

- Studies have shown that when caregivers voice questions and perceive that their questions have been answered, satisfaction and quality of life are improved and there are fewer depressive symptoms.
- Preparing caregivers for death must be individualized. They will have different information seeking styles and different needs for information.

Summary

- Autonomy can only be fully exercised when full informed consent is given.
- What do they want? Truth, Touch and Time
- Important to make time for discussion (script conversation and assess for understanding and literacy).
  - Remember to ask ”Did I explain myself?”
  - This can be done in 15 minutes

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- Questions ?