Palliative Care and Stroke

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“Apprehension, uncertainty, waiting, expectation, fear of surprise, do a patient more harm than any exertion”—Florence Nightingale
Vocabulary

- “Palliare”: To cloak
- “Patient”: To tolerate suffering
- “Care”: To attend to or assist those in need; mental suffering, anxiety or grief
- “Advocate”: To support and defend on another’s behalf

So, if we put those things together, Palliative CARE ADVOCATES to CLOAK those who SUFFER.
What is Palliative Care? (Palliare: “To Cloak”)

- Palliative care is an interdisciplinary specialty that aims to relieve suffering and improve quality of life for patients with advanced illness, and their families. It is provided simultaneously with all other appropriate medical treatment.
- Palliative Care can occur at the same time as curative or disease modifying therapy.
Desired Image of Palliative Care
Barrier Image of Palliative Care

Palliare??
“To Cloak”?
Questions

• Is it possible to care while we are curing disease?
• Can we only care if we are doing something to cure?
• So if we are not curing disease, how then do we care?
• Caring is a verb, our patients and their families have the right to tell us how to CARE for them regardless of how that looks.
Thought

• As a society, we seem to advocate loudly for the things we care about and we label it and allow it to define us: we are Republican, Democrat, pro-lifers, internationalists, secularists, suffragists, feminists, pacifists, Christians, Jews, Muslims, Buddhists, Hedonists, etc. It is just part of being American.....
• We as health care providers need to become ADVOCATES for the dignity and worth of patients who are suffering, regardless of whether or not they are seeking curative treatment. *We need to label that, to embrace that, and allow it to define QUALITY in health care from birth until death*
• Palliative Care is a voice of ADVOCACY for quality, dignified, goal-oriented care. It is NOT advocating for death or giving up or selective patient treatment (ageism).
Changing the image will take compassionate, educated providers

• The health care environment tells us that what can't be cured must be endured. This conceptualized medical mantra must change.
• Palliative Care reminds us that, even for someone with an incurable disease, life is not something to be endured, but enjoyed.
• It is not about defying or defeating death, it is about living life on your terms with the time you have left.
Where are we failing?

• “We sure spend a lot of time telling people how to be cured and how to die, but we spend very little time discussing how a person can take care of themselves while they are living with a disease.”

• Our patients and their families have to define quality of life. Health providers need to ask that question, EVERY time there is a new interaction with that patient.

• We tend to present every option, even those that may be inappropriate, rather than discuss living well with a disease and preparing for death.
  • Does the risk outweigh the burden?
Where are we failing?

• We all know that to get into medicine does not happen by failing everything.
  • **But dying is not getting an “F” on an exam.**
• The goal of medicine cannot always be cure....at some point death must be recognized as a spiritual problem to be faced as part of life
• Running from death through technology can make it come quicker....technology can be toxic and burdensome and induce suffering
• When is it time to let go and let God (or whatever you call peace) come in?
• When is it about vital healing not vital signs?
What is does Palliative Care Provide?

• Palliative Care is a patient-centered model of medicine that:
   • Recognizes that the patient and the family (whoever the patient defines that to be) is the unit of care
   • Reduces the level of *suffering* among patients with serious illness
   • Improves the ability of patients’ families to cope and care for their loved one
   • Improves patient and family satisfaction with care
   • Provides grief and bereavement support to health providers who care for the ill and dying
   • Enhances communication among patients, families, and care providers to ensure the dignity and wishes of the patient are honored
What ISN’T Palliative Care

• Palliative Care IS NOT only for actively/imminently dying patients
• Palliative Care IS NOT doing nothing
• Palliative is never futile
• Palliative Care DOES NOT start when curative treatment stops; it is simultaneous along the continuum of care
• Palliative Care DOES NOT convince patients to stop treatment
• Palliative Care DOES NOT take the place of care by the patient’s personal physician
• Palliative Care IS NOT Hospice Care
Disease Modifying Therapy
Curative, or restorative intent

PALLIATIVE CARE ACROSS THE DISEASE CONTINUUM
Concordance of values and goals in critical care and palliative care. QoL, quality of life.
What is the Evidence?

• “As the US health care system undergoes restructuring and pressure to reduce cost intensifies, patients worry that they will receive less compassionate care. So do health care providers. In a survey of 800 patients and 510 physicians, it was found that compassionate care is ‘very important’ to successful medical treatment. However, only 53% of patients and 58% of physicians said that the health care system generally provides compassionate care. Given strong evidence that such care improves health outcomes and patients’ care experiences, we recommend that national quality standards include measures of compassionate care; that such care be a priority for comparative effectiveness research to determine which aspects have the most influence on patients’ care experiences, health outcomes, and perceptions of health-related quality of life; and that payers reward the provision of such care. We also recommend the development of systematic approaches to help health care professionals improve the skills required for compassionate care.” Health Affairs, Sept 2011, Schwartz Center for Compassionate Healthcare, Harvard Medical School
American Stroke Association Statement

- 2013 Guidelines: *Early Management of Ischemic Stroke*
  - “Many (especially elderly) patients who survive massive hemispheric or brain stem strokes may be candidates for palliative care.....Early discussion with the patient and family can ensure any prior do-not-resuscitate or limitations-of-care orders are respected. Additionally, it is critical to conduct discussions with patients and families regarding post stroke prognosis to allow them to make informed decisions regarding any new do-not-resuscitate or limitations-of-care orders.” (p. 51)
  - Very little evidence currently involving palliative care and stroke. It has been recommended as a topic for further research.
Palliative and End of Life Care in Stroke—Guideline 2014
Summary of Guideline

• “The palliative care needs of patients with serious or life-threatening stroke and their families are enormous: complex decision making, aligning treatment with goals, and symptom control.”

• In 2010, there were 130,000 stroke-related deaths
  • 73% ischemic
  • 16% ICH
  • 13% sequelae of stroke
  • 4% SAH
  • 50% of those deaths occurred in hospital or LTAC
  • 35% of those deaths occurred in a nursing home
  • 15% of those deaths occurred at home or other setting

• Primary palliative care should be available to all patients with serious or life-threatening stroke and their families throughout the entire course of the illness
  • Stroke is the leading cause of disability and 30% of those disabled remain disabled for the remainder of their life
Summary continued.....

• Palliative team teams working with stroke survivors should focus on:
  • Promotion of patient and family centered care
  • Effective prognostication: what aspects of recovery are important to patient/family and communicate uncertainty
  • Developing goals of care: Communication and dialogue
  • Evidence for common stroke decisions with end of life implications: how does the surrogate become involved, DNR, ANH
  • Assessment and management of stroke symptoms: Pain, fatigue, incontinence, seizures, sexual dysfunction, sleep, depression, anxiety, delirium, caregiver burnout, requests to hasten death, EOL, organ/tissue donation
  • Training and experience with end of life treatments
  • Assisting with referrals to palliative care specialists or hospice as necessary
  • Bereavement plan of care for families
  • Participate in QI and research
Evidence for Stroke Family Caregiver and Dyad Interventions: 2014
Objective of Statement

• “To critique, analyze and synthesize the evidence on the impact of family caregiver and dyad interventions on stroke survivor and caregiver outcomes”

• Recognizes that:
  • Stroke is a leading cause of long-term disability which requires the assistance of a family caregiver
  • Caregiver stress has been demonstrated to adversely impact the rehabilitation of the survivor as well as result in social isolation, health issues, and increased mortality in the caregiver
  • Depression rates in caregivers are higher than in survivors

• Defined family caregiver as a:
  • Relative
  • Partner
  • Friend
  • Neighbor
Design of Analysis

- 366 articles reviewed
  - 32 included in synthesis
  - 69% were RCT
- Answered 4 Questions:
  1. “Do family caregivers and dyad interventions improve stroke survivor outcomes?”
  2. “Do family caregiver and dyad interventions improve caregiver outcomes?”
  3. “What types of family caregiver and dyad interventions are most effective for improving stroke survivor and caregiver outcomes?”
  4. “What recommendations can be made for designing and implementing family caregiver and dyad interventions that improve stroke survivor and/or caregiver outcomes?”
Conclusions

• Needs future research, especially later in the trajectory of disease
• There is evidence that stroke caregiver and dyad interventions have potential to provide significant improvements in our healthcare system. The best delivery of these interventions is unclear.
• Support groups are not the best formats to do these interventions/training sessions. Needs to be integrated clinically (inpatient and home health)
• Interventions including skill building, psycho-educational information and support in combination provided best results
• All interventions should be tailored to caregiver/patient needs and provided face to face or by telephone (not web/computer based)
  • Goal setting
  • Communication
  • Stress management
  • Managing common care issues for stroke (S/S, behavior, transfers, feeding etc.)
  • Engaging with peers for support
Conclusions

• Target interventions for both survivor and caregiver
  • Caregiver interventions when caregiver outcomes are desired
    • Improves perceptions of preparedness, confidence, self-efficacy, competence, and quality of care
    • Improves depression symptoms and coping strategies
    • Interventions provided mixed results on social functioning and HRQOL in caregivers (one more thing to go to)
    • Some supportive evidence for improved satisfaction with care for caregivers with specific caregiver and dyad interventions
  • Dyad interventions when survivor outcomes are desired
    • Improves physical functioning (limited), anxiety, HRQOL, social functioning
  • Ask how the caregiver is when assessing well-being of the survivor
Recommendations

• More research is needed in:
  • Development of beneficial interventions that improve caregiver and survivor outcomes
  • Delivery methods of these interventions
  • Studies that occur later in the stroke trajectory
  • Training for health providers on content, delivery, and follow-up of most effective interventions
    • Must begin to see the unit of care as the stroke survivor and their caregiver (palliative care)
Palliative Needs for Stroke Patients

• Physical (suffering)
  • Pain
  • Fatigue—how does this affect rehabilitation?
  • Restlessness
• Emotional (suffering)
  • Low mood
  • Anxiety
  • Poor concentration
  • Confusion
• Spiritual (suffering)
  • 1 in 5 patients in one study agreed with the term “Life is not worth living.”
  • Research suggests ‘spiritual beliefs may protect individuals with stroke from emotional distress.’
  • Conflict between feelings and convictions
• Existential (suffering)
  • Greater than half of patients in a study in England worried most about their family and the effect the stroke would have on them
  • Worry about being a burden to others
  • Uncertainty in prognosis
  • Fear of another stroke
  • Loss of independence
Concern #1

• Am I going to die?
  • How would you answer that question?
  • Honest information about what you are assessing
  • Talk about treatment being considered right now
  • Reassure on the things going right or well
  • Talk about your concerns as a health care provider
  • Tell them who else on the team is coming to help
  • Keep family at bedside
**Most Common Reasons for PC Consultation in Stroke**

- Imminent Death
  - Large stroke with mass effect
  - Poor protection of airway
  - Spontaneous bleed with/without thromobolytics
  - Advanced directives
  - Non-surgical candidates
  - Obtundation/Loss of consciousness
  - SAH/ICH

- Nutritional Needs
  - Dysphagia
  - Feeding tube placement
  - Hydration
Barriers to Palliative Care Consultation in Stroke Care

- Difficulty with prognostication for stroke patients (3 categories)
  - Recovery is anticipated and are likely to gain benefit from rehabilitation
  - Extent of stroke and irreversible damage is unclear and this patient remains at risk to die in 30 days
  - Extensive stroke with profound irreversible damage and death is a probable outcome in days
    - *Are you looking at the tree (organ) or the forest (person)?*
  - Recommendations for palliative care in stroke is based on end of life care on a model of care derived from cancer populations
  - Much of the care is focused on stabilization and transfer for rehabilitation
Barriers to Palliative Care Consultation in Stroke Care

• Palliative needs may be identified and treated in outpatient or rehabilitation setting rather than acute setting
• Research into palliative care in stroke care indicates that clinicians in stroke services equate palliative care to terminal care
• Stroke professionals are trying to do palliative care without training in palliative care....this delays decision making and at times causes moral distress in health providers and caregivers
Reality

• Post-stroke mortality remains high (28 day and 3 months and 1 year)....highest mortality of all palliative patients seen
• Stroke patients on palliative services studies are more functionally impaired, less likely to have capacity, more likely to die in the hospital and have fewer physical and psychosocial symptom burdens than patients with CHF, COPD, and dementia
• Most palliative consults in stroke patients are for ICH/SAH and guidelines recommend use of palliative care with brain death testing and determination
• Focus on stroke as TCD with acute admission contributes to high acuity survival which may increase palliative needs
Reality

- Stroke patients and their caregivers need support in coping with their disease process
- Symptom control remains an issue for many stroke patients, especially with communication issues
- Caregiver burden is significantly high post-stroke
- Decisions, such as feeding tube placement, are complex and require discussion/communication between health care providers, patients and families
Recommended Components for Stroke Care

- Processes that compliment acute stroke care include:
  - Access to specialist palliative services and experts in EOL care
  - Access to a multi-disciplinary team skilled in stroke and palliative care
  - Exceptional care for end of life (when appropriate) with protocol for symptom management
  - Proactive (not reactive) communication with families
  - Nutrition and hydration are part of core care and meetings occur early with dysphagia screenings to make a plan for rehabilitation and necessary artificial nutrition and hydration with open discussions of withdraw and withhold scenarios
  - Spiritual and religious care is open and accessible
  - Ethical discussions of principles of withdraw and withhold
  - Family and caregiver are supported in acute and transitional setting
  - Advanced care planning specific to stroke and co-morbidities for patient with designation of DPOA (this needs to be done when patient has capacity)
The Most Important Tool: A Palliative Meeting

• The Palliative Family Meeting (and a chair) is considered the clinical tool of the Palliative Care Team
• The meeting is about listening to the patient and family and ascertaining their understanding of the disease process, prognosis, and treatment options
• The meeting is about setting goals around how the patient defines quality of life and exploring the interventions that can meet those goals
• The initial meeting is usually not a decision making meeting
Palliative Meeting (cont.)

• Each team member will prepare for the meeting from their own discipline:
  • Physician: Disease, \textit{prognostication (PPS with screening)}, trajectory, possible technological interventions, burdensome symptoms
  • ARNP/RN: Functional status, ADLs, general care in the hospital, holistic care, decision makers identified, code status, burdensome symptoms, grief and bereavement
  • Social Services: Financial concerns, discharge plans, qualification for hospice or other placement, psychosocial issues, grief and bereavement, cultural assessment
  • Chaplain: Spiritual (not religious rituals) assessment, grief and bereavement, support systems, contact for spiritual care or funeral arrangements, cultural assessment
  • Pharmacist: Medication for symptom relief, dose conversions
  • Rehabilitation: PT/OT/ST daily assessments and recommendations for rehabilitation potential at discharge
How and when do we talk to patients and families?

• My conviction: “Courage is the resistance to fear, the mastery of fear—not the absence of fear.”—Mark Twain

• How do help our patients to live with their disease with courage? How do we help our patients to become warriors of their disease and not victims?
  ✓ Build a milieu of collaborative trust through HONEST communication, diligence, and all efforts to improve the patient’s QOL
  ✓ Communicate that there is no agenda, only the patient’s goals and concerns; we simply come along side where ever they are at
Talking (cont.)

• Give them the choices by informing them
  • Listen to their fears, hopes, burdens and acknowledge uncertainty both for them and for you
  • Discuss their EOL options to prepare for an event that they are unable to speak for themselves
  • Discuss the life limiting nature of their disease and the risk of death at the time of diagnosis to avoid the “surprise” later when the patient is deteriorating. Helps them fight the disease with compliance to treatment
  • Talk about dying when the patient inquires about it, when it is required for decision making about interventions, or with a decline in status
  • Make a PLAN, however hard that is and however many times it has to be discussed
  • Use decision aids to help when appropriate (see next slide)
Welcome

What are patient decision aids?
Patient decision aids are tools that help people become involved in decision making by providing information about the options and outcomes and by clarifying personal values. They are designed to complement, rather than replace, counseling from a health practitioner.

How can I find decision aids and learn about their quality?
A to Z inventory: allows you to search for decision aids on particular health topics.

Ottawa Personal Decision Guide: a general decision guide that can be used for any health or social decision.

New! iShould an easy to use decision application on Facebook.

How do I develop a decision aid?
Development Toolkit: provides information for developers and researchers interested in producing decision aids.

How can I implement decision aids in clinical practice?
Implementation Toolkit: provides tools and training for incorporating decision support in practice centres.

Cochrane Decision Aid Registry
Developers can login to the Decision Aid Library Inventory (DALI) system to enter and manage the information about their decision aids for inclusion in the Cochrane Inventory (69 KB Excel file) and the A to Z Inventory.

Ottawa Decision Support Tutorial (ODST)
An online auto-tutorial available to help practitioners develop skills in providing decision support.
What are our options when considering palliation in Critical/Acute Care for Stroke?

• Maximize treatment options while being alert to suffering
• Embrace the fact that palliative care is provided on the basis of need for each patient and family
• Remember Palliative and EOL discussions are a procedure and take just as much skill as a cardiac catheterization
• Balance treatment with symptom management
• Always, always move in the direction of the patient’s goals
• Listen and then talk when asked (within reason): ASK—TALK—ASK model
• The patient and/or family should be talking more than you (70/30 rule). Silence is ok—count to 7.
Options (cont.)

• Communicate goals of care with all providers of the team, even the difficult conversations surrounding EOL
• Recognize that death is a part of life and it is not optional.
  • *It is an option to plan and accomplish a good death.*
• We have the chance to make this a good memory for loved ones, one that they will carry the rest of their lives
• If we look at death as the enemy, we will set ourselves and our patients up to fail. Because in the end, death always wins.
I alone cannot change the world, but I can cast a stone across the waters to create many ripples.

Mother Teresa
In conclusion.....

- The results accomplished by adding palliative care that make me most proud:
  - Nurses are advocating for their patients and focus on the relief of suffering based on patient and family goals
  - Long standing problems like pain and delirium are seen as suffering and the focus is to alleviate this so QOL is improved
  - Patients are being seen as whole persons, not as disease entities that require treatments
  - Providers are asking, “Am I treating a disease or prolonging dying?” to guide treatment decisions and documenting their EXPERT opinions
  - The time we spend with patients and families gives us insight into the best ways to provide care (pain, sedation, delirium, mobility, cognitive testing, discharge setting)
  - The team becomes inter-disciplinary rather than patriarchal
  - Movement into disease specific advanced care planning
  - The goals of health care standards for improved patient satisfaction, reduced LOS and reduced readmissions come along side an output of mission: “providing compassionate, quality health care in an environment of trust and collaboration”.
"The very first requirement in a hospital is that it should do the sick no harm."

-Florence Nightingale