A Model for Rural Palliative Care

By Angie Fuller, ACHPN, APNP, Hospice and Palliative Care Nurse Practitioner for Life Choices Palliative Care at Tomah Memorial Hospital, Tomah, WI:

Most everyone will leave this world due to one or more chronic, life-limiting health conditions. Palliative care (PC) is a health care model to support the primary care provider’s and patient’s goals of care in those with chronic, progressive, life-limiting illnesses, regardless of stage of disease, whether they are seeking curative and/or other aggressive life-prolonging treatments, or for those who are in the very last phase in their lives but are not accepting of or ready to transition to hospice service.

PC professionals assist in preventing and relieving suffering from pain and other symptoms, optimizing functioning and decision-making on advance care preferences. Emotional support and education are important components of PC to assist patients, caregivers and family members both near and far cope with the numerous changes they face when overall health, and with it functional status, declines.

The PC team assists with allocating resources that may be helpful in caregiving along with management of daily activities and responsibilities. They also may provide physical tools for optimal care, along with bereavement services to the loved ones when the patient dies on the palliative service.

PC derives from a team approach, potentially consisting of the PC Provider, PC Medical Director, PC Director, PC Coordinator, NPs, RNs, LPNs, CNAs, Licensed Clinical Social Worker, Social Worker, Chaplain, Volunteer Coordinator and volunteers. The expertise of multiple disciplines are utilized in PC and referrals made (e.g., dietician; physical, occupational, and speech therapy; funeral directors). PC has a role in various settings other than the home (e.g., emergency department, intensive care, long-term care).

PC providers evaluate how patients, caregivers, and families understand the diagnoses and treatment options. They clarify misconceptions such as “no interventions equals no care” to assist in dispelling these myths and misunderstandings.

PC providers take time to discuss advance care treatment preferences and goals of care. The focus is on the discussion and planning, not on technology. These are difficult conversations most patients do not feel comfortable discussing with loved ones or do not know how to initiate. The following are some of the many issues that may be discussed, with the emphasis on choices:

- Deactivation of a defibrillator when the patient’s goal of care at end-of-life is comfort as defibrillation would cause prolonged suffering until death

“It’s not that I’m afraid to die, I just don’t want to be there when it happens.” - Woody Allen
Discontinuance of dialysis, chemotherapy, radiation, and/or frequent blood transfusions to allow a natural death and not prolonging dying

- even though a therapy has started doesn’t mean it has to be continued

- withdrawing a treatment does not mean withholding care, but instead providing even more specialized, in-depth and patient-centered care for symptom management

- emphasis on the difference between allowing a death and causing a death

Living arrangements and/or caregiving options should health necessitate more advanced care (CBRF, nursing home, in-home hired caregiving, home health care); this is explored not only for desirable options, but also undesirable (e.g., would be ok to go to nursing home “X” but not “Y”)

Patient preferences are then potentially documented on specific forms:

- Power of Attorney for Healthcare
- Living Will
- Physicians Orders for Life Sustaining Treatment
- “5 Wishes” from www.agingwithdignity.org

Goals are reviewed when a patient’s condition changes, has any new diagnoses and treatment options, and during/after hospitalizations. Conference or follow-up calls are made with family members unable to be present for input on family meeting so all members are aware of patient preferences to avoid inter-family conflict.

The following are helpful resources used in making the type of tough choices described above:

- “What Everyone Should Know About Life-Sustaining Treatment” at www.channing-bete.com
- “Hard Choices for Loving People” by Hank Dunn
- “Gone From My Sight” by Barbara Karnes
- “Finding Your Way: Medical Decisions When They Count Most” by the Center for Healthcare Decisions at www.chcd.org
- Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO), is a national consumer and community engagement initiative to improve care at the end of life at www.CaringInfo.org
- Hospice and Palliative Nurses Association at www.hpna.org
- National Palliative Care Research Center at www.npcrc.org

Some patients with life-challenging and/or chronic health conditions may not be appropriate for PC if perhaps they do not have a life-limiting disease trajectory, but may benefit from a one-time pc consultation to relieve suffering and/or improve upon quality of life. PC focuses on that improvement of quality of life for patients, their families, and their caregivers.

**Editors’ Note:** The Wisconsin Medical Society has an initiative, Honoring Choices Wisconsin, to build system change, advocacy and education around advance care planning. Info at: [http://ow.ly/sIQE](http://ow.ly/sIQE)

**Hospital Medicare Cuts Deep & Indiscriminate**

The following is from “Impact of Several Hospitals Cuts To Date” by the Wisconsin Hospital Association (WHA). It does an excellent job summing up what is at risk for all hospitals in the Washington budget battles.
Issue Overview—“Hospitals and health systems are in the midst of massive health care changes. From moving forward with electronic medical records, implementing major care delivery reforms, testing new payment models, adjusting to substantial upheaval in the health care insurance market, managing significant regulatory policy shifts while all the while absorbing billions of dollars in reduced federal payments for hospital care provided to Medicare and Medicaid patients, hospitals need some breathing room as all of these changes converge. Our health care professionals and all others within the hospital environment are daily trying to manage in this rapidly changing, hectic environment. It is not easy, and we are asking for Congress to provide some measure of relief going forward.”

Enacted Cuts to Wisconsin Hospitals—“Before looking at more options for cutting Medicare and Medicaid payments, Wisconsin hospitals urge Congress to consider the cuts our high-value hospitals are already seeing due to other laws enacted by Congress over the past few years. WHA and Wisconsin hospitals believe we have already been providing higher value care than many others and have faced billions in Medicare payment reductions already. Additional cuts will have an impact on our hospitals, their employees, and patients. A sample of the payment cuts our hospitals are already seeing are as follows.”

Patient Protection and Affordable Care Act of 2010—“PPACA is the federal health reform law enacted in 2010. PPACA seeks to expand Medicaid enrollment, creates health insurance exchanges, and mandates health insurance coverage among other changes. In order to fund these various changes, PPACA enacted billions in Medicare payment reductions, including:

- Some $700 billion in Medicare reductions, including $155 billion to hospitals nationally.
- WHA estimates that due to these Medicare reductions, Wisconsin hospitals face approximately $2.6 billion in reduced payments over 10 years.”

Budget Control Act of 2011—“The BCA, enacted August of 2011, addressed the nation’s debt ceiling crisis. The BCA called for a super-committee to find over a trillion in savings over ten years. Sequester was a mechanism included in the BCA to prod Congress to reach that compromise, but unfortunately, the super-committee failed to reach a compromise, triggering the sequestration’s $1.2 trillion in budget cuts. Sequester was originally scheduled to begin January 1, 2013, but was delayed for 60 days until March 1, 2013. Under the BCA, hospitals face the following:

- BCA cuts all Medicare providers 2% in each of the next nine years. Cuts are to all Medicare providers such as hospitals, physicians, nursing homes among others.
- WHA estimates the 2% cuts equal $1 billion to Wisconsin hospitals.”

The Middle Class Tax Relief & Job Creation Act of 2012—“MCTRJCA was enacted in February 2012 to address various fiscal issues such as the payroll tax and Medicare physician reimbursements (ie: the Sustainable Growth Rate). In order to stop the impending SGR cuts to physicians, Congress chose to cut hospital payments in the MCTRJCA, including:

- Reducing hospital bad debt payments for inpatient prospective payment system (PPS) hospitals from 70% to 65% and from 100% to 65% for critical access hospitals.
WHA estimates this bad debt cut at $55 million to Wisconsin hospitals over 10 years.

Worse yet, while hospitals face 10 years of bad debt cuts, these were to pay for an SGR fix lasting only 10 months.”

The American Taxpayer Relief Act of 2012--“The ATRA ended the ‘fiscal cliff’ crisis when it was passed on January 1, 2013, and enacted by President Obama on January 2, 2013. The ATRA addressed dozens of fiscal and tax related polices that expired at the end of 2013. In order to pay for various provisions in the ATRA, including how to address physician payments under the SGR (again), the law cut hospital payments (again). In addition, the ATRA also delayed the effective date of the sequester by 60 days until March 1, 2013.) Among the cuts the ATRA instituted is:

- Cutting hospital Medicare payments for ‘coding and documentation’ changes.
- WHA estimates coding and documentation cuts will cost WI hospitals $161 million over four years.”

The Bipartisan Budget Act of 2013--“The BBA provides a two-year budget agreement limiting the level of sequester cuts to defense and non-defense discretion spending. Unfortunately, in order pay-for those sequester reductions, a sequester extension is to be applied to Medicare providers, including hospitals and physicians. In conjunction with the BBA, a short-term SGR patch was also approved. Again, hospitals were among the ‘pay-fors’: 

- Extends mandatory sequester FYs 2022, 2023, a $212 million cut to Wisconsin hospitals
- Medicaid DSH cuts extended an additional year into FY 2023. Impact unknown.”

Conclusion--“Wisconsin provides high quality and cost-efficient care. This has been confirmed in the recent reports from the Agency for Healthcare Research and Quality (AHRQ), ranking Wisconsin hospitals are proven innovators and leaders in delivering value in health care (high quality, cost-efficient care). Continued cuts disadvantage high performing providers and states like ours will force hospitals to reassess services, programs and employment needs and diminish Wisconsin’s ability to attract business growth here. We are asking for Congress to provide some measure of relief moving forward.”

Rural Obesity Prevention Toolkit

Developed by the Rural Assistance Center, the Toolkit is available at www.raconline.org/ or as a single pdf at http://ow.ly/sLYF6 (slow download):

The Rural Obesity Prevention Toolkit is supported by a grant from the Office of Rural Health Policy, Health Resources and Services Administration, U.S. Department of Health and Human Services.

“The Toolkit is designed to help pinpoint factors in your community that promote obesity, convene partners to help address those problems, and apply proven obesity prevention strategies. It is made up of several modules. Each concentrates on different aspects of obesity prevention programs. Modules also include resources for you to use in developing a program for your area:

Understanding Obesity--Learn about rural obesity in the United States, so you can develop practical solutions to address it.

Creating an Obesity Prevention Program: Where to Begin--First steps in creating a rural obesity prevention program.

Targeting Audiences--Choosing the audience for your rural obesity prevention program.
**Evidence-Based Interventions** – Evidence-based practices for addressing rural obesity.

**Developing Interventions** – Using appropriate evidence-based interventions to meet your community’s rural obesity prevention needs.

**Addressing Obesity** – Rural prevention strategies for health care providers, schools & communities.

**Evaluating Efforts** – Evaluating rural obesity programs to help communities assess program effectiveness and build the evidence base for what works in rural communities.

**Prevention Clearinghouse** – Examples of rural obesity programs that have been implemented in clinical, school, and community settings.

**Excerpt: Module 1: Understanding Obesity**

“Rural areas in the United States have higher rates of obesity than urban areas, with the rural south having the highest rates of overweight. Rural communities have a unique set of factors that can contribute to higher rates of obesity. This module looks at factors contributing to obesity in rural areas, such as:

- Environmental characteristics
- Limited transportation options
- Lack of availability of healthy foods
- Lack of public health funding and infrastructure
- Barriers to access
- Rural population characteristics

“Since the makeup of rural areas is culturally, socially, economically and ethnically diverse, there is no one factor or set of factors responsible for rural obesity. Strategies used to address obesity should be based on each community’s unique strengths and challenges.

Practical solutions to the problem of obesity can be developed by collaborating to map local assets and needs. Additionally, pooling community assets and resources can provide a ‘place-based approach’ to meet community requirements.”

**In this module**

- What is obesity?
- Factors contributing to obesity
- At-risk populations
- Resources for understanding obesity

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**Influenza Immunization Reporting 2014**

By Ann Lewandowski, Southern Wisconsin Immunization Coalition Coordinator. Additional information is at available at [www.RWHC.com/SWIC.aspx](http://www.RWHC.com/SWIC.aspx)

Influenza rates are beginning to rise across Wisconsin. Milwaukee has seen nearly 100 people hospitalized as of January 7, 2014. The most prevalent strain the H1N1 strain identified in California in 2009, which has more complications for the young and otherwise healthy than other strains. The best way to protect you and your community is to get your annual influenza shot. Nationally, influenza rates are reported to be up 3% from this time last year. Rates in Wisconsin have risen slightly from last year, but the percentage of young children ages 0-4 are currently significantly below what they were at this time last year.

The Wisconsin Department of Health Services, Division of Public Health, Bureau of Communicable Disease and Emergency Response, publishes a weekly Respiratory Virus Surveillance Report at [http://ow.ly/sqaCy](http://ow.ly/sqaCy). The report is based on voluntary submission to the Wisconsin Immunization Registry (WIR) from immunization providers. The most recent WIR report which detailed the influenza situation for the week ending on Friday, January...
2, 2013, shows Wisconsin’s rates have exceeded the CDC’s national rates by nearly 6% covering 47% of Wisconsin’s children. Unfortunately, the year over year comparison does not deliver such good news; the total rate of children immunized in this group has fallen by 20% from approximately 67% verses one year ago. This age group is a particularly complicated one to manage as they need two shots for their first year to be fully protected.

Immunizing children in the primary care or hospital setting is more important during the 2013-2014 influenza season as public health clinics can now only administer vaccines to children who are not insured or are eligible for BadgerCare. Insurers, physicians, and parents should not depend on retail pharmacy locations for first or second doses because they cannot administer vaccines to children under the age of six. Providers are encouraged to book return appointments on the day the first dose is administered. Additionally, only about half of the public health departments in Wisconsin participated in school based mass vaccination exercises further decreasing access to influenza vaccine for all children across the state. The news is not all bad. Hospitals and clinics have begun their own vaccination clinics providing access to communities on a walk-in basis.

Rates may be artificially suppressed due to delays in reporting to WIR. New and community providers may not be used to entering immunization data into WIR. Records can be updated anytime by the immunizing provider or health care entity. Patients and their guardians may also view and edit their WIR record after they have received at least one immunization in Wisconsin.

Influenza has not hit peak activity yet and the season runs until May. There is still time left to vaccinate.

Support NRHA Rural Leadership Development

The National Rural Health Association has launched a permanent endowment for programs that identify emerging leaders from and for rural communities. The mission is to provide training and resources to help them play a lead role in ensuring access to quality health care for rural Americans.

Go to http://ow.ly/ejmLf to learn more.

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about the credentialing process, so our response is timely and helpful.

For more information, please contact Bonnie Laffey at blaffey@rwhc.com or 1-800-225-2531.

Leadership Insights: “Adapt”

The following is from RW HC’s Leadership Insights newsletter by Jo Anne Preston, RW HC Organizational Development Manager. Go to www.RWHC.com for back issues.

“Searching for a stretch goal in 2014? Adaptability is one of the most sought-after qualities in a leader, and being inflexible, even if you are technically talented, derails more careers than any other issue.”

“Think about the last time things did not go as planned or a change came about that you did not care for. How did you respond? Do you ‘go to the mat’ for things to be done the old way?”

“I grew up hearing that Charles Darwin’s quote was ‘survival of the fittest,’ but he actually said, ‘Survival of the most adaptable.’ While we definitely have an instinct to survive, the brain fights us a little on adapting. Our brains like ‘grooves’ and that is why developing habits is great for helping us to do the things we might not always feel like doing (working out, getting up early), but sometimes the hook of habits can put us on autopilot and blind us to new ways of solving problems. It’s worth developing some mental agility muscle.”

“Switch your response from ‘that’s WRONG’ to ‘that’s DIFFERENT.’ The latter is a small change that keeps your mind’s door from slamming shut. It offers you a chance to listen and learn. And you don’t have to speak the words ‘that’s wrong’ to believe it yourself, or for others to believe your body language that says so.”

“Be a secret early adopter. Is it possible that you have already earned a reputation as inflexible? Then find something new to learn about (the latest gadget, a function your electronic medical record can do that no one else knows yet) and learn all about it. Offer to share what you have learned with others to show them you are willing to learn and grow and they will be more likely to keep you in the loop of communication in the future. One of the pitfalls of being seen as a resister is that people avoid telling you about changes because they dread hearing, ‘That will never work/we tried that years ago/why fix what isn’t broken, etc.’ This information vacuum feeds your old reputation and creates a vicious cycle for you. Break it.”

“Make a daily practice of trying something new. Tie your shoes with the opposite loop first, park in a different spot, work in a different location. Flip a meeting agenda bottom to top. Small actions, but the brain responds and it will help when more weighty issues need you to be more open minded.”

“Work on your internal perception that ‘change is difficult.’ Our ability to adapt (or not) shows up most in times of change. ‘When things settle down, we’ll be able to_______’ (fill in the blank). We hold our breath and tighten our muscles through change just waiting for comfort. Adaptability is working toward getting comfortable DURING the change. Examine this belief about change by looking back on past changes that ended up being just fine. How much time and energy did you spend struggling? What did you miss? What would you have done differently if you had known it would all be ok?”

“Consider that if you are digging in your heels, it may be about some kind of fear. Experiencing fear is perfectly legal, but many of us hide it as if we have secretly committed a crime. Fear of change is usually tied to a perceived loss. There are antidotes to these fears of loss:
¬ **Loss of Competence**—Address with skill building.
¬ **Loss of Status**—Take initiative to reach out to others to build new relationships.
¬ **Loss of Freedom**—Ask for ideas; ask to share your ideas; discuss alternatives.
¬ **Loss of Certainty**—Identify what you *can* control.”

“*Can you be too adaptable?* We are not going after a ‘Gumby’ level of flexibility here. Some signs you may be over-flexing:

- **Others perceive**—or you feel like—*you are wishy-washy*. Sometimes flexibility is born from trying to please everyone (everyone but you perhaps?) If so, a) Welcome to a popular club, and b) Examine your motives to find a more attainable purpose than pleasing everyone.

- **You are not feeling confident.** It does take confidence to be an effective leader, but confidence is a journey with its ups and downs. Self-doubts are natural when you are new to your role, you have recently increased responsibilities, or when you don’t have any training in an area that you must now lead. These self-doubts may leave you swaying with whatever wind is blowing the strongest. Find a mentor who can help you crystallize a vision of where you are headed. The details may have to stay flexible, but a clear destination will give you that North Star to guide the way.”

Contact Jo Anne Preston for individual or group coaching at jpreston@RWHC.com or 608-644-3261. For Info re the RWHC Leadership Series 2013 go to www.RWHC.com and click on “Services” or contact RWHC Education Coordinator Carrie Ballweg at cballweg@RWHC.com or 608-643-2343.

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