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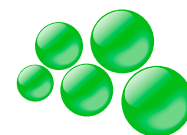


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\*Upton D., Solowiej K. The impact of atraumatic vs conventional dressings on pain and stress. Journal of Wound Care. Vol 21, No 5, May 2012.



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All healthcare encounters are cross-cultural through language, religion, and gender. The healthcare community has a culture of its own, and this is apparent as soon as you enter the physician's office or the hospital. Case managers must be sensitive to potential roadblocks in communicating with diverse patient communities as well as other healthcare providers.

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##### Case Management and Health Literacy

BY MARY MCLAUGHLIN-DAVIS, DNP, RN, MSN, ACNS-BC, CCM

Case managers must be cognizant of how our patients' health literacy impacts their decision-making capability and health-related outcomes. The awareness of the importance of a patient's health literacy directs the case manager's plan for patient education and care management.

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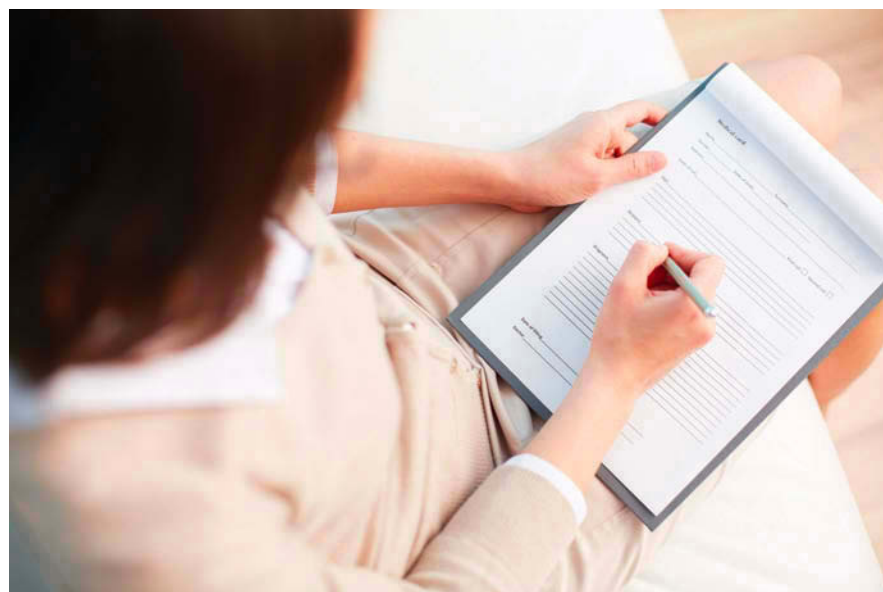
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# Case Management and Health Literacy

BY MARY MCLAUGHLIN-DAVIS, DNP, RN, MSN, ACNS-BC, CCM



**T**he case manager establishes a relationship with his or her patient as the first step in assisting that patient to experience optimal health. It is in the initial patient assessment that the case manager determines if the patient is able to speak English, and if not, accommodations are made to communicate through an acceptable interpreter.

Language is one potential barrier in the relationship between the case manager and the patient. However, there is another, less obvious roadblock to communication and relationship in serving diverse patient communities. Case managers must be cognizant of how our patients' health literacy impacts their decision-making capability and health-related outcomes. The awareness of the importance of a patient's health literacy directs the case manager's plan for patient education and care management.

The Institute of Medicine (IOM), The Agency for Healthcare Research and Quality (AHRQ) and the American Medical Association (AMA)

have all issued reports on health literacy. All reported that as many as one-half of all adults lack the literacy skills needed to function and navigate in the healthcare system. Patients with limited health literacy come from all segments of society, and most are white, native-born Americans (Weiss, et al., 2005).

Health literacy is also the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. It involves the ability to use and interpret text, documents, and numbers effectively — skills that might seem to be distinct but are highly correlated with one another (Weiss, et al., 2005).

Health literacy is also the ability to perform basic reading and math skills required to function in the healthcare environment. Limited literacy increases the gap between the health provider and the patient, and makes mutual understanding more challenging. In the U.S., one-third of English-speaking patients had low health literacy. There is an association

between limited health literacy and worse health outcomes (Chew, Bradley, & Boyko, 2004; Sarkar, Schillinger, Aronson, 2015).

All healthcare encounters are cross-cultural through language, religion, and gender. The healthcare community has a culture of its own, and this is apparent as soon as you enter the physician's office or the hospital. We do not intentionally miscommunicate, but we do not always look for the signs of fear and deference to our roles as care providers.

While limited health literacy is found most often in individuals with low global literacy, the IOM revealed that nearly half of all adults in the U.S. have basic or below basic English-language literacy skills. Patients may have adequate health literacy but limited understanding of basic math; in combination, this can still affect health. Equally important are critical-thinking skills that allow patients to make thoughtful decisions about when and how to take their medications and make appropriate health choices (Misra-Herbert, Isaacson, 2012; Sarkar, Schillinger, Aronson, 2015). Low numeracy literacy impacts outcomes of chronic disease conditions such as glycemic control for patients with diabetes and unnecessary hospital admissions for patients with asthma (Misra-Herbert, Isaacson, 2012; Sarkar, Schillinger, Aronson, 2015).

Only 12 percent of U.S. adults have the health literacy skills needed to manage the demands of our complex healthcare system, and even these individuals' ability to absorb and use health information can be compromised by stress or illness (Sarkar, Schillinger, Aronson, 2015).

Health literacy may impact health via three pathways: access and utilization of care, patient provider relationship and self-care. Health literacy is linked to both an individual's and a community's socio-economic context. It is the mediator of the social determinants of health and a necessary element for achieving health

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equity (Sakar, Schillinger, Aronson, 2015; Logan, Wong, Villaire, et al., 2015).

There is a financial cost, too. Medicaid enrollees with low literacy incur healthcare costs estimated at \$10,688 vs. \$2,891 for health-literate enrollees. The total cost of limited health literacy to the U.S. healthcare system is estimated at 50 to 73 billion dollars (Misra-Hebert, Isaacson, 2012).

We have two avenues open to assessing health literacy. We can adopt universal precautions and assume all patients have difficulty comprehending health information and accessing health services, or we can ask one research-based question that will provide us with an indicator of a patient's

health literacy. The question is, "How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?" You may also ask, "How confident are you filling out medical forms by yourself?" (Morris, et al., 2006; Wallace, Roskos, Holiday, Weiss, 2016).

The case manager must have an awareness of his or her own unconscious stereotyping of minority groups or patients with low health literacy. We must incorporate into our practice the responsibility to engage patients to incorporate their belief system into their well-understood healthcare decisions (Mirsa-Herbert, Isaacson, 2012).

In closing, case managers know the barriers patients face in navigating the healthcare system. Please take the time to learn about the candidates running for office in your area and the issues in his or her sphere of influence. Consider how the candidate's platform will affect your case management practice and your patients' healthcare needs. Take time from your important work to vote this November. ■

**Mary McLaughlin-Davis, DNP, RN, MSN, ACNS-BC, CCM**

President, CMSA 2016-2018



**Dr. McLaughlin-Davis** is the president of CMSA. She has been a certified case manager since 1993; she is a clinical nurse specialist for adult health and the senior director for care management for Cleveland Clinic, Avon Hospital.

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### Standards of Practice for Case Management



The Evolution of the Standards  
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## CMSA'S STANDARDS OF PRACTICE FOR CASE MANAGEMENT, REVISED 2016

The Case Management Society of America (CMSA) is proud to announce the release of CMSA's 2016 *Standards of Practice for Case Management*. The impetus for the 2016 revision of the *Standards* is the need to emphasize the professional nature of the practice and role of the case manager.

The maturity of the practice of case management, the importance of protecting the professional role of case managers and the enactment of new laws and regulations including the Patient Protection and Affordable Care Act all legitimize professional case management as an integral and necessary component of the health care delivery system in the United States.

"I believe that professional case managers are critical members of the collaborative care team as their contributions are crucial in assisting the care team to achieve positive outcomes for our patients," stated Kathleen Fraser, CMSA executive director. "We recognized the need to revise the *Standards* in order to be reflective of the expanding role of the professional case manager and to help define the contributions and value case managers bring to the changing health care system."

The 2016 *Standards* contain information about case management including an updated definition, practice settings, roles and responsibilities, case management process, philosophy and guiding principles, as well as the standards and how they are demonstrated. CMSA provides these standards as a resource to professional case managers and the healthcare industry.

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# Are You Culturally Competent?

BY ELIZABETH J. CLARK, PHD, MSW, MPH



**“Achieving and maintaining competency is a dynamic process, and each practitioner must take responsibility for learning what she or he doesn’t know.”**

**Y**ou want to be the best practitioner you can be. You have spent years developing your technical proficiency and keeping current with your field. You continuously work to enhance your communication skills. You are a compassionate, caring, and ethical professional. You are also an advocate for your clients, your profession and your community.

You are competent in so many areas, but can you claim that you are culturally competent? What does cultural competency actually mean?

Can you define it? Can it be measured? How can you know if you are achieving it?

Before we can define cultural competency, we need to define culture. There are many accepted definitions of culture, but, generally, culture refers to a set of interrelated beliefs, values, languages, behaviors, customs, rituals, communications, and institutions of a racial, ethnic, religious, social or political group.

Culture is especially important in healthcare. It impacts one’s definition of health and illness.

**“Culture is especially important in healthcare. It impacts one’s definition of health and illness. It affects when and where care is sought, what symptoms are presented, what treatments are acceptable, and how and whether adherence takes place.”**

It affects when and where care is sought, what symptoms are presented, what treatments are acceptable, and how and whether adherence takes place.

The culture of the healthcare professional plays an equally significant role in the client-practitioner exchange. Our own personal attitudes, beliefs, and behaviors may, consciously or unconsciously, influence our interaction with, and care of, our patients. Competence, then, is an indicator of attitudes, knowledge, and skills that enable effective cross-cultural practice. A comprehensive definition of cultural competency is provided by the National Association of Social Workers (NASW, 2015, page 13):

*The process by which individuals and systems understand and respond respectfully and effectively to people of all cultures, languages, classes, races, ethnic backgrounds, religions, spiritual traditions, immigration status, and other diversity factors in a manner that recognizes, affirms, and values the worth of individuals, families, and communities, and protects and preserves the dignity of each.*

We have become fairly good at defining it, but we also need to be able to document and evaluate it. The Case Management Society of America’s recently released *Standards of Practice for Case Management* (CMSA, 2016) includes a Standard of Cultural Competency (Section M). It states that cultural competency is demonstrated in part by:

- *development of a case management plan of care to accommodate each client’s cultural and linguistic needs and preferences of service.*
- *pursuit of professional education to maintain and advance one’s level of cultural competence and effectiveness*

*while working with diverse client populations.*

Similarly, last year, NASW updated its cultural competency standards and incorporated a companion document on indicators for achieving cultural competency. Now titled the *NASW Standards and Indicators for Cultural Competence in Social Work Practice* (NASW, 2015), the content is based on the efforts and best thinking of three NASW National Racial and Ethnic Diversity Committees spanning a period of 15 years. It reflects the growth, understanding, and complexity of cultural competency that results from our country’s changing demographics and the increased diversity in our population.

The ten standards identified by social work experts as necessary components of cultural competency include:

1. Ethics and Values
2. Self-Awareness
3. Cross-Cultural Knowledge
4. Cross-Cultural Skills
5. Service Delivery
6. Empowerment and Advocacy
7. Diverse Workforce
8. Professional Education
9. Language Diversity
10. Cross-Cultural Leadership

An interpretation is provided for each standard and is then followed by a set of indicators that practitioners can use to monitor and evaluate both their own practice as well as institutional and regulatory policies. The indicators also can help professionals and agencies set goals for increasing cultural competencies. (To read the document in its entirety, go to [www.socialworkers.org](http://www.socialworkers.org) > Resources and enter “cultural competency” in the search box.)

The concept of cultural competency continues to be refined. Previously, we

spoke in terms of cultural awareness, cultural sensitivity, cultural responsiveness, or cultural proficiency. Today the focus is on being culturally competent, but the newest thinking includes a complement of cultural humility, a life-long commitment to self-assessment and learning (NASW, 2015).

Achieving and maintaining competency is a dynamic process, and each practitioner must take responsibility for learning what she or he doesn’t know. Those of us working in healthcare have an ethical obligation to be as culturally competent as we possibly can be. Our patients and clients deserve no less. ■



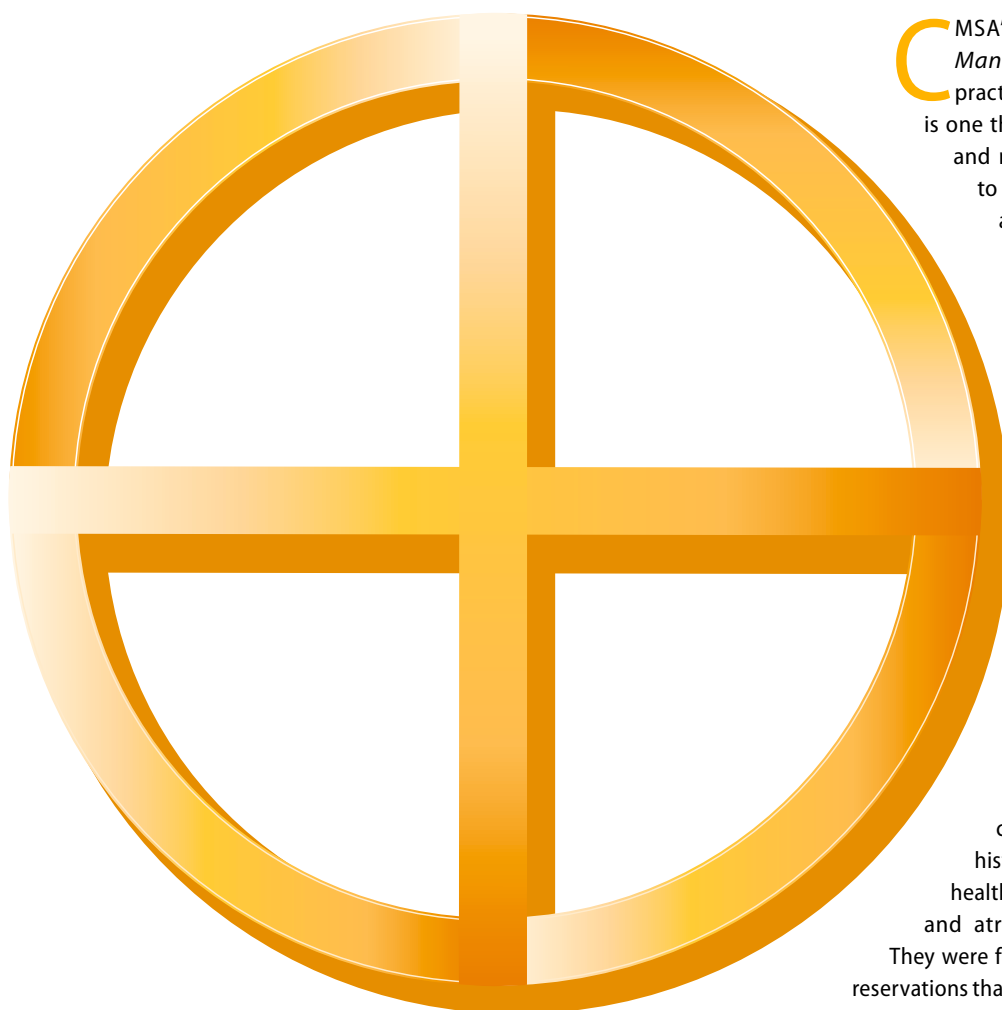
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# Return to Culture –



CMSA's *Standards of Practice for Case Management*, revised 2016, guide us to practice with cultural competence. Our nation is one that welcomes many diverse populations, and most Americans can trace their heritage to immigrants. Immigration is the result of a need to experience political, religious and economic freedoms. As individuals continue to immigrate to the U.S., we as care managers are working with groups that speak languages other than English; they have beliefs and cultural practices that differ from those that are considered mainstream. We are challenged to incorporate and respect the beliefs and cultural practices of others, and explore how those beliefs impact health. In addition, we consider whether the appropriate language is available, both in spoken and written word.

There is an often forgotten nation and culture: the indigenous peoples of North America. Native Americans are still significantly underserved because their cultural and spiritual beliefs have not been historically recognized and incorporated into health practices. History tells us of the injustices and atrocities imposed on Native Americans. They were forced from their ancestral lands to live on reservations that were vast and did not support their native way of life; children were forced to attend American schools, adopting Christian names and forbidden to speak their native languages or dress in native clothing. Until the American Indian Religious Freedom Act of 1978, many Native American spiritual beliefs and practices were outlawed (Hodge & Lamb, 2010).

Prior to the arrival of Europeans, Native Americans had their own holistic practices, which included spirituality, the use of traditional healers, community involvement in the healing process and a generational knowledge of the healing properties of various types of plants (Lucero, 2011). Infectious diseases like smallpox, measles, and venereal disease did

# Return to Healing

BY REBECCA PEREZ, BSN, RN, CCM

not affect Native Americans until the arrival of the Europeans. So not only were they exposed to disease, war, and famine that resulted in diminished numbers, they were subjected to many forms of cultural destruction (Lucero, 2011). Mandated federal policies beginning with the Indian Removal Act of 1830 can be directly connected to this cultural destruction. For those that survived the federal mandates, their tribal communities were disconnected from their ancestral lands, their origin stories, medicine and overall way of life (Lucero, 2011).

Fast-forward to the 20th and 21st centuries. Only 38 years ago, the federal government reversed the illegality of Native American cultural practices. The atrocities imposed on Native Americans in the 18th and 19th centuries resulted in trauma associated with these sociopolitical histories (Lucero, 2011). We are starting to see more research that demonstrates the need to be more inclusive of culture when working with Native Americans in healthcare.

An American Indian/Native Alaskan scholar, Maria Yellow Horse Brave Heart, developed a paradigm after 20 years of research known as the Historical Trauma Theory (Lucero, 2011). The definition of Historical Trauma is the cumulative psychological wounding and trauma over a lifespan or across generations (Lucero, 2011). The trauma has resulted in Native Americans feeling a loss of self-determination, shame for cultural beliefs, and loss of community. Native Americans operate from a different worldview than non-Natives. The trauma experience of Native Americans has often resulted in poor physical and mental health, substance use, family dysfunction, crime, poverty, violence and spiritual imbalance (Nebelkpopf & Wright, 2011).

*"For Native Americans, balance means health. As part of our responsibility to practice care management with cultural competence, we must be open to acknowledging the Native American approach to healing."*

Enough research has occurred to demonstrate that a holistic approach of self-help, empowerment, and building a healthy community are the best strategies to return balance (Nebelkpopf & Wright, 2011). Spirituality plays a pivotal role in health for Native Americans. Interestingly, The Joint Commission has been requiring healthcare facilities that serve Native populations to conduct spiritual assessments. This requirement has been in place since 2011 and also includes behavioral health providers and those providing addiction services (Hodge & Lamb, 2010).

*"Indeed, although the dominant secular narrative often ignores spirituality, or even frames it as pathological, spirituality plays a central role in health and wellness for many Native Americans" (Hodge & Lamb, 2010).*

For Native Americans, balance means health. As part of our responsibility to practice care management with cultural competence, we must be open to acknowledging the Native American approach to healing, rather than forcing Western Medicine. There are several models that have been implemented with success demonstrated in literature; we will briefly look at three.

The Indigenous Research Agenda developed by Linda Tuhiwai Smith demonstrates the environments indigenous people move through in order to achieve healing and wellness: Survival, Recovery, Development, and Self-determination, allowing for healing to become a way of life (Lucero, 2011). The Medicine Wheel is used to depict the areas of focus in Smith's model, and these are (Lucero, 2011):

- **Healing**, which does not occur in a linear fashion; it happens at different times and different stages
- **Decolonization** results in healing when psychological struggles are reduced with a feeling of empowerment and rejecting victimization
- **Mobilization** results in healing when communities reconnect and collaborate
- **Transformation** results in healing when an individual believes his or her needs are being met

For Native Americans living in the urban areas of the San Francisco Bay Area, the Friendship house Association of American Indians has developed a Holistic System of Care (Nebelkpopf & Wright, 2011). This model also takes a whole-person approach and links treatment with prevention and recovery. The Holistic System of Care for Native Americans in an Urban Environment has developed specific interventions to reduce substance abuse among adult Native American men and women, the homeless, reduction in substance use in Native American adolescents, and is assisting in increased social connectedness of Native Americans with HIV/AIDS. The multiple approaches of the program have resulted in a 24 percent reduction of substance abuse after 30 days and an 11 percent increase in full-time employment. School enrollment also increased by 10 percent, and criminal

“Indeed, although the dominant secular narrative often ignores spirituality, or even frames it as pathological, spirituality plays a central role in health and wellness for many Native Americans.”  
(Hodge & Lamb, 2010)

offenses decreased by 26 percent (Nebelkpopf & Wright, 2011).

A program that can be found throughout the United States is Wellbriety, an addiction recovery program developed with culture-specific methods found in Native Americans and Alaska Natives. This program combines known best practices with the healing practices of the indigenous peoples. Substance use and mental illness are especially problematic for native peoples. They do not see these conditions as diseases — they see them as symptoms of imbalance.

Alcohol was introduced to Native Americans by the Europeans. Contrary to a common belief, Native Americans are not biologically and racially pre-disposed to alcoholism (Coyhis & Simonelli, 2008). In fact, Native Americans have been trying to resist and recover from the effects of alcohol for over 250 years (Coyhis &

Simonelli, 2008). Finding and returning balance means recovering one’s culture by returning to culture. This translates to Native Americans’ desire to live through the best attributes of their native culture while firmly staying in contemporary life. Wellbriety incorporates the Medicine Wheel, the 12 steps of Alcoholics Anonymous, and weaves in cultural practices such as prayers in one’s native language, smudging, drumming, tribal ceremonies and songs.

Wellbriety means both sober and well: achieving sobriety and abstinence of substance use and misuse by entering a journey of healing and balance — mentally, physically, emotionally and spiritually (Coyhis & Simonelli, 2008). The program emphasizes the need to go beyond sobriety in order to heal the deep, intergenerational wounds carried by almost all Native peoples (Coyhis & Simonelli, 2008).

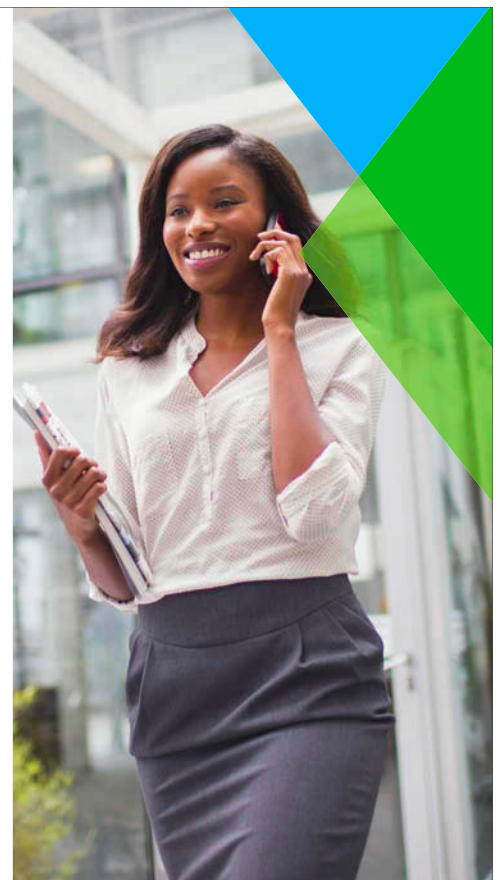
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One of the individuals who inspired the Wellbriety movement, Don Coyhis, tells us that the many layers of guilt, shame, anger and fear as a result of the last 250 years require healing using traditions, culture and spirituality.

Native American culture emphasizes the development of an inner life that is reflected in the outer world (Mehl-Madrona, 1999). Individuals may seek to complement Western Medicine with spiritual practices, and care managers must be supportive of this choice. Some Native Americans may choose their spiritual practices exclusively (Mehl-Madrona, 1999). Native Americans want their beliefs and practices respected, and we should support the integration into treatment.

*"The way we start to deal with this is to begin to form our circles to start to talk and to start talk and start to share. The knowledge that we have to have is*

*within us. This journey that we have to make is not about the white man, it is not a white man's problem, it is not about the Bureau of Indian Affairs, and it is not the government. All those things we talk about that happened to our people **did happen**. But this is a journey that we must make ourselves in our communities as Native Peoples."* — Don Coyhis (Coyhis & Simonelli, 2008) ■



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# Appalachian Culture: A Guide for Case Managers

BY JANET S. COULTER, MSN, RN, CCM



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## OVERVIEW

Appalachia is a beautiful region of rugged wooded hills, narrow valleys and winding streams that follows the Appalachian Mountain range. "Appalachia" is a Native American word that means "endless mountain range." The region stretches through 13 states: Mississippi, Alabama, Georgia, South Carolina, North Carolina, Tennessee, Kentucky, West Virginia, Virginia, Maryland, Ohio, Pennsylvania and New York. It covers 200,000 square miles, with a population of approximately 23 million people and includes some of the poorest counties in the United States. In 1965, the Appalachian Regional Development Act (ARDA) made it a legally designated area (Appalachian Regional Commission, 2009). Residents of this region do not usually refer to themselves as "Appalachian." Instead, they are referred to as "Mountaineers," "Mountain People," or "Hillbillies."

## A UNIQUE CULTURE

The Appalachian culture is unique for several reasons. The original pioneers in the region were Native American, Irish, English, Scottish, German and Polish. Most came to Appalachia to escape persecution and find a better life. They brought with them an emphasis on family and strong religious beliefs that became the core of the culture. Appalachia has a long history of isolation and exploitation. The rocky, inaccessible mountain terrain contributed to Appalachia's isolation from the rest of the country. The area is extremely rich in natural resources, which have been exploited by outsiders. The profits from these natural resources were not shared with residents of the region. In addition, outsiders have constantly tried to change the culture. All of these factors have contributed to the mistrust of outsiders and development of a distinctive culture.

Appalachian culture has been preserved mostly by families and churches. Culture and religion are interwoven. The culture is revealed through its arts and crafts, music, foods, customs, traditions and language. Arts and crafts include tool making, basket weaving, quilting, wood working, knitting, crochet, canning, needlework and a multitude of homemade items. Music is played on a banjo, fiddle, dulcimer or homemade instruments. Singing is an essential part of

religion and storytelling. Traditional dancing includes clogging and flat-foot dancing. Greens, potatoes, beans with cornbread, fried chicken, and biscuits and gravy are traditional foods. Traditions include storytelling, group games, large family gatherings and formation of informal musical groups. Appalachian language is a unique blend of Scottish and Elizabethan English that is directly related to the early pioneers.

Although most continue to live in the Appalachian region, there is a substantial population in many urban Midwestern areas such as Cincinnati, Cleveland and Detroit. Those "Urban Appalachians" often retain their original culture and are proud of their strong family ties, self-reliance, values, heritage and community involvement. Assimilation into a new community can be difficult and stressful. Returning "home" for visits is a regular occurrence.

In order to understand the Appalachian culture, it is important for case managers to recognize five distinctive groups. One group consists of descendants of the original pioneers. They are usually landowners, politicians and business people who are stable with strong family ties, self-reliant, independent, and hardworking. A second group is composed of hardworking coal miners, loggers or factory workers. The average worker has a large family, little education, few skills, no wealth and few choices for a vocation.

Another group is composed of professionals and their families who have moved to Appalachia related to job opportunities. This group includes bankers, lawyers, teachers, ministers, and physicians. Members of this group are usually not readily accepted by Appalachians. The fourth group includes professional individuals born, raised and educated in Appalachia. They have chosen to stay in Appalachia and raise their families. Members of this group include nurses, teachers, physicians and ministers. The remaining group consists of returning Appalachians. They grew up in the mountains, moved away and have returned. Many of them find it difficult to adjust to the lifestyle they left years before.

## HEALTH IN APPALACHIA

Appalachians have a high rate of diabetes, heart disease and stroke. Death rates related to heart disease, cancer and strokes exceed national averages. Health in Appalachia is influenced by many environmental factors including toxic waste, unclean air, poor water quality and occupational hazards. Depression is a major issue. Self-medication is common and has led to an increase in substance abuse. The most common substances abused are nicotine and opioids.

Barriers to healthcare include a shortage of physicians, limited access to healthcare, poverty, unhealthy lifestyle, low education

## TO LEARN MORE ABOUT THE APPALACHIAN CULTURE

### MOVIES:

- "The Appalachians"—A film (DVD) on the history and culture of Appalachians that features Johnny Cash, Rosanne Cash, Loretta Lynn, Little Jimmy Dickens, Marty Stuart, Ricky Skaggs and others.
- "Mountain Talk"—A unique portrait of the language and life of the Southern Appalachian Mountains.
- "October Sky"—A young boy in Coalwood, West Virginia, embarks on a mission to build and launch his own homemade rockets with the help of his loyal band of friends. Though their frequent mistakes nearly get them shut down, their successes inspire the whole town to believe that miracles can happen and there's nothing wrong with shooting for the stars.

### BOOKS:

*Yesterday's People: Life in Contemporary Appalachia* by Jack E. Weller and published by The University Press of Kentucky, Lexington, KY.

### Websites:

[www.ARC.gov](http://www.ARC.gov) (Appalachian Regional Commission)

levels, fear, lack of facts about healthcare and distrust of the medical system.

Appalachians consider both their faith and the possible benefits of obtaining healthcare when seeking solutions to health problems. Traditionally, they do not seek attention and try to manage their own problems. First they turn to family for assistance, then the local church. Being self-reliant is very important. They are characterized as proud, private, taking care of their own and not accepting of charity.

Personal trust is hard to gain, but, once gained it is hard to lose. Trust is a critical factor in their acceptance of health-related information and use of healthcare services. Generally, Appalachians are content when their basic needs are met for shelter, food and transportation.

## UNDERSTANDING THE CULTURE

Working with people of Appalachian culture requires multicultural expertise, just as working with other minorities. The first step is to understand the culture. Appalachians expect others to respect their freedom, independence and self-sufficiency. Poverty is a reality. There are regional differences within the culture, and many modern-day Appalachians try to distance themselves from the stereotypes of the culture. However, Appalachians have now become somewhat homogenized with other regions. This is primarily related to watching the same television shows, reading the same magazines and books, and shopping at branches of the same retail stores.

Although many television programs and films have portrayed the Appalachian culture in a negative way, this culture has remained stoic, proud, and independent. ■



**Janet S. Coulter, MSN, MS, RN, CCM**, currently serves on the CMSA National Board as a Director and Member at Large. She is past president of Southern Ohio Valley CMSA. She has over 40 years of nursing experience and

11 years of experience in workers compensation case management. Janet has worked in managed care, acute hospital and education settings. She is currently Chair, Breckinridge School of Nursing and Health Sciences. Janet was born, raised, and educated in Appalachia, and she considers herself a "Mountaineer!"

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## TABLE 1 CHARACTERISTICS OF APPALACHIANS

- Very independent
- Strong family ties
- Believe in God
- Self-sufficient
- Hardworking
- Content with where they live
- Strong community ties
- Very close to nature
- Friendly
- Kind
- Helpful
- Take care of others
- Strong sense of what is right and what should be
- Deep mistrust of anyone new or strangers
- Resist change
- Slow to accept outsiders
- Reluctant to accept authority
- Closely guard family secrets/business
- Strong sense of purpose

## TABLE 2 SUGGESTIONS FOR EFFECTIVE CASE MANAGEMENT INTERVENTIONS

- Be familiar with your own culture and values.
- Become familiar with Appalachian culture.
- Be on time and reliable.
- Active listening is very important.
- Allow the client to tell his or her story.
- Try to see client's perspective.
- Start with pleasantries/small talk during the first meeting.
- Ask for an explanation if you do not understand terms.
- Don't be the "expert."
- Avoid giving "orders."
- Strive to establish trust and rapport.
- Avoid confrontation whenever possible.
- Gently return client to goal or topic when avoiding.
- Avoid technical jargon.
- Show respect: clients who do not feel respected will not return.
- Include family, community, and church whenever possible.
- Explore spirituality/religious beliefs if indicated.
- If substance abuse is an issue, explore client's perception as illness and/or sin.

## TABLE 3 BARRIERS TO HEALTHY LIVING IN APPALACHIA

- Limited access to clinics, hospitals, and specialists
- Cost of health care
- Lack of faith/distrust in modern medicine
- Rural
- Rugged terrain/limited areas to walk
- Use of folk medicine, herbs and homemade remedies
- Pride may prevent them from seeking/accepting help from others
- Distrust of outsiders and outside organizations
- Limited access to quality foods
- Poverty
- Dependence on family
- Travel distance to wellness centers
- Superstitions

## TABLE 4 DID YOU KNOW...

- Did you know the government declared a "war on poverty" in Appalachia many years ago?
- Did you know that the people of Appalachia have some of the worse health issues in this country?
- Did you know that they have very high morbidity from chronic illnesses such as heart disease, hypertension, depression and drug addiction?
- Did you know that they have one of the highest rates of diabetes and obesity in the nation?

# Professional Case Management's Ethical Quartet for 2017: Part 1, Workplace Bullying and End of Life Care

BY ELLEN FINK-SAMNICK MSW, ACSW, LCSW, CCM, CRP

## INTRODUCTION

Most professional case managers know that nagging feeling. Something happens on the job; it feels very wrong, to the point of untenable. The clinical gut each practitioner possesses and is warned to heed screams loudly for action to be taken, but exactly what action becomes the larger issue to reconcile. One known fact exists amid the rush of emotion and concerns prompting endless mental calisthenics. Independent of the course of action taken, these situations will impact the quality of care that every case manager advocates diligently to safeguard, with potential ethical, if not also legal consequences.

Amid the fluid landscape of professional case management are five constants. These are the ethical tenets of practice:

- **Autonomy:** To respect individual's right to make their own decisions
- **Beneficence:** To do good
- **Fidelity:** To follow through and keep promises
- **Justice:** To treat others fairly
- **Nonmaleficence:** To do no harm

(Case Management Society of America, 2016)

Each tenet, and subsequently each case manager, is challenged daily by rapidly shifting societal constructs (Fink-Samnack, 2013). Moving through 2016 into 2017, these issues present as tougher and more complex to manage, each one striking case managers at their ethical core. The Ethical Quartet for 2017 is composed of the following constructs:

1. Workplace bullying
2. End-of-life care

3. Technology and social media

4. Mandated duty to warn

This article will span two parts, each providing a comprehensive overview of two constructs with respect to the scope, incidence, and considerations for professional case management practice. Part 1 will address workplace bullying and end-of-life care, with Part 2 to focus on technology and social media, as well as mandated duty to warn. In addition, there will be alignment with CMSA's recently revised *Standards of Practice for Case Management* (2016).

## Workplace Bullying

### DATA AND DEMOGRAPHICS

Workplace bullying refers to the repeated, health-harming mistreatment of one or more persons (the targets) by one or more perpetrators. It is marked by abusive conduct that is:

- threatening, humiliating, or intimidating, or
- work interference — sabotage — which prevents work from getting done, or
- verbal abuse.

(Workplace Bullying Institute, 2016)

The number of U.S. workers affected by bullying in the workplace has risen to well over 65 million persons, equivalent to the combined population of 15 states (Namie, 2014). This detrimental behavior is not limited to nurses who "eat their young" or physicians who berate and/or harass residents, plus other health professionals. Workplace bullying (also referred to as lateral violence) impacts the entire interprofessional team. It is four times more

prevalent than sexual harassment or racial discrimination, with the healthcare profession having among the highest incidence (Drexler, 2013). Over 72 percent of employers deny, discount, encourage, rationalize, if not also defend this obstructive behavior (Farouque and Burgio, 2013; Namie, 2014).

Bullying has a profound impact for professional case managers, particularly those who interface with interprofessional teams. This topic has been discussed with increasing frequency in the literature and has been related to gender predisposition, professional education and practice culture (both among and across distinct disciplines), as well as endemic to the healthcare culture overall (Dellasega, 2009; Fink-Samnack, 2015 and 2016a; Getz, 2013; Nesbitt, 2012; and Tulshayan, 2012). Another dimension to this dilemma aligns workplace bullying with medical errors, and the consequences of poor and/or fragmented team communications secondary to bullying and other disruptive behaviors (Fink-Samnack, 2016a; The Joint Commission, 2008).

The industry continues to reel from research earlier this year that identified medical errors as the third leading cause of death in the United States (Cha, 2016). Back in the 1990s, medical errors were identified as an epidemic leading to the deaths of 44,000 to 98,000 people in the United States and warranting immediate attention (Institute of Medicine, 1999). Researchers broke down medical error occurrences across the categories of diagnostic, treatment, preventive, and other (Leape, et al., 1993). While *failure of*

communication, appears in the “other” category, it is easy to consider how the concept can transcend the additional categories as well. Table 1 provides a listing of medical error categories.

The Joint Commission cited medical errors as a concerning outcome of bullying in 2008, validating how intimidating and disruptive behaviors fuel medical errors and lead to preventable adverse outcomes (Joint Commission, 2008, Larson, 2014). With continual emphasis across practice settings on patient quality and safety, it is alarming to accept how disruptive behaviors by healthcare team members contribute to the medical error equation. Studies show nearly 30 percent of medical errors contribute to patient deaths, as high as 250,000 deaths a year (Brown, 2011; Cha, 2016; Painter, 2013). Most errors are reflective of systemic problems that include:

- poorly coordinated care
- fragmented insurance networks
- the absence or underuse of safety nets and other protocols, and
- unwarranted variation in physician practice patterns that lack accountability (McMains, 2016)

Yet, again, consider the impact of communication in each of these instances.

When professionals feel disempowered in their dialogues with team members and/or other healthcare professionals due to bullying behaviors (e.g. insults, harassment, threats of employment sabotage), there will be an impact to the quality and safety of patient care. Outcomes will have potentially deadly consequences when members of the healthcare team lose the ability to effectively communicate with each other. Consider how often case managers seek to clarify orders, medication dosages, or treatment plan objectives. Now reflect on the potential detriment caused to the patient and his or her overall care process when these conversations are unable to occur.

The impact of bullying on workforce retention wields an equally heavy hand. Twenty-one percent of workforce turnover in healthcare alone is related to incivility in the workplace (Robert Wood Johnson Foundation, 2013). More than 20 percent

**Table 1 Medical Error Categories (adapted from Leape, et al., 1993)**

Category of Errors	Types of Errors
<b>Diagnostic</b>	<ul style="list-style-type: none"> <li>• Error or delay in diagnosis</li> <li>• Failure to employ indicated tests</li> <li>• Use of outmoded tests or therapy</li> <li>• Failure to act on results of monitoring or testing</li> </ul>
<b>Treatment</b>	<ul style="list-style-type: none"> <li>• Error in the performance of an operation, procedure, or test</li> <li>• Error in administering the treatment</li> <li>• Error in the dose or method of using a drug</li> <li>• Avoidable delay in treatment or responding to an abnormal test</li> <li>• Inappropriate (not indicated) care</li> </ul>
<b>Preventive</b>	<ul style="list-style-type: none"> <li>• Failure to provide prophylactic treatment</li> <li>• Inadequate monitoring or follow-up of treatment</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>• Failure of communication</li> <li>• Equipment failure</li> <li>• Other system failure</li> </ul>

of bullying victims meet the criteria for post traumatic stress disorder in the new *Diagnostic and Statistical Manual of Mental Disorders*, 5<sup>th</sup> ed. (DSM-5). Over 80 percent experience debilitating anxiety, 49 percent clinical depression that is either new for the person or exacerbated by the bullying event, and 52 percent experience panic attacks (Workplace Bullying Institute, 2016).

## ACTION ON THE HORIZON

At the time of this writing, there continues to be no federal law to protect healthcare professionals from workplace bullying. High levels of advocacy persist by professional associations and organizations to manage workforce issues, with a bevy of guidelines, standards and policies released in recent years to address incivility across practice settings (American Nurses Association, 2015; American

**Table 2: The Healthy Workplace Bill FAQs (Data from The Healthy Workplace Bill, 2016)**

<b>For Employers</b>	<ul style="list-style-type: none"> <li>• Precisely defines an “abusive work environment” — it is a high standard for misconduct.</li> <li>• Requires proof of health harm by licensed health or mental health professionals</li> <li>• Protects conscientious employers from vicarious liability risk when internal correction and prevention mechanisms are in effect</li> <li>• Gives employers the reason to terminate or sanction offenders</li> <li>• Requires plaintiffs to use private attorneys</li> <li>• Plugs the gaps in current state and federal civil rights protections</li> </ul>
<b>For the Workforce</b>	<ul style="list-style-type: none"> <li>• Provides an avenue for legal redress for health-harming cruelty at work</li> <li>• Allows you to sue the bully as an individual</li> <li>• Holds the employer accountable</li> <li>• Seeks restoration of lost wages and benefits</li> <li>• Compels employers to prevent and correct future instances</li> </ul>
<b>What the HWB Does Not Do</b>	<ul style="list-style-type: none"> <li>• Involve state agencies to enforce any provisions of the law</li> <li>• Incur costs for adopting states</li> <li>• Require plaintiffs to be members of protected status groups (it is “status-blind”)</li> <li>• Use the term “workplace bullying”</li> </ul>

Organization of Nurse Executives, 2016; CMSA, 2016; Emergency Nurses Association, 2016; National Association of Social Workers, 2013; U.S. Department of Veterans Affairs, 2015).

From the scope of federal legislation, the Healthy Workplace Bill (HWB) has been introduced in 31 legislatures across 29 states and two territories, through the United States and Canada. The purpose of the HWB is to get employers to prevent bullying with universal policies and procedures that apply to all employees. In addition, the HWB will provide needed action and support for workforce members in “at will” situations and/or states (Healthy Workplace Bill, 2016). *At will* means an employer can terminate an employee at any time for any reason except an illegal one or for no reason without incurring legal liability. Likewise, an employee is free to leave a job for any or no reason with no adverse legal consequences (National Conference of State Legislatures, 2016). **Table 2** provides a detailing of the HWB FAQs. A map showing the current landscape of bill action can be viewed at the Healthy Workplace Bill website, <http://healthyworkplacebill.org/states/>.

## CONSIDERATIONS FOR PROFESSIONAL CASE MANAGEMENT

CMSA’s revised Ethics Standard (2016) addresses workplace bullying through recognition of a new secondary obligation for all professional case managers: engagement in and maintenance of respectful relationships with coworkers, employers and other professionals. By virtue of their role, case managers intervene regularly with all involved stakeholders of the care process — the patient, his or her family caregiver plus other members of the support system, and the interprofessional team. Courtesy of technology, that interaction now spans the patient’s entire personal health record across the continuum of care and may be in person or virtual. Professional communication and the aligned competency of engaging and establishing rapport have been elevated to critical levels of importance in assuring a successful case management process.

Should case managers find themselves in a bullying situation, there are three significant steps to work through:

- **Step 1:** Direct discussion between involved parties to confront the actual behavior
- **Step 2:** Seek all available resolution routes through your employer
- **Step 3:** Consider filing a complaint against the colleague with the requisite credentialing body

While these situations are never easy to maneuver, using a gradient action plan assures a higher level of support, if not success in managing the disruptive behaviors and those engaging in them.

## End of Life/Death with Dignity

Managing patients living with chronic and/or terminal illnesses is not new to professional case management. However, what has dramatically changed in recent years is the amount of attention given to assuring that high-quality, cost-effective care is rendered at the end of life. Major challenges are impeding this effort, incorporating growing numbers of older adults, barriers in access to care for certain populations, the expanding cultural diversity of society and a fragmented healthcare systems (IOM, 2015). Add the intense media attention focusing on advocacy by patients and families striving to seize control of the dying process, with heightened attention to the passage of state and national legislation (Fink-Samnack, 2016b). End of life, or *Death with Dignity* as it is often referred, is front and center as a national priority.

## DATA AND DEMOGRAPHICS

Patients with chronic illness in their last two years of life account for approximately 32 percent of total Medicare spending, with a majority of the dollars going toward physician and hospital fees associated with repeated hospitalizations (The Dartmouth Atlas of Health Care, 2016). More than 25 percent of older adults have given little thought to how they want their life to end, most postponing the decision, or deferring it to their physician (IOM, 2015). While many patients indicate a preference to die at home, more than 55 percent died in the hospital (The Dartmouth Atlas of Health Care, 2016). The numbers for pediatric populations are relatively consistent with those for adults (The Worldwide

Palliative Care Alliance and the World Health Organization, 2014).

The programming and services to meet the needs of these patients is far from optimal. Even the rapid expansion of palliative care services to address pain control and symptom relief is not as widely utilized as expected (Armour, 2014). Reports show alarming gaps in service access for millions of persons in the United States, whether at home or in the hospital setting. Despite steady growth of hospital-based palliative care programs, and universal access in large U.S. hospitals and academic medical centers, access to palliative care is uneven (Dumanovsky, et al., 2015).

The year 2016 ushered in a number of reimbursement changes for Medicare, for which third-party payers followed suit. It began with new CPT codes in the 2016 Medicare Physician Fee Schedule, reimbursing \$86 to discuss end-of-life care in an office visit or the hospital. It would not surprise many case managers to know that in a recent poll of 736 primary care doctors and specialists, only 14 percent actually billed Medicare for those visits. While over 75 percent accepted responsibility to initiate end-of-life discussions, less than 50 percent detailed any formal training on how to engage in these dialogues (Ostrov, 2016).

On the hospice front, there have been several major reimbursement changes. One enhancement was the development of a two-tiered per diem payment for hospice care (higher in the first 60 days and lower thereafter). This payment model replaced the per diem model used by Medicare since the start of the hospice benefit. A retrospective Service Intensity Add-on payment was also included to adjust for increased acuity during the final week of a patient’s life (Taylor, et al., 2015).

There are 141 hospices actively involved in the Medicare Care Choices Model demonstration project. The goal of this effort is to provide end-of-life care and counseling to those patient who are dying, while at the same time receiving treatment to extend their lives. This is an innovative approach that industry experts view as long in coming. The model is being phased in across facilities in two-year increments, over a total of four years, ending on Dec. 31, 2020. One-half of the facilities began back on Jan. 1, 2016, with the

remainder to provide services beginning Jan. 1, 2018 (CMS, 2016). An interactive map and further information about the Medicare Care Choices Model can be viewed on its designated website, at <https://innovation.cms.gov/initiatives/Medicare-Care-Choices/>.

Finally, a number of third-party payers have recently expanded homecare benefits and other programming for cancer and patients who qualify for hospice and often palliative care. An increasing number of insurance companies cover the costs of visits to mental health practitioners for patients and family members to address counseling issues specific to the illness course and dying process (McCluskey, 2015; Miller, 2016; Taylor, et al., 2015). The times are definitely changing with respect to care access, coverage and more comprehensive management of end-of-life care.

## ACTION ON THE HORIZON

Four states have formal Death with Dignity legislation in place at the time of this writing: Oregon, Washington, Vermont and California. In Montana, the end-of-life option is legal through the state Supreme Court ruling (Death with Dignity National Center, 2016). Staunch efforts are occurring across the states to pass new laws to enhance the quality of intervention and available options for those persons maneuvering the end-of-life process. The legislative landscape is a moving target. There are still 27 states that have no legislative activity this year or session. An interactive map of current legislative happenings can be viewed on the Death with Dignity National Center website, at <https://www.deathwithdignity.org/take-action/>.

## CONSIDERATIONS FOR PROFESSIONAL CASE MANAGEMENT

Today's professional case managers must be proficient in new reimbursement strategies, ever-expanding resources, plus definitive strategies to intervene effectively with their patient populations engaged in end-of-life care. The ethical tenets play a strong role in this endeavor, particularly those of autonomy, nonmaleficence, and fidelity. It is the case manager who dialogues directly with the

patient about his or her end-of-life choices. It is the case manager who advocates for the patient's unique circumstances to be considered by the interprofessional team, as they reconcile the most appropriate treatment options and plans. Finally, it is the case manager who has a primary obligation to his or her clients, assuring all are treated fairly with regard to gender identity, race or ethnicity, practice, religious or other cultural preferences, and/or socioeconomic status (CMSA, 2016).

While all of the CMSA *Standards of Practice for Case Management* (2016) are applicable for professional case managers who intervene with the end-of-life population, those with specific relevance include:

- B – Client Assessment
- C – Care Needs and Opportunities Identification
- J – Legal
- K – Ethics
- L – Advocacy
- M – Cultural Competence
- N – Resource Management and Stewardship.

Each one of the above standards affirms the integral right of patient individuality and autonomy through unique assessment of his or her unique cultural context. Assessing the interplay of medical, cognitive and behavioral, social, and functional components to comprise each patient's reality serves as a principal competency for case managers. The ability to monitor and orchestrate proper resource management, while assuring high levels of advocacy as needed, is equally vital.

In the context of ethical case management practice, shared-decision making (SDM) provides the solid foundation for professionals to engage in a structured process which promotes sharing of key information with patients and families while respecting their individuality (Elwyn, et al., 2012; Fink-Samnick, 2016b). The process involves collaboration in that it provides patients and their providers the opportunity to make healthcare decisions together, taking into account the best scientific evidence available, as well as the patient's values and preferences (Informed Medical Decisions Foundation, 2016). Respect for patient self-determination and autonomy is paramount.

Several models have been created for practitioners to engage in SDM with patients

and families, guiding what can present as an emotionally laden and complex process. Among these valuable resources is the Three Step Model (Elwyn, et al., 2012), which involves the following phases:

- 1. Choice Talk:** Make sure patients know reasonable options are available
- 2. Option Talk:** Provide more detailed information about options
- 3. Decision Talk:** Support the work to consider preferences and decide what is best

A fresh rendering of SDM for professional case management (Fink-Samnick, 2016b) provides an essential fourth step called *Touch Back*, with the model shown in **Figure 1**. This revision provides those persons involved in these intense conversations an extra opportunity to review where dialogues end and then define any further information needed to advance, if not complete, the decision-making process. The fourth step provides case managers the chance to intervene in one final *Touch Back* interchange with the patient and/or family. Those involved with this population know the difference that a single final interaction can make, often becoming the most meaningful element in achieving resolution of a complex decision-making process.



**Figure 1: The Shared Decision Making Four Step Model for Professional Case Management (Adapted from Elwyn, et al., 2012, Fink-Samnick, 2016b)**

## NEXT STEPS

This concludes Part 1 of this article series. Watch for Professional Case Management's Ethical Quartet for 2017: Part 2, Technology/Social Media and Mandated Duty to Warn in Issue 1 for 2017. ■



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*Continued on page 32*



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# Diversity of Role Reversal: When the Case Manager Becomes the Patient

BY WENDY DE VREUGD, RN, BSN, PHN, FNP, CCDS, MBA; ANNE LLEWELLYN, RN-BC, MS, BHSA, CCM, CRRN;  
MARGARET (PEGGY) LEONARD, MS, RN-BC, FNP

In keeping with the theme of this issue, Diversity in Healthcare, we share three stories that explain the role reversal when the case manager becomes the patient. The stories that follow are from three case management leaders who had major

healthcare challenges in 2015. Each contributor shares her experiences and take-away messages that have allowed her to view the healthcare experience with a renewed vision. It is their hope that their experiences inspire you to look at your role as a case manager and

how you are working to meet the needs of the patients who transition through your setting. They hope that their stories will impress upon you to realize the critical role you play in helping each patient and caregiver have a sensitive and caring healthcare experience.



**ANNE LLEWELLYN, RN-BC, MS,  
BHSA, CCM, CRRN**

Over my 28 years as a nurse case manager, I have been privileged to work with patients, their families and the providers who cared for them as they transitioned through the broad healthcare system. I also worked closely with their payer case manager to ensure care was evidence-based and was meeting the individual needs of each patient. I kept all who were involved updated and worked closely with the team to ensure the patient was progressing. My role was to effect change and to educate and empower patients so they were actively

involved in their care and had their voices heard. When problems were identified, I notified the team and shared information so the patient could be re-evaluated and the plan of care reorganized to meet new needs. As a professional case manager, I used my clinical expertise to coordinate care with the team and my knowledge of community resources to meet the individual needs of each patient. As my patient's advocate, I was there to make sure they had a voice in their care and received the best care to meet their needs. I was a good case manager and proud of my work over the years. I had always thought that if I ever became sick, I would have a case manager like me.

On Nov. 24, 2014, I was thrust into the complex work of healthcare after being diagnosed with a Central Nervous System Lymphoma. All of my training, expertise and expectations went out the window as I

listened to the doctor tell me and my husband what was going to happen.

I don't recall much of the next few weeks, but over time, the blanks have been filled in by my husband and friends who became my advocates. The day I was admitted, my husband called my good friend and long-time case management colleague, Marilyn Van Houten. Marilyn immediately took on the role of being my case manager and helped my husband understand what was going on and made some suggestions that helped him cope with a sick wife and a complex and scary healthcare system.

The hospital I was in was a small community hospital; Marilyn and my husband knew that my condition was way too complex for this setting and thought I would fare better in a teaching academic medical center. Marilyn took to the phones, used her connections and got me an appointment with a neurosurgeon

*"I was a good case manager and proud of my work over the years. I had always thought that if I ever became sick, I would have a case manager like me."*

at the University of Miami. She helped my husband explain the decision to the treating physician that we wanted to have another opinion with the doctor at the University of Miami. As a result, I was discharged and seen the next day by the neurosurgeon. Immediately after the initial evaluation, a biopsy was scheduled to determine the pathology of the tumor. Once the pathology report was received, the neurosurgeon referred to a hematologist who specialized in the type of cancer that I had. As my condition was serious, I was started on aggressive chemotherapy right away.

I was lucky that the tumor was receptive to the chemotherapy, and after the third round of chemo, the tumor was gone according to the MRI. The plan of care was to continue the chemotherapy regime, which was administered on an inpatient basis every two weeks for the next eight weeks. As the chemo continued to do its work, I became more alert over time, but the treatment took its toll on me physically and mentally. Eventually I was able to absorb what was going on around me and was grateful to my husband, who was by my side every step of the journey. I also realized that I had many people praying and sending positive thoughts, and I am forever grateful. Once chemo was completed, I realized how weak I was and asked my doctor if he thought rehabilitation would help. He agreed, and I called a case management colleague at a Health South facility near my home. She expedited an appointment with the medical director. He evaluated me and agreed that inpatient rehabilitation was needed, so I was admitted for aggressive rehab. The expertise of my therapy team helped me gain strength and confidence.

Over the next few months, I have continued to recuperate and gain strength. I did have complications from the chemo, which have impacted my ability to walk, but with braces and the use of a cane/walker, I am adapting and doing more and more on my own. I am grateful that my tumor remains in remission.

My journey as a patient has taught me that being a patient is the hardest, loneliest and scariest experience of my life. I realized that every patient needs an advocate when he or she enters the healthcare system, as it is almost impossible to comprehend what is going on when you are sick and faced with mounting challenges. Whether it is a family member or

paid advocate, having a second set of eyes and ears is critical. My husband was with me every step of the way. He talked to the team, asked questions, challenged decisions and made decisions on my behalf. He saved me from medical errors and made sure I was safe. He helped me move from the bed to the chair, to the bathroom when I was too weak to do it myself and the staff was busy doing their work. He kept in touch with Marilyn and listened to her advice and guidance. Prior to each admission, I had to have lab work and see my hematologist. On those visits we would see people alone and wonder how they did it.

I learned invaluable lessons as a patient, and it has helped me see the healthcare system from a different view as a case manager. I realized the system is set up "for the system," and the patient has to learn how to adapt to the system. This was not easy for me as a seasoned healthcare professional, so I can only image how it is for the average person. The main person missing from my care in the acute care setting was a case manager. This was disappointing to me as I wondered why I was not assigned a case manager. Wasn't I sick enough?

As I transition back to working professional case manager, I have set new goals for myself. One is to find a way to help consumers and their caregivers to better understand their role and help them to better navigate the complex healthcare system. To do this, I started a blog called *Nurse Advocate*. The blog delivers information based on my own experiences and provides tips and resources readers can use to take an active role in their care. In addition, the posts are written to help all members of the healthcare team understand the challenges patients have and the importance of being sensitive to the individual needs of each patient. The process has been received well by those who read the blog and therapeutic for me as I continue to move forward.

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**MARGARET (PEGGY) LEONARD, MS, RN-BC, FNP**

Most of us are familiar with Sesame Street's Kermit the Frog's famous line, "It is not easy being green." Well, for a seasoned registered nurse, family nurse practitioner and case manager, "it is not easy being the patient." Although the learnings from being a patient for a protracted period of time are unique, enlightening and invaluable, it still is not easy being green.

My story began last June when I was diagnosed with Stage III C plus Colon Cancer. Metastatic cancer with involvement of 6-8 nodes. I had 9 nodes involved. First, as any of us might expect, I was in shock and then in disbelief; next, I was overwhelmed and finally, devastated. Thank God for my husband Ron, who held me as we both cried about all the good times, tried to laugh about the not so good times and anguished about our future. God has also blessed me with loving children, caring family members, friends and colleagues. This seasoned healthcare professional became totally dependent on someone else: my case manager and my daughter, Denise. She did it all, even though her only training for this role was her love, dedication, great poise, organizational and people skills and common sense. She was my voice. Thank goodness, because while there are so many excellent and skilled licensed and unlicensed caregivers in my story, there was no one person who stepped up to the plate and help me put it all together. I would be remiss if I didn't mention that unfortunately there were also some folks in my story who clearly had chosen the wrong profession.

*“Advocacy is one of the Standards of Practice for case managers. (CMSA, CMSA’s 2016 Standards of Practice for Case Management, rev. 2016). Case managers are needed to advocate at many levels: the patient level, the case managers’ level, and the regulatory and legislative level.”*

You know who you are (which is a story for another day).

As I reflect now on the experience wearing my leadership hat, I can see how many opportunities there are for case managers/care coordinators in our healthcare system today, more than I ever realized. And I thought I had a very good handle on what was going on in our field from an advocate’s view looking at our nation’s regulatory and legislative agenda and from a business perspective as vice president of medical management for MVP HealthCare, a managed care organization serving over 750,000 members in New York. This is a community-based organization which has won several awards and grants for its integrated case management programs.

However, until I reversed my role and became the patient, I didn’t realize how great the need was for case managers. The world NEEDS case managers! This tremendous need comes from providers, patients and their caregivers, and from payers. The diagnosticians need case managers to assist them in managing the patients’ reactions to the diagnosis and the families’ shock and apprehensions. The case managers are needed to coordinate all the steps in the process and to gather the much-needed data and resources to help both the family and the patient make informed, life-altering decisions quickly: which surgeon, which hospital, which treatment center will offer them the best and most convenient care, which oncologist should be engaged, is a second opinion needed, and if yes, how is that decision made? What will this all cost; will insurance cover everything? Is a leave of absence from work indicated, and what about disability insurance? Where do post-op care, home care, chemotherapy, lab work and port insertion surgery happen? The list goes on and on, and most people just shake their heads and say, “Where do I begin?”

Well, I am here to tell you, you begin with getting a **case manager**.

There are a number of organizations out there that can help. However, the real opportunity is in your primary care provider’s office, especially if he or she is the one who made the referral for the diagnostic tests which set the world shifting under your feet.

Licensed healthcare professionals who understand the system, who know how to safely coordinate your transitions of care from setting to setting, ensuring a comprehensive, effective “warm hand off,” can calm patients’ fears, alleviate the families’ anxiety and stress, can furnish answers and develop a comprehensive, patient-centered, integrated plan of care with input from all stakeholders are at a premium. Patients need case managers to be their **voice**. Even the most educated patients can become helpless, vulnerable and speechless at times like these.

Advocacy is one of the *Standards of Practice* for case managers. (CMSA, CMSA’s 2016 *Standards of Practice for Case Management*, rev. 2016). Case managers are needed to advocate at many levels: the patient level, the case managers’ level, and the regulatory and legislative level.

The opportunities for case managers have never been greater. Good case managers can do direct case management in different settings — hospitals, urgent care centers, ambulatory surgical suites, family health centers, home care, primary care offices, managed care organizations, and now in New York, Health Homes (a federally funded program). All members enrolled in Health Homes receive case management services. There are opportunities for hands-on case managers, telephonic work, administrative work, and government liaison work. The healthcare arena is open today as it has never been before for case managers. So be the best you can be; don’t waste any time, and if you have been thinking about becoming a case manager, go to the CMSA website to learn more. If you are already

a case manager, continue your education, become certified and get involved.

As the need for us grows stronger and more and more people recognize the value of our services, we need to advocate for CMS to develop billing and reimbursement codes for our service. We also need to continue to design curricula to accommodate case managers at every level — baccalaureate, masters and doctorate, and strongly encourage certification.

Dear fellow case manager, the sky is the limit for us in today’s healthcare world. We are very fortunate to be at the epicenter of this wonderful and exciting time when case managers, providers, patients, caregivers and payers have begun to realize that **together we can make a difference**.

**Margaret Leonard, MS, RN-BC, FNP**, is Sr. VP for Clinical Services at MVP. To reach out to Peggy, email her at [margaretleonard012@gmail.com](mailto:margaretleonard012@gmail.com).



**WENDY DE VREUGD, RN, BSN, PHN, FNP, CCDS, MBA**

**T**he case manager competencies and traits necessary to support client-centered and culturally appropriate care in practice are many: how to assess and evaluate, formulate a plan, encourage self-care, negotiate, be persistent, communicate effectively, be culturally diverse and advocate for our patients — to name only a few.

However, when a case manager lands on the “other side of the bedrails” due to a serious health challenge, she or he may experience that those same strengths you think you have can be temporarily lost; or even worse, one can revert to feeling like a complete neophyte in the “system” we think we all know so well. *How does that happen?* Experiencing a role

“When a case manager lands on the ‘other side of the bedrails’ due to a serious health challenge, she or he may experience that those same strengths you think you have can be temporarily lost; or even worse, one can revert to feeling like a complete neophyte in the ‘system’ we think we all know so well.”

reversal certainly brings to one a higher level of understanding.

This was the case as my Acute Ischemic Stroke (AIS) occurred. I tell myself in retrospect *that I should have known better* as an experienced nurse and case manager! I intellectually knew of “self-care,” “work-life balance” and “staying down” when one is ill. However, I also silently praised myself for my persistence in the relentless pursuit of life goals and in the care of others around me. Then God stepped in and gave me a warning shot across my bow.

It was a perfect storm for me: overwork, fatigue, being ill. I was working 80-hour work travel weeks, finishing my MBA, and sick with the flu and sinus infection for the previous 10 days. Yes, I had seen my doctor, but the antibiotics were not working. I added over-the-counter (OTC) cold medicine to keep me going while traveling. *Did you know that over-the-counter (OTC) drugs containing ephedrine, pseudoephedrine, or phenylpropanolamine (PPA) increase your risk of stroke?* With the addition of the OTC medicine, the ischemic event started to slowly flood my boat before I even knew it was more than a small squall.

It started with the inability to focus my vision on a plane in the sky. I thought, “Hmmm... I’m getting old and need glasses.” The next day I woke up and leaped out of bed to catch another flight for work. I veered and hit the wall. “What? My balance is completely gone,” I thought. I went to the doctor and was neurologically examined. “You’re fine,” he said. “No, I don’t feel fine, but the doctor says I am.” The next day I woke up and the left side of my face, tongue, and palate was numb. “Uh-oh. Better get to the emergency room right away.” I jumped in my car and started to pull out (which was not a good idea, but panic presided at that moment over common sense). “My car battery is dead!” I took a taxi. Angels were watching over me.

Then the hospitalization. I thought, “OK, I’m a nurse; I can handle this!” But by day two my lower lip was trembling. *What just happened to me?* The physicians stood in my hospital room doorway. I said, “Doctor, can you please sit down and talk to me eye-to-eye on what is happening, instead of being almost out the door?” The nurse entered my room, smiled cheerfully and said, “How are we today?” “I’m not fine, I’m scared; didn’t you hear me? Can you talk to me? I feel

*like crying,”* I thought. After a battery of tests, I was discharged home two days later on Christmas Eve. My physicians asked me why it is that I don’t remember what they told me two days ago. I was thinking, “No, I don’t... I was medicated; could you repeat it please? I am going home alone. Do I get physical therapy? When? Home health? When? What will happen now?”

I should know the answers to all these questions from my nursing case manager experience, but when you are afraid, fearful, and dealing with a life-altering event, many of your developed skills seem to float away like a feather in the wind. I thought, “Can I be the patient and rely on you to advocate for me? Ask the right questions for me? I’m not the strong one now!”

I am grateful that I am in good health without significant residuals from the stroke. And I would never wish such an unfortunate healthcare event upon any healthcare provider. But having been through such an event is certainly an experience that has boosted my understanding and lessened any tendency to ever pre-judge my patients’ reactions to illness. I have learned to listen more to the psychological effects of illness and bring to bear the memories of my own experiences to benefit my patients. My patient, I am here to help get you through it all, because I know intimately how it feels. ■

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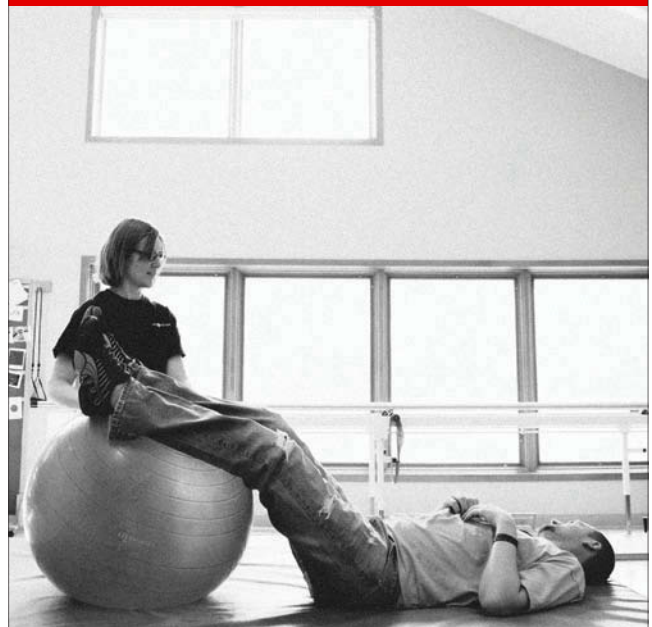
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