



Patient Advocates: A Powerful Nurse Resource

Webinar Summary

Aug. 8, 2013

Presenters:

James Dickens, DNP, NP, FAANP President, American Nurse Practitioner Foundation, Captain, U.S. Public Health Service, Office of Minority Health, Region VI, Office of the Assistant Secretary for Health, U.S. Department of Health and Human Services

Regina Holliday, caregiver, patient advocate and artist

Susan Hassmiller, PhD, RN, FAAN, Robert Wood Johnson Foundation's Senior Advisor for Nursing & Director for the Future of Nursing: *Campaign for Action*

Background:

In the landmark 2010 Institute of Medicine report which is a blueprint for the future of nursing, one of the strong recommendations is that nurse practitioners in every state should be able to practice to the full extent of their education and training.

Up to 25 million people will become eligible for health insurance next year, and nurse practitioners can help to ensure that patients don't face delays in seeing a primary care practitioner

The focus of the new patient-centered health system should in fact be the patient. Communication among all parties – the patient, the family and the provider – is essential to patient care.

James Dickens, President of the American Nurse Practitioner Foundation, noted that ANPF, formed in 1998 was the first national nurse practitioner foundation in the United States. Their focus is on solutions to costly healthcare outcomes related to unmanaged chronic disease .

He said that Texas has “moved the needle slightly” on nurse practitioners by telling patient stories and building coalitions at the grass roots level.

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Webinar Goals

- Understand patient's rights and provider relationships
- Identify ways healthcare providers and patients can collaborate to create legislative change
- Understand the role of the family caregiver
- Establish ways to focus on patient centered messaging while utilizing the healthcare provider

Overview

In this webinar, **Regina Holliday**, a caregiver and artist and passionate patient advocate, fights for patients and their families to be treated with compassion, insists that providers communicate with patients and that they have access to their medical records. She believes that patients and providers must act together and communicate in order to ensure the best patient outcomes.

Also in this webinar, **Susan Hassmiller** explores the important role nurse practitioners have in the health care system and how to approach policy makers with messages that resonate and can lead to change.

Holliday's Story

Regina Holliday tells the poignant story of her husband Fred, an assistant professor of Theatre and Literature at American University, who unexpectedly fell into the health care system only to suffer at the hands of indifference and at times incompetence as he struggled for his life – a struggle he would eventually lose.

She recounts the days when Fred complained of being tired and was diagnosed as hypertensive. At one point he was given four medicines for pain and two muscle relaxants. They went to the ER one day because he was in so much pain. They waited three hours before being sent home.

Regina relives through her art the time she left her husband alone in the hospital to take care of their two sons, (one who is autistic) and then go to work. It was then while he

was alone, the doctors told him he had “tumors and growths.” Then his oncologist left town for four days for a medical conference and was not reachable by phone or email.

Eventually in a doctor’s consult, the doctor never closed the door, the doctor spoke first and a lot and told her he didn’t like online research. He used words “I didn’t understand.”

When they sought a second opinion about his cancer, they needed his medical records. It would cost 73 cents a page (a binder full of paper) and they’d have to wait 21 days.

They were caught in a “data prison.” After five days, they were sent to another hospital with out of date and incomplete medical records. The new staff spent six hours trying to cobble together a current medical record, using a phone and fax machine. During all this Fred was on a path to death.

Finally, Fred was admitted to hospice. He died within days on June 17, 2009.

Regina’s story underscores that patients and their family members need to be full partners with providers. And both need to work together as a team to achieve high-quality care.

Creative Thinking and Change

Often what is missing in health care is creative thinking, she says. Regina relates a story from her childhood. Working on a school project, her father, holding a clothes pin, asks her what is this. A clothes pin, she says. No, he says, it’s a bear trap.

The answer clicked. “Things can be different and be used in different ways. And we can change the world through that.”

A passionate patient advocate for change, Regina says often the patient is not included in the conversation. As a young girl, everyone thought she was slow and unable to learn until she was diagnosed with dyslexia. Then in fourth grade when she finally participated in her care, doctors found out from her she needed glasses.

Patients and their caregivers should have access to medical records. Regina finally got to read her husband’s complete medical record but it was too late.

“I was furious. It was full of actionable data, which couldn’t be acted on because I couldn’t see it and nobody was reading the record in its entirety.”

As an artist, she created a vital clinical information card, much like a nutrition label. It was easy to read and complete. It was another example of change that helps the patient.

There should also be an “Open Notes” policy in hospitals where patients can read the doctor’s notes.

“There may be set backs on our way to patient data access but we will prevail.”

She asks why a patient’s bedside tray table is used for incontinent bedding change and within a few hours the same tray is used for food service. “This must change.” And she asks why there aren’t hospice cards in stores, which could spark the conversation about end of life.

Social Media Unites Everyone

Regina says social media connects everyone and is a way to spread the need for action. She used social media – mainly facebook and twitter – to connect to others, find out more about her husband’s cancer and relate the horror of her husband’s experience.. She got more information from being on social media talking to other people than from the hospital.

At one point she connected with Dave, who the same day put her in touch with his oncologist about her husband’s cancer. She posted messages on facebook and twitter about her husband’s condition to keep her followers updated.

“Standing out and looking different can be uncomfortable or frightening but is often needed for advocacy. You can take a negative and turn it into a positive.”

Through her art and a dramatic narrative, Regina presents her experiences all over the world and pleads for patient’s rights, including the right to know what is going on and the right to be treated with respect and compassion.

“Awareness is building,” she says.

Put the Patient First

Hassmiller noted that the RWJF and AARP are committed to ensuring that patients receive high-quality patient-centered care. And that’s why they are advocating for the removal of outdated scope-of-practice barriers as part of the Future of Nursing: Campaign for Action.

“We need to stop engaging in turf battles and start putting the patient first. We need to make sure that patients receive timely access to care.”

As nurses and nurse practitioners, **Hassmiller** said “we all too often see the adverse ramifications when our health care system fails to place the patient first.”

For example, Jody Hoppis is a nurse practitioner who owns a house calls practice in Bellingham, Washington. Although she can generally practice to the full extent of her education and training, a Medicare policy resulted in one of her patients receiving worse care.

The patient was bedridden. Jody diagnosed a wound and recommended visiting nurse services. However, it took more than a week for the patient to receive treatment, and as a result, the wound became larger and took longer to heal.

Why the delay? Jody must follow a Medicare requirement for physician certification of home health services. That means she needed to find a physician willing to countersign home health orders and set up a contract.

Since the physician's office that she found was located two hours away, Jody spent time and resources faxing authorizations back and forth between her practice, the physician and home health agencies. It took Jody a week to obtain authorization for wound care for this patient and for the home health agency to accept the orders.

Fortunately, Jody lives in Washington State, where NPs face few legal barriers to practice .

Some 31 states have outdated barriers that prevent nurses from practicing to the full extent of their education and training.

"We need to remove these barriers to improve patient care. We know that patients will benefit when policy-makers eliminate outdated scope-of-practice barriers."

Nurses' Need to Be Patient Focused

Far too often, says **Hassmiller**, nurses and nurse practitioners don't emphasize the benefits to patients.

"We focus on our own qualifications and how scope-of-practice barriers hurt our ability to provide care. And quite frankly, policy-makers don't care about turf battles."

"We can't change scope-of-practice laws by focusing on ourselves. But we can convince policy-makers to change laws, regulations and institutional policies by focusing on how patients are harmed by outdated scope-of-practice regulations.

"We need to use patient-focused messaging when we talk to policy makers."

Policy makers should know that nurse practitioners are more likely than physicians to practice in underserved remote and rural areas and make up a significant portion of the

nation's safety net providers. Hospitalized patients are more likely to receive care from an advanced practice registered nurse if they live in a rural area.

A recent op-ed published in *The State*, a South Carolina newspaper, emphasizes how patients will benefit if nurse practitioners are able to practice to the full extent of their training and as it states in the title: "Nurses can help solve pending crisis."

The author, Stephanie Burgess, describes the current health care crisis in South Carolina and says the state will have to provide primary

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The ANF Foundation has given more than \$1 million in scholarships and vital research grants to help overcome the impending shortage of Primary Care Providers and assist research efforts to improve patient care.

care to 800,000 new patients as a result of the new Affordable Health Act. She describes the implications: longer waits for well-care visits, more crowding in ERs and an increase in cost for primary care.

An "obvious solution" exists: over 2,500 advanced practice nurses already in South Carolina. She states that giving patients the option to select an advanced-practice nurse as their primary care provider could give them access to an additional 3,000 providers.

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Only then does she mention scope of practice barriers in South Carolina and assert that these barriers mean that "patients struggle to get the care they need in a timely and safe manner." She provides evidence supporting APRN practice and mentions that 19 states already allow them to practice to the full extent of their education and training.

She ends by calling on policy leaders to take swift action to allow advanced practice nurses to "provide the care that so many South Carolinians need before the burden on our health-care system becomes even greater

This article is so important, says **Hassmiller**, because it focuses on the patient and the benefits the patients receive through care of an advanced practice nurse

Patient Messaging

Hassmiller of RWJF said that when nurses and coalition members speak with policy-makers about legal, regulatory and institutional barriers, always describe the impact on patients and patient care. She offers these examples:

- **The issue: Legal/Regulatory Barriers.** The majority of states require most APRNs to have a formal agreement, such as New Jersey's joint protocol with a collaborating physician, in order to diagnose, treat and prescribe. Further, some physicians charge fees for their services that APRNs can't afford.

The message: We need to explain that the risk of delays in care is high when collaborating physicians are not readily available.

One of APN's members shared a story about a boy in Texas who experienced a severe asthma attack. His family took him to his physician's office for treatment. But the physician had died earlier that week. The office was closed, even though a nurse practitioner worked there and could have provided care if Texas wasn't subject to a collaborating physician agreement. Instead, the nurse practitioner was at home because she didn't have a collaborating physician to work with, and the boy didn't receive timely care.

- **The issue: Medicare regulations** Some Medicare regulations do not allow APRNs to admit patient to hospitals, lead medical homes or sign orders for home health services.

The message should be that patients who have a good relationship with an APRN will be forced to be examined by strangers.

- **The issue:** In some states, Medicaid won't reimburse APRNs for certain codes or pharmacy supplies.

The message should be that restrictive reimbursement practices can force patients to pay out-of-pocket or find a different provider.

Katie Lavery, a certified nurse midwife in Michigan, says that because Medicaid won't reimburse her office for Depo-Provera, her patients have to go to a pharmacy to pick up the prescription and bring it back to her office for the injection.

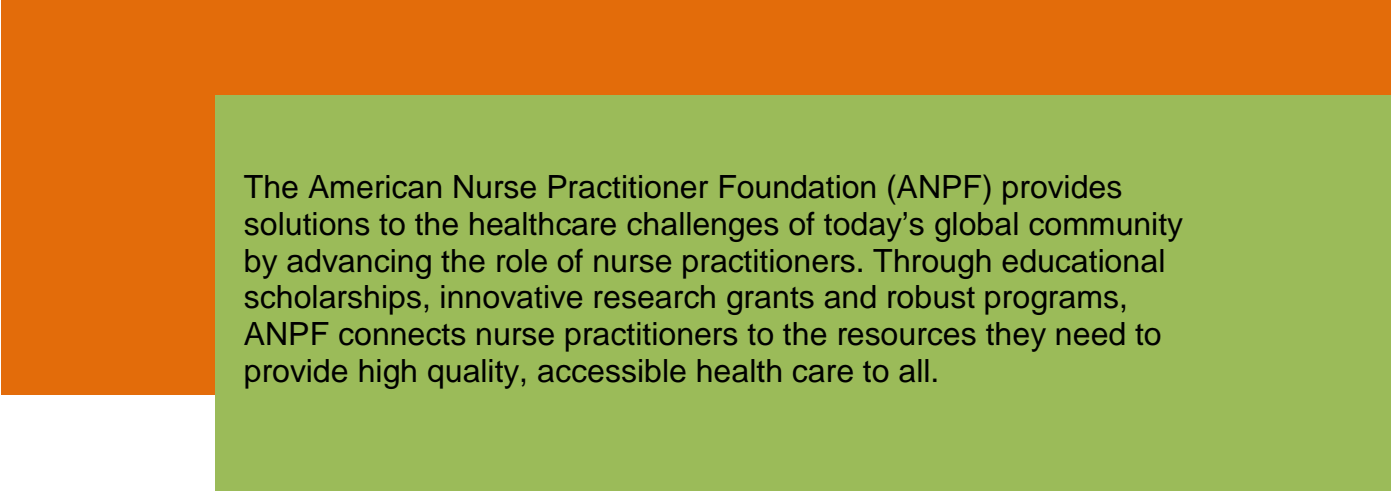
- **The issue:** In some parts of the country, APRNs are not recognized as primary care providers by Medicare or private health insurance companies.

The message should be that excluding APRNs can limit the supply of available clinicians in a time of growing demand.

- **The issue:** At some hospitals, medical staff bylaws prohibit APRNs from admitting patients or performing certain procedures. Only anesthesiologists at some hospitals can perform invasive monitor placements, for example.
- **The message** should be that at some hospitals, patients may have to wait for treatment even if a qualified APRN is available.

Hassmiller urged APRNs to become involved in the national campaign. Visit www.campaignforaction.org to sign up.

“Join the *Campaign for Action* and become a force for change to make nurses a valued partner in health care improvements. Together, let’s create a health system that



The American Nurse Practitioner Foundation (ANPF) provides solutions to the healthcare challenges of today’s global community by advancing the role of nurse practitioners. Through educational scholarships, innovative research grants and robust programs, ANPF connects nurse practitioners to the resources they need to provide high quality, accessible health care to all.

provides accessible, affordable and quality care to every American. ”

As **Hassmiller** said in response to a question, “This is hard work. Don’t give up.”

Email questions to foundation@anp-foundation.org

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