Being Your Own Best Health Advocate
Carolyn M. Clancy, MD
Director
Agency for Healthcare Research and Quality
AA&MDSIF Annual Patient and Family Conference in 2010
Bethesda, MD – July 10, 2010

Bone Marrow Failure Diseases
- Every year, nearly 20,000 Americans are diagnosed with aplastic anemia, MDS or PNH
- Some groups (e.g., ethnic Asians) are affected more than others
- We have come a long way in understanding and treating bone marrow failure diseases
- But we don’t know what causes these diseases
- And we don’t have a perfect cure

So What?
- Doctors know a lot, but we don’t know everything
- ‘Nothing about me, without me’
- You are your own best advocate!
Being Your Own
Best Health Advocate

Health Advocacy as a Critical Quality Strategy
AHRQ Roles & Resources
Health Advocacy: Questions and Tools
A Look Ahead
Q & A

What Is Health Advocacy?

Understanding:
- Diagnosis
- Options
- Treatment
Taking medications safely
Getting the right tests
Preparing for surgery
Avoiding error
Being an active participant in your care

The Numbers Don’t Lie…

Health care quality varies – A LOT
There is a substantial gap between best possible care and actual care
Up to 98,000 Americans die each year due to medical errors
Up to 90 million Americans are unable to understand basic information about their own health status and health care
The Quality Challenge

What Is Quality?

The Right Care  For The Right Person  At The Right Time

A Quality Disconnect

Health care costs are rising fast

Health care quality is improving slowly

Driving Factors in Quality

- Transparency: your right to know
- Safety: reducing risk by delivering the best possible care
- Payment: to reward the right care, not just a lot of care
- Information: Keeping everyone informed, including your doctors and yourself

Being Your Own Best Health Advocate

- Health Advocacy as a Critical Quality Strategy
- AHRQ Roles & Resources
- Health Advocacy: Questions and Tools
- A Look Ahead
- Q & A
HHS Organizational Focus

NIH
Biomedical research to prevent, diagnose and treat diseases

CDC
Population health and the role of community-based interventions to improve health

AHRQ
Long-term and system-wide improvement of health care quality and effectiveness

AHRQ’s Mission

Improve the quality, safety, efficiency and effectiveness of health care for all Americans

AHRQ Priorities

Patient Safety
- Health IT
- Patient Safety Organizations
- New Patient Safety Grants

Effective Health Care Program
- Comparative Effectiveness Reviews
- Comparative Effectiveness Research
- Clear Findings for Multiple Audiences

Medical Expenditure Panel Surveys
- Annual Quality & Disparities Reports

Other Research & Dissemination Activities
- Quality & Cost-Effectiveness, e.g. Prevention and Pharmaceutical Outcomes
- U.S. Preventive Services Task Force
- MRSA/VAP
Reports Show Pace of Improvement is Slow

- Quality is improving, but the pace is slow (median rate about 2% a year), especially for preventive care and chronic disease management.
- Some areas merit urgent attention, including patient safety and health care-associated infections.
- Many disparities are not decreasing.

NHQR Findings: Communication

- Good health care requires communication between patients and doctors.
  - From 2002 to 2006, the percentage of adults 18-64 who reported poor communication in a doctor’s visit fell from 11.6% to 10.4%.
  - Those with public insurance or no insurance report worse communication.

CAHPS: The Importance of the Consumer’s Voice

- Surveys developed for care in:
  - Ambulatory settings (e.g., health plans, physician offices).
  - Facilities (e.g., hospitals, nursing homes, dialysis facilities, home health care services).

More than 130 million Americans are enrolled in plans or have received treatment in facilities for which data are collected.
CAHPS Questions: Potential Content

- Patient-centered care
  - Information sharing, coordination of care, management of symptoms, provider communication

- Treatment alternatives
  - Was information about treatment alternatives offered? Information about side effects?

- Patient safety
  - Were procedures used to ensure that right treatment was given to the right patient?

Essential Questions Posed by Comparative Effectiveness

Is this treatment right?
Is this treatment right for me?
Comparative Effectiveness: AHRQ Effective Health Care Program

- Created in 2005
- To improve the quality, effectiveness, and efficiency of health care delivered through Medicare, Medicaid, and S-CHIP programs
- Focus is on what is known now: ensuring programs benefit from past investments in research and what research gaps are critical to fill
- Focus is on clinical effectiveness

The Recovery Act: What’s In It for You?

The $787 billion Recovery Act included both immediate incentives and features several long-term health care goals, including:
- Initiating a process to encourage widespread adoption of electronic health records
- Health care cost cutting measures
- Comparative effectiveness research

Health Reform Law

- Patient Protections and Affordable Care Act – H.R. 3950
- Now Public Law 111-148
- Insurance reform
- Lower costs
- Significant health care quality provisions
What’s In It for You?

- Greater choices
  - More affordable choice and competition, one-stop shopping, extends dependent coverage
- Quality, affordable care
  - Preventive care, more primary care practitioners

Being Your Own Best Health Advocate

- Health Advocacy as a Critical Quality Strategy
- AHRQ Roles & Resources
- Health Advocacy: Questions and Tools
- A Look Ahead
- Q & A

New ‘Healthy Men’ Patient Engagement Campaign

Message: When you get a preventive medical test, you’re not just doing it for yourself. You’re doing it for your family and loved ones.

http://www.ahrq.gov/healthymen/index.html
5 Steps to Safer Health Care

1. Ask questions if you have doubts or concerns
2. Keep and bring a list of ALL the medicines you take
3. Get the results of any test or procedure
4. Talk to your doctor about which hospitals is best for your health needs
5. Make sure you understand what will happen if you need surgery

Preventing Medical Errors

- The single most important thing you can do to prevent medical errors is to be an active participant in your own care
- That means taking part in every decision about your health
- Errors can occur because patients and doctors fail to communicate

Talking with Your Clinician

- Give information
- Get information
- Follow up
- Understand your diagnosis
- Choose quality
Getting Medical Tests

- Why do I need this test done?
- How is it done?
- Will it hurt?
- What kind of information will it provide?
- Is this the only way to provide this information?
- What are the benefits and risks of this test?
- What do I need to do to prepare for it?
- How will I get the results?
- What are the next steps?

Planning for Surgery

- Why do I need surgery?
- What kind of surgery do I need?
- Are there alternatives?
- What will it cost?
- What are the benefits and risks of the surgery?
- What if I don’t have the surgery?
- What kind of anesthesia will I need?
- How much experience do you have doing this surgery?

Getting a Prescription

- Track your medicines
- Take your medications safely
  - Know what the medication is for and how to take it
  - Ask about side effects
  - Read the label
  - Ask your pharmacist!
- Follow a treatment plan
  - Ask if you need a refill
  - Don’t share your meds
Build Your Own Question List

- Did your clinician give you a prescription?
- Are you scheduled for medical tests?
- Did you receive a diagnosis?
- Are you choosing a hospital? Health plan? Doctor? Long-term care?
- Have you been recommended for surgery?

No matter the health concern, you need to ask questions!

www.ahrq.gov/questionsaretheanswer/questionBuilder.aspx

Being Your Own Best Health Advocate

- Health Advocacy as a Critical Quality Strategy
- AHRQ Roles & Resources
- Health Advocacy: Questions and Tools
- A Look Ahead
- Q & A

Keeping the Patient at the Center

- Quality is defined as care that is safe, timely, effective, efficient, equitable and patient-centered
- Patient-centeredness is perhaps the most difficult goal to achieve
- But it’s the most important, because it’s why we’re here
What Does It Mean to Be Patient-Centric?

Technology and Consumers

- We create tools that make care more efficient for clinicians.
- Consumers already are comfortable with the technology; they're leading us, not the other way around.
- Consumers are demanding tools to make their care more about them.

Take a Strong Role In Your Care

- Remember… YOU must be at the center of care.
- Information can help you make better decisions, receive a higher level of care, reduce medical mistakes and feel better about your health care.
- Ask questions, and keep asking until you're satisfied with the answer.
- If you need help from a friend or relative, ask for it.
Being Your Own
Best Health Advocate

- Health Advocacy as a Critical Quality Strategy
- AHRQ Roles & Resources
- Health Advocacy: Questions and Tools
- A Look Ahead
- Q & A