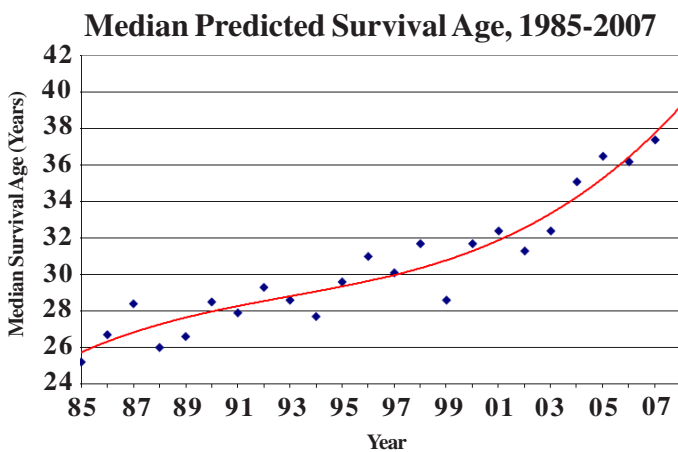


It's All About Suzy: Quality Improvement in CF Care

It is all about Suzy. She has many friends, is active in sports and dreams of being an astronomer. She gets up in the morning, takes her aerosol treatment, does airway clearance, eats a high-calorie breakfast, takes her medicine and leaves for school. Suzy represents every person with cystic fibrosis (CF). We want Suzy to achieve her life goals: an education, career, a family, and a long and healthy life.

Since the 1950s, CF care has continually improved. The CF Foundation is committed to the vision of *exemplary* care at all CF care centers to further extend quality and length of life. *Concepts of quality improvement* are being applied to reach this vision of exemplary CF care.



What is quality improvement (QI)? What does it mean for Suzy? The Institute of Medicine published reports about how to improve the quality of healthcare in the United States. Brent James, M.D., M.Stat, a professor at University of Utah and co-author of one report, defines quality improvement as “the science of *process* management.” Process management involves knowing what happens in each step of the process, how the steps *interrelate*, the *human factors* - including normal *variation* - and how learning can continue. In simple terms, QI is using a scientific approach to look at and improve the process of clinical care using teamwork and

leadership. For Suzy, QI may be working with her care center to better organize clinic visits. So, Suzy would come to clinic ready to ask her questions. The care center staff would meet before clinic so they know who should see her and identify areas to discuss during her visit. Both Suzy and the care center would work together to make sure she gets the care she needs.

THE GOOD NEWS ABOUT CF CARE

The good news is that CF care is always improving. The increasing life span from the CF Foundation’s Patient Registry is proof of this improvement. However, the CF Foundation is working to speed-up the rate of improvement. The seven QI goals, set by the CF Foundation, are listed in the box titled “CF Foundation’s Goals for Quality Improvement” (page 2). Also, you can read the *CF Foundation Patient Registry Annual Data Report* on the CF Foundation’s Web site (www.cff.org) for more information.

Goals & Plan:

1. *People with CF and their families are full members of the care team.*

Communication is a two-way street. The doctors, nurses and the rest of the care center listen to Suzy’s concerns and answer questions. She and her family need to openly communicate with her CF care center. This includes information about what care Suzy does at home. In return, her care center must clearly tell Suzy what her treatment options are and make sure she understands the benefits and risks of each. It is important that Suzy and her family actively participate in her healthcare decisions with the care center. This sharing and discussion of treatment options creates a plan that everyone agrees to for Suzy’s CF care.

Since the early 1990s, the CF Foundation has developed care guidelines for people with CF (see table at top of next page). A first step in improving care is to make sure you or your child visit the CF care center four times a year and get the recommended tests.

- Words that appear in *bold italic* are defined at the end.
- All referenced Web sites are at the end.

Guidelines for CF Care and Percentage of Children (C) and Adults (A) Who Meet Guidelines		
Clinic Visits — 4 or More Per Year	(C) 72.4	(A) 58.9
Pulmonary Function Tests — (PFT) 2 or More Per Year	(C) 84.4	(A) 81.0
Respiratory Cultures — At Least 1 Per Year	(C) 95.3	(A) 90.3
Influenza (Flu) Vaccine — Every Year	(C) 72.4	(A) 61.7

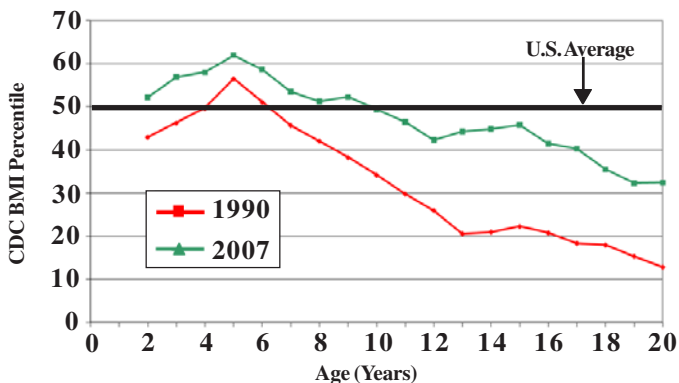
As Suzy gets older, she will need to take more responsibility for her care. Learning more about CF and her increasing responsibility will help prepare Suzy to move away from home. Her doctors, nurses, dietitian, therapist and social worker also need to learn more about the latest therapies and research. This learning will help Suzy, her family and CF care center staff talk about, and agree on, her CF healthcare. Guidelines for care, the Quality Improvement Toolkit, Virtual CF Education Day Web casts and the yearly medical CF conference are examples of how the CF Foundation is working to support ongoing learning in the CF community.

2. *Children and teens will have normal growth and good nutrition. Adults' nutrition will be maintained as near to "normal" as possible.*

There is a link between good nutrition and survival. Progress has been steady in improving the nutrition of children with CF. However, according to the 2007 CF Foundation Patient Registry, the body mass index (BMI) percentile of children with CF is still below the average U.S. population. For Suzy, we want her to grow at the same rate as others her age.

To help her, the CF Foundation is working to provide nutrition guidelines to the care centers so that they can continue to improve Suzy's nutrition. These guidelines are based on the latest information published in the medical literature.

Median CDC BMI Percentiles vs. Age, 1990 and 2007 for Children with CF



3. *Everyone with CF will receive the right therapies to decrease the number of **pulmonary exacerbations** or respiratory infections and keep lung function steady.*

The goal of every person with CF and their healthcare team is to keep the lungs as healthy as possible. There are a number of therapies now available. Some care centers use these therapies differently than others. For example, one care center may recommend chest physical therapy, sometimes called “clapping,” for airway clearance. Another center may recommend a mechanical device such as a vibrating vest. There are many reasons for these variations between care centers and between people with CF. The CF Foundation is working to find out if these variations in practice make a difference in the *clinical outcomes*. Guidelines for doing airway clearance state that doing it regularly is more important than exactly how or what device is used. For Suzy, her family and CF care center, they need to work together to find a way that she will do airway clearance every day and fit it into her busy life. This simple therapy may help Suzy avoid pulmonary exacerbations, improve her health and lung function.

You can learn more about the CF Foundation's goals for quality improvement by reading the *CF Foundation Patient Registry Annual Data Report*, available in the “Living With Cystic Fibrosis” section of the CF Foundation's Web site (www.cff.org).

CF Foundation's Goals for Quality Improvement:

- People with CF and their families are full members of the care team.
- People with CF will have normal growth and nutritional status.
- Everyone with CF will receive early diagnosis of infections and the right therapies to keep lung function steady.
- People with CF and care centers will work together to decrease the spread of germs between people with CF.
- People with CF will be monitored for complications of CF, with the goal to prevent and/or treat them early.
- Everyone with CF will be able to receive appropriate therapies, treatments and support regardless of race, age, education or insurance coverage.
- Everyone with CF will be supported when making decisions about transplantation and end-of-life care.

WHAT YOU CAN DO!

The CF Foundation and care centers are working hard to improve healthcare quality. However, we need your help. Research has shown that if you are more involved in your healthcare, you can get better results and feel more satisfied with that care. Here are some simple things you can do:

- **Ask questions**, and keep asking them until you understand the answers. Many people are involved in your or your child's care. So, talk with your CF care center often and get your questions answered.
- **Tell your CF care center about all of the medicines you take.** Be sure to include nutritional supplements, herbal supplements, over-the-counter drugs, vitamins and prescription drugs from other doctors or previously prescribed at your care center.
- **Read the label on your prescription** when you get your medicine. Make sure you are getting what your doctor ordered. For example, is it the right brand of enzymes?
- **Work with** your CF healthcare team to agree on a plan for you or your child's healthcare.
- **Know that "more is not always better."** Be sure to find out why you need a test or treatment and how it can help you.
- **When you or your child has an X-ray or laboratory test**, do not assume that "no news is good news." Ask when and how you will receive the results. Will it be in person, by mail or by phone? If you do not receive the results when you expect them, contact your CF care center and ask for them.
- **Ask your CF care center what the *scientific evidence* has to say** about CF treatment options. You can find more information on the CF Foundation's Web site (www.cff.org) or from PubMed, a service of the National Library of Medicine with more than 15 million medical and research documents (www.ncbi.nlm.nih.gov/entrez/query.fcgi).

QUALITY OF CARE

More public and private groups are developing and using *quality measures* and reports. One quality measure is *accreditation*. This is a "seal of approval" given by a private, independent group. CF care centers are accredited when they meet the standards of clinical care, research and teaching as set by the CF Foundation's Center Committee. To learn more about these standards, ask your CF care center or contact the CF Foundation.

The CF Foundation also measures how well the QI goals (see box on previous page) are being met. The CF Foundation's Patient Registry is one way the goals are being measured and reported. These goals are not just words or ideas; rather, they are real and measurable. The CF Foundation's Web site has the Care Center Network data reports.

The resources section on the last page has more information about accreditation and quality measures. You can also ask your CF care center, hospitals, or home care companies about their quality improvement work.

CHOOSING QUALITY HEALTHCARE

Here are some tips for including quality in your healthcare decisions. Such decisions involve CF care centers, treatments, health plans and you.

Look for a CF care center that:

- Has received accreditation by the CF Foundation;
- Is working to improve the quality of care they provide;
- Has the training and experience to meet your needs;
- Takes steps to prevent illness — for example, will talk to you about getting the screening tests or is working to avoid the spread of germs;
- Will work with you to make decisions about your or your child's healthcare;
- Can get you or your child admitted to, or treated at, a hospital with experience in caring for CF;
- Will partner and communicate with your primary healthcare provider;
- Is part of your health plan.

When choosing a treatment, make sure you understand:

- When and how soon problems need to be treated;
- Your treatment options;
- The benefits and risks of each treatment;
- The costs of each treatment;
- Whether the treatments are based on the latest scientific evidence.

Make sure you have a health plan that:

- Allows you to use an accredited CF care center;
- Allows you to use a pharmacy and hospital familiar with CF care;

- Provides the benefits (CF medicines and covered services) you need;
- Provides services where and when you need them;
- Does a good job of helping people stay well and get better;
- Has been given high ratings by its members on the things that are important to you.

To learn more about choosing a health plan or insurance, read “Day-to-Day: Know Your Health Insurance Coverage” available from your CF care center or on the CF Foundation’s Web site.

The CF Foundation’s mission is to assure the development of a means to cure and/or control CF and improve the quality of life for people with the disease. Quality improvement is all about Suzy and keeping her healthy so she can reach her life goals. It will take everyone working as a team to improve her CF healthcare and quality of life.

GLOSSARY

Accreditation: A “seal of approval” that shows an organization meets national standards.

Clinical outcomes: Results of a person or group’s health based on a measurement. For example, gaining weight is a clinical outcome of eating.

Concepts: Ideas or abstract thoughts.

Exemplary: Excellent; worthy of confidence.

Human factors: What each person involved brings to a project or situation, which varies with each person.

Interrelate: To work together.

Process: A series of actions or steps that lead to an end point or conclusion.

Pulmonary exacerbations: Signs and symptoms of an infection in the lungs.

Quality improvement: Using a scientific approach to look at and improve the process of clinical care using teamwork and leadership.

Quality measures: How a person knows if healthcare is getting better, worse or remains the same.

Scientific evidence: Information that is proven through independent research and study.

Variation: The differences between items or measures.

RESOURCES

The more you know about CF and its treatment, the more likely you are to get the best possible care and clinical outcomes. You can find more information on the Internet. Most local libraries have computers you can use and staff that can help you learn to search the Internet. The following are some resources:

CF Care & Insurance:

- The CF Foundation has information about CF, how to find CF Foundation-accredited care centers, the latest in research and current clinical trials (www.cff.org or **800 FIGHT CF**).
- *CF Foundation Patient Registry Annual Data Report* has information about current clinical outcomes in CF (www.cff.org).
- CF Services, Inc., a national mail-order pharmacy and subsidiary of the CF Foundation, can help you get prescription drugs (www.cfservicespharmacy.com/ or **800-541-4959**).
- CF Patient Assistance Foundation, a non-profit organization to help people with CF afford the medications and devices they need to manage their disease (www.cfpaf.org or **(888) 315-4154**).
- New Health Partnerships, Improving Care by Engaging Patients (www.newhealthpartnership.org).
- Institute for Family-Centered Care works with healthcare organizations to involve patients and families in healthcare (www.familycenteredcare.org).
- Medline Plus a service of the U.S. National Library of Medicine and the National Institutes of Health has information about CF (www.nlm.nih.gov/medlineplus/cysticfibrosis.html).
- PubMed, a service of the National Library of Medicine, has more than 15 million medical and research documents (www.ncbi.nlm.nih.gov/entrez/query.fcgi).

Accreditation:

- Joint Commission on Accreditation of Healthcare Organizations (JCAHO) evaluates and accredits hospitals, healthcare networks and managed care organizations. For information, visit Quality Check at www.jointcommission.org/qualitycheck/06_about_qc.htm or call **(630) 792-5000**.

- Community Health Accreditation Program (CHAP) evaluates and accredits home healthcare organizations. To find out more, call CHAP at **800-669-9656, ext. 242**, or visit CHAP's Web site (www.chapinc.org/chap-consumer.htm).

Quality: Reports and Measures

- CF Foundation-accredited Care Center Data reports - www.cff.org and click on "Care Center Network."
- *Improving Health Care Quality: A Guide for Patients and Families* - www.ahrq.gov/consumer/qntlite/.
- For quality reports about Medicare managed care plans, call **800-MEDICARE**, or look for Medicare Compare at www.medicare.gov.

DISCLAIMER

We have listed several organizations, Web sites and phone numbers here to help you find out more about healthcare quality. This information is provided only as a service to readers and does not imply endorsement or promotion by the CF Foundation of these organizations, any products or services they offer, or any groups they may link with through their Web sites.

Internet References:

- *Improving Health Care Quality: A Guide for Patients and Families*. AHRQ Publication No. 01-0004, October 2000. Agency for Healthcare Research and Quality, Rockville, MD. www.ahrq.gov/consumer/qntlite/