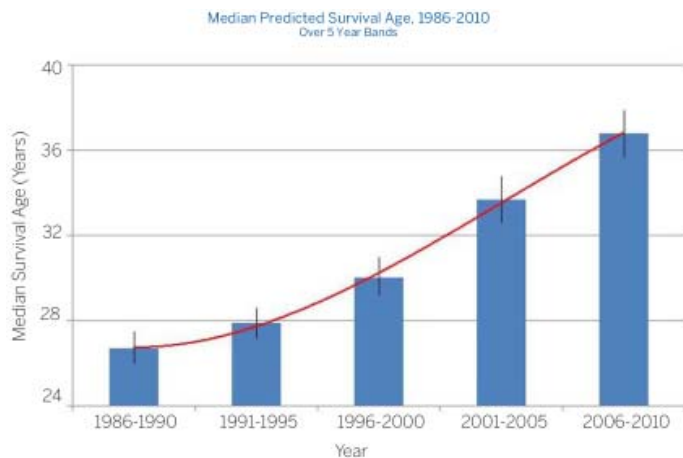


It's All About Suzy: Quality Improvement in CF Care

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. *Quality improvement* is being used to reach this vision.



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 set the goals for her health and make sure she gets the care she needs to reach her goals.

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 wants care to improve faster. 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, their families, and CF health care professional make up the CF 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. In turn, she and her family openly communicate with her CF care center. This includes information about what care Suzy does at home. In return, her care center clearly tells Suzy what her treatment options are and make sure she understands the benefits and risks of each. Suzy and her family actively participate in her healthcare decisions in partnership 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 (www.cff.org/treatments/CFCareGuidelines/) 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.

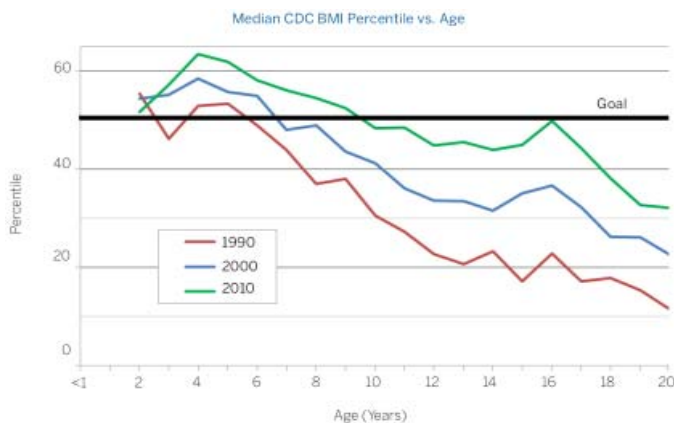
Care, Screening and Prevention Guidelines for People with CF	People with CF Who Met the Guidelines (%)	
	2009	2010
4 or more clinic visits	57.97	63.19
4 or more respiratory cultures	42.65	44.77
2 or more pulmonary function tests (PFTs) if 6 years of age or older and physically able	81.49	81.50
An influenza (flu) vaccine if 6 months of age or older	71.11	73.00
Fat-soluble vitamin levels measured	78.54	80.59
An oral glucose tolerance test (OGTT) if 10 years of age or older	13.02	19.33
Test to measure liver enzymes in the blood	78.18	72.26

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**, **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, teens and adults with CF will have normal growth and nutrition.*

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 2010 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.



3. *All people with CF will receive appropriate therapies for maintaining lung function and reducing acute episodes of infection.*

There are a number of therapies now available for people with CF to keep the lungs as healthy as possible. 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.

CF Foundation’s
Goals for Quality Improvement:

- 1) People with CF, their families, and CF health care professional make up the CF care team.
- 2) Children, teens and adults with CF will have normal growth and nutrition.
- 3) All people with CF will receive appropriate therapies for maintaining lung function and reducing acute episodes of infection.
- 4) People with CF, their families, and CF health care professionals will be well informed and active partners in reducing acquisition of respiratory pathogens, particularly *P. aeruginosa* and *B. cepacia* complex.
- 5) People with CF will be screened and managed aggressively for complications of the disease, particularly CF-related diabetes.
- 6) Severely affected people with CF and their families will be well supported by their CF health care professionals when facing decisions about transplantation and end-of-life care.
- 7) People with CF and their families will have access to appropriate therapies, treatments and supports regardless of race, age, education or ability to pay.

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.

You can learn more about quality improvement and what you can do on the CF Foundation's Web site at <http://www.cff.org/LivingWithCF/QualityImprovement/ImproveYourCare/>.

GLOSSARY

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.

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. The following are some resources:

CF Care & Insurance:

- The CF Foundation has information about CF, how to find CF Foundation-accredited care centers, and more. Visit www.cff.org or call **(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 mail-order pharmacy and CF Foundation subsidiary, can help you get prescription drugs. Visit www.cfservicespharmacy.com or call **(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. Visit www.cfpaf.org or call **(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.ipfcc.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).

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

The organizations, Web sites and phone numbers listed are 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/.