

Regional and national variation in rates of pediatric CF patients at risk of and in nutritional failure: opportunities for improvement

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The Northern New England Cystic Fibrosis Consortium



The NNECFC is a regional, voluntary consortium of more than 80 clinicians and researchers from the CF care centers in Maine, New Hampshire and Vermont.

The mission of the group is to improve CF care and patient outcomes.

Goal

- To examine national variation in pediatric nutritional outcomes, and regional variation in Northern New England.

Methods

- The dataset consisted of the 18,475 patients less than 18 years of age reported in the 2002 Cystic Fibrosis Foundation (CFF) Annual Patient Registry.
- A minimum of 10 pediatric patients were required for a center to be included in the analysis.
- The 2001 CFF Pediatric Nutrition Consensus Conference guidelines for malnutrition were applied, using variables available in the CFF Registry:
 - ideal body weight (IBW)
 - height and weight percentile
 - weight for length percentile
 - body mass index (BMI)
 - BMI percentile
- Additional criteria for risk or failure, genetic height potential and weight loss or plateau with $IBW \geq 90\%$, were not available for these analyses.

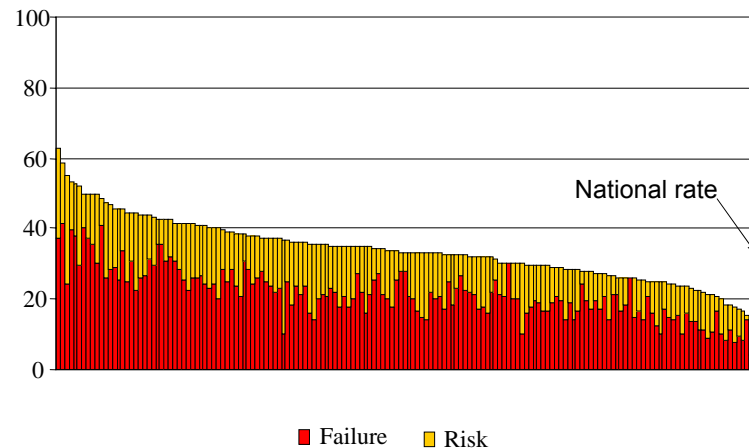
Definitions of At Risk of and in Nutritional Failure in Patients as Measured in the US CFF Patient Registry

Age group	At Risk	Nutritional Failure
0 to 2 years of age	Weight for length percentile 10 th to 25 th	Height percentile <5 th , or weight for length percentile <10 th , or IBW <90%
2 to 20 years of age	BMI percentile 10 th to 25 th	BMI percentile <10 th or IBW <90%

Results

- Nationally, 1629 pediatric patients (12.1%) met the criteria for at risk of nutritional failure.
- At risk rates by center ranged from 0 to 31.0%.
- Failure rates by center ranged from 4.0% to 41.1%: representing 2801 pediatric patients (20.8%).
- The combined rate of those either at risk of nutritional failure or in failure ranged from 8.3% to 62.5%.
- In Northern New England, the combined rate ranged from 18.6% to 42.9%.

Percent of patients <18 years of age in nutritional failure or at risk of failure, by Center 2002



Each bar represents the rates for a US CF care center. A minimum of 10 pediatric patients were required to be included in the analysis.

Conclusion

- There is more than a seven-fold variation in the combined rate of at risk of nutritional failure and in failure between the lowest and highest centers in the United States. In Northern New England, there is more than a two-fold variation.
- The Registry should be updated to collect more detail to assess the nutritional status of patients as laid out in the Guidelines, since the current variables may produce an undercount of the rate of nutritional risk or failure.
- The enormous variation in malnutrition rates nationally represents a substantial opportunity to learn from centers with the lowest rates to improve patient outcomes.