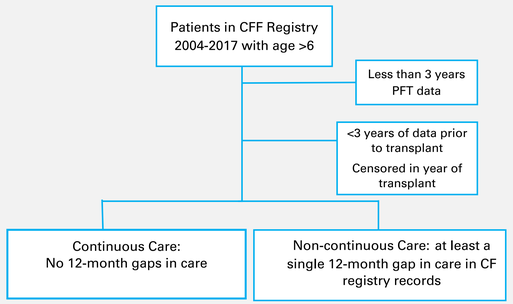
Association between gaps in care and lung function decline in the US CF Foundation Patient Registry

PRESENTER:
Edmund "Ted" Sears

Missing CF clinic visits is associated with **lower lung function.**

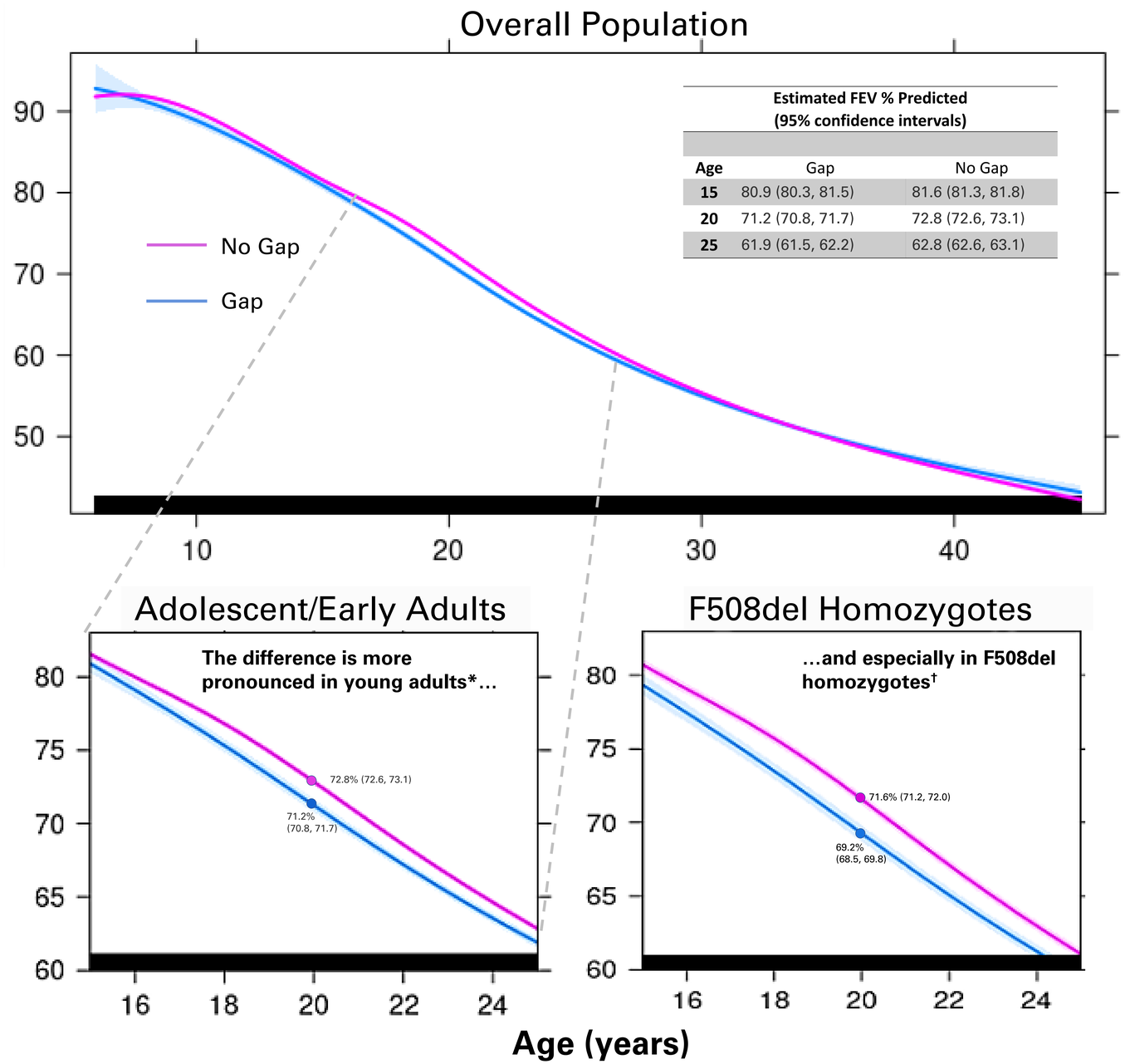
Rationale: No large-scale studies have examined relationships between prolonged gaps in care and pulmonary outcomes in CF patients. We hypothesized that prolonged gaps in care would associate with accelerated lung function decline (LFD) in the US CF Foundation Patient Registry (CFFPR).

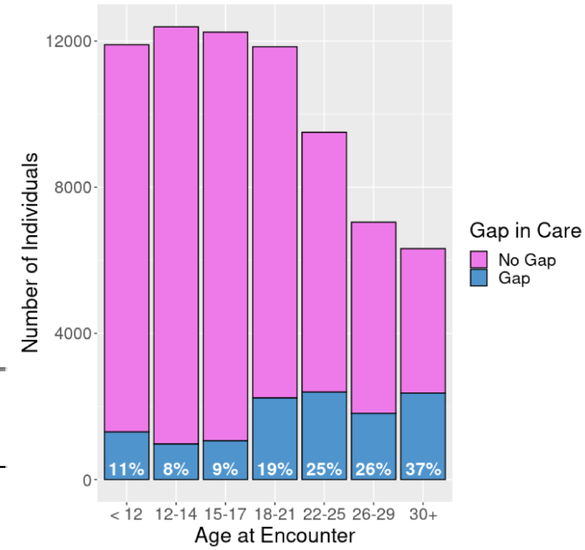


Methods: We modeled FEV1 % predicted (FEV1PP) using longitudinal semiparametric modeling with natural cubic splines for age and with subject-specific random effects. Our model adjusted for gender and genotype and included time-varying covariates for gaps in care of at least 12 months, insurance type, nutritional failure, and CF-related diabetes. After careful analysis, we did not include chronic infections in our main model, since inclusion did not modify effect estimates by more than 10%.

Characteristic	Gap in Care: At least 1 Gap N = 8,951 (37%)[1]	Gap in Care: No Gaps N = 15,377 (63%)[1]	p-value[2]
Demographics			
Female	3,860 (43%)	7,839 (51%)	<0.001
Age at Diagnosis	0.6 (0.2, 3.9)	0.4 (0.1, 2.4)	<0.001
Genotype - Categories			<0.001
F508del heterozygotes	3,395 (38%)	5,734 (37%)	
F508del homozygotes	3,902 (44%)	7,634 (50%)	
Other/Unknown	1,654 (18%)	2,009 (13%)	
Patient Died During Study Period	383 (4.3%)	888 (5.8%)	<0.001
Birth Cohort			<0.001
Before 1981	2,008 (22%)	2,014 (13%)	
1981-1988	2,685 (30%)	2,460 (16%)	
1989-1994	2,235 (25%)	2,919 (19%)	
1995 and after	2,023 (23%)	7,984 (52%)	
Ever Experienced			
Ever Underweight	2,982 (33%)	5,246 (34%)	0.2
Ever had Nutritional Failure	3,419 (38%)	6,327 (41%)	<0.001
Ever Low SES Proxy (on State, Federal, or without insurance)	5,827 (65%)	9,875 (64%)	0.2
Ever had Chronic Pseudomonas	5,913 (66%)	10,133 (66%)	0.8
Ever had Chronic MRSA	2,646 (30%)	5,777 (38%)	<0.001
Ever had Chronic Burkholderia	467 (5.2%)	857 (5.6%)	0.2
Ever had Cystic Fibrosis-Related Diabetes	3,064 (34%)	5,308 (35%)	0.6

[1] Median (IQR); n (%)
[2] Wilcoxon rank sum test; Pearson's Chi-squared test; Fisher's exact test





*** Interaction between age and gaps in care significant at p<.0001**

† Interaction between genotype and gaps in care significant at p<.0001

Conclusions

Our analyses of the CFFPR show a strong association between prolonged care gaps and LFD. This relationship was seen across strata of genotype, chronic infection, and age, with the greatest magnitude being in late adolescence and early adulthood. A strength of our approach is that we use longitudinal semiparametric modeling of care gap as a time-varying covariate which offers greater power and flexibility than previous approaches. A limitation of this study is its retrospective and associational nature. Also, lack of data in the CFFPR does not exclude contact with the medical system.

Edmund H Sears, MD[1]
Alexandra Hinton, MPH[2]
Christine W. Lary, PhD[2]
Jonathan B. Zuckerman, MD[1]

[1]Division of Pulmonary and Critical Care, Maine Medical Center, Portland, ME 04102
[2]Center for Outcomes Research and Evaluation, MMC Research Institute, Portland, ME 04101

Maine Medical Center
Adult CF Program

Take a picture to **download** abstract & further graphs