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Resumo	Cystic fibrosis [CF, OMIM (Online Mendelian Inheritance in Man) n° 219700] is a genetic condition associated with the presence of pathogenic variants in the CFTR (Cystic Fibrosis Transmembrane Regulator) gene. Historically, the clinical phenotype of the illness was associated with the presence of salty sweat, which resulted in the use of chloride ion quantification in the sweat as a diagnosis criterion. In Brazil, although its higher prevalence is ascribed to individuals of Caucasian descent, it has also been observed in other ethnic and racial groups. In the last few years, due to advancements in its treatment, the survival rate of patients with CF has increased. Therefore, individuals who would probably die at birth or in the first few years of their life were seen to live up to adolescence, and more recently, to adulthood. However, there are still discrepancies in the life span among different populations of patients with CF and among those in the same population. For this reason, greater importance has been given to the patients' genetic profile as well as their access to healthcare, diagnosis, and treatments using precision and personalized medicine. Taking these factors into consideration, we sought to evaluate the death rate of patients with CF and determine the most affected age groups in Brazil. To achieve the study aim, we evaluated data stored in the Brazilian death register pertaining to patients with CF [International Classification of Diseases (ICD): E84], which showed 3,837 deaths within a period of 27 years. Curiously, unlike the literature reports, most deaths were recorded among adults or old individuals. These data were in conflict with the epidemiological data as recorded in the Brazilian Cystic Fibrosis Registry. According to the Brazilian Cystic Fibrosis Registry, in 2021, the CF patients' population was predominantly young and 74.4% of the individuals were younger than 18 years. Also, in 2021, 50 deaths resulting from CF were reported in a population whose mean age was 21.5 ± 9.9 years. In contrast, in the Open-Data-SUS record of deaths, its Death Information System registered 272 deaths only that year, out of which 51 individuals who died were older than 80 years [Brazilian Death Information System—SIM (from Portuguese *Sistema de Informações sobre*

	Mortalidade), Open-Data-SUS]. Considering the Open-Data-SUS as the source of information about the health of the Brazilian population and the evidence of errors found in death registers by this research, in which CF was possibly confused with idiopathic pulmonary fibrosis as the cause of death, we concluded that this is an urgent issue, needing a discussion as it has become an unavoidable ethical commitment.
Fomento	