Economic disparity lowers neuroendocrine cancer diagnosis

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Background

The purpose of this study was to evaluate the impact of financial hardship in neuroendocrine cancer patients on diagnosis and incidence. The goal is to understand barriers to specialized care access and potentially apply the lessons learned to improve education and outreach. The real incidence of neuroendocrine cancer is probably much higher than that observed or reported. This is probably due to barriers that prevent diagnosis. The purpose of this study was to examine the impact of personal bankruptcy on NET diagnosis. Our long-term goal is to better understand obstacles that impede access to specialist care and clinical trials. Using this data we can design/advocate countermeasures that will improve diagnosis, quality of life, and overall outcomes. This study is not focused on medical bankruptcy, or debt arising from medical bills resulting in bankruptcy. Rather we are investigating the effect of bankruptcy on outcomes and diagnosis. Specifically, we are asking: 1) does bankruptcy effect NET outcomes, and 2) does bankruptcy effect NET diagnosis.

The impact of this study is to better understand NET burden in the USA. By identifying barriers to diagnosis and attempting to quantify their impact healthcare providers, policy makers, patient advocates, lobbyists and legislatures are educated for the need to improve access to specialist healthcare and diagnostic resources for rare cancers. Moreover, this data has the potential to foster similar studies identifying and quantifying other socioeconomic factors that could impact NET diagnosis, quality of life, and/or overall survival.

Lay abstract: It is well known and that financial hardship can have a significant impact on patients with cancer. The primary purpose of this study was to quantify any influence of bankruptcy on overall survival in NET. We hypothesized that limited finances would impede patients access to specialized medical treatment which would lower survival. To test this, we cross referenced deceased NET patient medical records with public records for bankruptcy. The bankruptcy rate for NET patients was 10.4% and the average age for filing for bankruptcy was 52yr. Contrary to our hypothesis there was no difference in overall survival between NET patients that had filed for bankruptcy and those that had no history of financial problems. However, we observed an interesting anomaly with our data. On average bankrupt NET patients were diagnosed earlier and died earlier then non-bankrupt NET patients. While it is plausible that bankrupt NET patients would die earlier due to inability to access treatment it is harder to explain why bankrupt NET patients would be diagnosed earlier also. One reason for this is that the bankrupt data set is incomplete and is missing older people with NET that have not been diagnosed. To correct for this potential, we performed statistical modeling of the data and estimate that approximately 927 NET tumors/year fail to be diagnosed. This is speculative at the moment and additional studies and corroboration by other centers is required.

Methods

To avoid confidentially issues this study was limited to deceased NET patients.

Deceased NET patients were identified from medical records between 2006 and 2022 and were cross referenced against public records for bankruptcy to create a REDCap database for analysis (n=1236).

From this database, bankruptcy rates were calculated and correlated against overall survival, age at bankruptcy, and age at death.

Figures

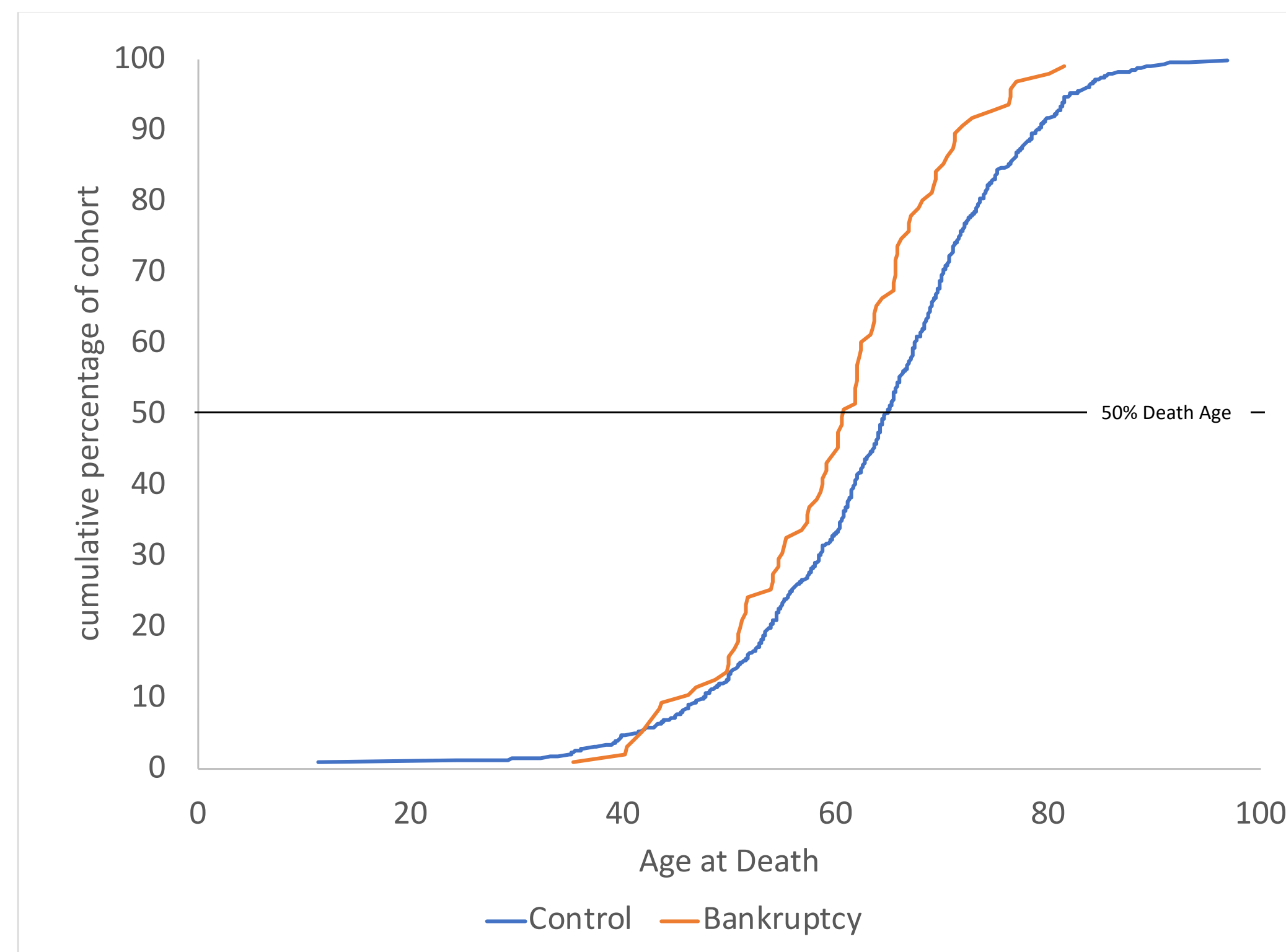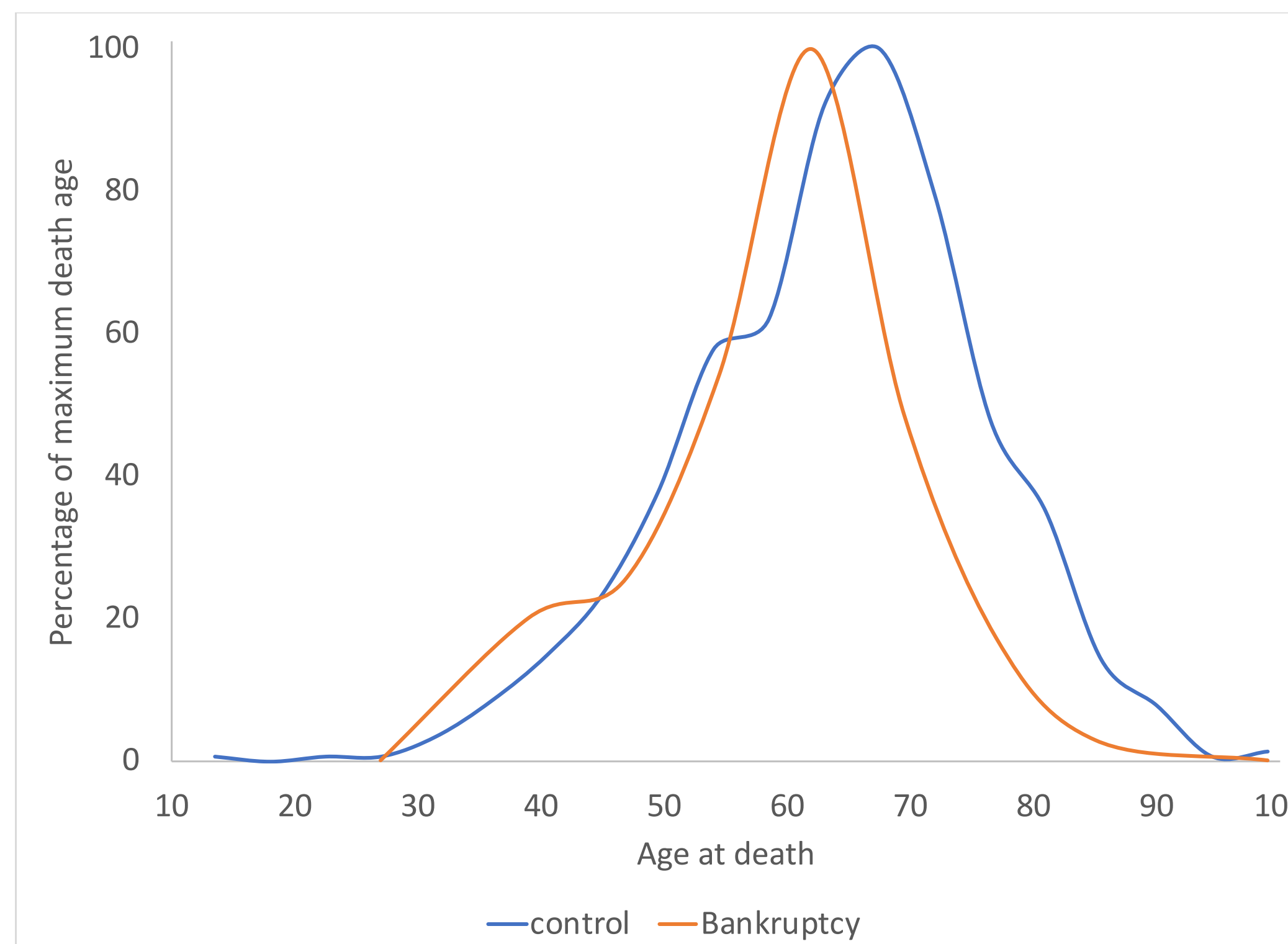Figure 1. Bankruptcy patients die earlier then controls

Figure 2. Bankruptcy causes a left shift in age of NET diagnosis


Results

Of the 1236 NET patients, 10.4% had filed for bankruptcy (chapter 7 or chapter 13) during their life. The average age of first-time bankruptcy filing (a small subset of patients filed for bankruptcy multiple times) was 52 ± 12yrs. In response to the specific aims of the project:

1) Bankruptcy had no effect on overall survival. There was no statistical difference in overall survival between NET patients who filed for bankruptcy (1853 ± 171days) vs controls (1906 ± 61days p=0.38).

2) The data suggests that bankruptcy reduced NET diagnosis and there are a cohort of NET tumors that are never diagnosed. This observation is implied by differences in the age of death and age of NET diagnosis between NET patients that had filed for bankruptcy vs controls.

3) The average age of death for patients who had filed for bankruptcy was significantly lower (60 ± 1yrs) when compared to controls (64 ± 0.4, p<0.01). In a similar manner, the average age for NET diagnosis was earlier in patients who had filed for bankruptcy (56 ± 0.9yrs) when compared to controls (59 ± 0.6, p=0.01).

These differences are an anomaly of the data set. We know of no reason why bankruptcy would accelerate the onset of NET resulting in younger diagnosis and younger death. The most logical explanation is that the data sets for bankrupt NET patients are incomplete, particularly due to missing older NET patients that never received a diagnosis. There are numerous statistical modeling methods that can be used to address missing data by imputing missing values. To correct for missing data, the bankrupt NET patient age at death data was subjected to maximum likelihood modeling based on data from non-bankrupt NET patients. The percentage of imputed missing values was calculated to be 37.5%. Consequently, the corrected bankruptcy rate in NET patients would be increased to 12.3%.

Figure 3. Bankruptcy patients are diagnosed earlier then controls
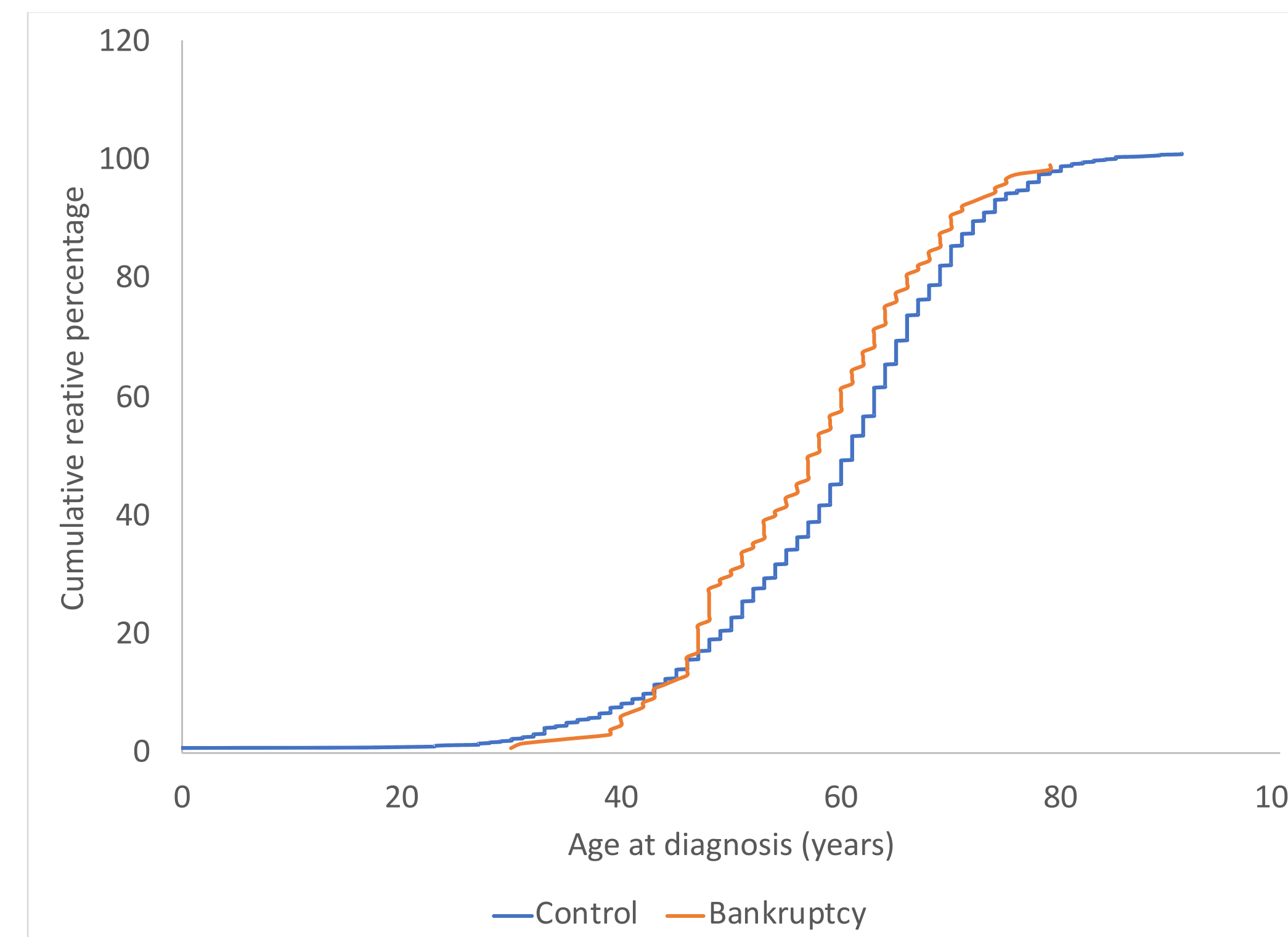
Conclusions

Bankruptcy does not affect overall survival in patients that are diagnosed with NET. However, bankruptcy does impact the probability of diagnosis. It is plausible that an individual with an undiagnosed NET could endure financial hardship, file for bankruptcy, and lose health insurance and access to diagnostic resources. Failure to diagnose will skew resulting data sets.

Based on NET incidence of 6/100,000, US population of 332.4 million, bankruptcy rate of 12.3%, and 37.5% underreporting, we estimate that economic disparities in the USA leads to a failure to diagnose in approximately 927patients/year. Further correlative studies are required to strengthen the value of this data to facilitate medical or legislative initiatives to expand access to specialized care for NET patients. Future studies will monitor potential narrowing of the differences between bankrupt NET patients and controls with changes in health care access and affordability. For example, the majority of the patients represented in this data were diagnosed before the Affordable Care Act and expansion of Medicaid/Medicare.

Tables

	No Bankruptcy	Bankruptcy
Age at bankruptcy filing (years)	n/a	51.6±11.8
Gender		
Male	567	70
Female	668	79
Race		
Caucasian	916	97
African American	141	32
Asian	3	1
American Indian or Alaskan native	3	0
Native Hawaiian or other pacific islander	0	0
Other	2	1
Not known	167	18
Overall Survival (days)	1954±1738	1903±1637
Life lost (years)	12.8±11.8	17.4±9.7
Age at diagnosis (years)	58.9±12	55.7±11
Age at death (years)	64±12	59.7±9.7

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