

POSTER PRESENTATION

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Changing causes of death in Familial Adenomatous Polyposis: 20 years of progress

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Background

Patients with FAP are at risk of dying from multiple benign and malignant tumors, from surgical complications, and comorbid diseases. We previously evaluated and published causes of death in FAP patients in 1990. This study analyzes patterns of mortality in the ensuing 2 decades and compares the two time periods to determine if advances in medicine and technology have changed clinical outcomes.

Methods

Causes of death were extracted from the 1990 study via the manuscript. Causes of death since then were determined from the registry database and confirmed by chart review.

Results

In 1990 there were 178 FAP families in the registry. Currently, 761 families are enrolled in the registry. The mean age of patients in the registry before 1990 was 36.5 and the mean age since then is 54.5. There is a

significant increase in life expectancy in patients after 1990. 212 patients have died (0.28 deaths per family); 110 before 1990 (0.62 deaths per family) and 102 since (0.17 deaths per family). Causes of death are listed in Table 1.

“Other” deaths include cancers of the thyroid, stomach, esophagus, pancreas, breast, ovary and lung. There were also 2 suicides and one death from pancreatitis. Overall there have been fewer deaths per family since 1990. Deaths from colorectal and periampullary/duodenal cancer have declined (even if the “unknown” category is excluded) while those for desmoid remain constant. Perioperative deaths are fewer.

Conclusion

Although the main causes of death in FAP remain the same, improvements in education and in access to screening and surgical techniques have decreased the overall mortality rates. Continued improvements in all aspects of patient care could further improve patient outcomes in FAP.

Table 1

Cause of death	Before 1990	Age at death	Since 1990	Age at death
Colorectal cancer	64 (58.2%)	41.1	41 (40.2%)	49.4
Desmoid disease	12 (10.9%)	33.8	9 (8.8%)	34.6
Periampullary cancer	9 (8.2%)	49.1	4 (3.9%)	51.7
Brain cancer	8 (7.3%)	19.6	2 (2%)	81
Perioperative	5 (4.5%)	32.6	3 (2.9%)	59.5
Accident	3 (2.7%)	31.3	0	0
Other	9 (8.2%)	38.4	24 (23.5%)	53
Unknown	0	0	19 (18.6%)	57.8
Overall cancer (excluding desmoids)	85 (77.3%)		57 (55.9%)	

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