Evaluation of ‘Likely Deceased’ for Improving Follow-Up in Metropolitan Detroit SEER Data, 1973-1994
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METHODS

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BACKGROUND AND PURPOSE

Background:
• SEER evaluates registries’ follow-up completeness by the Data Quality Profile (DQP), which requires 90-95% follow-up of cases diagnosed 1995+.
• SEER requires registries to maintain follow-up for all cases from a registry’s 1st year of data collection. For Metropolitan Detroit this is 1973.
• Maintaining follow-up for cases diagnosed 1973-1994 is challenging, but essential for calculation of long-term survival trends.
• We investigated cost effectiveness of intensive active follow-up of ‘likely deceased’ cases in this earlier timeframe.

Purpose: Decrease burden of follow-up for earlier diagnosed cases

METHODS

Criteria:
• Cases diagnosed 1973-1994 in Metropolitan Detroit SEER data
• Did not have a follow-up date of 2013 or later when evaluated in mid-2014

Analysis:
• Evaluated by age, race, cancer site and stage
• To determine categories of ‘likely deceased’ individuals
• Where more intensive follow-up methods might find vital status
• Intensive follow-up included:
  • reviewing the central cancer registry database (DB) for death certificates
  • researching cases on Lexis-Nexis© and
  • calling patients’ last known phone number

Outcome:
• Staff time in hours tracked to measure cost effectiveness

RESULTS

Los to Follow-up

- Age 100+: 217 (0.2%)
- Distant Stage: 169 (0.2%)
- Other LTFU: 90,539 (99.6%)

Lost to Follow-up

- Small, but low hanging fruit

Cancer diagnosed in Metropolitan Detroit, 1973-1994

- Active: 1011
- Dead: 736

Currently ‘Alive’ Cases diagnosed in Metropolitan Detroit, 1973-1994

- Lost to Follow-Up: 90,539
- Currently Followed-up: 911

RESULTS

- Of 396,187 total cases,
  • 85% were deceased, 15% alive.
  • 27% of living cases had no follow-up after 2012
  • 212 cases were age 100 or older (Elderly) and
  • 169 were distant stage (Distant) for selected cancer sites.
  • 48.5 hours to investigate Elderly and
  • 49.0 hours for Distant cases.

- After intensive follow-up, results were:
  • Death Certificate found on database management system (DMS) (Elderly: 12%, Distant: 1%),
  • Death found in Lexis-Nexis (Elderly: 21%, Distant: 10%),
  • Alive found in Lexis (Elderly: 13%, Distant: 0%),
  • Lost to Follow Up (LTFU) (Elderly: 28%, Distant: 15%),
  • Patient found Alive via phone call (Elderly: 4%, Distant: 68%), and
  • Case needs further research after more intensive follow-up methods, therefore perhaps not time effective (Questionables) (Elderly: 20%, Distant: 6%).

COST ANALYSIS

Age 100+

- Staff Time for Targeted Intensive Follow-up

DISTANT

- Staff Cost for Targeted Intensive Follow-up

DISTANT

- Small, but low hanging fruit

CONCLUSIONS

- Intensive follow-up in 1973-1994 diagnosed cases targeted to:
  • ages >= 100 years old at diagnosis and
  • distant stage at diagnosis cases

- Improved follow-up in cases diagnosed 20+ years ago

- These more focused methods for selected cases appear to be cost effective.