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Using Large Date to Present Uncertainty for Risk Prediction in the Era of Precision Medicine: The RESPECT Algorithm for Predicted Death at End-of-Life

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Introduction

In Ontario, only 52% of people received palliative care in their last year of life, with only 20% of those receiving it at home, which can improve the dying experience. Existing algorithms identifying people at end-of-life can potentially improve access to palliative care but are difficult for patients to understand.

Objectives and Approach

To predict and communicate risk of death for community dwelling older adults using a pre-specified and published approach (Trial registration NCT02779309). All assessments from community-dwelling Ontarians (N = 488,636) who received at least one home care assessment from the residential assessment instrument – home care (RAI HC) from 2007 to 2013 (N=1,331,273) were included. The algorithm used a two-step approach by rank ordering participants into 61 groups based on six-month probability of death (from Cox-proportional hazard models) and generated Kaplan-Meier five-year survival curves for each group. Median Survival time is reported with uncertainties expressed with 25th to 75th percentiles.

Results

The median predicted probability of death within six-months was 0.1095 (0.1093-0.1097, 95% CI). Risk varied among the 61 groups from 0.0158 (0.0158-0.0159) to 0.9820 (0.9810-0.9830). Median observed survival time varied from 27 days (10 to 81 days, 25th and 75th percentile) in the highest risk group to 10 years (3655 days (2111 to >3655 days)) in the lowest risk group. Discrimination and calibration were satisfactory between the derivation (2007-2012 assessments) and valida-

tion (2013 assessments) cohorts, with a C statistics of 0.77 and discrimination plot intercept 0.094, slope 0.914. The Kaplan-Meier five-year survival curves for each of the 61 groups will be visually represented in six different ways displaying the risk and uncertainty, and can be altered to yield information of interest specific to each patient/caregiver.

Conclusion/Implications

RESPECT is adaptive and personalized, with instantaneous feedback as the user provides a response to each question. We will present RESPECT's development and implementation processes and set up an interactive presentation of the calculator, demonstrating RESPECT's ability to deliver patient-comprehensible end-of-life prognoses with uncertainty to patients and their caregivers.