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Continuity of physician care over the last year of life in different end-of-life trajectories: A retrospective population-based study.

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ABSTRACT

Background: The mix of care provided by family physicians, specialists and palliative care physicians can vary by dying trajectory at the end-of-life (EOL). Continuity of care with the same care provider is associated with improved health outcomes but may be disrupted at the EOL. This study measured continuity of outpatient physician care in the last year of life across differing EOL trajectories and assessed factors associated with higher continuity.

Methods: We conducted a retrospective descriptive study involved adults who died in Ontario between 2013 and 2018 (n= 417,627), using linked provincial health administrative data. Three measures of continuity (usual provider, Bice-Boxerman and sequential continuity), which range from 0 to 1, were calculated from outpatient physician visits over the last year of life for terminal illness, organ failure, frailty, sudden death and other EOL trajectories. Multivariable logistic regression models were conducted to evaluate associations between characteristics and continuity ≥ 0.5 .

Results: Mean usual provider, Bice-Boxerman and sequential continuity indices were 0.37, 0.30 and 0.37, respectively, with continuity being the lowest for those with terminal illness (0.27, 0.23, 0.33). Higher number of comorbidities, number of outpatient physician visits, higher neighbourhood income quintile and all non-sudden death trajectories were negatively associated with continuity ≥ 0.5 .

Interpretation: Continuity of physician care is low in the last year of life overall, but especially in the terminal illness trajectory. Upon considering known differences in EOL care patterns

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differences across diseases, more meaningful continuity of care measures may need to be conceptualized.

Keywords: end-of-life care, cohort studies, cancer, health services research

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BACKGROUND

The population in many countries is ageing, and increasing numbers of people require health care for at least one progressive life-limiting illness, with needs escalating in the last year of life.¹⁻⁴ Despite experiencing more frequent transitions between settings,⁵⁻⁷ most people spend the majority of their time at home or in a home-like setting, receiving health care primarily as outpatients.^{7,8} Good care in the community near the end of life might include involvement of specialist physicians to care for specific diseases (e.g., oncologists for cancer; respirologists for complex chronic obstructive pulmonary disease; cardiologists for heart failure, etc.) alongside a family physician or palliative care specialist, to address symptoms and quality of life.^{9,10}

Continuity of care has been defined as “*the degree to which a series of discrete healthcare events is experienced as coherent and connected and consistent with the patient’s medical needs and personal context*”,¹¹ and is considered to be one driver of quality care.^{12,13} In patients with chronic diseases, greater continuity of care with the same provider is associated with improved patient satisfaction and health behaviours, and reduced incidence of hospitalization and mortality.^{14,15}

Varying patterns of physician care have been found across different end-of-life trajectories, with notable differences between cancer and non-cancer trajectories.¹⁶⁻¹⁹ Some studies have found that in patients with a terminal (i.e., cancer) end-of-life trajectory, usual provider continuity is associated with reductions in acute care use near the end of life.²⁰⁻²² However, current quantitative measures of continuity of care based on encounters with the same physician(s) are not designed to account for patterns that typically occur near the end of life such as the introduction of palliative care physicians alongside disease specialists who treat the life-limiting illness(es).^{23,24 25} Moreover, there are several approaches to measuring continuity of

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care. Examples of measures that can be applied to encounter-based healthcare data include continuity with the usual provider (e.g., usual provider continuity index²⁶) concentration of care among all providers (e.g., Bice-Boxerman continuity of care index²⁷) and the extent of sequential continuity with the same provider over time (e.g., sequential continuity index²⁸).

High-quality end-of-care for both cancer and other end-of-life trajectories has been prioritized in Canada,^{29,30} necessitating the investigation of health care measures that are useful as performance indicators. Little is known about the extent of continuity of care received by patients near the end of life and whether continuity differs by end-of-life trajectory and other factors. To understand the potential utility of continuity of care measures in end-of-life care, this study described measures of continuity of outpatient physician care in the last year of life in differing end-of-life trajectories and assessed factors associated with higher continuity for the usual provider continuity index,²⁶ an adapted Bice-Boxerman continuity index ²⁷ and the sequential continuity index²⁸.

METHODS

Study design and data sources

We conducted a retrospective descriptive study using linked population-based health administrative databases in Ontario, Canada, held at ICES (formerly known as the Institute for Clinical Evaluative Sciences). ICES is an independent, non-profit research institute whose legal status under Ontario’s health information privacy law allows it to collect and analyze health care and demographic data, without consent, for health system evaluation and improvement. ICES data holdings include a comprehensive set of healthcare sectors in Ontario, which has a population of over 14 million residents with mostly universal health care coverage for physician

and hospital services (see Supplementary File 1 for a description of databases used). Datasets were linked using unique encoded identifiers and analyzed at ICES.

Study cohort

The cohort comprised of all decedents 18 years of age or older who died between January 1, 2013, and December 31, 2018. Decedents who were older than 105 years at death (in case of administrative error), were ineligible for insured health services at any point in the last year of life, had an address outside Ontario at the time of death or had no administrative data (i.e., no healthcare utilization) in the five years prior to death were removed. Other exclusion criteria were living in a long-term care home at any time in the last year of life, having fewer than two outpatient physician encounters in the last year of life (to enable calculation of continuity) or having no cause of death listed (to determine decedents' end-of-life trajectory).

Outcomes of Interest

Continuity of care measures typically apply to physician care because it can be measured using routinely collected health administrative data.^{31,32} We used outpatient physician encounters from physician billing claims to the Ontario Health Insurance Plan database over the last 12 months of life, which include unique identifiers for the physician and their specialty, to calculate three indices (see Supplementary File 2 for formulae).

The *Usual Provider Continuity (UPC) index* is a measure of the proportion of ambulatory physician encounters (between 0% and 100%) that occur with the usual provider, among all ambulatory physician visits in a given time period.^{26,33} The index reaches a maximum value of one when all encounters are with the usual provider and a minimum value of zero when all encounters are with different providers. To determine the usual primary care physician, we used

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3 an algorithm that determines first whether the patient is formally enrolled to a primary care
4 physician, and if not then assigns the patient to the primary care physician who billed the
5 maximum value of 23 commonly billed primary care codes in 2 years.^{34,35}
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10 The *Bice-Boxerman Continuity of Care (CoC) index* measures the extent of dispersion of
11 care across different healthcare providers. The index reaches a maximum value of one when all
12 encounters are with the same provider and a minimum value of zero when all encounters are to
13 different providers.²⁷ It accounts for the increasing number of visits with increasing numbers of
14 physicians. It can be used to measure continuity within a specific specialty (e.g., usual family
15 physician among all family physicians involved) or across different specialties. We used the
16 modification by Jones et al.(2020) which accounts for the reduction in the index when a patient
17 sees multiple physician specialties, as the physicians operating within the different specialties
18 will be different. ³⁶ The modified index reaches 1.0 when all encounters within each specialty are
19 with the same physician and approaches zero when each encounter is to a different physician.
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33 The *Sequential Continuity (SECON) index* is the fraction of sequential encounter pairs at
34 which the same provider is seen.²⁸ It ranges from 0 to 1.0. The index considers both the number
35 of providers and the number of consecutive encounters with each provider. A patient who has all
36 encounters with the same provider will have a score of 1.
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42 **Decedent characteristics and contextual factors**
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44 Decedents' end-of-life trajectory, socio-demographic characteristics and comorbidities
45 were identified. Age at time of death and sex were obtained from the Registered Persons
46 Database (RPDB). Neighbourhood level income and rurality were assigned based on decedents'
47 postal code from the RPDB at one year prior to death, linked through a postal code conversion
48 file to 2011 Canadian census data. Prevalent comorbidities were determined by looking back 5
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years from the death date, using previously developed algorithms that use diagnosis codes and medication data to assign conditions.³⁷⁻⁴⁶

Decedents' end-of-life trajectory was assigned according to major categories of functional decline at the end of life, which are defined by main cause of death as per prior research,^{1,47,48} and have also been validated in Canada.^{2,49} These trajectories included: terminal illness (e.g., cancer), organ failure (e.g., chronic heart failure), frailty (e.g., Alzheimer's disease), sudden death (i.e. unanticipated events such as accidents) and other causes. Cause of death information used in this algorithm was captured through the Ontario Registrar General – Deaths database.

Statistical Analyses

Descriptive results are presented as proportions for categorical variables, and as mean and standard deviation (SD), or median (with interquartile range (IQR) for variables with skewed distribution) for continuous variables. For socio-demographic and health-related factors we examined age category, sex, rural residence, terciles of the number of prevalent conditions and quintiles of the number of outpatient physician encounters in the last 12 months of life.

We created histograms of indices and calculated mean, SD, median and IQR, for the overall cohort and each end-of-life trajectory group. We conducted a multivariable logistic regression using entry method complete case analysis for each index to evaluate decedent and contextual factors associated with having greater than 0.50 continuity of care. This cutoff was chosen based on the distribution of the indices in our study, and on previous literature for indicating at least moderate continuity.⁵⁰⁻⁵⁴ Variables examined for association with continuity included age group (reference group: 19 – 44), sex (reference group: Female), rural versus urban

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residence (reference group: urban), neighbourhood income quintile (reference group: lowest quintile), end-of-life trajectory (reference group: sudden death), comorbidity status (reference group: lowest empirical tercile), and quintile of the volume of physician outpatient encounters (reference group: lowest quintile). Odds ratios (OR) and 95% confidence intervals (CI) were produced for the odds of the index score being 0.5 or higher.

Statistical significance was set at $p < 0.05$ (two-tailed). All analyses were completed using SAS Enterprise Guide v. 7.15.

Ethics Approval

The use of data in this project was authorized under section 45 of Ontario’s *Personal Health Information Protection Act*, which does not require review by a Research Ethics Board.

RESULTS

From January 1, 2013, to December 31, 2018, there were 589,977 decedents, resulting in a cohort of 417,867 for analysis after applying exclusion criteria (Figure 1). The mean age of decedents was 74.9 years (SD 14.7) and 46.1% were female (Table 1). Approximately one-third of decedents were categorized in each of the terminal illness (36.0%), and organ failure (33.1%) trajectories, followed by frailty (19.8%), sudden death (5.2%) and other (5.9%).

Decedents had a mean of 17.6 (median 14) outpatient physician encounters in the last year of life. Figure 2 shows the means and distributions of each measure for each trajectory. The overall mean UPC, CoC and SECON indices were 0.37, 0.30 and 0.37 (median 0.32), respectively (Figure 2). Decedents with frailty (mean 0.44, 0.37, 0.40 respectively) or sudden death (mean 0.44, 0.37, 0.41 respectively) trajectories experienced higher continuity. Decedents

with a terminal illness trajectory experienced the lowest continuity for UPC, CoC and SECON (mean 0.22, 0.23 and 0.33 respectively).

The proportion of decedents with continuity ≥ 0.50 , was 33.1%, 17.5%, and 29.6% for UPC, CoC, and SECON respectively. For all indices there was a negative association between each trajectory and higher continuity, compared to the sudden death category (Figure 3). The odds ratio was lowest for the terminal illness trajectory for the UPC (OR= 0.37; 95% CI= 0.35, 0.38), CoC (OR=0.31, 95% CI=0.30, 0.32) and SECON (OR=0.60, 95% CI=0.58, 0.62). A higher number of outpatient physician encounters was also strongly negatively associated with higher continuity for all three indices. Compared to the age group 19-44 years, age groups 85-94 year and 95 years and older were consistently positively associated with higher continuity, as was rural residence compared to urban.

INTERPRETATION

In this study of continuity of care assessed using outpatient physician encounters in the last year of life, mean continuity was low. The three measures of continuity were generally similar, with sequential continuity being slightly lower on average than the usual provider continuity and the Bice-Boxerman continuity indices. Continuity varied by decedents' end-of-life trajectory and was lowest for decedents with a terminal illness trajectory across all three continuity measures. Decedents with a higher number of overall outpatient physician visits were also at risk of experiencing lower continuity, while those who were 85 years of age and older and those with a rural residence were more likely to experience higher continuity as measured by all three indices.

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High quality palliative care in Canada has been largely developed in response to the end-of-life trajectory of cancer.^{19,55,56} Therefore, it was surprising to find that continuity, considered an indicator of quality care, was lowest among decedents with a cancer trajectory. High quality palliative care may not be contingent on care being provided by the same individual, and other important aspects of continuity such as informational and management-related may be achieved through a team approach to palliative care that is not reflected in current continuity indices.

The result of low continuity may not be surprising, given that closer to the end of life, patients may experience exacerbations of the diseases contributing to their death. Only one-third of decedents had more than half of their physician encounters with their usual family physician in the last year of life. More physicians may become involved in managing the disease itself, while palliative care or family physician encounters are driven by symptom management. It is well documented that active disease management often continues until close to the end of life in patients with progressive life-limiting illnesses.⁵⁷⁻⁵⁹

In addition to the negative strong associations between end-of-life trajectory and volume of encounters and continuity, continuity was also related to demographic characteristics. Living in a rural area and being 85 years of age and older were associated with continuity of 0.5 or greater. The relative lack of access to specialized palliative care in rural areas compared to urban areas may result in less ability to receive care from multiple physicians in outpatient settings.^{60,61} Previous research has shown care by family physicians increases relative to specialists with advancing age and comorbidities ³⁷ which may partially explain the greater continuity in older decedents.

Limitations

This study has some limitations. We did not account for disruptions in continuity caused by transitioning in and out of hospital, and which may lead to new consultations in outpatient settings. The health administrative data includes only encounters with physicians and, therefore, we could not identify models of team care at the end of life that include key roles for other professionals such as nurses and personal support workers, as continuity with these providers has been identified as an important factor in patients' end of life experience.^{5,25 62} This study is based on one Canadian province (representing approximately 40% of the population) and while all jurisdictions have mostly universal health care coverage, systems are organized provincially, therefore the results may not be generalizable in all respects.

Conclusions

Given the consistently low continuity of care found using three measures that reflect different aspects of care patterns, current concepts of continuity may not be appropriate indicators of quality of health care in the end-of-life period. This is reinforced by the result that continuity was lowest for decedents with a terminal illness trajectory, even though they are most likely to receive high quality palliative care. Further research is needed to understand how to define and measure aspects of continuity of care that are linked to improved outcomes for various illness trajectories and be useful system performance indicators.

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DECLARATIONS

Contributor Statement

MH, SI, PT, AH conceived the study. All authors designed the study and interpreted the results. AG analyzed the data. MH wrote the manuscript. All authors revised the manuscript critically for important intellectual content, gave final approval of the version to be published, and agreed to be accountable for all aspects of the work.

Research ethics

The use of data in this project was authorized under section 45 of Ontario’s *Personal Health Information Protection Act*, which does not require review by a Research Ethics Board.

Data management and sharing

The data set from this study is held securely in coded form at ICES. While data sharing agreements prohibit ICES from making the data set publicly available, access may be granted to those who meet pre-specified criteria for confidential access, available at [www. ices.on.ca/DAS](http://www.ices.on.ca/DAS). The full data set creation plan and underlying analytic code are available from the authors upon request, understanding that the computer programs may rely upon coding templates or macros that are unique to ICES and are therefore either inaccessible or may require modification.

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Table/Figure Legend:

- Table 1: Cohort characteristics table
- Figure 1: Cohort creation flowchart
- Figure 2: Distribution of outpatient physician continuity of care in the last 12 months of life among decedents who died in Ontario, Canada, from 2013 to 2018 (n=417,627).
- Figure 3A: Associations between decedent characteristics and higher Usual Provider Continuity scores (≥ 0.50), among decedents from Ontario, Canada, from 2013-2018 (n= 416,026).
- Figure 3B: Multivariate associations between decedent characteristics and higher Bice-Boxerman Continuity of Care scores (≥ 0.50), among decedents from Ontario, Canada, from 2013-2018 (n= 416,026).
- Figure 3C: Multivariate associations between decedent characteristics and higher Sequential Continuity scores (≥ 0.50), among decedents from Ontario, Canada, from 2013-2018 (n= 416,026).

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Table 1: Profile of decedents aged 18 years or older who died between January 1, 2013, and December 31, 2018, in Ontario, Canada (excluding long-term care residents and decedents with less than the 2 outpatient encounters in the last year of life required to calculate continuity of care indices).

Variable	Total Cohort (n=417,627)
Age at death in years, n (%)	
18-44	15,135 (3.6%)
45-54	23,472 (5.6%)
55-64	54,568 (13.1%)
65-74	85,907 (20.6%)
75-84	113,939 (27.3%)
85-94	106,471 (25.5%)
95+	18,136 (4.3%)
Mean (SD*)	74.9 (14.7)
Median (IQR†)	77 (66 - 86)
Female, n (%)	192,595 (46.1%)
Rural residence, n (%)	54,575 (13.1%)
Neighborhood Income Quintile, n (%)	
1 (lowest)	103,821 (24.9%)
2	92,275 (22.1%)
3	80,112 (19.2%)
4	70,952 (17.0%)
5 (highest)	68,866 (16.5%)
End-of-life trajectory, n (%)	
Terminal Illness (e.g., Cancer)	150,254 (36.0%)
Organ Failure (e.g., CHF, COPD)	138,258 (33.1%)
Frailty (e.g., Dementia)	82,888 (19.8%)
Sudden Death	21,789 (5.2%)
Other	24,439 (5.9%)
Illness History**, n (%)	
Cancer	142,754 (34.2%)
CHF	99,307 (23.8%)
COPD	87,507 (21.0%)
Renal Disease	63,976 (15.3%)
Number of prevalent conditions, n (%)	
0-2	155,219 (37.2%)
3-4	151,350 (36.2%)
5+	111,059 (26.6%)
Mean (SD)	3.4 (2.0)
Median (IQR)	3 (2 - 5)
Patient of a primary care enrollment model, n (%)	250,301 (59.9%)
Number of outpatient physician visits in last year of life, n (%)	
Quartile 1: 2 – 6	102,388 (24.5%)
Quartile 2: 7 – 13	94,706 (22.7%)
Quartile 3: 14 – 22	112,606 (27.0%)

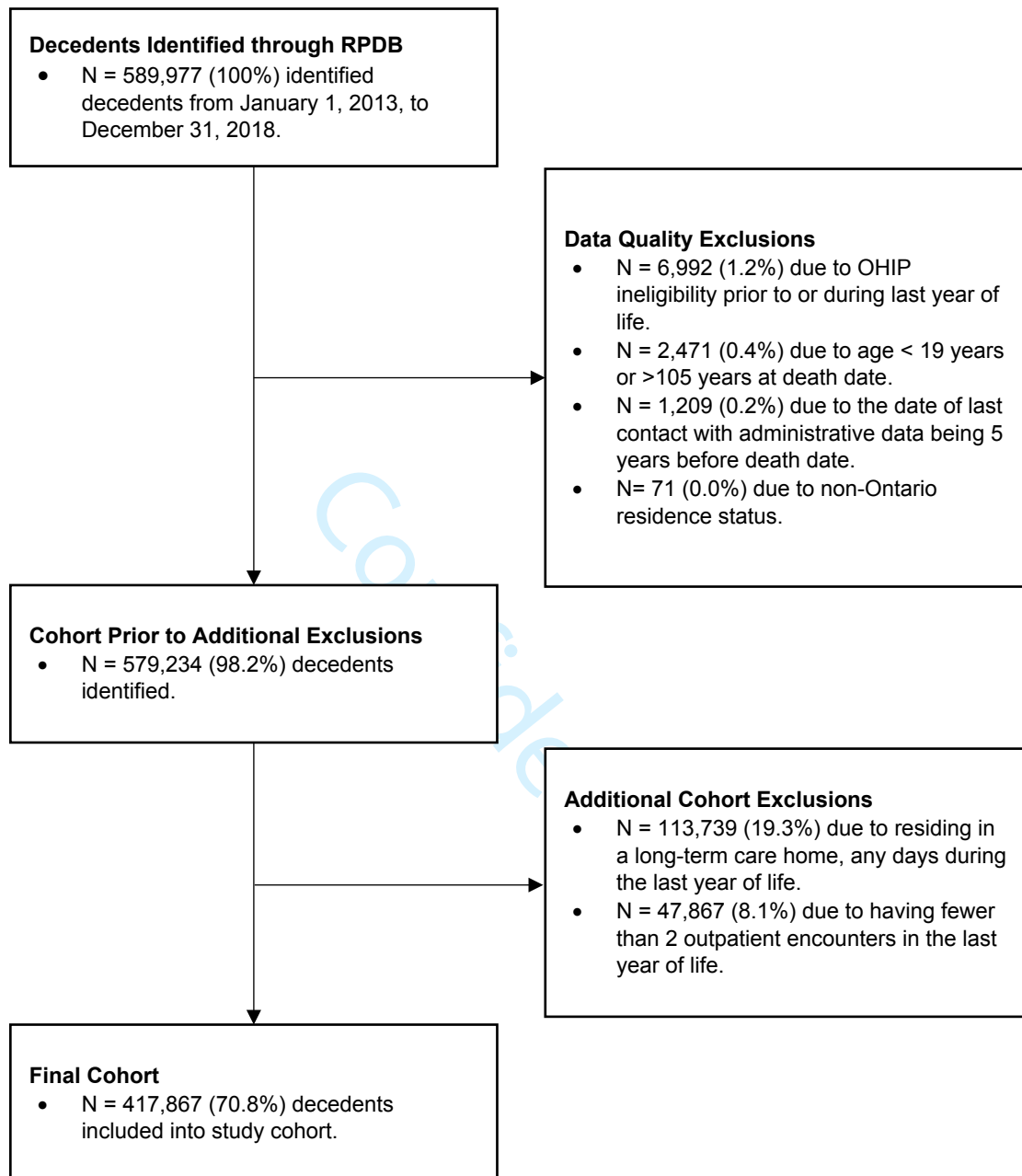
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Variable	Total Cohort
Quartile 4: > 22	107,928 (25.8%)
Mean (SD)	17.6 (13.7)
Median (IQR)	14 (8 - 24)

* Standard deviation; † Interquartile range. CHF = congestive heart failure. COPD = Chronic Obstructive Pulmonary Disease.
**Patient may have these chronic diseases without dying of them, as captured in 'end-of-life trajectory'.

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Figure 1: Cohort Creation Flowchart



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Figure 2: Outpatient physician continuity of care in the last 12 months of life among decedents who died in Ontario, Canada, from 2013 to 2018 (n=417,627).

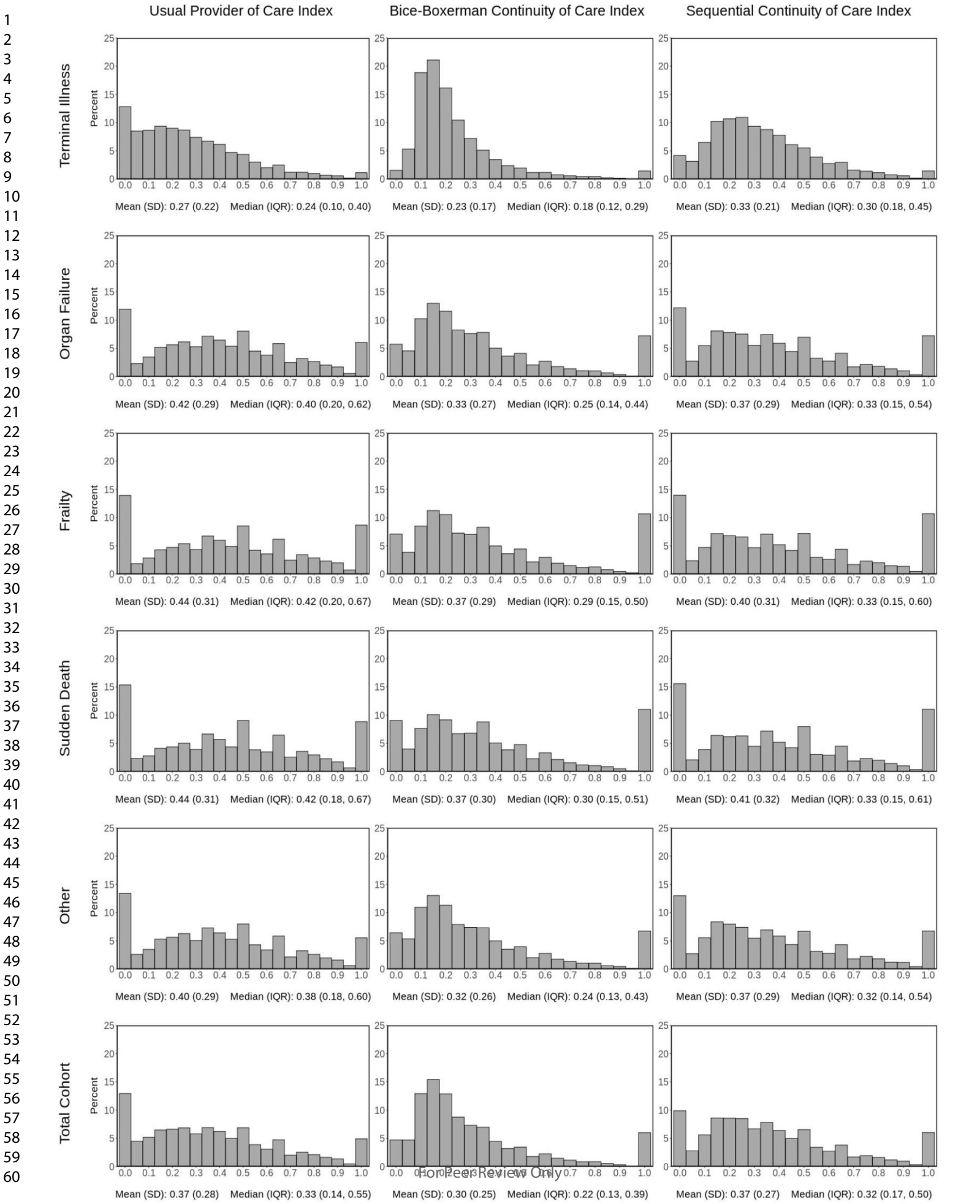


Figure 3A: Multivariate associations between decedent characteristics and higher Usual Provider Continuity scores (≥ 0.50), among decedents from Ontario, Canada, from 2013-2018 (n= 416,026).

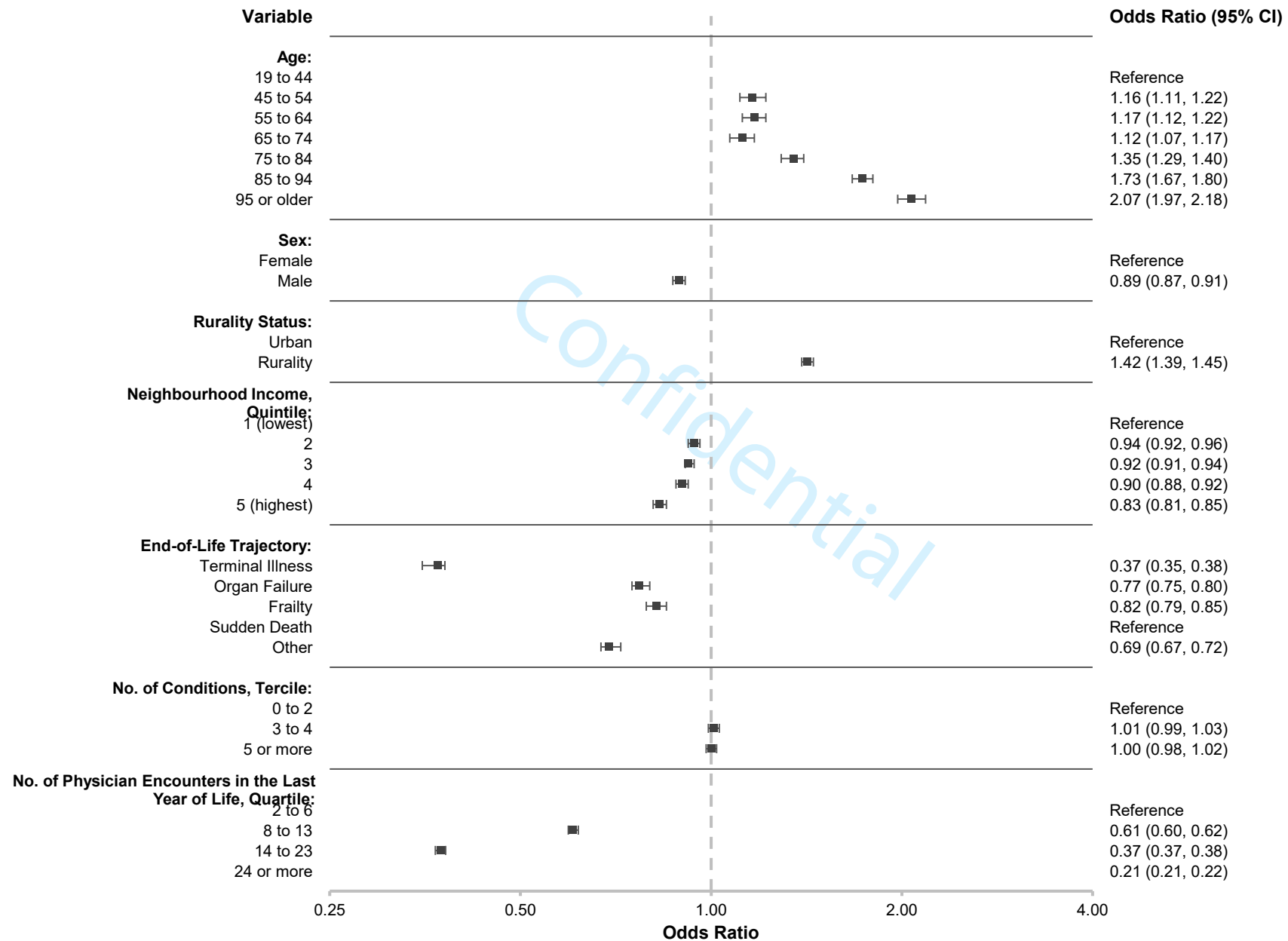


Figure 3B: Multivariate associations between decedent characteristics and higher Bice-Boxerman Continuity of Care scores (≥ 0.50), among decedents from Ontario, Canada, from 2013-2018 (n= 416,026).

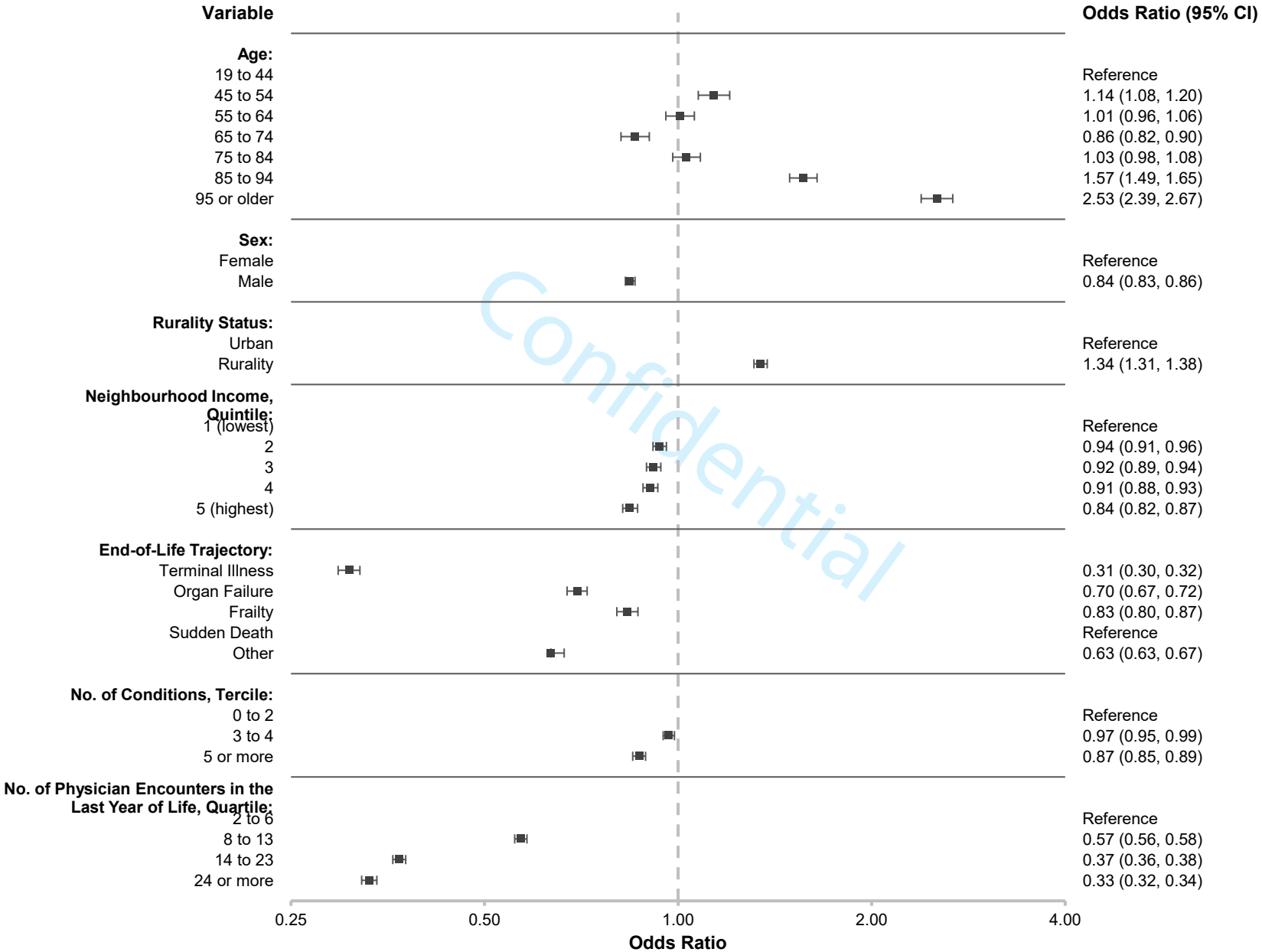
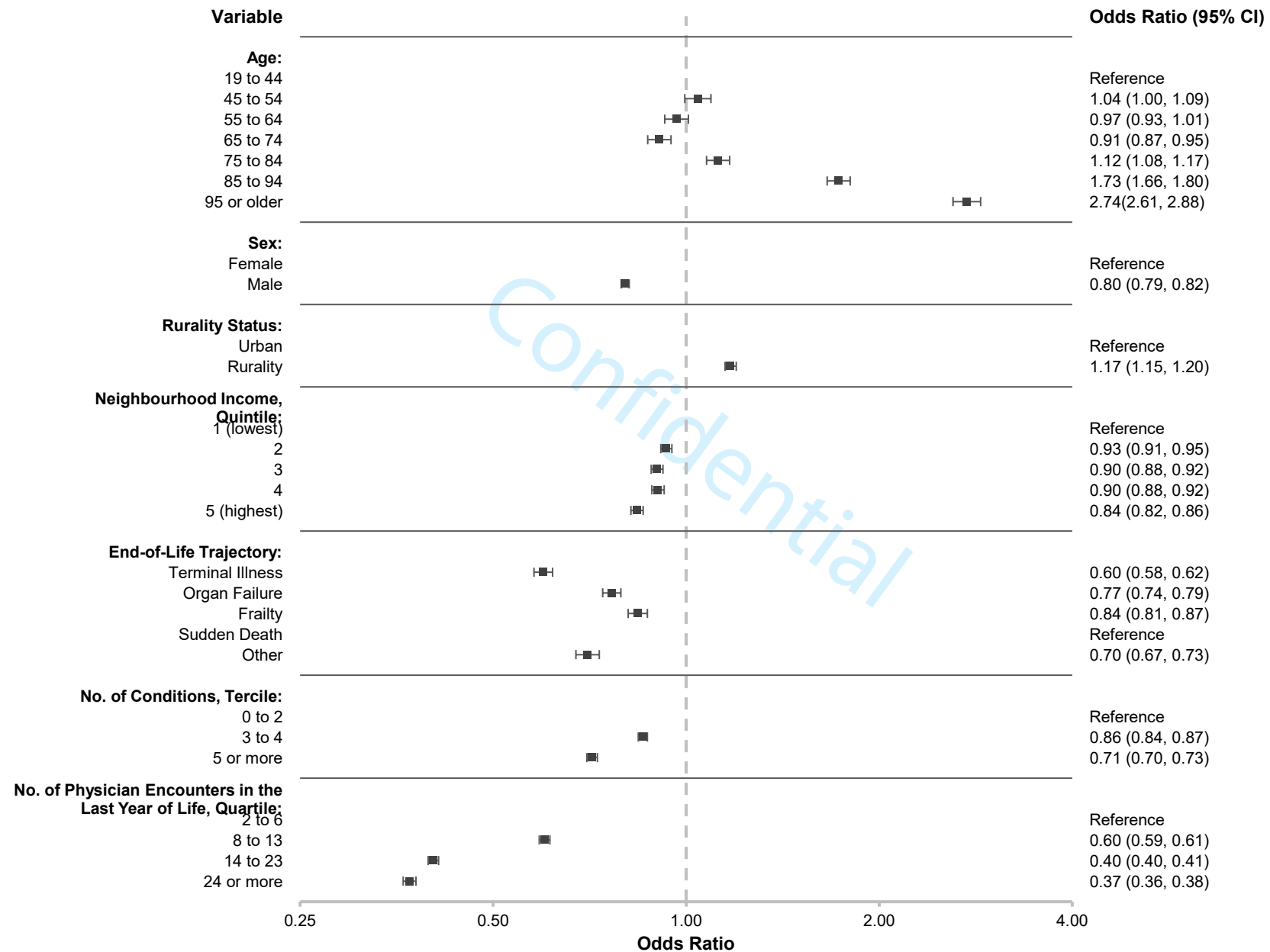


Figure 3C: Multivariate associations between decedent characteristics and higher Sequential Continuity scores (≥ 0.50), among decedents from Ontario, Canada, from 2013-2018 (n= 416,026).



Supplementary File 1: Description of health administrative databases held at ICES used in study.

Database	Content
ICES-derived cohorts	Validated cohorts of individuals with specific diseases and conditions. These include: Ontario Asthma Dataset (ASTHMA); Congestive Heart Failure (CHF) database; Chronic Obstructive Pulmonary Disease (COPD) database; Ontario Dementia Dataset (DEMENTIA); Ontario Hypertension Dataset (HYPER); Ontario Crohn’s and Colitis Cohort Dataset (OCCC); Ontario Diabetes Dataset (ODD); Ontario Myocardial Infarction Dataset (OMID); and the Ontario Rheumatoid Arthritis Dataset (ORAD).
Ontario Health Insurance Plan database (OHIP)	These data record all claims by Ontario physicians for inpatient and ambulatory visits, consultations and procedures. The data also include claims from optometrists for publicly-funded reimbursement and from laboratories for all diagnostic tests performed.
Ontario Registered Persons Database (RPDB)	Demographic, place of residence and vital status information for all persons eligible to receive insured health services in the province, including date of birth, sex, home address.
Ontario Registrar General – Deaths (ORGD) database	This database contains information (demographic, place of death, cause of death) for all decedents in Ontario.
Home Care Database (HCD)	This dataset contains clinical information for home care recipients. Information includes assessments, program admission dates, and service records.
Ontario Drug Benefit Claims (ODB)	This database contains information (recipients, payments, claims, practitioners) for the Ontario Drug Benefit Program.
Discharge Abstract Database (DAD)	This data captures patient-level information (administrative, clinical, and demographic) on hospital discharges. Discharges include deaths, sign-outs, and transfers to other healthcare settings.
Client Agency Program Enrolment (CAPE) Dataset	This dataset details a list of patients registered to a primary care organization and identifies association with a specific primary care physician and what type of primary care organization.

Supplementary File 2: Equations for continuity of care indices

Index	Equation	
Usual Provider of Care	$\max \left(\frac{n_i}{n} \right)$	n = the total number of visits n_i = the number of visits to the usual provider
Bice-Boxerman Continuity of Care Index	$\frac{\left(\sum_{i=1}^k n_i^2 \right) - n}{n(n-1)}$	k = the number of different providers seen in n visits n = the total number of visits n_i = the number of visits to i^{th} provider
Sequential Continuity Index	$\frac{\sum_{i=1}^{n-1} S_i}{n-1}$	n = the total number of visits $S_i = 1$, if the same provider is seen sequentially and 0 if otherwise.

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