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Continuity of care with the primary care physician and involvement of other physicians in the last year of life in community-dwelling adults: A retrospective population-based study.

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ABSTRACT

Objective: To describe the timing of involvement of various physician specialties over the last year of life across different levels of primary care physician continuity for differing causes of death.

Methods: We conducted a retrospective cohort study of adults who died in Ontario, Canada, between January 1, 2013, and December 31, 2018, using linked population level health administrative data were used. Outcomes were median days between death and first and last outpatient palliative care specialist encounter, last outpatient encounter with other specialists and with the usual primary care physician. These were calculated by tertile of score on the Usual Provider Continuity index, defined as the proportion of outpatient physician encounters with the patient's primary care physician.

Results: Patients' (n= 395,839) mean age at death was 76 years. With increasing category of usual primary care physician continuity, a larger proportion were palliative care generalists, palliative care specialist involvement decreased in duration and was concentrated closer to death, the primary care physician was involved closer to death, and other specialist physicians ceased involvement earlier. For patients with cancer, palliative care specialist involvement was longer than for other patients.

Conclusions: Compared to patients with lower continuity, those with higher usual provider continuity were more likely to have a primary care physician involved closer to death providing generalist palliative care.

Keywords: End-of-life care, Cohort studies, Cancer, Primary Care, Palliative Care, Continuity of Care

Abbreviations: UPC=Usual Provider Continuity; SD=Standard Deviation

KEY MESSAGES

What is already known about this topic:

- Continuity of care with a usual primary care physician is associated with several positive health care outcomes at the end of life.
- Near the end of life, multiple physician specialties may become more involved in care, disrupting continuity.

What this study adds:

- Patients with higher continuity with their usual primary care physician experienced primary care physician involvement until closer to death.
- Patients with higher continuity also experienced less frequent and shorter duration of palliative care specialist involvement and earlier cessation of other specialist physician involvement compared to decedents with lower continuity.

How this study might affect research, practice or policy:

- Patients with higher continuity of care scores are more likely to receive generalist rather than specialist-led end-of-life care, compared to those with lower continuity scores.
- Future research should seek to understand the most important aspects of continuity of primary care at the end of life.

BACKGROUND

In many health care systems in resource rich or developed countries, patients have a usual primary care physician (i.e., general practitioner or family physician) who is the main provider or manager of care for most diseases and across all stages of life. People with progressive life-limiting illnesses often experience increased symptom burden, distress and care needs in the last months of life.[1, 2] Primary care physicians are the most frequent providers of care in the community over the last year of life,[3] however towards the end of life, patients also experience an increasing level of involvement of various physicians across different care settings.[4-6] Patterns vary by disease, with patients with cancer more likely to receive care from specialized clinics until near the end of life and to receive palliative care outside their usual primary care setting compared to patients with other causes of death.[7, 8]

Continuity of care is 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”.[9] Substantive evidence demonstrates that continuity with primary care is associated with decreased emergency department use, hospitalizations, and decreased mortality,[10-12] which may align with patient preferences for end-of-life care.[13-15] There is evidence that continuity of care is also associated with preventive care[16] and patient satisfaction.[17] The involvement of primary care at the end of life is associated with reduced use of hospitals,[16] intensive care and costs[18-22] however one population-level study found that continuity of care with the primary care physician in the last year of life is low compared to what is generally considered good continuity of primary care.[22]

We sought to understand how the duration of physician involvement varied over the last year of life according to the extent of continuity of care with the usual primary care physician. Specifically, we described the duration of involvement relative to the patients’ death date and volume of care provided in the outpatient setting by the usual primary care physician, palliative

care specialists and other physician specialties, across different levels of continuity with their usual primary care physician for different cause of death categories.

METHODS

Study design and data sources

We conducted a retrospective descriptive study using linked population-based health administrative databases in Ontario, Canada. Ontario is Canada's most populous province with nearly 14 million residents. All residents of Ontario have universal access to hospital care and medically necessary physicians' services through the Ontario Health Insurance Plan (OHIP) (see Supplementary File 1 for a description of databases used). Datasets were linked using unique encoded identifiers and analyzed 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 (section 45 of Ontario's Personal Health Information Protection Act [PHIPA]) allows it to collect and analyze health care and demographic data, without consent, for health system evaluation and improvement. Projects that use data collected by ICES under section 45 of PHIP for these purposes, and use no other data, are exempt from REB review.

Study cohort

Adults who died between January 1, 2013, and December 31, 2018, were included. We excluded people who were older than 105 years of age at death (in case of administrative error in documenting the persons' date of birth or death date), were ineligible for OHIP at any point in the last year of life, had an address outside Ontario at the time of death or had no healthcare utilization in the five years prior to death. Other exclusion criteria included residing in a long-term care home at any time in the last year of life as the billing arrangement is such that each

billing does not correspond to an encounter. We also excluded people with no cause of death listed (precluding assignment to a cause of death category variable, described below), or assigned a “sudden death” category (i.e., injury, accident) where health care would not be expected to reflect the person’s proximity to death.

Measures

We categorized outpatient physician encounters into those provided by primary care physicians, palliative care specialists and all other specialist physicians. Physician specialty was obtained through the OHIP billings. An additional step was taken to identify palliative care ‘specialists’, because their identification is not possible using the health administrative data, and palliative care codes can be billed by any type of physician. In Canada, palliative care was only recently recognized as a designated subspecialty. Most palliative care specialists in Canada have pursued a credential through additional formal training in palliative care (i.e., 1-year training following completion of family medicine residence) or informal training through electives and/or continuing medical education. Therefore, to identify physicians likely to be functioning as palliative care specialists, we used a previously created algorithm. The threshold of 10% or more of billings as palliative care had high sensitivity and positive predictive value for identifying physicians who self-reported to be palliative care focused.[23] This threshold has also been endorsed by palliative care experts in Ontario to represent physicians likely to have advanced credentials in palliative care.[24] To apply this algorithm, we identified physicians providing any palliative care during the last year of life for the cohort. Looking back two years from the first service provided to the cohort patient, we identified the percentage of palliative care billing codes for each physician across all their patients. Based on previously identified patterns of

palliative care provision by physicians in Ontario, we also created a category of palliative care ‘generalists. These were physicians of any specialty who likely do not have a focused practice in palliative care, but who billed any palliative care services up to 10% of their total billings.[24] We applied the algorithm to the physicians providing care to individuals during the study period, January 1, 2012, to December 31, 2018, using billing codes.

We used the *Usual Provider Continuity (UPC) index* as the continuity of physician care measure, calculated as the proportion of outpatient physician encounters (between 0% and 100%) that occur with the usual provider, among all outpatient physician visits in a given time period.[25, 26] The UPC index was calculated using encounters in the last year of life to ensure the timeframe for selecting the usual provider did not overlap with the timeframe for the index calculation. We determined the usual provider as the usual primary care physician by first ascertaining *patients formally registered to a primary care organization or physician who operates under a capitation payment model*, , and subsequently assigning patients without a registered physician to the primary care physician who billed the most primary care codes within the two years prior to the last year of life.[27]

We categorized our population into 5 continuity groups including individuals who did not have a usual primary care physician identified, individuals without any encounters in the last year of life with their identified usual primary care physician resulting in a UPC score of 0.0, and low, medium, and high continuity groups based on tertiles of the UPC.

Outcomes

The outcomes of interest were the timing of physician encounters in relation to patients’ death. Timing was defined as a) days between the last outpatient encounter with the usual

primary care physician and death, b) days between the last outpatient encounter with any specialist physician and death, and c) days between the first and last outpatient palliative care-related encounter from a palliative care specialist and death.

Patient characteristics

Patients' cause of death category, socio-demographic characteristics and comorbidities were identified. Neighbourhood level income and rurality were assigned based on patients' postal code at one year prior to death, linked through a postal code conversion file to 2011 Canadian census data. Prevalent comorbidities were determined by looking back five years from the death date, using previously developed algorithms to assign the prevalence of 18 conditions.[28-36]

Each patient's cause of death category 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, 37]¹ and have been validated in Canada.[2] These categories included: terminal illness (mostly cancer), organ failure (e.g., heart failure), frailty (e.g., Alzheimer's disease), sudden death (i.e., anticipated events such as accidents) and a grouping of other causes (e.g., infections). Cause of death information used in this algorithm was captured through the Ontario Registrar General – Deaths database.

Analyses

Descriptive results are presented as proportions for categorical variables, and as mean and standard deviation (SD), or median (with interquartile range for variables with skewed distribution) for continuous variables. We created whisker plots of the outcomes, stratified by

UPC tertiles, and calculated the mean, SD, median and interquartile range, for the total cohort and for each cause of death category. We conducted a sensitivity analysis to consider the impact of dying in the hospital on the timing of the final physician encounter by excluding patients who died in hospital and reporting the duration of physician involvement for patients who died in the community. All analyses were completed using SAS Enterprise Guide v. 7.15.

RESULTS

The cohort included 395,839 patients (Figure 1). The mean age was 75.9 (SD 13.7) at death (Table 1). The most common cause of death category was terminal illness (38.0%), then organ failure (34.9%), frailty (20.9%) and other causes (6.2%).

In the last year of life, patients had a mean of 17.9 (SD 13.8) outpatient physician encounters, 8.1 (SD 8.0) with family physicians, 2.2 (SD 5.8) with palliative care specialists and 7.6 (SD 7.8) with all other specialist physicians (Table 2). As UPC tertile increased, the percentage of patients who experienced at least one encounter with a palliative care specialist decreased (Tertile 1: 47.0%; Tertile 2: 28.1%; Tertile 3: 13.7%). Patients in higher UPC tertiles also had slightly higher percentages of their identified usual provider family physician being a palliative care generalist (Table 2).

Across increasing UPC tertiles, patients had increasingly later encounters with their usual primary care physician.. The last usual primary care physician encounter occurred 121 days from death for tertile 1, 49 for tertile 2, and 29 for tertile 3 (Figure 2, Supplementary File 2). Palliative care specialist involvement decreased in duration and concentrated closer to patients' death date. For tertile 1, the first palliative care billing by a palliative care specialist occurred 45 days before death, and the last palliative care billing occurred 8 days before death. For tertile 2, the first palliative care billing occurred 23 days before death, and the last palliative

care billing occurred 7 days before death. For tertile 3, the first palliative care billing occurred 14 days before death, and the last palliative care billing occurred 6 days before death. As tertiles increased, usual primary care physician care was increasingly concentrated closer to death while all other specialist physicians (excluding palliative care specialists) ceased involvement earlier. For patients without a usual primary care, their first palliative care billing from a palliative care specialist occurred 23 days before death and the last billing occurred 5 days before death, while their last specialist encounter was 27 days prior to death. For patients without encounters with their usual primary care physician in the last year of life, the first palliative care billing from a palliative care specialist occurred 32 days before death and the last billing occurred 6 days before death, and their last specialist physician encounter occurred 33 days prior to death. Results within each cause of death category were similar to overall results, apart from palliative care specialist involvement starting earlier and ending later among patients with the terminal illness cause of death category compared to patients in other categories (Figure 3). We conducted a sensitivity analysis by excluding 173,184 (29.4%) patients who died in a hospital to measure whether duration of physician involvement would be different for patients who died in the community. Despite this exclusion, the identified patterns of physician involvement remained similar (Supplementary File 3 & 4).

DISCUSSION

Main Findings

In this study of people at the end of life in Canada, those in the highest category of usual primary care physician continuity experienced care from their primary care physician closer to death and were less likely to have palliative care specialist involvement compared to those with lower continuity of care. For patients in the lowest continuity of care category, specialists other than primary care or palliative care remained involved closer to death compared to patients in the highest continuity of care category. The proportion of patients whose usual primary care physician was a palliative care generalist increased across categories of increasing continuity, although most patients' primary care physicians were not palliative care generalists. Patients without an identified usual primary care physician or those that did not see their usual

primary care physician in the last year of life experienced earlier initiation and longer duration of palliative care specialist involvement compared to patients with higher continuity. Altogether, these results suggest that patients experiencing higher continuity of care with their primary care physician also have their end-of-life care addressed by this physician.

For patients with organ failure, frailty and other non-cancer causes of death, the involvement of a palliative care specialist was concentrated in the last 20 days of life, regardless of continuity with the primary care physician. Patients in the terminal illness cause of death category who had the lowest primary care physician continuity or no primary care physician contact experienced earlier initiation and longer involvement of a palliative care specialist. This would suggest that for patients dying with cancer, primary care physicians are less involved in palliative care compared to palliative care specialists. Our results align with previous research in which specialized palliative care services in Canada are more commonly provided to patients with cancer compared to non-cancer causes of death, and for longer durations, compared to patients with non-cancer deaths.[24, 38, 39]

Strategies to achieve access to palliative care have emphasized the importance of shared-care models led by primary care physicians with expert palliative care consultations when needed.[40-42] Our results show that there are various physicians involved at different times near the end of life. There was involvement of the usual primary care physician, specialists and palliative care specialists until the end of life, especially in the group of patients with non-cancer causes of death. There is evidence that sicker more complex patients under the care of specialists continue to see them alongside their family physician close to time of death, resulting in reductions to measured continuity of care,[43] even though this may represent good care. Another study found that primary care physicians infrequently see their patients near the end of life after external home palliative care services begin.[44] Further research could investigate the extent to which physicians are collaborating in the patient's care, and whether discontinuation of encounters with specialists and primary care physicians indicates a transition to palliative care, if there are other reasons for discontinuation.

Strengths and Limitations

A strength of this study is the use of comprehensive routinely collected health administration data from one large area of Canada over several years, with nearly universal health care insurance. The health care system is similar to many other countries with publicly funded healthcare, in that a large proportion of the population has a usual primary care source. This study also has limitations. Our study population included patients who died up until December 31, 2018, the most recent available information on cause of death. Our findings may not reflect more recent patterns of health care as the COVID-19 pandemic significantly affected

healthcare delivery since early 2020. We cannot conclude from this observational study whether there are causal relationships between the involvement of different physician specialties at various times, we did not examine outcomes of care, and our analysis was descriptive in nature. Our study excluded decedents who resided in long-term care homes, and as such, our findings may not represent the care received by people residing and dying in long-term care homes.

Conclusions

Patients with high usual primary care physician continuity in the last year of life experience involvement of their primary care physician closer to the end of life, later and shorter duration of involvement of a palliative care specialist, and earlier cessation of involvement of other specialist physicians compared to those with low usual primary care physician continuity in the last year of life. For patients with cancer cause of death, palliative care specialist involvement was longer than for non-cancer causes. Patients with high usual primary care physician continuity were more likely to have a primary care physician who provides palliative care as a **generalist**. Future research should investigate the impacts of continuity of primary care and generalist palliative care for differing end-of-life trajectories.

DECLARATIONS

Conflicts of Interest

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Author Contributions

MH, SI, PT, ATH, CW, AJ, MS, 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 availability

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. 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.

Table/Figure Legend:

- Table 1: Profile of patients aged 19 years or older who died between January 1, 2013, and December 31, 2018, in Ontario, Canada, per Usual Provider Continuity (UPC) Index tertiles.
- Table 2: Outpatient healthcare utilization patterns in the last 12 months of life among patients who died in Ontario, Canada from 2013 to 2018, by Usual Provider Continuity (UPC) index tertiles.
- Figure 1: Cohort creation flow diagram.
- Figure 2: Timing of physician specialties among in the last 12 months of life among patients who died in Ontario, Canada from 2013 to 2018, per Usual Provider Continuity (UPC) index tertiles.
- Figure 3: Timing of involvement of physician specialties among in the last 12 months of life among patients who died in Ontario, Canada from 2013 to 2018, per Usual Provider Continuity (UPC) index tertiles and cause of death category.

Supplementary File Legend:

- Supplementary File 1: Description of health administrative databases held at ICES used in study.
- Supplementary File 2: Timing of physician specialties among in the last 12 months of life among patients who died in Ontario, Canada, per by cause of death category, from 2013 to 2018, per Usual Provider Continuity (UPC) index tertiles.
- Supplementary File 3: Timing of physician specialties among in the last 12 months of life among patients who died in the community in Ontario, Canada from 2013 to 2018, per Usual Provider Continuity (UPC) index tertiles.
- Supplementary File 4: Timing of physician specialties in the last 12 months of life among patients who died in the community in Ontario, Canada from 2013 to 2018, per Usual Provider Continuity (UPC) index tertiles and cause of death category.

Table 1: Profile of patients aged 19 years or older who died between January 1, 2013, and December 31, 2018, in Ontario, Canada, per Usual Provider Continuity (UPC) Index Tertiles.

Variable	Total Cohort N = 395,839	No usual primary care physician identified.	No encounters with usual primary care physician. (UPC = 0.000)	UPC Tertile 1 (0.004 - 0.249)	UPC Tertile 2 (0.250 - 0.499)	UPC Tertile 3 (0.500 - 1.000)
		N = 13,013	N = 76,540	N = 102,532	N = 97,034	N = 106,720
Age at death in years, n (%)						
19-44	8,983 (2.3%)	587 (4.5%)	3,047 (4.0%)	2,678 (2.6%)	1,236 (1.3%)	1,435 (1.3%)
45-54	19,815 (5.0%)	1,210 (9.3%)	5,333 (7.0%)	6,170 (6.0%)	3,499 (3.6%)	3,603 (3.4%)
55-64	50,919 (12.9%)	2,886 (22.2%)	10,953 (14.3%)	16,214 (15.8%)	10,709 (11.0%)	10,157 (9.5%)
65-74	83,254 (21.0%)	3,185 (24.5%)	14,786 (19.3%)	26,402 (25.8%)	21,278 (21.9%)	17,603 (16.5%)
75-84	111,180 (28.1%)	2,676 (20.6%)	17,794 (23.2%)	29,297 (28.6%)	31,553 (32.5%)	29,860 (28.0%)
85-94	103,925 (26.3%)	2,033 (15.6%)	20,158 (26.3%)	19,480 (19.0%)	25,608 (26.4%)	36,646 (34.3%)
95+	17,763 (4.5%)	436 (3.4%)	4,469 (5.8%)	2,291 (2.2%)	3,151 (3.2%)	7,416 (6.9%)
Mean (SD*)	75.9 (13.7)	70.1 (14.8)	74.7 (15.5)	73.2 (13.2)	76.8 (12.1)	79.2 (12.9)
Median (IQR†)	78 (67 - 86)	70 (60 - 82)	77 (64 - 87)	74 (65 - 83)	79 (69 - 86)	82 (72 - 89)
Female, n (%)	184,818 (46.7%)	5,340 (41.0%)	37,245 (48.7%)	46,871 (45.7%)	43,003 (44.3%)	52,359 (49.1%)
Rural residence, n (%)	51,948 (13.1%)	2,300 (17.7%)	8,597 (11.2%)	10,586 (10.3%)	12,731 (13.1%)	17,734 (16.6%)
Neighborhood Income Quintile, n (%)						
1 (lowest)	97,382 (24.6%)	4,155 (31.9%)	20,185 (26.4%)	22,473 (21.9%)	22,897 (23.6%)	27,672 (25.9%)
2	87,609 (22.1%)	2,843 (21.8%)	16,820 (22.0%)	22,123 (21.6%)	21,708 (22.4%)	24,115 (22.6%)
3	76,233 (19.3%)	2,313 (17.8%)	14,117 (18.4%)	20,105 (19.6%)	19,171 (19.8%)	20,527 (19.2%)
4	67,563 (17.1%)	1,926 (14.8%)	12,515 (16.4%)	18,322 (17.9%)	16,995 (17.5%)	17,805 (16.7%)
5 (highest)	65,599 (16.6%)	1,694 (13.0%)	12,483 (16.3%)	19,213 (18.7%)	16,009 (16.5%)	16,200 (15.2%)
Cause of death category, n (%)						
Terminal Illness (e.g., Cancer)	150,254 (38.0%)	5,633 (43.3%)	27,754 (36.3%)	59,532 (58.1%)	36,917 (38.0%)	20,418 (19.1%)
Organ Failure (e.g., CHF, COPD)	138,258 (34.9%)	4,102 (31.5%)	26,126 (34.1%)	25,645 (25.0%)	34,903 (36.0%)	47,482 (44.5%)
Frailty (e.g., Dementia)	82,888 (20.9%)	2,482 (19.1%)	17,614 (23.0%)	12,698 (12.4%)	19,101 (19.7%)	30,993 (29.0%)
Other	24,439 (6.2%)	796 (6.1%)	5,046 (6.6%)	4,657 (4.5%)	6,113 (6.3%)	7,827 (7.3%)
Number of prevalent conditions, n (%)						
Mean (SD)	3.4 (2.0)	1.8 (1.9)	3.3 (2.0)	3.4 (2.0)	3.7 (2.0)	3.5 (1.9)
Median (IQR)	3 (2 - 5)	1 (0 - 3)	3 (2 - 5)	3 (2 - 5)	3 (2 - 5)	3 (2 - 5)

* Standard deviation; † Interquartile range.

Table 2: Outpatient healthcare utilization patterns in the last 12 months of life among patients who died in Ontario, Canada from 2013 to 2018, by Usual Provider Continuity (UPC) index tertiles.

Outcome	Total Cohort N = 395,839	No usual primary care physician identified.	No encounters with usual primary care physician (UPC = 0.000)	UPC Tertile 1 (0.004 - 0.249)	UPC Tertile 2 (0.250 - 0.499)	UPC Tertile 3 (0.500 - 1.000)
	N = 395,839	N = 13,013	N = 76,540	N = 102,532	N = 97,034	N = 106,720
No. encounters with all physicians						
Mean (SD)	17.9 (13.8)	12.3 (12.2)	16.2 (15.0)	25.6 (15.1)	18.1 (10.9)	12.2 (10.0)
Median (IQR)	15 (8 - 24)	8 (4 - 17)	12 (5 - 22)	23 (15 - 33)	16 (10 - 24)	10 (5 - 16)
No. encounters with primary care physicians						
Mean (SD)	8.1 (8.0)	3.8 (6.5)	6.4 (9.1)	8.8 (8.8)	8.5 (6.0)	8.8 (7.6)
Median (IQR)	6 (3 - 11)	2 (0 - 5)	3 (1 - 9)	6 (3 - 11)	7 (4 - 11)	7 (4 - 11)
No. encounters with palliative care specialists						
Mean (SD)	2.2 (5.8)	2.0 (5.6)	2.7 (7.1)	4.3 (7.6)	1.4 (3.2)	0.6 (3.3)
Median (IQR)	0 (0 - 2)	0 (0 - 2)	0 (0 - 2)	1 (0 - 6)	0 (0 - 1)	0 (0 - 0)
No. encounters with all other specialist physicians						
Mean (SD)	7.8 (7.8)	6.5 (7.2)	7.0 (8.3)	12.5 (9.4)	8.2 (5.9)	2.8 (3.2)
Median (IQR)	5 (2 - 11)	4 (2 - 9)	4 (2 - 10)	11 (6 - 17)	7 (4 - 11)	2 (0 - 4)
Any encounters with a palliative care specialist (>10% palliative care billings), n (%)	133,343 (33.7%)	4,381 (33.7%)	27,390 (35.8%)	55,535 (54.2%)	31,605 (32.6%)	14,432 (13.5%)
Patient's identified usual primary care physician is also a palliative care generalist (>1% but <10% palliative care billings), n (%)	62,442 (15.8%)	-	9,504 (12.4%)	14,203 (13.9%)	16,343 (16.8%)	22,392 (21.0%)

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