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Title: Do patient characteristics determine who receives care from their family physician near the end of life after referral to home care? A retrospective cohort study

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Reviewer 1: Dr. Romaine Gallagher

Institution: Providence Health Care

General comments (author response in bold)

Thank you for the chance to review this article. It is great to see data on how practice actually seems to be occurring. This data appears to point out that rostered physicians do not continue to visit their patients even at end of life. There is no conjecture or data provided as to why this might be.

1. The article is too long for the information it conveys. There are several unnecessary references and sentences some of which I have tried to suggest in the attached manuscript. It is not necessary to refer to work previously validated and then explain the validation.

We appreciate the review and the suggestion to focus this work on the salient points. We have shortened the introduction. We did not receive the attached manuscript (but would be happy to look at again), however, we have updated the section describing the validation of the disease trajectories:

Pg 7: removed “using the International Classification of Diseases, 10th Revision (ICD-10) codes and a modified Delphi process to discriminate how cause of death corresponds to similar health care utilization costs and illness trajectories”

2. I question the assumption that referral to home care means the patient needs more medical attention. I believe you need to justify that as a marker.

We appreciate this insight and agree that the medical complexity of a patient cannot be determined by a referral to homecare. The referral to home care was chosen as a system-level indicator that narrows our population to those living in the community with recently recognized needs for homecare: a service which is designed for those who require additional supports to be able to live independently – which is the stated mandate of the Home and Community Care sector of the Ontario government.⁹

3. Strongly suggest that you reveal how many patients in Ontario are rostered physicians as compared to those who are not. This should not just be mentioned in the limitations but should be up front in the introduction.

The number of Ontario patients enrolled to a physician in 2012 was 9.9 million and represented 73% of the Ontario population.¹ These numbers remain consistent in work conducted since the afore referenced study. In our cohort creation, we noted that 76.3% of homecare referred patients were rostered to a physician, which is aligned with the previous estimates of proportion of rostered patients.

We have added to the background:

Pg 5: “In Ontario between 2017 and 2018, 75% of primary care physicians belonged to a remuneration model with patient enrollment, with 73% of the population rostered to a physician.”

4. The ideal study would identify more reasons why physicians do not visit patients near the end of life. As a palliative care physician, I have seen that primary care physicians and specialists tend not to visit when palliative care is involved, and it appears to stem from physicians not understanding the value of their presence and not knowing what to say to people when they can no longer offer a treatment. I think some comments about this may add more than data to your study and may spark more useful recommendations for education of physicians.

We are also interested in the reasons why physicians do not visit patients near the end of life. Ongoing quantitative and qualitative work by our team is looking at physician-related factors that contribute to this dearth of care. Thank you for the insights! We hesitate to add information about these reasons as we believe it may be out of scope for this analysis regarding patient-related characteristics. We have included the need for future research in our conclusion:

Pg 12: “[Our findings highlight the need] ... to explore physician- and system-related factors that influence the provision of home visits, and to outline...”

Reviewer 2: Dr. Ahmad Tarakji
Institution: Yarmouth Regional Hospital
General comments (author response in bold)

This is a very good study aiming mainly to find the frequency of home visits by primary care physicians for their rostered patients in their end-of-life years. It involved great efforts in linking so many databases. There are so many numbers (percentages, means with STD, odds ratio) so it is sometimes difficult to track. I have the following points that need clarification:

1- Table 1, page 17: I prefer to add a percentage in the "Total Column" for every patient's characteristic.

Yes, thank you for the suggestion. We have updated table 1 with a column percent in the total column.

2- How "Rural" status was defined?

We have defined rurality according to individual's postal codes. These are linked to other geographic identifiers that flags rural and urban areas according to the publicly available conversion file system: Statistics Canada's Postal Code Conversion File Plus (PCCF+).

Please see pg 25: Appendix II and this website:

<https://www150.statcan.gc.ca/n1/en/catalogue/82F0086X> for more details

3- For the "Frailty" group, I assume they did not have any terminal illness or organ failure that contributed to their death, isn't it?

Not necessarily. They may have multiple comorbidities; however, their cause of death is recorded as the condition that is attributed to their death. Diagnoses being coded as frailty has a trajectory that is characterized by a slow, gradual decline and is distinct from the other disease groups. The full details of how this was determined can be found here:

<https://doi.org/10.1016/j.jpainsymman.2009.04.007>

4- What is the difference between "Terminal illness" and "Organ Failure"? For example, end-stage heart failure or end-stage COPD?

The disease trajectories are determined by the individual's leading cause of death, as recorded on their vital statistics record. The list of ICD-10 codes was compiled

by a different team in Alberta and previously validated in Ontario. Table 1 of that work is shown below (<https://doi.org/10.1016/j.jpainsymman.2009.04.007>) and categorized terminal illness as ICD-10 codes for Cancer, ESRD, ALS, and HIV, while Organ Failure was classified as CHF, COPD, and other organ failure.

Trajectory	Underlying Cause of Death
Sudden death	Accidental death
Terminal illness	Cancer, ESRD, ALS, HIV
Organ failure	CHF, COPD, other organ failure
Frailty	Infections, weight loss, dementia, Parkinson's, osteoporosis, chronic heart disease
Other	Mental health, neonatal frailty, nonclassifiable

5- I did not see chronic kidney disease or End-stage renal disease (~ 10% prevalence in the general population).

Thank you! Yes, we did capture this and have updated Table 1 to include:

Prevalent conditions							
AMI	948	50	5.3%	282	29.7%	616	65.0%
Arrhythmia	6320	365	5.8%	2009	31.8%	3946	62.4%
Asthma	10110	530	5.2%	2901	28.7%	6679	66.1%
Cancer	35706	1744	4.9%	8682	24.3%	25280	70.8%
CHF	17458	1069	6.1%	5118	29.3%	11271	64.6%
COPD	14690	855	5.8%	4403	30.0%	9432	64.2%
Coronary	7569	420	5.5%	2474	32.7%	4675	61.8%
Dementia	7599	611	8.0%	1899	25.0%	5089	67.0%
Diabetes	22401	1140	5.1%	6551	29.2%	14710	65.7%
Renal Disease prevalent	11,407	584	5.1%	2,965	25.9%	7,858	68.9%
IBD	733	31	4.2%	209	28.5%	493	67.3%
Other Mental health	5215	251	4.8%	1310	25.1%	3654	70.1%
Stroke	2191	136	6.2%	547	25.0%	1508	68.8%

6- For the primary outcome, please consider a pie chart for a better understanding since it points toward the lack of service needed for patients who are dying at home from their rostered primary care physicians who know them the best. [Ed note: I'm not convinced a pie chart would be the ideal visual]

Response: We agree that we want to highlight that many patients may not be receiving services in the community near the end of life, that may contribute to higher rates of avoidable acute care use. We do not feel strongly about the addition of pie charts that are often not suggested in journals – but happy to do so if the editors desire the addition.

7- Figure 1 on page 21 should be Figure 2. Also, this figure is difficult to understand the rate of visits as “home visits per 1000 person-days” in “each month”, i. e., there are two time dimensions. Why not visits per person only?

We calculated the rates per 1000 person-days to reflect the methodology of how this rate was calculated for a population-based estimate. This is not interpretable at an individual-level, given the high variability in distribution across the population (see standard deviation in Appendix I for reference). We distributed the rate across months before death to explore whether the rate of visits remained steady or changed.

8- For secondary outcomes, page 9, needs some revisions:

- 31.1% (of the 67.2% who did not receive care from their rostered physicians) received outpatient care from non-rostered physicians so $(100 - 31.3 = 68.9\%$ did not receive any care) and $0.689 * 0.672 = 0.463$ or 46.3% of ALL patients did not receive any care from any physicians before they died, as rightly mentioned in the Interpretation section on page 10. But this does not match Appendix III, page 25 (42.9%).

We appreciate this is confusing, since we had provided a number without a data table as reference.

The 31.1% comes from the number of patients who were NOT receiving care from their rostered physician, the number in Appendix II (42.9%) is the percentage of decedents with complete cause of death information who received care from a non-rostered physician. We propose adding this as an additional appendix (IV) to clarify.

	TOTAL (column percent)	Patients with a home visit from rostered physician in last year of life	Patients with office/mana gement from rostered physician	Patients without encounter from rostered physician in last year of life
	N=58,753	N=3,125	N=16,162	N=39,466
Patients who received care from non-rostered physicians, n (%)	25,206 (42.9%)	1,975 (63.2%)	10,974 (67.9%)	12,257 (31.1%)
Palliative care specialists, n (%)	10,280 (17.5%)	867 (27.7%)	3,527 (21.8%)	5,886 (14.9%)
Palliative care generalists, n (%)	18,694 (31.8%)	1,449 (46.4%)	8,879 (54.9%)	8,366 (21.2%)
Other family physicians, n (%)	3,541 (6.0%)	248 (7.9%)	1,863 (11.5%)	1,430 (3.6%)
All other specialties (non palliative)	19,203 (32.7%)	1,507 (48.2%)	10,576 (65.4%)	7,120 (18.0%)

- Page 9: “and the most, 2.78 (STD 9.08), home visits provided ..”, most means a percentage number not mean w STD so please reward the sentence.

We agree and appreciate the suggestion. We have updates as follows:

Pg 9: “the highest mean number, 2.78 (STD 9.08), of home visits provided by palliative care specialists”

9- Appendix III: Patients who received home care from non-rostered physicians = $17.6 + 31.8 + 6.0 + 32.6 = 88\%$, not 100%.

Also, I assume there were overlaps in visits between those types of physicians, i. e., some patients were visited by more than one type of physician, right?

Yes, the percentages in this table represent the proportion of the total number of patients in the cohort of decedents with complete cause of death information (n=58,242). We did not create mutually exclusive categories, so there are overlaps with each other. There could also be overlaps with rostered physician visits, so the number of patients without any physician-based care may be underestimated.

10- One of the limitations is that databases are not accurate all the time, especially regarding documentation of all diagnoses.

We agree, this is a limitation. We have used validated methods (as noted in our methods) for most of the notable chronic conditions with high levels of sensitivity and specificity, however agree that there are still margins of error. We have added to our limitations:

Pg 11: “...data does not capture all clinical characteristics or care coordination precisely,...”

Reviewer 3: Dr. Christopher Frank

Institution: Queen's, Providence Care

General comments (author response in bold)

Thanks, as someone who has done home visits with some regularity it is always nice to see attention paid to this interesting and important part of medicine.

Questions and comments

Introduction

1. A bit of a quibble-is physician-based care really “optional” I would have assumed that the physician has responsibilities for medical care regardless of home care involvement? If you mean home-based physician care, it might be good to state that specifically.

Thanks so much for the review! We agree and have updated this sentence to reflect it:

Pg 4: “Physician home-based care is not mandated, even after homecare services are initiated”

2. Page 13 line 8: I assume that most people who are at the end stages of life (or who have significant frailty) have some form of home care services, but it would be helpful to understand why the population chosen was specifically those referred to home care towards end-of-life rather than focusing on the EOL population. Was this only because of accessibility of the data in the database? It looks like there were a lot of decedents (300000) who did not get referral to home care, which made me wonder who they were! I agree that HC referral is a marker that would tend to be associated with possible need for home visits, but for me the number without HC referral was surprisingly large.

This is an important point that our team feels must be tackled and is not due to a lack of data – although there are some patients that were self-referred or referred through another professional that were not captured in our analysis. However, there is published literature about the end-of-life period, showing a significant number of patients who receive care and die in acute care settings, rather than in the community. This analysis was intended to narrow the focus on the patients with an established relationship to a rostered physician who were also identified as needing community-based support and is likely capturing the best case scenario, as those dying without a referral to homecare or having a rostered

physician may experience even less care. We hypothesized this population would receive more home-based care and would also receive more office and telephone management. Establishing this baseline of community-based physician could be helpful in moving towards establishing when a physician could initiate care and how home care supports might be an important part of care planning.

Methods

3. Page 13 line 36-the abstract and introduction mention the last year of life but in the method section it states that the initial population was those referred in the last 5 years of life. I suspect other readers will be a little uncertain why this was done.

Our descriptive cohort was those referred in their last year of life, however we captured a larger cohort initially and modelled on all those referred in the previous five years with complete covariate information. We have updated the Appendix I and the methods:

Pg 5: "...referred to formal homecare services during the last year of life (Appendix I)."

4. Page 15, line 8-although most clinicians would agree that a dementia like Alzheimer's disease plays a significant role in development of clinical frailty, most frailty models do not specifically include cognition as a factor. Comorbidities such as seen in organ failure tend to be more congruent with models of frailty. I also understand the patients in this group would likely be in the frailty stream, especially if they are a bit older, but I am a little unclear as to how they were identified? How was organ failure separated out from frailty, particularly in an aged person?

We used a validated approach that have been shown to have high specificity and sensitivity for identifying persons whose disease progression and clinical symptoms have been characterized by one of five distinct disease trajectories: Terminal Illness, Organ Failure, Frailty, Sudden Death, and other diseases. There has been extensive work done on this by other teams, our team used the already existing definitions for this work. There are further examples and explanations referenced in our manuscript.⁸

5. Given the high rate of death in hospital in Ontario, people with long LOS before death might have an impact on the number of home visits. Is this data identified somewhere? Potentially relevant because rates of home visits go up in last 3 months of life but many older people spend weeks to months in hospital before death. Sorry if I missed this info in the charts.

Yes, we expect a large proportion of these patients would receive care in a hospital as they experience changes in health status. We did calculate the rate based on days spent in the community to account for those who went to hospital. However, there is evidence that many people remain in the community, so the low rate of visits remains an important aspect.

Other:

6. Any thoughts on why the likelihood of not having home visit was related to referral to HC being made in the last year of life? Page 17- line 5

This could be related to the high number of patients who receive palliative care and from other non-rostered physician specialities (Appendix III and IV).

7. For patients with significant illness who are not getting any primary (or specialty care) presumably they are getting care somewhere beyond the Home Care staff? Are

some of them receiving care in Emergency- is that data available as would be relevant from care and cost perspective?

Yes, we expect a large proportion of these patients would receive care in a hospital as they experience any changes in health status. This data is available and there are research studies showing the healthcare costs of the end-of-life period.^{10,11}

8. How were phone visits captured? Before the pandemic I think most people did them but never billed for phone calls to patients or to Home Care staff- we do it now but would it be captured well during study time?

We used a set of OHIP billing codes that are both telephone and care management codes (e.g. physicians bill them if they are reachable over the phone by patients or “on-call”).

K071	Acute home care supervision (first 8 weeks following admission to home care program)
K072	Chronic home care supervision (after the 8th week following admission to the home care program)
G512	Palliative care case management fee
G511	Telephone management regarding a patient receiving palliative care at home
K730	Referring - Physician to physician telephone consultation
K731	Consultation - Physician to physician telephone consultation
K732	CritiCall Referring Physician - general practice
K733	CritiCall Consultant Physician -general practice
K887	Community treatment order (CTO) initiation - including completion of form and preceding services
K888	CTO supervision including all associated CTO services except those related to initiation or renewal
K889	CTO renewal including completion of the CTO form and all preceding CTO services directly related to CTO renewal

9. My biggest concern is that there is little discussion about why rostered physicians were chosen as focus. It is mentioned that the model was presumably set up to facilitate this type of care but has not been helpful in achieving that goal obviously. I wondered how the rates would compare to similar patients in non-rostered practice model and I think that would make the paper more thought-provoking (comparing apples to apples). It was stated that the paper provides insights into the “why” the proportion with visits was low but my take-home from the paper was that the proportion was low rather than the reason. What were the insights you gleaned about “why”?

We believed this model of care would be aligned with more home-based care service provision and comprehensive care throughout the end-of-life period. We did use patients as the unit of analysis and tried to keep the focus on those receiving care from physicians with whom they had an ongoing relationship to see if we could elicit patient characteristics that would help explain “why”. For example, we thought that having a terminal trajectory, may be a characteristic that would be significantly associated with more home visits as this is characterized by a predictable, steady decline in health with evidence suggesting these patients receive some of the most comprehensive end-of-life care. However, trajectory was not significantly associated with a home visit, and although some

patient characteristics were associated with greater likelihood of a home visit, occurrence was very low regardless.

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