# Race and birth country are associated with discharge location from hospital: A retrospective cohort study of demographic differences for patients receiving inpatient palliative care

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# Summary

**Background** While past studies investigated access to palliative care among marginalized groups, few assessed whether there are differences in clinical process indicators based on demographics among those receiving palliative care. We aimed to: describe demographics among patients receiving inpatient palliative care; and evaluate whether demographic variables are associated with differences in disposition (i.e., discharge location), length of stay (LOS), and timing of inpatient palliative care referral and consultation.

**Methods** Retrospective cohort study using electronic medical record data to study patients seen by inpatient palliative care at Mount Sinai Hospital in Toronto, Canada between April 2018 to March 2019. Primary outcome was disposition. Secondary outcomes were LOS, time from admission to palliative referral, and time from referral to consultation. We summarized quantitative data descriptively and used fisher exact tests to explore relationships between categorial variables. For continuous outcomes, we ran one-way ANOVA tests.

**Findings** A total of 187 patients were referred to palliative care and met inclusion criteria. Mean age was 68.8 and 55.6% were female. 46.7% were born in Canada, 58.2% were White and 78.4% preferred English communication. Variables significantly associated with disposition were: birth country (p = 0.04), and race/ethnicity (p = 0.03). Language (F ratio = 3.6, p = 0.004) was significantly associated with time from admission to palliative care referral. No variables were associated with LOS or time from referral to consult.

**Interpretation** Inequalities in disposition, and how long it takes to refer to palliative care may exist. Further studies should focus on understanding the underlying practices that constructed, and maintained these inequalities in care.

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# Introduction

There is an imperative to make visible marginalization and exclusion in healthcare. At its core, health equity is defined as a fair and just opportunity to be healthy regardless of individual characteristics.<sup>1</sup> Health equity results from the absence of systemic and socially-produced, preventable and unjust differences in care eClinicalMedicine 2022;45: 101303 Published online xxx https://doi.org/10.1016/j.

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## **Research in context**

## Evidence before this study

Identifying health inequalities - observable differences between health outcomes or healthcare access - are the first step towards understanding health inequities, which are systemic, socially produced and preventable. Inequalities in access to palliative care services have been observed among marginalized groups and specifically among equity stratifiers including race, ethnicity, immigration history, language and age. Few studies have investigated differences in clinical process indicators associated with equity stratifiers among patients receiving inpatient palliative care consultation. Search terms included (rac\* OR cultur\* OR ethnic\* OR lanquage\* OR age OR Immigra\* OR "health equity" OR "health inequality" OR "health disparit\*") AND (palliati\* OR (end of life)). Search period was from January 2000 to September 2021. Sources searched included Pubmed, Google Scholar, and gray literature.

#### Added value of this study

In our analysis of palliative care clinical outcomes for a cohort of patients receiving specialized inpatient palliative care, we identified four patient factors that were associated with differences in clinical process indicators. Birth country and racial or ethnic group were both significantly associated with disposition (i.e., discharge location) from hospital; preferred language and age were significantly associated with time from admission to referral to palliative care.

#### Implications of all the available evidence

Among patients who receive inpatient specialist palliative care, clinical process indicators may vary along sociodemographic lines. More work is required to identify and evaluate the underlying causes of these observed differences and determine whether they represent health inequity.

between populations.<sup>2</sup> Health inequalities (i.e., observable differences between health outcomes or healthcare access) in combination with equity stratifiers (i.e., demographic characteristics such as sex, gender, ethnicity, geography, income, spiritual affiliation, and sexual orientation) are indicators for evaluating health inequities, which cannot be directly measured themselves.<sup>3,4</sup>

Quality improvement initiatives targeting health equity often begin with identification of differences between groups based on common equity stratifiers.<sup>5</sup> Observed differences can guide future work that determines whether differences are unfair and unjust – that is, whether they are inequitable. This understanding helps to target systemic issues that can be addressed.

Palliative care addresses the pain and symptom needs of patients with life-threatening illnesses with the ultimate goal of improving patients' and their caregivers' quality of life.<sup>6</sup> When a patient's needs are too complex to be met by their primary care team, palliative care specialists—clinicians with advanced knowledge and skills related to pain and symptom management, and communication about planning for death with empathy and compassion—may be consulted to help with or take over care.<sup>7–9</sup>

Inequalities in the access to and utilization of palliative care services have been observed among marginalized groups and specifically among equity stratifiers. Racial and ethnic disparities exist in palliative care.<sup>10-13</sup> For example, among decedents in Ontario, Canada, Chinese patients were more likely, and South Asian patients were less likely, to receive specialist palliative care compared to the general population.<sup>14</sup> Studies have also shown that immigrants, especially from countries where English is not the primary language, were less likely to receive specialist palliative care,<sup>15</sup> more likely to be unaware of their diagnosis, have poorer symptom control, and less likely to die at home<sup>16</sup> even if they received palliative care. Older age (>75 years) has also been associated with decreased likelihood of accessing specialist palliative care.<sup>17,18</sup> In terms of other commonly reported demographics, evidence shows that race/ethnicity contribute to challenges in end-of life care and/or unavailability of end-of life palliative care resources.<sup>19</sup> Although the research on health disparities is growing, there is less research focusing on marginalized patients receiving palliative care in Canada.

The studies described above investigated questions of access to palliative care; however, none investigated differences in clinical process indicators associated with equity stratifiers among patients receiving inpatient palliative care consultation. To address this gap in the literature, our study had two objectives. First, we described commonly used demographic variables among a cohort of patients in a tertiary hospital receiving specialized inpatient palliative care consultation. Second, we evaluated differences in clinical process indicators (i.e., discharge location, length of stay (LOS), and timing of inpatient palliative care referral and consultation) when stratified by these demographic characteristics.

## Methods

## Study design

The study used a retrospective cohort design based on data obtained from a chart review of demographic data collected as part of a regional health equity initiative and clinical data available in the electronic medical record at Mount Sinai Hospital in Toronto. This study was approved by the Research Ethics Board at Mount Sinai Hospital on January 29, 2020 (# 19-0349-C). Participants did not provide consent as this study was part of a retrospective chart review.

# Context

The inpatient palliative care team, comprised of five palliative care specialist physicians and a Clinical Nurse Specialist, provides palliative consultation to patients who are admitted to the emergency, internal medicine, oncology, general surgery, cardiology, and critical care inpatient services at Mount Sinai Hospital.

As part of a regional health equity initiative, Mount Sinai Hospital collects demographic data from patients who are seen in the follow locations: Admitting, Labour and Delivery, Medical Imaging, and Electrocardiogram-Echocardiogram using a standardized demographic form. This data is not available for the full cohort of patients because not all patients referred to the palliative care team are seen at these locations, this data is not always systematically collected, and some patients receiving palliative care may be too ill to complete these forms.

## Population

We included all patients referred to and seen by the inpatient palliative care team at Mount Sinai Hospital in Toronto, Canada between April 1, 2018 to March 31, 2019. We excluded patients who were referred to palliative care but did not receive a consultation as these patients typically have inappropriate referrals, die before being seen, or wish to not receive palliative care. We also excluded those who did not have a completed demographic form available in their chart. Our sample size was based on how many patients had completed the demographic form during the timeframe of interest, which was a hospital-wide initiative distinct from the research study. We did not conduct a sample size calculation.

#### Data sources

There were two sources of data for this study. First, demographic data that trained interviewers at Mount Sinai Hospital collected and stored in patients' electronic medical records. Items included questions regarding preferred language for communicating with health providers, whether the patient was born in Canada, race/ethnicity, religious/spiritual affiliation, sexual orientation, and total family income.

Second, additional demographic variables and clinical process indicators were obtained from the patient's electronic medical record, including: age; sex; primary diagnosis; disposition (i.e., discharge location); and dates of admission, palliative care referral, palliative care consult and discharge. When possible, these clinical process indicators were obtained from a patient visit that coincided with the date that the demographic form was collected (which was the case for 63% of the data). If this was not possible, this data was obtained from a patient's visit that occurred closest to when the demographic form was collected (which ranged from I day to 734 days). All clinical process indicators occurred during April 1, 2018 to March 31, 2019; however, the demographic characteristics might have been collected before or after this time period.

## Demographic characteristics

Demographic characteristics included age, sex, sexual orientation, birth country, year of arrival in Canada, race/ethnicity, language, religion, and income. Age was treated continuously, while all other characteristics were treated categorically. The data collection form contained many answer choices for each question, so we collapsed categories of a variable into groups representing the largest proportion of the sample. All survey questions included the answer option "prefer not to answer"; this was not treated as missing data as some participants intentionally selected this answer likely because they were uncomfortable providing this information.

#### **Clinical process indicators**

Our primary outcome was disposition, a categorical variable consisting of: died, home, palliative care unit (PCU) (including hospice), other (including rehabilitation, and long-term care). Hospice is grouped with PCU, as in Ontario, they have similar admissions criteria, services provided, and patient length of stay. All hospices in Toronto are facilities where the patient goes to stay rather than home hospice. Disposition is of particular interest to palliative care, as the inpatient palliative care team at our hospital is heavily involved in informing and facilitating discharge planning. Our secondary outcomes were hospital LOS, the time from hospital admission to palliative care referral, and the time from palliative care referral to palliative care consult (Table 1).

#### Statistical analysis

All statistical analyses were conducted using the statistical software Stata (version 13)<sup>20</sup> for Windows. Significance was assigned at the 95% confidence interval and p < 0.05. Data was analyzed using descriptive statistics. For continuous variables describing the patient's characteristics (e.g., age) or clinical outcomes (e.g., LOS), we presented the mean and standard deviation. For categorical variables (e.g., race/ethnicity), we presented their frequency and proportions. For the categorical outcome of disposition, we conducted fisher exact tests. For the outcome of disposition, and the predictor of age, we ran ANOVA. For the continuous outcomes (e.g., LOS), we ran one-way ANOVA tests. For significant models, we conducted post-hoc Tukey tests. We checked that residuals of the ANOVAs were normally distributed using Q-Q plots. For the continuous outcomes, and the predictor of age, we ran linear regression models.

The reporting of this study adheres to the RECORD checklist.<sup>21</sup>

	Disposition					
Characteristic	Died (n = 48)	Home ( <i>n</i> = 92)	PCU (n = 38)	Hospital (n = 2)	Other ( <i>n</i> = 7)	Total No. (%) of patients (n = 187)
Age (mean $\pm$ SD)	68.6 ± 16.9	66.1 ± 19.8	73.3 ± 11.3	71.5 ± 29.0	81±10.2	68·8 ± 17·6
Sex						
Female	28 (58.3)	51 (55.4)	20 (52.6)	0 (0)	5 (71.4)	104 (55·6)
Sexual Orientation						
Heterosexual	40 (85.1)	68 (77.3)	27 (73.0)	2 (100.0)	5 (83.3)	142 (78.9)
Gay	0 (0)	1 (1.1)	0 (0)	0 (0)	0 (0)	1 (0.6)
Bisexual	0 (0)	4 (4.6)	0 (0)	0 (0)	0 (0)	4 (2·2)
Prefer not to answer	7 (14.9)	15 (17.1)	10 (27.0)	0 (0)	1 (16.7)	33 (18·3)
Birth Country						
Canada	20 (42.6)	38 (42.7)	23 (62.2)	2 (100.0)	2 (28.6)	85 (46.7)
Other	25 (52.2)	36 (40.5)	9 (24.3)	0 (0)	5 (71.4)	75 (41·2)
Prefer not to answer	2 (4.3)	15 (16.9)	5 (13.5)	0 (0)	0 (0)	22 (12·1)
Year of arrival in Canada (mean +SD	$1974\pm20.3)$	$1983 \pm 20.7$	$1969\pm8.6$	0	$1973 \pm 20.9$	$1978\pm20.0$
Racial or Ethnic Group						
White (White European, White North-American)	29 (61.7)	48 (53.3)	25 (65.8)	2 (100.0)	3 (42.9)	107 (58-2)
Asian (Asian-East, Asian South, Asian South East)	9 (19.2)	19 (21.1)	1 (2.6)	0 (0)	0 (0)	29 (15.8)
Black (Black African, Black Caribbean, Black	6 (10.6)	4 (4.4)	1 (2.6)	0 (0)	0 (0)	11 (6.0)
North American, Indian-Caribbean)						
Other (Middle Eastern, First Nations, Indigenous/	1 (2.1)	3 (3.3)	2 (5.3)	0 (0)	2 (28.6)	8 (4-4)
Aboriginal, Inuit, and Metis, Other)						
Prefer not to answer	3 (6.4)	16 (17.8)	9 (23.7)	0 (0)	1 (14.3)	29 (15·8)
Preferred language						
English	41 (87.2)	65 (71.4)	31 (81.6)	2 (100.0)	6 (85.7)	145 (78.4)
Italian	2 (4.3)	4 (4.4)	0 (0)	0 (0)	0 (0)	6 (3·2)
Chinese	1 (2.1)	4 (4.4)	1(2.6)	0 (0)	0 (0)	6 (3·2)
Portuguese	0 (0)	3 (3.3)	1 (2.6)	0 (0)	0 (0)	4 (2·2)
Other	3 (6.4)	6 (5.6)	0 (0)	0 (0)	1 (14.3)	10 (5.4)
Prefer not to answer	0 (0)	9 (9.9)	5 (13.2)	0 (0)	0 (0)	14 (7.6)
Religion					- />	
Christian	26 (56.5)	36 (40.9)	13 (35.1)	1 (50.0)	2 (33.3)	78 (43·6)
I do not have a religious or spiritual affiliation	4 (8.7)	16 (18.2)	8 (21.6)	0 (0)	0(0)	28 (15.6)
Judaism	4 (8.7)	5 (5.7)	4 (10.8)	1 (50.0)	3 (50.0)	17 (9.5)
Islam	3 (6.5)	3 (3.4)	0 (0)	0 (0)	0(0)	6 (3.4)
Other	2 (4.4)	10 (11.4)	3 (8.1)	0 (0)	1 (16.7)	16 (8-9)
Annual household in some hofers toward	7 (15.2)	18 (20.5)	9 (24.5)	0 (0)	0(0)	34 (19-0)
co to 20,000	F (11 O)	15 (10 5)	2 (5 7)	1 (50.0)	0 (0)	22 (12 0)
\$0 10 \$29,999	3 (11.9) 0 (0)	7 (9.6)	2 (3.7)	1 (50.0)	0 (0)	23 (13.9)
\$60,000 to \$89,999	0 (0) 3 (7 1)	5 (6 2)	3 (0.0) 4 (11 4)	0 (0)	0 (0)	12 (7.3)
\$00,000 to \$110,000	1 (2 A)	2 (0.2)	1 (2.0)	0 (0)	0 (0)	12 (7.3)
\$120,000 or more	1 (2.4) 2 (7 1)	2 (2.5)	1 (2.9)	0 (0)	0 (0)	4 (2·4) 8 (4 0)
Prefer not to answer	30 (71 4)	4 (4.9)	1 (2.3) 24 (68 6)	0(0)	4 (80.0)	106 (64.2)
Number of people household income supports	55(71.4)	$51 \pm 32$	$57 \pm 31$	$15 \pm 0.71$	4(00.0)	$5.3 \pm 3.2$
(mean $\pm$ SD)	515 <u>-</u> 512	5 <u>-</u> 5.2	5.7 - 5.1		0.0 ± 0.1	55 <u>-</u> 5£
Primary diagnosis						
Cancer	37 (77.1)	70 (76.9)	31 (81.6)	0 (0)	3 (42.9)	141 (75.8)
Gastrointestinal diseases	1 (2.1)	0 (0)	0 (0)	0 (0)	0 (0)	1 (0.5)
Heart and circulation disease	5 (10.4)	16 (17.6)	3 (7.9)	1 (50.0)	2 (28.6)	27 (14.5)
Musculoskeletal diseases	0 (0)	1 (1.1)	1 (2.6)	0 (0)	0 (0)	2 (1.1)
Neurological, psychiatric, and mood diseases	3 (6.3)	0 (0)	1 (2.6)	0 (0)	2 (28.6)	6 (3·2)
Pulmonary diseases	2 (4.2)	4 (4.4)	2 (5.3)	1 (50.0)	0 (0)	9 (4.8)
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Table 1 (Continued)

	Disposition						
Characteristic	Died (n = 48)	Home (n = 92)	PCU (n = 38)	Hospital (n = 2)	Other ( <i>n</i> = 7)	Total No. (%) of patients ( <i>n</i> = 187)	
Disability status							
No disabilities	21(47.7)	32(39.5)	15(40.5)	0(0)	2(40.0)	70 (41-42)	
Chronic Illness	10(22.7)	11(13.6)	7(18.9)	0(0)	1(20.0)	29 (17·2)	
Physical Disability	4(9.1)	13(16.1)	2(5.4)	1(50.0)	0(0)	20 (11.8)	
Other (mental or sensory)	3(6.8)	9(11.1)	6(16.2)	1(50.0)	2(40.0)	21 (12.4)	
Prefer not to answer	6(13.6)	16(19.8)	7(18.9)	0(0)	0(0)	29 (17·2)	
Length of stay (mean $\pm$ SD)	$\textbf{22.9} \pm \textbf{30.5}$	$\textbf{13.2} \pm \textbf{13.3}$	$\textbf{25.7} \pm \textbf{29.8}$	$\textbf{220.5} \pm \textbf{303.3}$	$\textbf{21.9} \pm \textbf{18.0}$	$20{\cdot}8\pm38{\cdot}3$	
Time from admission to palliative care referral	$10.1\pm28.2$	$\textbf{3.1} \pm \textbf{5.2}$	$\textbf{8.7} \pm \textbf{13.9}$	$\textbf{22.5} \pm \textbf{31.8}$	$\textbf{3.4} \pm \textbf{2.9}$	6·2 ± 16·5	
(mean±SD)							
Time from palliative care referral to consult	$\textbf{0.4}\pm\textbf{0.7}$	$\textbf{0.4}\pm\textbf{0.7}$	$\textbf{0.6} \pm \textbf{0.8}$	$2\pm1.4$	$\textbf{0.9}\pm\textbf{0.7}$	$0.5 \pm 0.8$	
(mean±SD)							
Table 1: Summary of demographic and clinical	characteristics.						

# Results

We identified 501 patients who were referred to the inpatient palliative care team between April 1, 2018 to March 31, 2019. We excluded 302 patients who did not have demographic data, and 12 patients who were referred to palliative care but not seen by palliative care, resulting in 187 patients who met the eligibility requirements for this study. The sample had a mean age of 68.8 years and was 55.6% female. Less than half the sample was born in Canada (46.7%), while the sample was predominantly White (58.2%) and preferred to communicate in English (78.4%). A large majority of the population had a primary diagnosis of cancer (75.8%), the mean LOS was 20.8 days, and the most common disposition was to home (49.2%). Further demographic and clinical characteristics are displayed in Table 1.

Two variables were statistically significantly associated with disposition using Fisher exact tests: birth country (p = 0.04) and racial or ethnic group (p = 0.03) (Table 2). Figure 1 illustrates the proportion of patients

Characteristic	p-value of Fisher's exact test
Age <sup>1</sup>	F(63,123)) = 1.32, p = 0.10
Sex	0.571
Sexual Orientation	0.693
Birth Country	0.040
Racial or ethnic group	0.031 <sup>2</sup>
Preferred language	0.409
Religion	0.078

#### Table 2: Demographics associated with disposition.

<sup>1</sup> Values listed are F statistic(degrees of freedom between, degrees of freedom within)=*F* ratio, *p*-value.

<sup>2</sup> This *p*-value represents the outcome of a chi<sup>2</sup> test as a fisher exact test could not be performed on this variable.

that died in hospital, or were discharged to home, to PCU or to Other according to each of these variables. Patients born abroad were more likely to die in hospital and less likely to be discharged to PCU than those born in Canada. Black patients were most likely to die in hospital and Asian patients were most likely to be discharged home; only small proportions of these groups went to PCU in comparison to White or Other patients.

No variables were statistically significantly associated with LOS (Table 3).

In terms of time from admission to palliative care referral, there was a statistically significant difference between groups of preferred language spoken with medical professionals as determined by one-way ANOVA (F(5179) =  $3 \cdot 6$ ,  $p = 0 \cdot 004$ ) (Table 3). A Tukey post-hoc test of language spoken revealed that time from admission to referral was statistically significantly higher in Other (m = 20.9) vs. English (m = 4.8) (p = 0.03), and statistically significantly lower in prefer not to answer (m = 1.7) vs. Other (m = 20.9) (p = 0.05); none of the other comparisons were significant.

Age was significantly associated with time from admission to referral (coefficient 0.18; 95% CI 0.05 to 0.32; p = 0.007) but was not significantly associated with the other outcomes.

In terms of time from palliative care referral to palliative care consultation, none of the demographic characteristics were found to be statistically significantly associated (Table 3).

# Discussion

Our retrospective cohort study of 187 patients who received inpatient palliative care at an academic hospital found that birth country and racial or ethnic group were significantly associated with disposition. Preferred language was significantly associated with time from



**Figure 1.** Mosaic plot of relationship between disposition and birth country and race. This mosaic plot illustrates the proportional representation of patient disposition by (a) whether or not the patient was born in Canada, (b) patient race and ethnicity. The area of each tile is proportional to the number of cases at each intersection.

admission to referral to palliative care. No demographic variables were associated with length of stay or time from palliative care referral to palliative care consultation. It is important to note that we found relatively few differences given that the vast majority of the tests we ran were insignificant. The demographic makeup of our sample has some variation from the City of Toronto as a whole. Patients in our sample were older (68.8 years in our sample versus 40.6 years in Toronto), had less Asian representation (15.8% vs 33.0%),

greater White representation (58.2% vs 49.0%), and a greater proportion of English speaking individuals (78.4% vs. 64.0%).<sup>22</sup>

Our findings suggest there may be potential inequalities in discharge location among patients seen by palliative care and how long it takes to refer to specialist palliative care. While the nature of our retrospective cohort study design does not allow us to fully explain the causes of these differences, we have surmised potential explanations here, but caution that further research

Sociodemographic Characteristic	Length of stay (F statistic (degrees of freedom between, degrees of freedom within)=F ratio, p-value)	Time from admission to referral	Time from referral to consult
Age (coefficient, 95% Cl, <i>p</i> -value)	0.10 (95%Cl −0.21, 0.31), p = 0.55	0.18 (95%Cl 0.05, 0.32), p = 0.007	-0.00(95%Cl -0.01, 0.00), p = 0.39
Sex	F(1185) = 0.67, <i>p</i> = 0.41	F(1, 185) = 0.33, p = 0.57	F(1185) = 0.33, p = 0.57
Sexual Orientation	F(3176) = 0.67, <i>p</i> = 0.57	F(3, 176) = 0.74, p = 0.53	F(3176) = 1.69, p = 0.17
Birth Country	F(2179) = 0·55, <i>p</i> = 0·59	F(2179) = 1.56, p = 0.21	F(2179)=0·29, p = 0·75
Racial or ethnic group	F(4, 179) = 0.36, <i>p</i> = 0.84	F(4, 179) = 1.07, p = 0.37	F(4179) = 1.70, <i>p</i> = 0.15
Preferred language	F(5179) = 0.92, <i>p</i> = 0.47	F(5179) = 3.6, <i>p</i> = 0.004	F(5179) = 0.54, <i>p</i> = 0.75
Religion	F(5173) = 0·31, p = 0·91	F(5173) = 0.60, p = 0.70	F(5173) = 0.50, p = 0.77

represents *p*-value <0.05).

is needed to investigate the motivating factors behind these observed inequalities. Further, by only running bivariate associations, there is a possibility that the relationship is explained by other variables. We believe our work raises more questions than it answers, which provides an inspiration for further in-depth exploration.

We observed that patients born outside of Canada were more likely to die in hospital and less likely to be discharged to a PCU. To our knowledge, no previous studies have investigated the association between immigration background and disposition among patients who have received specialist palliative care consultation. However, we can draw comparisons to a populationbased study of decedents in Ontario, which found that recent immigrants from East Asia, Central America and Mexico, South America, Africa, western and central Asia, Southeast Asia, and South Asia were more likely to die in the ICU and less likely to die at home or in hospice, compared to patients who were not immigrants.<sup>19</sup> While our study does not investigate the underlying causes for the differences observed, it is important to consider that possible contributors may include patient level factors (i.e., patient preferences, which themselves may be informed by prior negative experiences with the healthcare system), or system-level factors including systemic discrimination<sup>23</sup> and inadequate access to palliative care resources.<sup>24</sup> At the patient level, one study demonstrated that immigrant and non-immigrant patients had similar knowledge about palliative care<sup>25</sup> suggesting other factors may be at play. Though we cannot know for certain which factors influence disposition, there is a possibility that some patients of immigrant backgrounds may be wary of institutions based on previous experiences of discrimination, as has been previously discussed regarding undocumented immigrants in the United States.<sup>26</sup> This hesitancy towards institutions may prime individuals of immigrant backgrounds to be cautious of both receiving care in institutions and of recommendations made by healthcare providers, especially when these recommendations entail the cessation of active medical management (i.e., PCU).

Our study also showed differences in disposition based on race. Black patients were the most likely to die in hospital. The reasons behind this finding are not determined by our study. Studies from the US have indicated that some Black Americans may opt for more intensive medical interventions when facing a palliative diagnosis.<sup>27</sup> There may be wariness of the medical system amongst Black Americans due to personal experiences and intergenerational trauma,<sup>28-30</sup> which may result in a hesitation to choose comfort-focused care due to concerns that inadequate treatments are being offered due to biases. Furthermore, our study showed that Asian patients are the most likely to be discharged home. This may suggest that Asians had a preference for end-of-life care in the home, which has been shown in past studies to be related to distrust of physicians and healthcare systems.<sup>31</sup> Another study showed that South Asian Americans felt obliged to care for their parents,<sup>32</sup> which could also translate to more care in the home. It is important to flag that these studies are American and that end-of-life services differ between the US and Canada in several ways, but notably in that hospice is more prevalent in the US. It is also important to acknowledge that there is diversity in experiences and preferences within racial groups. There are several factors that might influence disposition including patient/caregiver relationship and choices, differences in end-of-life decision making, financial situation, and availability of caregivers. We have presented potential hypotheses but want to refrain from exhibiting a moral judgement upon how choices are made, especially when they are contrary to the majority perspective that care at home is preferable.33 Further research is needed to investigate potential reasons for why there are observed differences in disposition among people born and not born in Canada, and those of different racial backgrounds. Systemic discrimination may indeed be a contributing factor, that should be further explored in future research.

Patients whose preferred language was not English experienced significantly longer time to referral compared to patients whose preferred language was English; suggesting the potential existence of language barriers. Though not measured in our study, these barriers may relate to the use of interpretation services, as has been seen in previous studies.<sup>34</sup> At our institution, in-person and phone-based interpretation services are available, yet these findings suggest that these services may not be routinely utilized to facilitate end-of-life conversations. Consequently, medical decision-making is likely delayed. While utilizing an interpreter should be the standard of care, work is needed to standardize healthcare provider uptake of interpretation services when English is not the patient's preferred language and especially when palliative care is involved. Future work should examine among individuals whose preferred language is not English, and how use of interpretation services might be associated with outcomes among patients with advanced illness.

Our study has several limitations. Research that draws attention to inequities in healthcare may paradoxically be susceptible to invalid demographic categorizations. Investigators may arrive at conclusions that homogenize a heterogeneous sample of patients as a consequence of their shared membership to a demographic group. Our study commits this error. For example, the "Other" category of race/ethnicity includes patients who are Middle Eastern or from one of several Indigenous communities. The number of patients in each of these groups was sufficiently small to preclude statistical analysis, such that they were combined into one category. In addition, as a consequence of the sovereignty that Indigenous peoples in Canada have over data collected about them, we were unable to present their data singularly.35 Furthermore, while race and ethnicity are distinct concepts, the demographic questionnaire used grouped them together. It is imperative that investigators of health inequity be conscious of these potential fallacies when designing studies. Moreover, there is no best location of discharge, but ideally, patients would be discharged to their preferred location. Unfortunately, patient preferences were not routinely captured, and we were limited by the data available to evaluating differences in disposition between different population groups rather than how actual disposition compared against patient preferences. Identifying differences in disposition; however, helps to target future efforts to explain why these differences were observed.

Our study was not powered to detect differences between demographic and diagnostic groups, and may have been insufficiently sensitive to observe differences between these groups when they existed. Our sample size included all patients who were seen by the inpatient palliative care consultation service and who completed the demographic form during the timeframe of interest; we used all the data available to us as this study was a secondary analysis of existing data. Further, our sample size prevented us from running multivariate models, and consequently our bivariate findings should not be overemphasized and any significant findings should be

read with caution. A substantial number of patients responded "prefer not to answer" for demographic questions, which decreased the quantity of data that could be statistically analyzed. It is possible that the respondents felt their identity was not represented amongst the possible responses. Alternatively, this could represent sensitivity to the disclosure of their demographic identity. Further, our study was retrospective and observational, such that no definitive conclusions can be made about why the differences in disposition among demographic groups were observed. Moreover, our study runs the risk of multiple testing within a small sample; we endeavoured to engage in an exploratory approach examining multiple relationships in one study, but we concede this may result in over-mining of the data. Finally, our study may have limited generalizability for two reasons. First, it is a study based in one hospital in the urban centre Toronto, Canada where there is universally accessible healthcare; demographics and attitudes towards health equity are likely to vary across regions. Second, this study was restricted to patients who completed the demographic form, and many patients were excluded from the study as a result of not completing that form. Patients who completed the form were likely higher functioning and healthier than patients who opted not to complete the form. However, we do not have data available to verify this hypothesis. Additionally, we excluded patients who did not end up having a consult (these patients typically either have an inappropriate consult, die before being seen, or themselves or their families refuse to receive palliative care due to various reasons); the exclusion of these 12 individuals may have introduced some bias into our analysis.

Our study suggests that there may be inequalities in discharge location among patients seen by palliative care and disparities in how long it takes to refer them to palliative care. Specialist palliative care providers are as susceptible as other specialties to providing care that is not culturally safe, which has been cited as a barrier to quality end-of-life care among culturally- and spiritually-diverse groups.<sup>36</sup> The importance of culturally safe palliative care for racialized individuals also requires further exploration.

There are many practical implications palliative care programs could consider based on our research findings, including advocating for, and modelling the use of interpreters for patients who would benefit from them. Additionally, PCUs might consider how they can engage with community advocacy groups to better understand the barriers that may prevent racialized patients and immigrants from accessing this care.

Given that we observed that many Asian and other racialized patients were discharged home from hospital and that these groups already face disproportional systemic barriers in accessing healthcare compared to White patients, governments could consider investing in programs and policies that support increasing care at home for patients and families with palliative care needs. Policy makers and healthcare providers will need to develop partnerships with community organizations to implement these practice changes.

The literature and our research highlight potential variation in discharge location among patients seen by palliative care based on race and immigration background. Future research should investigate these questions with larger sample sizes and multivariate models, as well as consider whether the concept of preference oversimplifies a complex phenomenon of compelled decision-making that is influenced by personal and intergenerational oppression and trauma.

Our study found that, in a cohort of patients receiving inpatient palliative care consultations, variables significantly associated with disposition were birth country and race/ethnicity. Language was significantly associated with time from admission to palliative care referral. That said, there are several limitations with our study that suggest further research is needed. These preliminary findings suggest inequalities may exist in palliative care and point to specific areas that warrant a more robust analysis. The few possible inequalities we found need further study using larger sample sizes and multivariate models. Addressing inequalities will need further studies that focus on understanding the underlying practices that constructed and maintained these inequalities in care. There is additional value to this study as few health administrative databases contain detailed demographic data. Since the hospital had the special initiative to collect demographic data from patients, we were able to explore the relationship between these characteristics and various outcomes. Hopefully this paper helps to further the case for the prospective collection of this data and its ability to help us to identify health disparities.

## **Declaration of interests**

The Authors declare that there is no conflict of interest.

## Contributors

Sarina R. Isenberg conceived of the study, verified, analyzed and interpreted the data, drafted and revised the manuscript, approved the version to be published, and takes public responsibility for the content. At the time this research was conducted, Dr. Isenberg was a Scientist at the Temmy Latner center for Palliative Care at Sinai Health.

Michael Bonares analyzed and interpreted the data, drafted and revised the manuscript, approved the version to be published, and takes public responsibility for the content.

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Ramona Mahtani interpreted the data, drafted and revised the manuscript, approved the version to be published, and takes public responsibility for the content.

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### Data sharing statement

The datasets analyzed for the current study cannot be made available as participants included in analysis have not consented, and the datasets contain personal health information.

#### References

- P. Braveman, E. Arkin, T. Orleans, D. Proctor, A. Plough What is health equity? and what difference does a definition make? 2017. https://www.rwjf.org/en/library/research/2017/05/what-is-healthequity-.html. (Accessed 04, 2021).
- 2 Tyler I, Amare H, Hyndman B, Manson H. Health Equity Assessment: Facilitators and Barriers to Application of Health Equity Tools. Ontario Agency for Health Protection and Promotion (Public Health Ontario); 2014. https://www.publichealthontario.ca/-/media/documents/h/2014/health-equity-barriers.pdf. (Accessed 08, 2021).
- Canadian Institute for Health Information. In Pursuit of Health Equity: Defining Stratifiers for Measuring Health Inequality. Canadian Institute for Health Information; 2018. https://www.cihi.ca/sites/ default/files/document/defining-stratifiers-measuring-healthinequalities-2018-en-web.pdf. (Accessed 08, 2021).
   Health Equity Office, Sinai health system for the "Toronto central
- Health Equity Office, Sinai health system for the "Toronto central LHIN Measuring Health Equity" project. We ask because we care: collecting patient demographic data. 2021. http://torontohealtheq uity.ca/wp-content/uploads/2017/10/Measuring-Health-Equity-Guide-to-Demographic-Data-Collection.pdf. (Accessed o6, 2021).
- 5 Health Quality Ontario. Quality Improvement Plan Guidance: Using Sociodemographic Data for Targeted Improvement. Health Quality Ontario; 2018. https://www.hqontario.ca/Portals/0/documents/ qi/qip/qip-guidance-sociodemographic-data-en.pdf. (Accessed 04, 2021).
- 6 World Health Organization. News room fact sheet: palliative care. 2020. https://www.who.int/news-room/fact-sheets/detail/pallia tive-care. (Accessed o6, 2021).
- 7 Canadian Society of Palliative Care Physicians. Delivery of Palliative Care by Physicians in Canada: a Definition's Document. Canadian Society of Palliative Care Physicians; 2019. https://www.cspcp.ca/ wp-content/uploads/2019/09/Delivery-of-Palliative-Care-by-Palliative-Physicians-in-Canada-a-Definitions-Document-July-2019-final-EN.pdf (accessed o8 2021).
- 8 Forbat L, Johnston N, Mitchell I. Defining 'specialist palliative care': findings from a Delphi study of clinicians. Aust Health Rev. 2020;44(2):313–321.
- 9 Ontario Palliative Care Network. Who provides palliative care and where. 2021. https://www.ontariopalliativecarenetwork.ca/aboutpalliative-care/who-delivers. (Accessed o6, 2021).
- Crawley LM. Racial, cultural, and ethnic factors influencing end-oflife care. J Palliat Med. 2005;8(Suppl 1):S58–S69.
- Johnson KS. Racial and ethnic disparities in palliative care. J Palliat Med. 2013;16(11):1329–1334.
- 2 Payne R, Medina É, Hampton JW. Quality of life concerns in patients with breast cancer: evidence for disparity of outcomes and

experiences in pain management and palliative care among African-American women. *Cancer*. 2003;97(I Suppl):31I-317.

- 13 Bell CL, Kuriya M, Fischberg D. Hospice referrals and code status: outcomes of inpatient palliative care consultations among Asian Americans and Pacific Islanders with cancer. J Pain Symptom Manag. 2011;42(4):557–564.
- 14 Yarnell CJ, Fu L, Bonares MJ, Nayfeh A, Fowler RA. Association between Chinese or South Asian ethnicity and end-of-life care in Ontario, Canada. CMAJ. 2020;192(11):E266–EE74.
- I5 Currow DC, Agar M, Sanderson C, Abernethy AP. Populations who die without specialist palliative care: does lower uptake equate with unmet need? *Palliat Med.* 2008;22(I):43–50.
- 16 Chan A, Woodruff RK. Comparison of palliative care needs of English- and non-English-speaking patients. J Palliat Care. 1999;15 (1):26-30.
- 17 Burt J, Raine R. The effect of age on referral to and use of specialist palliative care services in adult cancer patients: a systematic review. *Age Ageing*. 2006;35(5):469–476.
- 18 Burge FI, Lawson BJ, Johnston GM, Grunfeld E. A populationbased study of age inequalities in access to palliative care among cancer patients. *Med Care*. 2008;46(12):1203–1211.
- 19 Yarnell CJ, Fu L, Manuel D, et al. Association between immigrant status and end-of-life care in Ontario, Canada. JAMA. 2017;318 (15):1479–1488.
- 20 StataCorp. Stata statistical software: release 13. 2013; 2013.
- 21 Benchimol EI, Smeeth L, Guttmann A, et al. The reporting of studies conducted using observational routinely-collected health data (RECORD) statement. *PLoS Med.* 2015;12:(10):e1001885.
- 22 Statistics Canada. Toronto, C [Census subdivision], Ontario and Ontario [Province] (table). Census profile. 2016 Census. Statistics Canada Catalogue no. 98-316-X2016001. 2017. https://www12.stat can.gc.ca/census-recensement/2016/dp-pd/prof/details/page.cfm? Lang=E&Geo1=CSD&Code1=3520005&Ge02=PR&Code2=35&Da ta=Count&SearchText=Toronto&SearchType=Begins& SearchPR=01&TABID=1&B1=All. (Accessed 06, 2021).
- 23 Nielsen LS, Angus JE, Howell D, Husain A, Gastaldo D. Patientcentered care or cultural competence: negotiating palliative care at home for Chinese Canadian immigrants. Am J Hosp Palliat Care. 2015;32(4):372–379.
- 24 Seto Nielsen L, Goldstein Z, Leung D, Lee C, Buick C. A scoping review of undocumented immigrants and palliative care: implications for the Canadian context. J Immigr Minor Health. 2019;21 (6):1394–1405.

- 25 Barwise A, Cheville A, Wieland ML, Gajic O, Greenberg-Worisek AJ. Perceived knowledge of palliative care among immigrants to the United States: a secondary data analysis from the health information national trends survey. *Ann Palliat Med.* 2019;8(4):451– 461.
- 26 Jaramillo S, Hui D. End-of-life care for undocumented immigrants with advanced cancer: documenting the undocumented. *J Pain Symptom Manag.* 2016;51(4):784–788.
  27 Barnato AE, Anthony DL, Skinner J, Gallagher PM, Fisher ES.
- 27 Barnato AE, Anthony DL, Skinner J, Gallagher PM, Fisher ES. Racial and ethnic differences in preferences for end-of-life treatment. J Gen Intern Med. 2009;24(6):695–701.
- 28 Lee MJH, Reddy K, Chowdhury J, et al. Overcoming the legacy of mistrust: African Americans' mistrust of medical profession. J Heal Ethics Admin. 2018;4(1):16–40.
- 29 S. Janssen Considering racial trauma in African American underuse of hospice/palliative care 2020. https://www.socialworktoday. com/archive/exc\_0219.shtml. (Accessed 06, 2021).
- 30 Dillon PJ, Basu A. Toward eliminating hospice enrollment disparities among african americans: a qualitative study. J Health Care Poor Underserved. 2016;27(1):219–237.
- 31 Mukherjea A, Shabana A, Smith JA. A human rights perspective on palliative care: unraveling disparities and determinants among Asian American populations. *Top Lang Disord*. 2020;40(3):278– 296.
- 32 Sharma RK, Khosla N, Tulsky JA, Carrese JA. Traditional expectations versus US realities: first- and second-generation Asian Indian perspectives on end-of-life care. J Gen Intern Med. 2012;27(3):311– 317.
- 33 Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. BMC Palliat Care. 2013;12:7.
- Silva MD, Genoff M, Zaballa Á, et al. Interpreting at the end of life: a systematic review of the impact of interpreters on the delivery of palliative care services to cancer patients with limited english proficiency. J Pain Symptom Manage. 2016;51(3):569-580.
   Canada Go. TCPS 2 (2018) - Chapter 9: research involving the
- 35 Canada Go. TCPS 2 (2018) Chapter 9: research involving the first nations, inuit and métis peoples of Canada. 2018. https:// ethics.gc.ca/eng/tcps2-eptc2\_2018\_chapter9-chapitre9.html. (Accessed 06, 2021).
- 36 Fang ML, Sixsmith J, Sinclair S, Horst G. A knowledge synthesis of culturally- and spiritually-sensitive end-of-life care: findings from a scoping review. BMC Geriatr. 2016;16:107.