

Advance Care Planning and Decision-Making in a Home-Based Primary Care Service in a Canadian Urban Centre



Madison Huggins, MPH¹, Margaret J. McGregor, MD, MHSc¹, Michelle B. Cox, MSc¹, Katie Bauder, MPH(Candidate)¹, Jay Slater, MD¹, Clarissa Yap, MN, NP(F), CHPCN(C)², Laurie Mallery, MD, FRCPC, MSM³, Paige Moorhouse, MD, MPH, FRCPC, MSM³, Conrad Rusnak, MD¹

¹Department of Family Practice, University of British Columbia, Vancouver, BC; ²Home-ViVE Program, Vancouver General Hospital, Vancouver, BC; ³Division of Geriatric Medicine, Dalhousie University, Halifax, NS, Canada

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Abstract

Background

Advance care planning (ACP) is a process that enables individuals to describe, in advance, the kind of health care they would want in the future, and has been shown to reduce hospital-based interventions at the end of life. Our goal was to describe the current state of ACP in a home-based primary care program for frail homebound older people in Vancouver, Canada. We did this by identifying four key elements that should be essential to ACP in this program: frailty stage, documentation of substitute decision-makers, and decision-making with regard to both resuscitation (i.e., do not resuscitate (DNR)) and hospitalization (i.e., do not hospitalize (DNH)). While these elements are an important part of the ACP process, they are often excluded from common practice.

Methods

This was a cross-sectional, observational study of data abstracted from 200 randomly selected patient electronic medical records between July 1 and September 30, 2017. We describe the association between demographic characteristics, comorbidities, and four key elements of ACP documentation and decision-making as documented in the clinical record using bivariate comparison, a logistic regression model and multiple logistic regression analysis.

Results

In 73% (n=146) of the patient records, there was no explicit documentation of frailty stage. Sixty-four per cent had documentation of a substitute decision-maker. Of those who had their preferences documented, 90.6% (n=144/159) indicated a preference for DNR, and 23.6% (n=29/123) indicated a

preference for DNH. In multiple regression modeling, a diagnosis of dementia and older age were associated with documentation of a DNR preference, adjusted odds ratio (AOR) = 4.79 (95% CI 1.37, 16.71) and AOR = 1.14 (95% CI 1.05, 1.24), respectively. Older age, male sex, and English identified as the main language spoken were associated with a DNH preference. AOR = 1.17 (95% CI 1.06, 1.28), AOR = 4.19 (95% CI 1.41, 12.42), and AOR = 3.42 (95% CI 1.14, 10.20), respectively.

Conclusions

Clinician documentation of some elements of ACP, such as identification of a substitute decision-maker and resuscitation status, have been widely adopted, while other elements that should be considered essential components of ACP, such as frailty staging and preferences around hospitalization, are infrequent and provide an opportunity for practice improvement initiatives. The significant association between language and ACP decisions suggests an important role for supporting cross-cultural fluency in the ACP process.

Key words: advance care planning, substitute decision-maker, frailty staging, do not resuscitate, do not hospitalize, home-based primary care

Introduction

Frailty is a “multidimensional syndrome of loss of reserves (energy, physical, ability, cognition, health) that gives rise to vulnerability”.⁽¹⁾ The prevalence of frailty increases with age, with the weighted average prevalence of frailty among seniors aged 85 and older ranging from 22% to 30%.⁽²⁾ The prevalence of frailty also increases as the number of co-morbidities increase. Moderate to severely frail elderly individuals also often respond poorly to surgical interventions⁽³⁾ and hospitalization.⁽⁴⁾

Despite this, many frail people are hospitalized multiple times in the last six months of life.⁽⁵⁾ The opportunity cost of hospitalization includes care that is focused on disease prevention and management at the expense of symptom control, prolonged periods of time spent in hospital in the final chapter of life, and the potential for interventions to result in further functional decline.⁽⁶⁾ Despite an increasing recognition of the prognostic significance of frailty, providers continue to struggle with how to identify and quantify frailty, and communicate this trade-off of life-prolonging treatments, their likelihood of success, and potential impact on remaining quality of life to families who are often unaware of the inability of medicine to reverse most aspects of frailty.⁽⁷⁾

Advance care planning (ACP) for frail populations is a multi-dimensional intervention that includes identifying a substitute decision-maker,* and making advance care statements. We identified four key elements that should be essential in ACP: frailty stage, documentation of substitute decision-makers (SDMs), and both decision-making with regard to resuscitation (i.e., do not resuscitate (DNR)) and hospitalization (i.e., do not hospitalize (DNH)). We felt these four elements are an important part of the ACP process, but often are excluded from common practice. ACP should encourage provider-navigated medical decision-making in anticipation of common health crises and documentation of these preferences in a form that is clear and easily accessible to the formal and informal caregiving team.⁽⁸⁾ Language and culture have been identified as important components of ACP as they influence communication and decision-making.⁽⁹⁾

This study used baseline data that were collected in anticipation of a practice change initiative (Palliative and Therapeutic Harmonization (PATH))⁽¹⁰⁾ to improve ACP competency amongst a team of health-care providers. Our goal was to describe the current state of ACP in a home-based primary care program for frail homebound older adults in Vancouver, Canada. We aimed to explore the documentation and distribution of the four key elements of ACP decisions that we identified (and noted above). We also aimed to understand the association of these key elements with demographic characteristics, case mix, and other health services characteristics.

METHODS

The setting was a population of seniors receiving longitudinal home-based primary care (Home ViVE—Home Visits for Vancouver’s Elders)⁽¹¹⁾ due to their inability to access usual ambulatory primary care as a result of dementia and/or physical frailty. Care is publicly funded and provided by a team of family physicians, nurse practitioners, registered nurses, health science professionals, and office administrative support. Services include planned regular home visits by a family physician or nurse practitioner, responsive day-time and after-hours care for emergencies, nursing and/or physical and occupational rehabilitative services as needed, and palliative support for a home death.

This was a point-in-time assessment, cross-sectional descriptive study of data extracted from the clinical electronic patient medical records (EMR) over a three-month time period from July 1 to September 30, 2017. The records of 200 individuals (representing approximately 50% of total active charts) were randomly selected from all patients actively receiving the home-based primary care service.

Data gathered from the EMR included demographic characteristics (age and sex), language in which a patient communicates most of the time, chronic conditions, the assessed stage of frailty using the ordinal Clinical Frailty Scale (Rockwood) definition for staging of frailty,[†] the documented Mini Mental State Examination (MMSE) and Montreal Cognitive Assessment (MoCA) scores, and the documentation of a substitute decision-maker(s). Cases where frailty was described as being in between two defined categories were re-categorized to the more advanced stage (for example, “mild-moderate” was reclassified as “moderate”).

Data regarding documented preferences for resuscitation status (DNR) and hospitalization in the event of an acute illness (DNH) were extracted. If categorical decision preferences were not noted in the EMR record face sheet, they were coded as missing. The face sheet is the front page of the electronic medical record that contains crucial patient information such as patient identification and personal information, clinical information, and family/substitute decision-maker identification. The presence or lack of a signed DNR order within the last 12 months was also recorded.

Data about palliative care were extracted from the EMR face sheet, including information whether palliative care services were actively involved or whether an application for palliative care[‡] was completed. In the population under study, some care providers (e.g., the community care system and ambulance services) are unable to access patients’ EMRs. Therefore, we also recorded whether completed paper copies of ACP forms were available in the patient’s home (including location), and whether they had been faxed to the relevant home-care services.

Chart abstractions were completed by one of the researchers (MH) with episodic cross-checking by another member of the research team (MMcG) to confirm inter-rater reliability. All physician and provider data were de-identified and stored in an electronically secure and encrypted database. Ethics approval was obtained from the University of British Columbia’s Behavioral Research Ethics Board and relevant ethics review boards within the Vancouver Coastal Health Authority region. All quantitative statistical analyses were conducted using SAS software, version 9.3 (SAS Institute Inc., Cary, NC, USA).

Data Analysis

Summary statistics of patient characteristics and comorbidities, and the presence or absence of the above-described elements of ACP, were calculated for the cohort. For continuous variables, the mean and standard deviation are presented, and

for dichotomous variables, percentages were tabulated and are presented. Bivariate analyses were conducted to explore the association of patient demographics, co-morbidity, and provider variation with a decision for or against DNR and DNH, or when no preference is indicated. For bivariate comparisons, including the ‘main language spoken’ variable, a dichotomous variable was created—English versus all other languages. Tests of comparison included two independent samples *t*-test or Wilcoxon-Mann-Whitney test for continuous data, and Chi-square test or Fisher’s exact test for dichotomous or categorical data.

Logistic regression was utilized to examine factors associated with a patient decision, in separate models for DNR and DNH. Variables that were significant in the bivariate analyses ($p < .05$) were entered in the stepwise multiple logistic regression model examining factors associated with a decision for DNR (or DNH), controlling for age and sex. Any variables that remained significant in the multiple logistic regression model at ($p < .05$) were retained in the final model. Odds ratios were determined for the adjusted models, and 95% confidence intervals were calculated.

RESULTS

Patient Characteristics

There were 200 individuals in the study cohort, with ages ranging from 60.0–106.0 years and a mean age of 87.7 (SD 7.1) years (Table 1). The patients’ spoken language was documented in 98.5% of cases ($n=187$). There was a wide range of languages spoken, with English (64.0%, $n=128$) (Table 1), and Cantonese (13.0%, $n=26$) being the most common. The median time for patient enrolment in the home-based primary care program was 1.6 years (data not shown). Most patients had multiple chronic health conditions documented, with the most common being dementia (54.0%), arthritis (45.0%), osteoporosis (31.5%), congestive heart failure (25.5%), stroke (25.0%), kidney failure (19.0%), and diabetes (19.0%) (Table 1). Of the 78 patients, for whom full test data were available, the mean (SD) Mini Mental State Examination (MMSE) score was 21.6 (6.8) and ranged from 3.0–30.0 (data not shown).

Advance Care Planning

Information on frailty stage was available for 27.0% ($n=54$) of the patients, ranging from mild to very severe frailty (Table 2). Since a small number of patients had frailty documented, it presented problems for the researchers when considering this factor. Severe frailty was the most prevalent stage (12.5% of the total population, $n=25$), followed by moderate frailty (12.0% of the total population, $n=24$) (Table 2). 63% of patients ($n=127$) identified a substitute decision-maker (Table 2). A total of 159 patients (79.5%) had documentation of resuscitation status; however, 20.5% ($n=41$) had no preference identified on the face sheet. A completed DNR form

was documented in fewer than one half (46.5%) of cases, and 63.4% of these forms were signed within the preceding 12 months (Table 2). Among those with a completed DNR form, 29% ($n=27$) indicated that a paper copy of the DNR form was

TABLE 1.
Patient characteristics and comorbidities among home-based primary care patients (N=200) in Vancouver, British Columbia, Canada (July 1 to September 30, 2017)

| <i>Patient Characteristics</i> | <i>Cohort N=200</i> |
|---------------------------------------------------------------------|-------------------------|
| Mean age in years (SD) | 87.7 (7.1) |
| Minimum–maximum | 60.0–106.0 |
| Male, % (n) | 32.5% (65) |
| Main language spoken, % (n) | |
| English | 64.0% (128) |
| Cantonese | 13.0% (26) |
| Punjabi | 4.5% (9) |
| Italian | 3.5% (7) |
| Mandarin | 2.0% (4) |
| Portuguese | 1.5% (3) |
| Tagalog | 1.5% (3) |
| Vietnamese | 1.5% (3) |
| Gujarati | 1.0% (2) |
| Hindi | 1.0% (2) |
| Persian | 1.0% (2) |
| Spanish | 1.0% (2) |
| Other ^a | 3.0% (6) |
| <i>Missing (spoken language not identified)</i> | 1.5% (3) |
| <i>Patient Comorbidities</i> | <i>Cohort N=200</i> |
| Dementia diagnosis, % (n) | 54.0% (108) |
| Mental health ^b diagnosis, % (n) | 15.5% (31) |
| Chronic conditions, % (n) | |
| Arthritis | 45.0% (90) |
| Osteoporosis | 31.5% (63) |
| Congestive Heart Failure | 25.5% (51) |
| Stroke | 25.0% (50) |
| Kidney Failure | 19.0% (38) |
| Diabetes | 19.0% (38) |
| Cancer | 15.5% (31) |
| COPD (emphysema/lung disease) | 15.5% (31) |
| Liver Disease | 0.0% (0) |
| Mean # of comorbidities (includes dementia & mental health) (SD) | 2.12 (1.30) |
| Minimum–maximum | 0–6.0 |

^aNon-English spoken languages identified include: Czech, Finnish, German, Greek, Polish, Serbian (each language was <1% of cohort).

^bMental health diagnosis includes: anxiety, depression, bipolar, schizophrenia

SD = standard deviation; COPD = chronic obstructive pulmonary disease.

TABLE 2.

Advance care planning documentation among home-based primary care patients (N=200) in Vancouver, British Columbia, Canada (July 1 to September 30, 2017)

| <i>Patient Documentation</i> | <i>Cohort N=200</i> |
|--------------------------------------------------------------------------------------------------------------------------|-------------------------|
| Frailty quantification, % (n) | |
| Mild | 1.5% (3) |
| Moderate | 12.0% (24) |
| Severe | 12.5% (25) |
| Very Severe | 1.0% (2) |
| <i>Missing (no frailty quantification)</i> | 73.0% (146) |
| Substitute decision-maker identified, % (n) | |
| On EMR face sheet ^a | 25.0% (50) |
| In other location | 38.5% (77) |
| <i>Missing (no substitute decision-maker identified)</i> | 36.5% (73) |
| <i>Do Not Resuscitate preference on EMR face sheet,^a</i> % (n) | |
| Resuscitate | 7.5% (15) |
| Do Not Resuscitate | 72.0% (144) |
| <i>Missing (no preference on face sheet^a)</i> | 20.5% (41) |
| Completed <i>Do Not Resuscitate</i> form on EMR, % (n) | |
| Yes | 46.5% (93) |
| No | 53.5% (107) |
| If completed form on EMR (N=93), face sheet ^a documentation that paper copy of form left in home, % (n) | |
| Yes | 29.0% (27) |
| No | 71.0% (66) |
| If completed form on EMR (N=93), date of last form signed within past 12 months, % (n) | |
| Yes | 63.4% (59) |
| No | 36.6% (34) |
| <i>Do Not Hospitalize preference on EMR face sheet,^a</i> % (n) | |
| Hospitalize | 47.0% (94) |
| Do Not Hospitalize | 14.5% (29) |
| <i>Missing (no decision on face sheet^a)</i> | 38.5% (77) |
| Palliative services clearly documented on EMR face sheet, ^a % (n) | 19.0% (38) |

^aThe face sheet is the front page of the electronic medical record that contains crucial patient information such as patient identification and personal information, clinical information, and family/substitute decision-maker identification.

EMR = electronic medical record.

located in the patient's home; however, none provided any indication that a copy of the DNR form had been shared with the involved home-care teams.

In 61.5% (n=123) of cases, patient preference regarding whether they would like to be hospitalized was provided. In cases where a preference was provided, 47.0% (n=94) of patients indicated that in the event of a medical crisis, they wished to be hospitalized, and 14.5% (n=29) indicated a

preference to avoid hospital transfer (38.5% (missing data/no decision on face sheet), n=77). Active involvement of palliative care services was documented in 19% (n=38) of cases.

Patient Characteristics by DNR or DNH Preferences

In the bivariate comparison, variables found to be significantly associated with a preference for DNR ($p < .05$) included older age ($p = .0004$), presence of dementia ($p = .011$), kidney failure ($p = .042$), and the presence of a mental health condition ($p = .029$). Variables significantly associated with a preference to not be hospitalized included older age ($p = .004$), fewer median months as a patient of the home-based primary care program (Home ViVE) ($p = .011$), English as the main spoken language ($p = .048$), and congestive heart failure ($p = .015$) (Table 3). Interestingly, 96% of Cantonese speaking patients with a noted DNR preference (n=23/24) indicated that they would like to receive cardiopulmonary resuscitation, and all with a noted DNH preference (n=18/18) indicated they wish to be hospitalized (data not shown). In the multiple regression model, variables significantly associated with a preference for DNR were dementia and age (Table 4), and variables significantly associated with a preference for DNH were English as the main spoken language, age, and male gender (Table 4).

DISCUSSION

Our study aimed to explore the current state of ACP in a sample of community-dwelling frail older adults receiving home-based primary care. We found that, although elements needed to understand frailty stage (including information about function and co-morbidity) were often documented, the patient's frailty stage was infrequently documented. Based on previous frailty literature in which the frailest individuals are more likely to have missing data, we would expect that those patients for whom frailty was missing would have, in fact, been among the most frail.⁽¹²⁾ While it is possible that the provider may have intuitively recognized the patient's frailty stage, the explicit documentation of frailty stage represents a succinct summary of the extent of functional impairment. At the time of a health crisis, information about the frailty stage may inform discussions between the on-call clinician, often unfamiliar with the patient, and decision-maker. Although ACP does not require frailty staging, the PATH approach emphasizes the importance of explicit frailty staging documentation for these reasons. While a majority of records identified a substitute decision-maker, this information was absent in over one-third of charts (36.5%, n=73). The absence of this information during a health crisis, when an acutely ill patient is often unable to speak for themselves, puts providers in a difficult position when deciding how to proceed.

While the majority of charts had documentation of resuscitation status, this is lower than the 97% frequency of code status recorded in a US home-based primary care service,⁽¹³⁾ but substantially higher than 6% of those with a hematological

TABLE 3.

Comparison of significant characteristics by *Do Not Resuscitate (DNR)* and *Do Not Hospitalize (DNH)* preferences among home-based primary care patients (N=200) in Vancouver, British Columbia, Canada (July 1 to September 30, 2017)

| <i>Patient Characteristic^a</i> | <i>No Preference Indicated N=41</i> | <i>Do Not Resuscitate (DNR) N=144</i> | <i>Resuscitate N=15</i> | <i>p value^b (DNR vs. Resuscitate)</i> |
|--------------------------------------------------|-----------------------------------------|-------------------------------------------|-----------------------------|------------------------------------------------------|
| Mean age in years (SD) | 84.9 (7.5) | 89.0 (6.6) | 82.5 (6.7) | .0004 |
| Minimum–Maximum | 71.0–96.0 | 60.0–106.0 | 69.0–93.0 | |
| Male, % (n) | 46.3% (19) | 27.8% (40) | 40.0% (6) | .321 |
| Dementia diagnosis, % (n) | 31.7% (13) | 63.2% (91) | 26.7% (4) | .011 |
| Mental health ^c diagnosis, % (n) | 19.5% (8) | 12.5% (18) | 33.3% (5) | .029 |
| Kidney failure, % (n) | 12.2% (5) | 22.9% (33) | 0.0% (0) | 0.042 |
| <i>Patient Characteristics^a</i> | <i>No Preference Indicated N=77</i> | <i>Do Not Hospitalize (DNH) N=29</i> | <i>Hospitalize N=94</i> | <i>p value^b (DNH vs. Resuscitate)</i> |
| Mean age in years (SD) | 87.0 (7.7) | 91.2 (5.9) | 87.2 (6.6) | .004 |
| Minimum–maximum | 71.0–106.0 | 80.0–104.0 | 60.0–101.0 | |
| Male, % (n) | 32.5% (25) | 41.4% (12) | 29.8% (28) | .244 |
| Median months in program (P10, P90) | 26.6 (2.3, 93.8) | 11.0 (2.5, 53.9) | 20.7 (5.3, 65.9) | .011 |
| Minimum–maximum | 0.9–216.0 | 0.5–66.0 | 1.3–216.0 | |
| English main language spoken, ^d % (n) | 67.5% (52) | 79.3% (23) | 56.4% (53) | .048 |
| Missing (spoken language not identified) | 0.0% (0) | 0.0% (0) | 3.2% (3) | |
| Congestive heart failure, % (n) | 27.3% (21) | 41.4% (12) | 19.1% (18) | .015 |

^aOnly patient characteristics significant at $p < .05$ are presented, as well as the demographic characteristics age and male. Other variables tested and found to be not significantly associated with a DNR preference were: arthritis, osteoporosis, congestive heart failure, stroke, diabetes, cancer, chronic obstructive pulmonary disease, liver disease. Other variables tested and found to be not significantly associated with a DNH preference were: dementia diagnosis, mental health diagnosis, arthritis, osteoporosis, stroke, kidney failure, diabetes, cancer, chronic obstructive pulmonary disease, liver disease. Frailty quantification was not tested for significance with either preference due to the large number of missing data for this variable.

^bTests of comparison included: two independent samples *t*-test or Wilcoxon-Mann-Whitney test for continuous data; Chi-square test or Fisher's exact test for categorical data.

^cMental health diagnoses include: anxiety, depression, bipolar, schizophrenia.

^dNon-English spoken languages identified include: Cantonese, Czech, Finnish, German, Greek, Gujarati, Hindi, Italian, Punjabi, Italian, Mandarin, Persian, Polish, Portuguese, Serbian, Spanish, Tagalog, and Vietnamese.

SD = standard deviation.

malignancy⁽¹⁴⁾ and the 17% to 21% of internal medicine patients aged 80 years or older⁽¹⁵⁾ described in previous research. The impact of this documentation and decision-making are profound, as a study conducted in the US found that “those who had advanced directives used less life sustaining treatment in their last month of life.”⁽¹⁶⁾

Despite the high rate of resuscitation status documentation, less than one-half (46.5%) of charts had a signed DNR form scanned into the EMR record and, of these, only 29.0% indicated that paper copies of the signed forms were available in the home. Paper-based documentation of code status is important because the ambulance service is often the first service to be called in the event of a medical emergency. Ambulance attendants do not have access to a patient's EMR, are trained to look for such forms and, if not present, will proceed with

full cardiopulmonary resuscitation, as indicated. The various steps in “closing the loop” by communicating resuscitation status between provider groups including the ambulance service, home care, and the hospital, is important given the potential harm of deploying CPR in frail patients.⁽⁶⁾ The time-consuming and complex nature of this information exchange may explain the low frequency of completion, and highlights the urgent need to develop records that are accessible across provider groups.

The high frequency of resuscitation status documentation (79.5%) contrasts with a somewhat lower frequency of documentation for preferences around hospital-based care (61.5%). This likely represents the greater complexity of ACP discussions with patients and substitute decision-makers about future hospital care. Whereas a discussion about resuscitation

TABLE 4.

Logistic regression, adjusted odds ratios for factors associated with a *Do Not Resuscitate (DNR)* or *Do Not Hospitalize (DNH)* preference among home-based primary care patients (N=200) in Vancouver, British Columbia, Canada (July 1 to September 30, 2017)

| <i>Factors associated with Do Not Resuscitate (DNR)^a</i> | <i>Adjusted OR (95% CI)^b</i> |
|---------------------------------------------------------------------|-----------------------------------------|
| Dementia diagnosis | 4.79 (1.37, 16.71) |
| Age | 1.14 (1.05, 1.24) |
| <i>Factors associated with Do Not Hospitalize (DNH)^c</i> | <i>Adjusted OR (95% CI)^b</i> |
| English main language spoken (vs. non-English) ^d | 3.42 (1.14, 10.20) |
| Age | 1.17 (1.06, 1.28) |
| Male | 4.19 (1.41, 12.42) |

^aOther variables tested for significance in simple logistic regression analyses included: male, mental health diagnosis, osteoporosis diagnosis, kidney failure.

^bMultiple logistic regression models included any variables that were significant in simple logistic regression analysis ($p < .05$). Any variables that remained significant in the multiple logistic regression model at $p < .05$ were retained in the final model.

^cOther variables tested for significance in simple logistic regression analyses included: median months in home-based primary care program, patient clinician, congestive heart failure diagnosis, arthritis diagnosis.

^dLogistic regression models including English language spoken variable utilized a binary variable with categories: English vs. Non-English languages. Non-English languages include: Cantonese, Czech, Finnish, German, Greek, Gujarati, Hindi, Italian, Punjabi, Italian, Mandarin, Persian, Polish, Portuguese, Serbian, Spanish, Tagalog, and Vietnamese.

OR = odds ratio; CI = confidence interval.

relates to a specific set of procedures, conversations with decision-makers about the potential harms and benefits of hospital care are more complex and encompass a wide permutation of factors including frailty stage, prognosis for future decline, the nature of the acute medical event, and caregivers' readiness to support home-based or hospice care at the end of life. Such conversations are iterative and lend themselves poorly to the binary decision-making represented by a DNH (yes vs. no) order. Despite their complexity, however, these features comprise essential aspects of ACP in frail populations. Documentation of preferences regarding hospital-based care is also important for physicians who share after-hours on-call support and use such documentation to guide how to proceed with the care of ill patients in their homes.

The frequency of a preference for DNR (90.6%, n=144/159) among those with a documented preference is higher than that reported in Canada's publicly-funded residential long-term care facilities, where the average proportion

of those with a DNR preference was found to be 75%.⁽¹⁷⁾ The observed 23.6% (n=29/123) frequency of a preference for avoidance of hospital and home-based care (DNH) among those with a documented preference is also slightly higher than the 20% observed in Canadian nursing homes.⁽¹⁷⁾ Given the high rates of dementia and advanced frailty in nursing home populations in Canada⁽¹⁸⁾ and the availability of around-the-clock care in a nursing home setting, one might expect the frequency of DNH to be higher in a facility setting compared to recipients of home-based primary care. One possible reason for this discrepancy might be the longer visit length by the home-based primary care providers (approximately 30 min), which allowed more time for ACP discussions. Both lack of time and decreased interaction with patients near the end of life have been identified as two major barriers to initiating ACP discussions with patients in primary care settings.⁽¹⁹⁾ Longer visits may enable more extensive ACP discussions with patients and families compared to nursing home visits, where doctors' and nurse practitioners' time with each resident is often shorter. Home-based primary care may also provide more frequent opportunities for providers to interact with patients' informal caregivers who live in the home and patients' substitute decision-makers. The importance of these conversations has also been reflected in cancer patients' decision-making, where end-of-life discussions were associated with the decision for DNR.⁽²⁰⁾ Often, as Mitchell et al. note, "when patients have a better understanding of their goals-of-care options and the likely outcomes, they tend to opt for less aggressive medical care at the end of life".⁽²¹⁾ It is also possible that the higher preference for DNR and DNH represents a selection bias of very frail individuals seen in the home-based primary care service who have opted to remain in their homes despite advanced frailty.

Despite having these important conversations, a study examining preferences for life-sustaining treatment for individuals who were seriously ill provided evidence that supported both common assumptions that some patients value quality over quantity of life, and that some patients are willing to endure invasive treatments while aware that there is a small chance of returning to their current health.⁽²²⁾ This difference in decision-making has also occurred on an individual level, as the trajectory of one's decision-making over time has been found to be inconsistent for those with both stable and variable health states.⁽²³⁾ The inconsistencies suggest that stable core values may not be the primary variable that influences decision-making, and that decisions are likely influenced by ephemeral factors.⁽²³⁾ This further emphasizes the importance of ACP conversations due to their potential impact decision-making.⁽²³⁾

English as the main language spoken was associated with a preference for DNH. A number of reasons for this association have been hypothesized. First, robust communication about end-of-life decision-making is more difficult when there is discordance in language. In our study, most providers are English speaking and rely on a combination of

telephone-based interpretation provided by the Ministry of Health, family, and/or other informal caregivers who are fluent in English to provide translation for ACP conversations. Second, in Chinese cultures (the largest ethno-cultural group in our study), there is evidence that discussions about death are associated with stigma.⁽²⁰⁾ Instead, more informal and indirect methods of communication are preferred.⁽²⁴⁾ Finally, research in ambulatory primary care settings has found that ethno-cultural discordance between patient and provider is associated with lower relational and management continuity, suggesting a reduced level of trust,⁽²⁵⁾ as was sometimes the case in the practice setting under study. Future qualitative ACP research is needed to better understand these issues.⁽²⁶⁾

Limitations

This study has a number of limitations. First, the presence of a documented resuscitation and hospitalization status on the chart does not guarantee that fulsome ACP conversations have taken place. Likewise, the absence of documentation does not mean these conversations have not taken place. Moreover, the quantitative methods used are unable to capture the nuances of the topics pertinent to ACP such as the influence of cultural fluency and family dynamics. The small sample size may have resulted in a loss of power for some statistical tests and potentially impacted the findings of this study.

This is a cross-sectional observational study that describes decisions that were documented at one point in time, which is significant as decisions and documentation can change over time. ACP conversations are re-visited every year as part of the annual complex care plan that family physicians are all incited to do with their frail patients. Most conversations are initiated by the physician or nurse practitioner responsible for the longitudinal primary care of the patient or most responsible practitioner (MRP). Additionally, ACP conversations are re-visited with patient and informal caregivers when any major change in health status occurs. However, we cannot confirm that this occurred with every patient, or the specifics of each discussion.

Like all observational research, our study is subject to unintended bias and confounding. However, to our knowledge, ours is the only study of its kind that uses data from clinical records to describe ACP activities and decision-making in a sample of frail elderly recipients of home-based primary care. Our findings, therefore, contribute to the relatively sparse literature on ACP preferences and the documentation of these preferences in community-based settings of frail populations.

CONCLUSION

Our study found that some elements of ACP documentation (resuscitation status) appear to be widely adopted, while other elements that should be important components of ACP (information about frailty stage, substitute decision-maker identification, and status regarding preferences for hospitalization) have

substantial missing data. Preferences for DNR and DNH were relatively high in this population compared to nursing home populations, possibly related to the model of home-based primary care. Consistent with prior research, we also found that language and cultural differences appear to influence patients' preference for hospital care. Further research on cross-cultural communication in the ACP process and practice change interventions to improve cross-cultural communication with robust evaluations of their effect are important future activities given the growing number of ethno-culturally diverse frail seniors in Canada's urban centres.

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CONFLICT OF INTEREST DISCLOSURES

The authors declare that no conflicts of interest exist.

*The substitute decision-maker in British Columbia is the person designated to make health decisions on behalf of another individual in the absence of a formal representation agreement.

†In cases where a patient is non-verbal as a result of stroke or dementia, the language spoken refers to the main language they used to communicate prior to the illness that resulted in their inability to communicate verbally.

‡This is a form completed by the physician for patients who are deemed to have less than 6 months to live, so they can access benefits not usually available under the public health-care plan.

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Correspondence to: Dr. Margaret McGregor, MD, MHSc, Department of Family Practice, University of British Columbia, 713-828 West 10th Avenue, Vancouver, BC V5Z 1M9, Canada
E-mail: mrgret@mail.ubc.ca