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Identifying individuals who could benefit from a palliative approach to their care using a multi-phase, consultative, iterative approach

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Abstract

Background Access to a palliative approach to care improves the quality of life of individuals with a serious illness and their families. This paper describes the development of a decision-support tool that identifies individuals receiving home care and long-term care services who could potentially benefit from a palliative approach to their care based on information available in interRAI assessments used in those sectors as part of regular practice.

Methods A consultative and iterative multi-phase approach was employed to develop the "Serious Illness Collaborative Action Plan" (or Serious Illness CAP), over an 18-month period. Criteria for triggering this CAP were established with 49 individuals across seven advisory groups; criteria were operationalized using items and measures available in interRAI instruments and tested using anonymized population-level data from home care ($N = 568,586$) and LTC ($N = 35,713$) sectors in three Canadian provinces were analyzed.

Results The CAP is based on the presence of health instability and potentially modifiable exacerbating issues (i.e., severe/excruciating daily pain, moderate/severe mood problems, severe fatigue, self-reported loneliness or social isolation, and condition/disease that create instability in thinking, self-care, mood, or behaviour patterns). The CAP identifies three distinct groups: those at high priority for a palliative approach, those at moderate priority, and those who don't trigger the CAP. Among home care clients in Ontario, 42% triggered the CAP; 10% ($n = 57,025$) at a high priority, and 32% ($n = 181,531$) at a moderate priority. Within LTC homes in Nova Scotia and Saskatchewan, these equaled 12% (overall), 5.2% ($n = 1,858$ as high priority) and 6.8% ($n = 2,411$ as moderate priority).

Conclusions The development of this new CAP will help support clinicians in home care and LTC settings to engage in conversations and promote awareness of the benefits of a palliative approach to care for individuals with serious or life-limiting illness and their families.

Keywords interRAI, Palliative care, Home care, Serious illness, Early identification

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Introduction

More people in Canada are living with chronic life limiting diseases such as cancer, renal disease, Alzheimer disease and related dementias and respiratory illnesses [1]. Many of these serious illnesses tend to be complex and have a less predictable trajectory towards death, which can make it difficult to estimate prognosis [2–4]. However, prognosis should not be the sole determinant of when to initiate a palliative approach to care. When palliative care (PC) is provided earlier in the illness trajectory, it has the potential to improve overall quality of life, reduce symptom burden, and may impact treatment choices and adherence [2, 3]. A palliative approach focuses on the needs, values, and wishes of the individual and their family and informal care providers, where quality of life is seen as the primary goal [5]. It is appropriate at any stage of the illness trajectory and in some countries, such as Canada, can be provided in conjunction with curative or life-prolonging treatments. Though there are an estimated 56.8 million people with life-limiting illness in need of PC globally, only about 14% of them receive it [6]. Many individuals are offered or receive PC later in the course of their illness [7]. It is well known that some groups experience inequities related to PC. In Canada, several underserved groups has been identified, including adults 85 + years, persons living with dementia, racialized groups, Indigenous people, persons living in rural/remote settings, persons experiencing homelessness; persons with severe and persistent mental illness [8]; persons with intellectual and developmental disabilities are also recognized underserved groups [9].

In 2017, all Canadian provinces and territories agreed to a common statement of principles on shared health priorities, highlighting the need to improve access to care provided in the home and community, with an emphasis on PC [10]. Older adults prefer to "age in place" and remain in their own homes for as long as possible [1, 11, 12]. This is also true as it relates to desired place of death, and where most people would prefer to receive PC [1, 12]. As PC can be provided in home settings, including residential care, efforts to better integrate it into home care and long-term care settings is needed to meet the needs of individuals, families, as well as government priorities.

In Canada, and internationally, interRAI assessments are used in home care (i.e., interRAI Home Care, or interRAI HC) and long-term care facilities (LTCF) (e.g., nursing homes; interRAI LTCF). These instruments contain roughly 300 items that cover key domains, such as cognitive status, physical functioning and health, mental health, social supports, and service utilization – many of which are shared across assessments (i.e., items which are identical in both wording and response options) [9]. Instruments are completed by a trained assessor (usually a registered health care provider) who gathers information from multiple sources to complete the assessment (e.g., individual, family, other professionals, health records). In home care, assessments are completed on admission for all clients expected to receive care for at least 60 days [13], and every 6–12 months thereafter [14] assessments are completed at admission and quarterly thereafter in LTCF [15]. Assessments are also completed if there is a significant change in clinical status.

The 300 + items are combined to generate actionable information in the form of outcome measures, and "Collaborative Action Plans" (CAPs). The HC and LTCF instruments generate a set of 27 CAPs that serve as a "flag" to support clinical and shared decision-making with individuals in different areas of physical functioning, cognitive/mental health status, clinical issues, and social life [14]. The assessment used to "trigger" each CAP are provided to clinicians, as are written guidelines to support next steps and actions; these are meant to inform clinicians, not replace clinical judgment, or take precedence over policies or legislation in any organization or jurisdiction using the assessments [16].

Given the emphasis on early incorporation of a palliative approach with those who have a serious or life-limiting illness, a focus on home-based PC delivery, and the widespread use of interRAI instruments in home care and long-term care facilities, we aimed to develop a new interRAI-based decision-support tool to identify persons who could benefit from a palliative approach to care in home care settings and LTCF. A secondary aim was to ensure that the Serious Illness CAP guidelines incorporated the contexts and needs of persons in underserved groups. The development of the new Serious Illness CAP was iterative and supported by discussions with project advisory groups (e.g., PC physicians and providers, providers working with underserved groups, and persons with lived experience of being in an underserved group), and analysis of existing, anonymized, population-level interRAI data. This new CAP has the potential to improve access to palliative approaches earlier in the illness trajectory, as well as improve the quality of that care, especially among underserved groups.

Methods

The development of the CAP spanned approximately 18 months (March 2024 – September 2025) and employed an iterative design [17]. First, we explored how to identify people who could benefit from a palliative approach to their care with advisory groups (described below). Next, quantitative analysis of existing data was conducted based on advisory input. Then, results were brought back to advisory groups for interpretation and additional input. There were multiple iterative cycles of consultation and analysis.

This project involved researchers from multiple institutions. An ethics waiver was granted for overall work with advisory groups (based on article 2.5 of the Tri-Council Policy Statement 2 (TCPS2), related to evaluation activities) and for secondary analysis of existing anonymized data by the Lakehead University Research Ethics Board (based on article 2.4 of the TCPS2, related to secondary analysis of existing data). It was recommended by the Research Ethics Board at Wilfrid Laurier University to obtain additional ethics approval for the provider advisory group, as they were working in a much more involved way with the research team based at Wilfrid Laurier University than other advisory groups (which were led by researchers outside of that institution). This Board reviewed and approved the project, and informed consent was obtained from all members of the provider advisory group (REB #8799). All methods were performed in accordance with the relevant guidelines and regulations.

Phase I: discussions with advisory groups

The project team (eight members) included researchers and clinicians (e.g., physicians, nurses) with expertise in palliative medicine, health services research, home and community care and knowledge translation. A subset of the project team met with seven different advisory groups, which were comprised of persons living with dementia, persons with serious and persistent mental illnesses, persons with intellectual and developmental disabilities, and organizations working with and for under-served populations (e.g., individuals experiencing homelessness, linguistic minorities, rural/remote/northern residents), and PC providers (e.g., clinicians, nurses), and decision-makers (e.g., CEOs of provincial and national hospice and palliative care organizations). All groups were important to ensure that the CAP development was clinically and statistically sound, as well as address concerns related to underserved groups. There was a total of 49 advisory members across seven groups, including 20 people with lived experience (i.e., intellectual and developmental disabilities, severe and persistent mental illness, and dementia), 18 representatives of organizations working with underserved populations (i.e., homelessness, linguistic minorities, rural/remote/northern communities), and 11 PC providers and decision-makers. Each advisory group met at least four times over the course of CAP development; groups comprising persons with lived experience met more often.

The project team spent several meetings building capacity with all advisory groups to understand interRAI instruments, the assessment process, and measures (including CAPs), as well as possible uses of that information at the individual, organization, and system levels. The next meetings were focused on identifying characteristics of individuals who would benefit from a palliative approach to their care. Given that the new CAP would be used by clinicians, the provider advisory group led this part of the CAP development, given their extensive knowledge and practical clinical PC experience. As they identified characteristics, available related interRAI items and measures were presented and discussed. The other six advisory groups weighed in on the items identified by the provider advisory group, often speaking to the impact of these issues on the lives of members of underserved groups and their loved ones. The characteristics identified informed Phase II (see below); also see Measures below.

Extensive notes were taken independently by two members of the research team during all meetings (e.g., input on characteristics/items, discussion of impact on the lives of people and families); meetings were not recorded. After each meeting, notes were reviewed, consolidated, and shared with the members of the advisories.

Phase II: quantitative secondary data analysis

Secondary analysis of anonymized, population-level data collected in Ontario's home care sector and in Nova Scotia and Saskatchewan's LTC sectors were used; these were available to the research team as part of a data-sharing agreement between interRAI and the Canadian Institute for Health Information (CIHI). Data are stored on a secure server at the University of Waterloo and made available to authorized users (e.g., research staff, students) working under the supervision of an interRAI Fellow (many co-authors are Fellows). Though home care and LTC sectors in other jurisdictions across Canada are using interRAI instruments, they are in a period of transitioning from older (e.g., Resident Assessment Instrument for Home Care (RAI-HC) and Minimum Data Set (MDS) 2.0) to the newest versions of the interRAI instruments. This study focused on data from the newest versions to ensure sustainable use moving forward. Analysis was based on the individual's first assessment; there were 568,586 unique home care clients and 35,713 LTCF residents.

Measures

The measures and items listed below are based on advisory input; all are available in the interRAI HC and interRAI LTCF.

Health instability and prognosis The Changes in Health, End-Stage Disease, Signs and Symptoms (CHESS) scale is a measure of health instability based on 12 items (e.g., prognosis, shortness of breath, peripheral edema); scores range from 0 to 5, where 0 = no health instability, 1 = minimal health instability, 2 = mild health instability, 3 = moderate health instability, 4 = high health instability,

and 5 = severe health instability. It has been shown to be highly predictive of mortality in several studies [18–21], and each one-point increase in score is associated with a nearly two-fold increased risk of dying [21–24]. Although a prognosis of less than six months is part of the CHESS scale, it was also considered as a separate dichotomous item due to its relevance in palliative care.

Exacerbating issues Several items and measures were identified to represent the concepts of interest:

1. *Pain* was explored using the Pain Scale and an additional item related to uncontrolled pain. The Pain Scale is based on the frequency and intensity of pain and has been validated using the Visual Analog Scale [25]. Its scores range from 0 = no pain, 1 = less than daily pain, 2 = daily pain but not severe, 3 = daily severe pain, 4 = daily excruciating pain [26, 27]; this study used a score of three or higher to indicate the presence of severe or excruciating daily pain. Uncontrolled pain was coded as "yes" if this had been recorded as present within the assessment observation period.
2. *Fatigue* was identified by a single item measuring the ability to complete normal day-to-day activities (e.g., activities of daily living). It is scored as 0 = no difficulty, 1 = minimal difficulty, 2 = moderate difficulty, 3 = severe difficulty, or 4 = unable to commence any normal day-to-day activities. Scores of three or four were used to identify severe fatigue.
3. *Mood problems* were identified using the Composite Mood Scale (CMS). The CMS is a nine-point summative scale across four clinician-rated and three self-rated items dealing with dysphoria, anxiety, and anhedonia [18]. A score of four or higher was used to indicate moderate/severe mood symptoms [28].
4. *Social issues* were explored by combining three items: [1] self-reported loneliness (yes/no) [2], visits with family or long-standing social relations, and [3] any other interactions with family or long-standing social relations. Social isolation was identified if the person was coded as "yes" on any one of self-reported loneliness or if they had not had any visits or other interactions with friends or long-standing social relations.
5. *Instability of conditions* was identified using the item on presence of a condition or disease that makes cognition, self-care, mood, or behaviour patterns unstable (yes/no).
6. Other items of interest were also examined based on feedback from the advisory groups. *Sleep disturbance* was represented by combining two items related to having difficulty falling/staying asleep and having too much sleep; it equaled "yes" if either was present. Dichotomous (yes/no) items were also available related to *dizziness*, *chest pain*, *constipation*, *diarrhea*, and *medical diagnoses* (i.e., stroke, congestive heart failure, coronary artery disease, hemiplegia/hemiparesis, multiple sclerosis, Parkinson's disease, hip fracture, other types of fractures, pneumonia, urinary tract infections, cancer, diabetes, chronic obstructive pulmonary disease, and Alzheimer's disease and/or related dementias). Well-established measures related to *cognitive performance* (Cognitive Performance Scale, or CPS) [19], functioning (Activities of Daily Living (ADL) Hierarchy) [21], and pressure ulcers (Pressure Ulcer Risk Scale) [22] were also considered. Age and sex were also explored in the analysis.

Analysis

The frequency distributions of all items considered are presented; all items are categorical. The analysis was based on the individual's first assessment in the home care ($n = 568{,}586$) and LTC ($n = 35{,}713$) data. Cross-tabs were used to compare each item across all CHESS scores, given its known strong association with mortality. Missing data are rare as the electronic assessment system does not allow for closing/submitting an assessment with blank fields.

Multiple triggering options were considered, for example, binary (triggered yes/no) vs. multi-level (triggered moderate vs. high) options. Sensitivity analyses examined inclusion of different exacerbating issues – both use of individual items and the overall number used. These results were reviewed and redone as part of the iterative advisory input and analysis process. The CAP triggering rates (prevalence) are provided for each sector, as well as by underserved populations.

Finally, we examined whether triggering the CAP on the initial (T1) and subsequent (T2) home care assessments was associated with receipt of PC services; this was examined for each level (i.e., not triggered, moderate priority, and high priority). The time between assessments was approximately 3 months. All analyses were performed using SAS software version 9.4 [29].

Results

Advisory input on items for the CAP

The list of characteristics and issues identified by advisories are listed in the Methods section. As previously noted, the CHESS scale is a measure of health instability that is known to be highly predictive of mortality; as such, it was seen as foundational for inclusion in the CAP. We started by examining the identified personal and clinical characteristics (not already included in the

Table 1 Demographic and clinical characteristics by CHESS score using interRAI Home Care data for Ontario

	CHESS = 0 (*n* = 94,588)	CHESS = 1 (*n* = 144,902)	CHESS = 2 (*n* = 165,345)	CHESS = 3 (*n* = 112,841)	CHESS = 4 (*n* = 47,437)	CHESS = 5 (*n* = 3,473)
	%					
Age						
18–64 years	21.7	15.8	13.1	11.6	8.3	11.0
65–74 years	15.9	18.0	17.6	17.6	15.0	16.8
75–84 years	28.5	31.2	32.8	33.1	33.5	32.5
85 + years	33.2	35.1	36.4	37.8	43.3	39.7
Sex						
Male	42.8	39.7	39.7	40.7	42.6	51.9
Female	57.2	60.3	60.3	59.3	57.4	48.1
Client has a prognosis of < 6 months to live						
No	100.0	99.5	98.9	96.8	88.0	0.0
Yes	0.0	0.5	1.1	3.2	12.0	100.0
Presence of disease diagnoses						
Stroke	13.2	13.7	14.4	14.2	16.5	12.2
Congestive heart failure	5.2	8.9	12.6	17.3	19.6	23.0
Coronary heart disease	19.7	24.7	28.5	33.1	35.5	35.3
Hemiplegia/hemiparesis	3.2	2.6	2.5	2.3	2.6	2.3
Multiple sclerosis	1.5	1.4	1.0	0.8	0.6	0.5
Parkinson's disease	3.8	4.1	4.2	3.9	4.1	2.3
Hip fracture	1.1	2.8	2.9	2.8	2.7	1.8
Other fracture	2.2	6.5	6.3	6.3	5.3	3.7
Pneumonia	1.0	1.8	2.8	4.5	5.2	6.5
Urinary tract infection	3.9	5.2	6.9	8.5	11.0	10.9
Cancer	12.7	14.2	15.5	19.6	23.2	56.4
Diabetes	25.2	27.9	29.0	30.4	30.1	27.5
Emphysema/COPD/asthma	4.8	10.9	14.4	18.3	18.0	22.7
Alzheimer's disease and/or related dementias	26.8	22.7	26.9	24.6	34.6	25.3
Client indicates that he/she feels lonely						
No	85.4	82.2	76.9	76.7	73.5	88.7
Yes	14.6	17.8	20.3	23.3	26.5	16.3
Composite Mood scale						
No/mild mood problems (0–3)	87.5	83.2	76.9	69.2	58.7	53.4
Moderate/severe mood problems (4–9)	12.5	16.8	23.1	30.8	41.3	46.6
Pain scale						
No pain/less than daily pain (0–2)	91.9	86.2	83.9	80.2	81.1	74.8
Severe/excruciating daily pain (3–4)	8.1	13.8	16.1	19.8	18.9	25.2
Fatigue						
No/minimal/moderate fatigue (0–2)	96.0	92.3	87.3	77.8	67.3	32.8
Severe fatigue/unable to commence any normal day-to-day activities (3–4)	4.0	7.7	12.7	22.2	32.7	67.2
Uncontrolled pain						
No	88.4	83.1	80.0	75.8	74.1	71.2
Yes	11.6	16.9	20.0	24.2	25.9	28.8
Activities of Daily Living (ADL) Self-Performance Hierarchy Scale						
Independent/supervision required (0–2)	77.2	75.8	70.6	64.9	53.4	33.1
Extensive assistance/total dependence (3–6)	22.8	24.2	29.4	35.1	46.6	66.9
Cognitive Performance Scale (CPS)						
No/mild impairment (0–2)	81.6	86.8	81.6	82.0	69.4	62.2
Moderate/severe impairment (3–6)	18.4	13.2	18.4	18.0	30.6	37.8
Pressure Ulcer Risk Scale (PURS)						
Low risk (0–2)	91.2	89.8	84.5	74.9	62.2	33.3
Moderate risk (3)	5.1	6.0	9.4	14.4	18.5	22.4
High/very high risk (4–8)	3.7	4.1	6.1	10.8	19.2	44.3

Table 1 (continued)

	CHESS = 0 (*n* = 94,588)	CHESS = 1 (*n* = 144,902)	CHESS = 2 (*n* = 165,345)	CHESS = 3 (*n* = 112,841)	CHESS = 4 (*n* = 47,437)	CHESS = 5 (*n* = 3,473)
	%					
Other problem conditions						
Dizziness	19.3	28.1	33.8	41.9	47.4	48.0
Chest pain	2.6	5.1	7.3	10.5	12.1	14.4
Constipation	13.4	17.4	20.2	24.7	27.7	33.2
Diarrhea	6.2	8.2	10.2	13.1	15.1	18.2
Difficulty falling asleep	24.5	31.6	37.0	43.5	45.2	42.3
Too much sleep	7.4	9.3	13.1	18.7	29.2	47.5
Client has conditions or diseases that make cognition, ADL, mood or behavior patterns unstable						
No	43.2	38.2	29.5	23.1	14.2	8.3
Yes	56.8	61.8	70.5	76.9	85.8	91.7

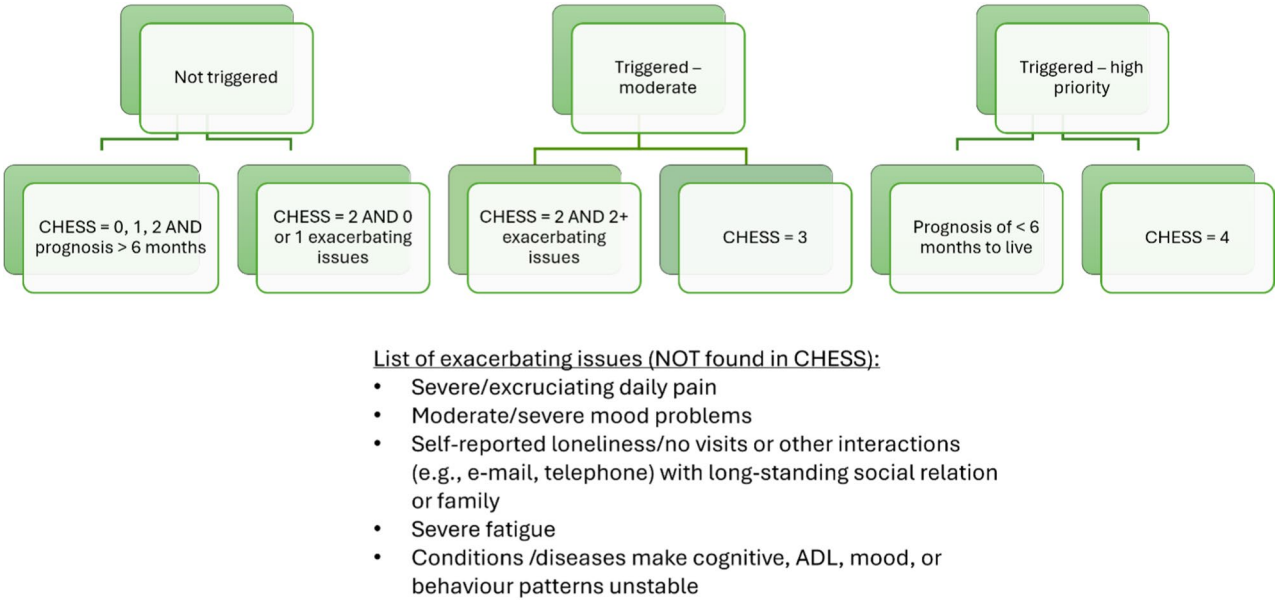


Fig. 1 Schematic of the serious illness CAP triggering groups

CHESS) by the CHESS score (Table 1). This analysis was restricted to home care as most persons in LTCF had no or little health instability. This informed discussions about the issues facing individuals with varying levels of health instability and decisions about which to include in the CAP.

While specific disease diagnoses were considered, we ultimately decided against this approach to avoid restricting the triggering to certain diagnoses, thereby creating inequities for those with other serious illnesses to be identified by this CAP. Several items considered were also excluded from the CAP due to low prevalence, lack of clinical relevance, or non-modifiability (see Supplementary Table 1). As the CAP aims to identify individuals earlier in their illness trajectory, the inclusion of modifiable factors was important.

The items selected for inclusion in the CAP include: the CHESS score, a prognosis of < 6 months to live, and the following exacerbating issues: severe/excruciating daily pain, moderate/severe mood problems, severe fatigue, social isolation, and having a condition/disease that makes cognition, ADL, mood, or behaviour patterns unstable. These exacerbating issues were chosen as they are potentially modifiable, and when present at the end of life, are often viewed as contributing to a "bad death" [30].

The Serious Illness CAP: items and levels

Figure 1 shows the ways in which the CHESS and items are used to create three triggering levels in the new Serious Illness CAP: (1) not triggered, (2) triggered as a moderate priority (i.e., could potentially benefit from a palliative approach), and (3) triggered at a high priority for a palliative approach to care. These levels were based on clinical input from the provider advisory group and analysis of the data. Earlier iterations of the CAP using

different cut-points for the exacerbating issues were explored (e.g., presence of one, vs. two, vs. three, vs. four, vs. all five issues). The current triggering algorithm strikes the balance between using too few or too many exacerbating issues and is based on examination of trigger prevalence (see Supplementary Fig. 1).

As can be seen in Fig. 1, the CHESS score and prognosis are the main determinants of the different triggering levels. Individuals with a prognosis of fewer than 6 months to live or who have high (CHESS = 4) or very high (CHESS = 5) health instability trigger the CAP at the highest priority level. Individuals who trigger as a moderate priority have either moderate health instability (CHESS = 3) or mild health instability (CHESS = 2) with at least two or more exacerbating issues. Those that do not meet the criteria for high or moderate priority do not trigger the CAP. Thus, the CAP cannot be triggered by persons with no (CHESS = 0) or low (CHESS = 1) health instability, or by persons with mild health instability (CHESS = 2) but no or only one of the exacerbating issues.

Prevalence of the Serious Illness CAP

Approximately 32% of home care clients triggered the CAP as moderate priority and 10% as high priority; these equaled 6.8% and 5.2% in the LTC data. Thus 58% of home care clients and 88.0% of people in LTCF did not trigger the CAP; this difference is largely attributable to very low CHESS scores seen in LTCF (Table 2).

Subsequent descriptive analysis using home care data compared CAP triggering rates between T1 and T2. It was found that 27.6% of those who triggered as high priority on both assessments went on to be offered or receive hospice/palliative care services. In comparison, this was true for only 8.9% of those who triggered as moderate priority at both times, and for 6.6% of those who didn't trigger the CAP at either time (Fig. 2). Members of the provider advisory believed this further supported that the CAP was identifying the right people in the high priority group.

At the request of the advisory groups, we examined triggering rates across the different underserved populations, which were similar to the overall home care (42%) and LTC (12%) populations for many of the groups (Supplementary Figs. 2 and 3). That said, the overall proportion of persons with an intellectual or developmental disability who triggered the CAP was lower in both home care (21.8%) and LTCF (8.2%). These differences are attributed to the low health instability seen in those with an intellectual or developmental disability. For example, only 0.14% of individuals with an intellectual or developmental disability had a CHESS score of 4 or 5 compared to 9% in the overall home care sample (data not shown).

Serious Illness CAP guidelines

The interRAI Serious Illness CAP recommends evidence-based suggested next steps for action depending on the trigger level. These recommendations are meant to inform decision-making and do not replace clinical judgment or the person's preferences.

The CAP guidelines were developed following completion of the CAP triggering rules. The actions recommended were largely informed by the literature and the provider advisory group. Next, the other six advisory groups provided important contextual information and input on incorporation of special considerations related to underserved populations. For example, the CAP notes the importance of supporting the person and their family, and the homelessness advisory group wanted it specified that family is whoever the person says it is, be it biological relatives or chosen family (e.g., "street family"). Persons with serious and persistent mental illness identified support with practical needs (e.g., housework, meals, transportation) was just as important as addressing spiritual, emotional, and physical needs. Those living with dementia noted that pain may manifest differently in people who have cognitive or communication difficulties, making visual cues (e.g., grimacing, clenching teeth) even more important in the assessment of pain. Finally, the advisory group of persons with intellectual or developmental disabilities continually advocated for ensuring health care providers are always talking with the person and asking them what they want, rather than assuming that they cannot answer for themselves and speaking only to others.

Discussion

This study focused on developing a new decision-support tool to identify individuals who could potentially benefit from a palliative approach to care based on interRAI assessment used as part of regular clinical practice in home care and long-term care. Once an assessor completes an assessment in home care or LTC, the Serious Illness CAP will be automatically generated to inform clinicians about whether a palliative approach to care should be considered. It is not meant to be prescriptive, nor does it replace clinical judgement. Rather, it acts as a flag to both encourage and support clinicians to engage in conversations to increase the awareness of the benefits of a palliative approach to care for symptom management and overall well-being. In the current study, over 40% of home care clients in Ontario triggered the CAP, representing a sizeable proportion of individuals who are experiencing symptoms that could likely benefit from a palliative approach. Though the data were from Canada, these tools are used in multiple countries; therefore, the Serious Illness CAP has the potential to identify more individuals who could benefit from a palliative approach

Table 2 Comparison of triggering groups across all items in the serious illness CAP for home care and long-term care

	interRAI Home Care (*N* = 568,586)			interRAI Long-Term Care (*N* = 35,713)		
	Not triggered (*n* = 330,030)	Triggered – moderate (*n* = 181,531)	Triggered – high[1] (*n* = 57,025)	Not triggered (*n* = 31,444)	Triggered – moderate (*n* = 2,411)	Triggered – high[1] (*n* = 1,858)
	%					
Age						
18–64 years	15.8	13.6	9.7	8.6	5.5	8.0
65–74 years	17.1	18.1	16.0	13.4	13.8	14.7
75–84 years	31.1	32.7	33.0	29.2	28.3	29.9
85 + years	36.0	35.6	41.3	48.8	52.4	47.4
Sex						
Male	41.0	39.2	43.9	38.6	36.4	41.7
Female	59.0	60.8	56.1	61.4	63.6	58.3
Client has a prognosis of < 6 months to live						
No	100.0	100.0	73.2	100.0	100.0	19.6
Yes	0.0	0.0	26.8	0.0	0.0	80.4
Changes in Health, End-Stage Disease Signs and Symptoms (CHESS) scale						
No health instability (0)	28.7	0.0	0.0	66.7	0.0	0.0
Minimal health instability (1)	43.7	0.0	1.2	25.3	0.0	17.9
Mild health instability (2)	27.6	39.8	3.2	8.0	58.9	17.1
Moderate health instability (3)	0.0	60.2	6.4	0.0	41.1	20.8
High health instability (4)	0.0	0.0	83.2	0.0	0.0	31.5
Very high health instability (5)	0.0	0.0	6.0	0.0	0.0	12.7
Composite Mood scale						
No/mild mood problems (0–3)	87.8	61.4	59.5	82.9	44.4	64.7
Moderate/severe mood problems (4–9)	12.2	38.6	40.5	17.1	55.6	35.3
Pain scale						
No pain/less than daily pain (0–2)	90.6	75.4	80.9	98.3	94.0	93.1
Severe/excruciating daily pain (3–4)	9.4	24.6	19.1	1.4	6.0	6.9
Fatigue						
No/minimal/moderate fatigue (0–2)	94.9	76.5	65.7	95.3	78.9	68.0
Severe fatigue/unable to commence any normal day-to-day activities (3–4)	5.1	23.5	34.3	4.7	21.1	32.0
Social isolation[2]						
No	78.0	59.3	66.5	75.1	48.0	72.2
Yes	22.0	40.7	33.5	24.9	52.0	27.8
Client has conditions or diseases that make cognition, ADL, mood, or behaviour patterns unstable						
No	41.3	18.4	14.8	68.5	27.8	36.2
Yes	58.7	81.6	85.2	31.5	72.2	63.8

[1]Individuals with a CHESS score of 1 or 2 have a prognosis of < 6 months to live

[2]Social isolation is the combination of three variables: self-reported loneliness and/or visits with long-standing social relation/family member and/or other interactions with long-standing social relation/family member

to their care. Also, though the CAP was developed using the newer version of the interRAI HC and LTCF assessments, it can still be generated using the older versions of these assessments, which are still in use in some areas.

The difference in triggering rates between home care and LTC was not altogether surprising as the distribution of CHESS scores between sectors is quite different (as seen in Table 2); very few people in LTC experienced health instability at the time of admission. More specifically, at admission, 72.4% of home care clients scored zero or one on the CHESS – this was true for 92% of people in LTC. While people admitted to LTC may have multiple, complex health conditions and functional decline, their overall status may be stable. Their conditions may not have reliable trajectories, and so do not receive a prognosis of six or fewer months to live, thereby excluding them from triggering as a "high priority". For example, more individuals with dementia or other cognitive related challenges are admitted to LTC and currently, these diagnoses are not often viewed as life-limiting. The triggering rates in the current study are based on the first assessment (intake) for each person in the data. We also explored the triggering rates using the most recent LTC assessment (as opposed to the admission assessment)

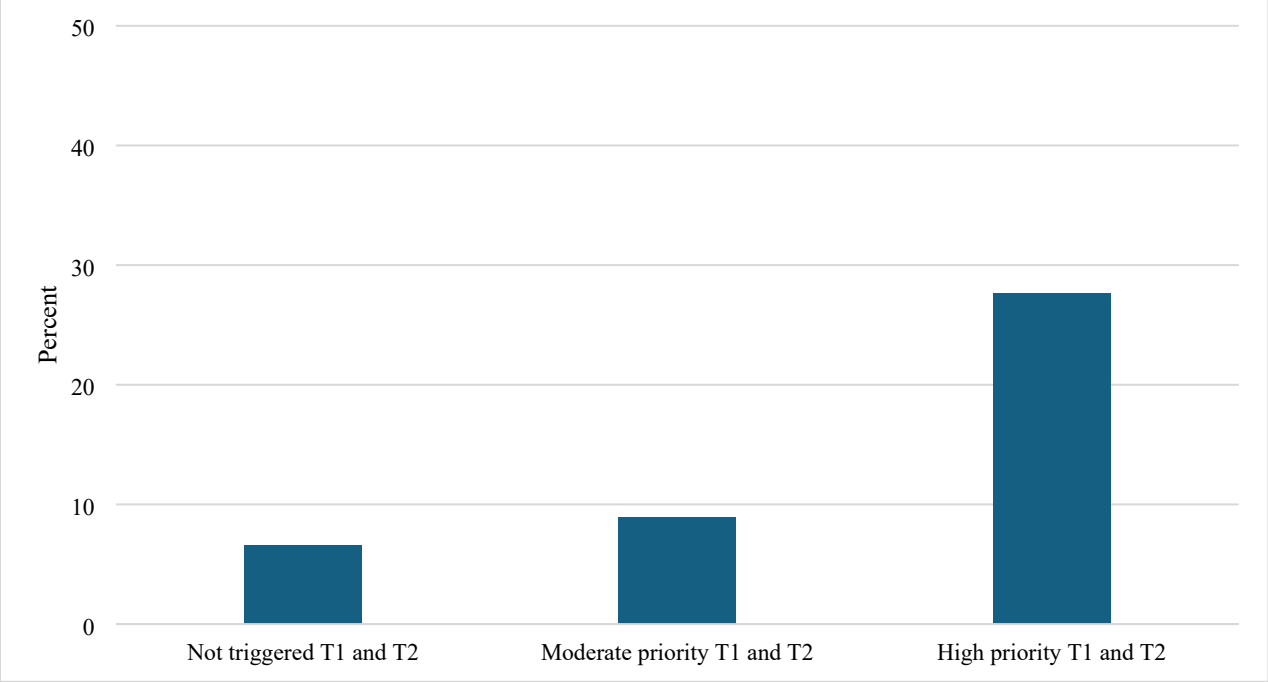


Fig. 2 Receipt of hospice/palliative care services (ordered or received) based on changes in the Serious Illness CAP triggering between two time points (≤ 3 months)

and found that the prevalence of those who trigger the CAP does increase (18%). While this is still lower than home care, it does suggest that time spent in LTC may influence triggering rates – i.e., that health instability and other exacerbating issues present or worsen the longer that they are in LTC. Our advisories of persons living with dementia viewed this diagnosis as a life-limiting condition and believe that 100% of persons in LTC with such a diagnosis could benefit from a palliative approach; this belief was shared by the provider advisory. As noted above, the CAP does not replace clinical judgment or the person's care preferences.

The overall goals of the CAP are to improve access to a palliative approach as well as identify areas for potential improvement. The CAP guidelines encourage providers to ensure that the individual, and their care partners and/or substitute decision-maker (if relevant) have sufficient knowledge of the medical situation (and prognosis, if present) to make informed decisions about their care. If applicable, the appropriate interventions should be implemented to address priority problems, which in turn may improve overall quality of life for the individual and their informal care network. Again, the guidelines that accompany the Serious Illness CAP can support clinicians as they develop care plans, but clinical judgement should always be used to determine if any follow-up or further evaluation may be needed [31]. Inclusion of individuals with lived experience of being in an underserved group was vitally important in the development of the Serious Illness CAP. A palliative approach to care is meant to be person-centered, focusing on the needs, values, and wishes of each person. Each advisory group provided unique perspectives that informed the development of CAP guidelines – their contributions will help to normalize what may not have been previously considered by clinicians.

This CAP will play an important role in the home care and long-term care sectors. While there are several other PC tools developed for use in hospital and community settings (e.g., RESPECT [32], HOMR [33], NECPAL CCOMS-ICO [34]), these mainly focus on prognosis and mortality risk. The Serious Illness CAP aims to facilitate access to a palliative approach earlier in the illness trajectory. The CAP is also not disease-specific, which allows for direct comparisons to be made across various diagnostic groups. Further, the exacerbating issues that are part of the CAP are potentially modifiable, which is important and has direct relevance to quality of life. For example, pain is one of the most common symptoms experienced in individuals with life-limiting illnesses [35, 36]. Uncontrolled or unaddressed pain can negatively affect all aspects of the persons' well-being. Similarly, distressed mood, including anxiety and depression are often unrecognized and untreated in those with a serious illness due to the normalization of psychiatric issues in chronic or life-limiting illnesses, difficulties differentiating symptoms of physical disease from psychiatric, and stigma

around psychiatric issues [37, 38]. Fatigue is often also viewed as "normal" or "expected" for individual's living with a serious illness. While there may be instances where the treatment of fatigue may no longer be recommended or possible, it should be fully evaluated to look for reversible causes as it is often associated with other symptoms (e.g., pain, depression, sleep disturbance) [39].

While there are several strengths in the current study, including the use of large home care and LTC datasets across multiple provinces in Canada, there are also limitations. The items that were included in the CAP triggering rules were limited to what is available with the two interRAI assessments. Given the comprehensive nature of the assessments and feedback from our provider advisory, we are confident the CAP captures the most important clinical issues. While the CAP does have content and face validity (via input from PC clinicians throughout its development), we were not able to test predictive validity. The CAP will soon be implemented and used in Canada for individuals receiving care in a home and facility-based settings. Future work is needed to examine whether those who triggered the CAP went on to receive a palliative approach/PC services, and whether this led to improved outcomes for individuals and their caregivers. We were also limited in terms of the subgroups that could be examined. We did not have access to Indigenous status and used primary language to identify persons in linguistic minority groups; there is no information on race or ethnicity in the interRAI assessments used in Canada. Future work is needed to examine whether, over time, use of the Serious Illness CAP reduces inequities in palliative care access among all groups, as well as which expands the underserved groups considered.

This CAP is an extremely important addition to the applications of the interRAI assessments used in home care and long-term care settings, and has the potential to inform system-level palliative care planning both within Canada and approximately 30 other countries using these instruments. The new CAP is automatically generated for everyone assessed, providing clinicians with real-time information to inform decisions around the appropriate time to initiate conversations about palliative approach, including the discussion of goals, wishes, values, and advance care planning. Having these conversations early and often helps ensure that the care provided is in line with the preferences of the individual and their family. Future research will also explore outcomes related to triggering the Serious Illness CAP, including quality of life, caregiver outcomes, advance care planning, and receipt of PC, as well as hospitalizations, emergency department use, and mortality.

Supplementary Information

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Supplementary Material 1.

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Authors' contributions

LM, JPH, and DMG contributed to the conception and design of the study. NW analyzed the data, while LM, JPH, AS, CV, MS, VMB, DMG and NW contributed to the interpretation of the data. NW and LM drafted the manuscript and all authors read and approved the final manuscript.

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Data availability

The data are not publicly available, but they are directly available to interRAI fellows and their staff and students. Other researchers can access the data from the Canadian Institute for Health Information for researchers who meet the criteria for access to confidential data. These data represent third party data that are not owned nor collected by the study authors. A data request form can be found here: [https://www.cihi.ca/en/access-data-and-reports/make-a-data-request].

Declarations

Ethics approval and consent to participate

Given the involvement of multiple institutions, this project received multiple ethics approvals. As a starting point, the Research Ethics Board at Lakehead University provided an ethics waiver under article 2.5 of the Tri-Council Policy Statement as the project's purpose was evaluative in nature. It was recommended by the Research Ethics Board at Wilfrid Laurier University to obtain additional ethics approval for the provider/clinical advisory group, as they were working in a much more involved way with the research team based at Wilfrid Laurier University than other advisory groups (which were led by researchers outside of that institution). The Research Ethics Board at Wilfrid Laurier University (REB #8799) reviewed and approved the project and informed consent was obtained from all participants on the provider/clinical advisory group. All methods were performed in accordance with the relevant guidelines and regulations.

This study also involves secondary analysis of anonymized data and was granted an ethics waiver by the Lakehead University Research Ethics Board under article 2.4 of the Tri-Council Policy Statement (TCPS2).

This paper reports on health services research conducted with individuals/community members acting in an advisory role, rather than on medical research involving human participants or that used identifiable human material or data. The authors declare that the work adheres to the general principles of the Declaration of Helsinki, for example, related to promoting and safeguarding the health, wellbeing, interests, and rights of all those involved with the work.

Further, free and informed voluntary consent was obtained for a subset of community members by a member of the research team. The authors declare that this was done in a way that fully adhered to the Declaration of Helsinki.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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