

**From Less Invisible to More Transparent: Need for and Outcomes of Formal Personal
Support Services in Long-Stay and Short-Stay Home and Community Care**

by

Chi-Ling Joanna Sinn

A thesis

presented to the University of Waterloo

in fulfilment of the

thesis requirement for the degree of

Doctor of Philosophy

in

Public Health and Health Systems (Aging, Health, and Well-Being)

Waterloo, Ontario, Canada, 2019

© Chi-Ling Joanna Sinn 2019

EXAMINING COMMITTEE MEMBERSHIP

The following served on the Examining Committee for this thesis. The decision of the Examining Committee is by majority vote.

External Examiner:

Dr. Margaret Penning
Professor, Department of Sociology
University of Victoria

Supervisor:

Dr. John Hirdes
Professor, School of Public Health and Health Systems
University of Waterloo

Internal Members:

Dr. George Heckman
Associate Professor (Schlegel Research Chair in Geriatric
Medicine), School of Public Health and Health Systems
University of Waterloo

Dr. Veronique Boscart
Associate Professor (CIHR/Schlegel Industrial Research Chair
for Colleges in Seniors Care), School of Public Health and
Health Systems
University of Waterloo

Dr. Jeff Poss
Adjunct Associate Professor, School of Public Health and
Health Systems
University of Waterloo

Internal-External Member:

Dr. Weizhen Dong
Associate Professor, Department of Sociology and Legal Studies
University of Waterloo

AUTHOR'S DECLARATION

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

ABSTRACT

Background: Home and community care is a critical part of an effective health care system. For many clients and families, home and community care services provide the necessary supports so they can manage various short- and long-term needs effectively and safely in their homes. In Ontario, personal support and homemaking (PS/HM) services account for three-quarters of all publicly funded home care services. PS/HM services assist clients with basic self-care and other tasks known as Activities of Daily Living and Instrumental Activities of Daily Living. Yet the processes for determining eligibility, priority, and allocation of publicly funded PS/HM services are neither consistent between Local Health Integration Networks (LHINs) nor accessible to clients and families. Client outcomes attributable to PS/HM service provision are also poorly understood. The overarching goal of this thesis is to develop and refine decision support tools to guide the allocation of publicly funded PS/HM services, and to characterise the relationship between the quantity of publicly funded PS/HM services and outcomes.

Study 1: Across Canada, Ontario is the sole province that has implemented the interRAI Home Care (HC), interRAI Community Health Assessment (CHA), and interRAI Contact Assessment (CA). The HC and CHA are standardised comprehensive assessments developed to assess the needs, values, and preferences of adults receiving services in home and community-based settings. The CA although much briefer follows the same interRAI standard, allowing direct comparisons across the three populations. To date, there is little published evidence on Ontario's CA- and CHA-assessed populations. This chapter comprised of four sub-chapters based on a single retrospective cohort of unique clients (age ≥ 18 years) newly admitted to Ontario's publicly funded home care program between April 1, 2016 and March 31, 2017 and assessed

with the CA or HC (n=268,667) and unique clients assessed with the CHA between April 1, 2015 and March 31, 2016 (n=15,307).

Sub-study A identified unique characteristics and service use patterns among Ontario's public home and community care clients assessed with the CA, HC, and CHA. Sub-study B modelled the relationship between the Assessment Urgency Algorithm (AUA) and time to HC assessment using cumulative incidence competing risk and Kaplan-Meier methods. Higher AUA levels are strongly associated with greater likelihood of receiving an HC assessment and shorter time to HC assessment, although 26.6% of clients in the highest AUA level were not subsequently assessed. The AUA calculated from the CA at intake is also moderately positively correlated with the Method for Assigning Priority Levels (MAPLe) algorithm that is used to guide decisions related to eligibility and priority for services and long-term care placement following the HC assessment. Sub-study C investigated the agreement between the receipt of publicly funded PS/HM services after the CA and HC. Three multivariable logistic models were fit to identify predictors of clients receiving significantly more or less service after the HC. As expected, measures of need are most strongly associated with service plan adjustments although enabling characteristics, especially the LHIN in which a client lives, are also highly influential. Sub-study D compared the self-reported and billed services data over the same seven-day lookback period and found that formal PS/HM services accounted for a small fraction of the total help that most home and community care clients received.

Study 2: In 2018, Ontario's LHINs formally adopted the Personal Support (PS) Algorithm as a standard approach to identify need for PS/HM services. The PS Algorithm classifies clients based on functional and cognitive impairment and other need characteristics known to be

associated with need for PS/HM services. Recent publications have suggested additional characteristics (“modifiers”) that may be relevant. The study sample consisted of 126,001 unique HC assessments completed between April 1, 2016 and March 31, 2017 that is a representative sample of Ontario’s public long-stay home care client population. To test the relevance of additional modifiers to the PS Algorithm, the median publicly funded PS/HM hours and total (i.e., formal and informal) home support hours per month were compared across PS Algorithm groups and selected modifiers. The PS Algorithm explains 25.5% and 33.4% of the variance in publicly funded and total PS/HM hours, respectively. Clients living alone receive more publicly funded PS/HM hours, but clients living with their primary informal caregiver receive much more total home support hours. Publicly funded and total PS/HM hours increase with the severity of cognitive impairment and caregiver distress, but generally do not respond to health instability except for very high health instability. Finally, comparison of the distribution of publicly funded PS/HM hours between FY 13/14 and FY 16/17 suggests that allocations have begun to cluster as LHINs move away from local allocation practices toward a common provincial standard.

Study 3: While the PS Algorithm is helpful for guiding the allocation of PS/HM services for HC-assessed home care clients, there is no equivalent tool to guide the allocation of PS/HM services for short-stay clients and within short-term service plans for long-stay clients. The goal of this study is to create a conceptually similar algorithm based on the CA that differentiates need for PS/HM services. The derivation sample consisted of 228,354 unique CA assessments completed between April 1, 2016 and March 31, 2017. Among CA-assessed clients, 15.4% received any publicly funded PS/HM services after the CA. Given the zero-inflated nature of the dependent variable, bivariate logistic models predicting the odds of receiving any publicly

funded PS/HM services were fit for the full derivation sample, and bivariate linear models predicting the amount of services were fit for clients receiving any publicly funded PS/HM services. Automatic and interactive decision trees were developed based on need characteristics identified in exploratory analyses. An out-of-time validation sample was used to assess each model's explained variance of the amount of publicly funded PS/HM services received after the CA and weighted kappa of the PS Group at the time of HC assessment. Consistent with the derivation of the PS Algorithm, measures of functional impairment, cognitive impairment, and caregiver distress are strongly associated with the amount of PS/HM hours received after the CA. Similar performance statistics were observed across the candidate trees; thus, the model replicating the PS Algorithm was selected as the final algorithm ("PS Algorithm for the CA"). In the validation sample, the PS (CA) Algorithm explains 20.4% of the variance in publicly funded PS/HM hours and is moderately associated with the PS Group at the time of HC assessment (weighted kappa statistic=0.36). In comparison, the AUA only explains 11.6% of the variance in publicly funded PS/HM hours.

Study 4: Derivation of the PS Algorithm and PS (CA) Algorithm was based on the premise that the average historical allocation of PS/HM services is an indicator of need. While the relative differences in allocation can be reliably used to differentiate levels of need, there is concern that the status quo may not represent the "right" amount of services and therefore the average historical allocation should not serve as a benchmark for future allocation practices. To address this concern, a multi-state analytic approach was used to test the hypothesis that some level of service below a threshold would increase the risk of poor outcomes or some level of service above a threshold would decrease risk of poor outcomes. Data for this study was provided by the

Hamilton Niagara Haldimand Brant LHIN. Clients referred on or after January 1, 2010 and subsequently admitted for home care services were eligible for the study. For each eligible client, all HC assessments completed on or after January 1, 2013 were retrieved. Each HC assessment up to December 2017 was assigned to one of three initial states based on the presence of caregiver distress. A period of up to 456 days (15 months) was allowed to observe a follow-up HC assessment or home care episode discharge. The sample consisted of 57,208 observation pairs representing 30,625 unique clients. The independent variable of interest was the quintile of publicly funded PS/HM services, where the reference group was the 3rd quintile that represents the median allocation within a given PS Group. Adjusting for baseline client characteristics, providing less than the median PS/HM services significantly increases the odds of new caregiver distress, moving to long-term care, and death. Among distressed caregivers, providing less than the median PS/HM services significantly decreases the adjusted odds of resolving caregiver distress. Among clients with non-distressed caregivers, providing more than the median PS/HM services significantly decreases the adjusted odds of moving to cluster residence.

Conclusions: This thesis sought to provide actionable evidence on the predictors and outcomes of publicly funded PS/HM service allocation in Ontario. It is the first comprehensive study of the CA since its province-wide adoption in 2010. The CA is part of an efficient assessment process that identifies clients who should be at the highest priority to receive the more comprehensive HC assessment. As well, information from the CA can be used in a structured way to guide the allocation of PS/HM services for short-stay clients as well as within short-term service plans for long-stay clients. Together, the PS (CA) Algorithm and PS Algorithm provide a unified evidence-informed approach for allocating publicly funded PS/HM services throughout the home

care episode. To date, Ontario's LHINs have adopted the PS Algorithm without the corresponding Framework of Hours for specifying hours of service. The final part of this thesis demonstrates that the Framework of Hours identifies minimum thresholds below which publicly funded PS/HM allocation may lead to poorer client and caregiver outcomes. The findings provide compelling evidence for policy-makers to set standard service guidelines and monitor PS/HM-sensitive outcomes. Doing so will ensure that clients and families know what supports to expect from the public home and community care system, that public resources are distributed fairly, that investments in home care can be demonstrated, and that the valuable contributions of personal support workers can be properly recognised.

ACKNOWLEDGMENTS

Thank you to Dr. John Hirdes for taking me under your wing and introducing me to the wonderful and complex world of health services research. Thank you for your time and encouragement. It is very telling that we first met in a coffee shop after work hours. Thank you for creating opportunities for me to experience first-hand the translation of research into practice and policy. This journey has been much more than picking up the content and methods knowledge. I have also found my passion and my voice over the past six years. John, you have been a role model for me in so many ways and I am grateful to have learned alongside you.

Thank you to my committee members for being a part of this journey. Dr. Jeff Poss, I am lucky to have learned about being a researcher from you. Your sense of wit combined with your analytic insights was always a recipe for lively and thoughtful discussion. Thank you for teaching me the importance of knowing the data and asking as many questions as I can think of. Dr. George Heckman and Dr. Veronique Boscart, the clinical and research work that you accomplish every day is inspiring. Your understanding of how individuals, families, and providers experience and interact with the health care system greatly benefitted the thesis. Thank you for always reminding me to look at the big picture and imagine the ideal system toward which we should all strive. Dr. Margaret Penning and Dr. Weizhen Dong, thank you for taking the time to review and offer constructive feedback on my work.

Thank you to the Hamilton Niagara Haldimand Brant Local Health Integration Network (formerly Community Care Access Centre) for providing access to their data used in Chapter 6 and supporting my research assistantship for the past five years. Thank you to Jane Blums, Gail Riihimaki, and Tom Peirce for supporting my provincial work in the early days. Thank you to

Lia Salam-White, Galina Grinchenko, Kim Hallman, Pam Fabi, and Dr. Iwona Bielska for believing in our contributions as academic secondees. A special thank you to Jennifer Vansickle with whom I worked so closely—I hope our paths (and big ideas!) cross again in the future.

What started as a project idea blossomed into the Personal Support Algorithm and inspired an entire thesis. Thank you to all the members of the Provincial Assessment Solution Working Group. It was such an exciting time for me to learn how to contribute to a clinical working group and participate in a research effort that engaged stakeholders every step of the way. Thank you to Janet McMullan, Nancy Ackerman, Aaron Jones, and Heebah Sultan for a fulfilling partnership. Additionally, thank you to the Levels of Care Expert Panel and the Ministry of Health and Long-Term Care for the opportunity to participate in discussions and provide analytical support toward the vision of a more transparent home and community care system.

Even though this thesis was years in the making, there were never a dull day with my friends and colleagues at interRAI Canada. Thank you to Julie Koreck for keeping everyone organised and our stress at bay. Thank you to Micaela Jantzi, Jonathan Chen, Leslie Eckel, and Nancy Curtin-Telegdi for all the ways you support us. To my fellow students and enviable graduates, I cannot thank you enough for your kindness and friendship over the years. On some days, our chats about weekend plans, Harry Potter, and riding e-scooters was just the break that I needed to dive back into work. Sophie Hogeveen, you'll always be my #gradlife office buddy, hotel roommate, and dancing friend.

Thank you to my family for supporting me through the last 10 years at Waterloo. Thank you for trusting the path I chose and offering help in whatever way you can (motivational text messages and packed meals included!). Mom and Dad, you taught me to dream big, work hard, and learn

something every day. Jonathan and Loreta, I mean this in the best way... thank you for keeping me from being too serious. I love you all so much.

Thank you to Aaron, my husband and closest friend. You have been a fan of my education since I can remember. Thank you for your understanding and patience until I finished this degree. On the days I carried what felt like a thousand pounds of stress to bed, you would listen and find ways to help me reset and prepare for the next day. I honestly could not have finished the degree (or dreamed of starting it) without you. There's nothing we can't accomplish together!

DEDICATION

To Mom. You always put us first.

TABLE OF CONTENTS

List of Figures	xx
List of Tables	xxiii
List of Abbreviations	xxvii
Chapter 1 : Introduction and Overview	1
1.1 Home and Community Care in Canada	1
1.2 Home and Community Care in Ontario	5
1.3 Personal Support Workers	9
1.4 Personal Support/Homemaking Services.....	11
1.4.1 Policy Context in Ontario	13
1.4.2 Personal Support Algorithm	17
1.5 Thesis Overview	20
1.6 Andersen-Newman Service Utilisation Model: Theoretical Framework	22
1.7 Health Care Need.....	26
1.7.1 Properties of Need.....	27
1.7.2 Views on Health Care Need.....	27
1.7.3 Health Care Need and Health Service Use	29
1.7.4 Equity.....	31
Chapter 2 : Literature Review.....	33
2.1 Introduction.....	33
2.2 Search Strategy	33
2.3 Literature on the Determinants of PS/HM Service Allocation or Utilisation.....	34
2.3.1 Measures of PS/HM Service Allocation or Utilisation.....	34
2.3.2 Predisposing Characteristics	35
2.3.3 Enabling Characteristics	37
2.3.4 Need Characteristics	38
2.3.5 Summary	43
2.4 Literature on the Outcomes of PS/HM Service Allocation or Utilisation	44
2.4.1 Mortality	44
2.4.2 Institutionalisation.....	46

2.4.3 Hospitalisation	47
2.4.4 Total Health Service Cost	48
2.4.5 Client Health	48
2.4.6 Caregiver Health	50
2.4.7 Summary	51
Chapter 3 : Who is assessed with the interRAI Contact Assessment, Home Care, and Community Health Assessment and who receives publicly funded home and community care services in Ontario?	52
3.1 Introduction.....	52
3.2 Objectives	57
3.3 Data Sources	58
3.3.1 Health Shared Services Ontario Data	58
3.3.2 Ontario Ministry of Health and Long-Term Care Data	60
3.4 Samples	61
3.4.1 Home Care Sample	61
3.4.2 Community Care Sample.....	62
Sub-Chapter 3A	63
3A.1 Objectives	63
3A.2 Variables of Interest.....	63
3A.2.1 Assessment Groups.....	63
3A.2.2 Predisposing Characteristics.....	63
3A.2.3 Enabling Characteristics.....	64
3A.2.4 Need Characteristics.....	65
3A.2.5 Formal and Informal Care.....	68
3A.3 Analysis Plan.....	70
3A.4 Results.....	70
3A.4.1 Group Characteristics.....	73
3A.4.2 Self-Reported Informal Care Received Prior to Assessment.....	81
3A.4.3 Self-Reported Formal Care Received Prior to Assessment.....	85
3A.4.4 Billed Formal Care Received After Assessment.....	88
3A.5 Discussion.....	93
3A.5.1 Strengths.....	97

3A.5.2 Limitations.....	98
Sub-Chapter 3B	99
3B.1 Objectives.....	99
3B.2 Scales of Interest.....	99
3B.2.1 Assessment Urgency Algorithm.....	99
3B.2.2 Method for Assigning Priority Levels.....	100
3B.3 Analysis Plan.....	101
3B.4 Results.....	101
3B.4.1 Relationship between AUA and Time to HC Assessment.....	101
3B.4.2 Relationship between AUA and MAPLe.....	108
3B.4.3 Selected Need Characteristics Assessed at Time of CA and Time of HC.....	109
3B.5 Discussion.....	112
3B.5.1 Strengths.....	116
3B.5.2 Limitations.....	116
Sub-Chapter 3C	117
3C.1 Objectives.....	117
3C.2 Variables of Interest.....	117
3C.3 Analysis Plan.....	117
3C.4 Results.....	118
3C.5 Discussion.....	134
3C.5.1 Strengths.....	138
3C.5.2 Limitations.....	138
Sub-Chapter 3D	139
3D.1 Objectives.....	139
3D.2 Variables of Interest.....	139
3D.2.1 Self-Reported Formal Care.....	139
3D.2.2 Billed Formal Care.....	140
3D.2.3 Self-Reported Informal Care.....	140
3D.3 Analysis Plan.....	140
3D.4 Results.....	141
3D.5 Discussion.....	143
3D.5.1 Strengths.....	146

3D.5.2 Limitations.....	146
Chapter 4 : What need characteristics are associated with receiving publicly funded PS/HM services among Ontario home care clients assessed with the RAI-Home Care (interRAI Home Care)?.....	147
4.1 Introduction.....	147
4.2 Objectives	150
4.3 Data Sources	151
4.4 Sample.....	151
4.5 Variables of Interest.....	152
4.5.1 Assessment Number.....	152
4.5.2 Enabling and Need Characteristics as Modifiers	152
4.5.3 Formal and Informal Care.....	153
4.6 Scales of Interest.....	155
4.6.1 Personal Support Algorithm	155
4.6.2 IADL-ADL Functional Hierarchy Scale.....	155
4.6.3 ADL Hierarchy Scale.....	155
4.6.4 Assessment Urgency Algorithm	156
4.6.5 Resource Utilization Groups Version III for Home Care (RUG-III/HC).....	156
4.7 Analysis Plan	156
4.8 Results.....	157
4.8.1 Sample Characteristics.....	157
4.8.2 Comparison of Scales and Algorithms	163
4.8.3 Additional Modifiers of Home Support Use.....	166
4.8.4 Updated Framework of Hours	174
4.9 Discussion.....	179
4.9.1 Strengths	185
4.9.2 Limitations	186
Chapter 5 : What need characteristics are associated with receiving publicly funded PS/HM Services among Ontario home care clients assessed with the interRAI Contact Assessment?.....	187
5.1 Introduction.....	187
5.2 Objectives	190
5.3 Data Sources	190

5.4 Samples	190
5.4.1 CA Derivation Sample	190
5.4.2 CA Validation Sample	192
5.4.3 HC Validation Sample	192
5.5 Descriptive Variables	192
5.6 Independent Variables	193
5.7 Dependent Variables	194
5.7.1 Publicly Funded PS/HM Service Utilisation	194
5.7.2 PS Group	195
5.8 Analysis Plan	196
5.9 Results	197
5.9.2 Exploratory Analyses and Development of Candidate Trees	202
5.9.3 CA Validation	211
5.9.4 HC Validation	214
5.9.5 Model Selection	215
5.10 Discussion	221
5.10.1 Strengths	226
5.10.2 Limitations	227
Chapter 6 : What is the relationship between publicly funded PS/HM services and outcomes among Ontario home care clients assessed with the RAI-Home Care (interRAI Home Care)?.....	228
6.1 Introduction	228
6.2 Objectives	230
6.3 Data Sources	230
6.4 Sample	232
6.5 State Transitions	234
6.6 Independent Variable	237
6.7 Covariates	238
6.8 Analysis Plan	239
6.9 Results	240
6.10 Discussion	257
6.10.1 Strengths	262

6.10.2 Limitations	263
Chapter 7 : Overall Implications.....	265
7.1 Summary of Findings.....	265
7.2 Implications for Clinical Practice and Policy in Ontario	267
7.2.1 Use in Specialised Home and Community Care Populations	272
7.2.2 Other Potential Uses and Misuses.....	276
7.3 Implications for Clinical Practice and Policy in Other Jurisdictions	279
7.4 Implications for the Andersen-Newman Model	279
7.5 Future Research	281
References	283
Appendix A: Literature Review	302
A.1 Ovid Search Strategy	302
A.2 EBSCO Search Strategy.....	304
A.3 Studies Included in Review of Literature on the Determinants of PS/HM Service Allocation or Utilisation	305
A.4 Studies Included in Review of Literature on the Outcomes of PS/HM Service Allocation or Utilisation	331
Appendix B: Additional Tables for Chapter 6.....	347

LIST OF FIGURES

Figure 1-1 Framework of Hours for the PS Algorithm.....	19
Figure 1-2 Andersen-Newman Service Utilisation Model	23
Figure 1-3 Definitions of Access within the Andersen-Newman Service Utilisation Model.....	25
Figure 3-1 interRAI Assessments and Assessed Populations in Home Care in Ontario	55
Figure 3-2 interRAI Assessments and Assessed Populations in Community Care in Ontario.....	56
Figure 3-3 New LHIN Home Care Referrals and Subsequent Assessment or Discharge Events, Unique Clients Admitted as SRC 91/92/93/94, Ontario FY 2016/17, n=307,251	71
Figure 3-4 Distribution of Monthly Informal Support Hours among Home and Community Care Clients, Self-Reported Utilisation, by Assessment Group, Ontario FY 2016/17 and FY 2015/16	84
Figure 3-5 Distribution of Monthly Formal (Publicly and Privately Funded) PS/HM Hours among Home and Community Care Clients, Self-Reported Utilisation, by Assessment Group, Ontario FY 2016/17 and FY 2015/16	87
Figure 3-6 Distribution of Monthly Formal Publicly Funded PS/HM Hours among Home Care Clients, Billed Utilisation, by Assessment Group, Ontario FY 2016/17	92
Figure 3-7 Schematic of the Assessment Urgency Algorithm.....	100
Figure 3-8 Distribution of AUA among Newly Admitted CA-Assessed LHIN Home Care Clients, Ontario FY 2016/17.....	102
Figure 3-9 Time-to-Event Curve for Receipt of HC Assessment among Newly Admitted CA-Assessed LHIN Home Care Clients, by AUA, Ontario FY 2016/17.....	103
Figure 3-10 Time-to-Event Curve for Receipt of HC Assessment among Newly Admitted CA-Assessed LHIN Home Care Clients in CA+HC Group, by AUA, Ontario FY 2016/17.....	105
Figure 3-11 Selected Need Characteristics among Newly Admitted CA-Assessed LHIN Home Care Clients in AUA 6, Ontario FY 2016/17	107
Figure 3-12 Difference in Monthly Publicly Funded PS/HM Hours Received After CA and HC, among CA+HC Clients Receiving No PS/HM Services After CA, Ontario FY 2016/17	120
Figure 3-13 Difference in Monthly Publicly Funded PS/HM Hours Received After CA and HC, among CA+HC Clients Receiving Some PS/HM Services after CA, Ontario FY 2016/17.....	121
Figure 4-1 Schematic of the Personal Support Algorithm.....	148
Figure 4-2 Representation of Need Characteristics in the PS Algorithm	149
Figure 4-3 Distribution of HC-Assessed Clients by PS Group and HC Assessment Number, Ontario FY 2016/17	161
Figure 4-4 Median Monthly Total Home Support Hours among HC-Assessed Clients, by PS Group and HC Assessment Number, Ontario FY 2016/17.....	162

Figure 4-5 Median Monthly Publicly Funded PS/HM Hours by PS Group and Living Arrangement among HC-Assessed Clients, Ontario FY 2016/17	167
Figure 4-6 Median Monthly Total Home Support Hours by PS Group and Living Arrangement among HC-Assessed Clients, Ontario FY 2016/17	167
Figure 4-7 Median Monthly Publicly Funded PS/HM Hours by PS Group and Cognitive Impairment among HC-Assessed Clients, Ontario FY 2016/17.....	169
Figure 4-8 Median Monthly Total Home Support Hours by PS Group and Cognitive Impairment among HC-Assessed Clients, Ontario FY 2016/17	169
Figure 4-9 Median Monthly Publicly Funded PS/HM Hours by PS Group and Health Instability among HC-Assessed Clients, Ontario FY 2016/17	170
Figure 4-10 Median Monthly Total Home Support Hours by PS Group and Health Instability among HC-Assessed Clients, Ontario FY 2016/17	170
Figure 4-11 Median Monthly Publicly Funded PS/HM Hours by PS Group and Client Mental Health among HC-Assessed Clients, Ontario FY 2016/17.....	171
Figure 4-12 Median Monthly Total Home Support Hours by PS Group and Client Mental Health among HC-Assessed Clients, Ontario FY 2016/17	171
Figure 4-13 Median Monthly Publicly Funded PS/HM Hours by PS Group and Caregiver Distress among HC-Assessed Clients, Ontario FY 2016/17	173
Figure 4-14 Median Monthly Total Home Support Hours by PS Group and Caregiver Distress among HC-Assessed Clients, Ontario FY 2016/17	173
Figure 4-15 Comparison of the Distribution of HC-Assessed Clients by PS Group, Ontario 2013 and FY 2016/17.....	174
Figure 5-1 Distribution of Weekly Publicly Funded PS/HM Hours Received after the CA among CA-Assessed Clients, by Client Status, Ontario FY 2016/17.....	201
Figure 5-2 Summary of Variable Importance Statistics from Automated Decision Tree Predicting Weekly Publicly Funded PS/HM Hours Received after CA among CA-Assessed Clients, Ontario FY 2016/17	207
Figure 5-3 Summary of Variable Importance Statistics from Automated Decision Tree Predicting PS Group at Time of HC Assessment among CA- and HC-Assessed Clients, Ontario FY 2016/17	207
Figure 5-4 Exploratory Tree Structure Replicating PS Algorithm, Using CA Items, Ontario FY 2016/17	209
Figure 5-5 Pruned Tree Structure Replicating PS Algorithm and Mapping of Root Nodes, Using CA Items, Ontario FY 2016/17.....	210
Figure 5-6 Distribution of CA-Assessed Clients by PS (CA) Group, Ontario April–December 2017.....	215
Figure 5-7 Distribution of PS Group by PS (CA) Group among CA- and HC-Assessed Clients, Ontario FY 2016/17	216

Figure 5-8 Scatterplot of Variance Explained by PS (CA) Algorithm of Publicly Funded PS/HM Services Received after CA (Ontario FY 2016/17) and Variance Explained by PS Algorithm of Publicly Funded PS/HM Services Received after HC (Ontario Jan–Dec 2013)	218
Figure 5-9 Proportion of CA-Assessed Clients Receiving Any Publicly Funded PS/HM Services after CA, by PS (CA) Group and LHIN, Ontario April–December 2017	219
Figure 5-10 Median Weekly Publicly Funded PS/HM Hours by PS (CA) Group and LHIN, Ontario April–December 2017	220
Figure 5-11 75 th Percentile of Weekly Publicly Funded PS/HM Hours by PS (CA) Group and LHIN, Ontario April–December 2017	221
Figure 6-1 State-Space Diagram for Transitions within Home Care.....	237
Figure 6-2 Proportion of HC-Assessed Clients in PS/HM Quintiles, by Initial State, HNHB LHIN January 2013–December 2017	245
Figure 6-3 Transition Proportions from Initial State to Follow-up State, HC-Assessed Clients, HNHB LHIN January 2013–December 2017.....	247

LIST OF TABLES

Table 1-1 Levels of Care Framework Proposed by the Levels of Care Expert Panel	15
Table 3-1 Clinical Sections and Number of Items in interRAI CA, HC, and CHA	66
Table 3-2 Classification of Home and Community Care Clients based on Type of Assessment, Ontario FY 2016/17 and FY 2015/16, n=268,667	72
Table 3-3 Predisposing Characteristics of Home and Community Care Clients, by Assessment Group, Ontario FY 2016/17 and FY 2015/16	73
Table 3-4 Enabling Characteristics of Home and Community Care Clients, by Assessment Group, Ontario FY 2016/17 and FY 2015/16	75
Table 3-5 Enabling Characteristics of Home Care Clients, by Assessment Group, Ontario FY 2016/17	76
Table 3-6 Need Characteristics of Home and Community Care Clients, by Assessment Group, Ontario FY 2016/17 and FY 2015/16	78
Table 3-7 Receipt of Informal Support among Home and Community Care Clients, Self-Reported Utilisation, by Assessment Group, Ontario FY 2016/17 and FY 2015/16	83
Table 3-8 Receipt of Formal (Public and Privately Funded) Care among Home and Community Care Clients, Self-Reported Utilisation, by Assessment Group, Ontario FY 2016/17 and FY 2015/16	86
Table 3-9 Receipt of Formal Publicly Funded Care among Home Care Clients, Billed Utilisation, by Assessment Group, Ontario FY 2016/17	89
Table 3-10 Frequency of Formal Publicly Funded Service Types among Home Care Clients, Billed Utilisation, by Assessment Group, Ontario FY 2016/17	89
Table 3-11 Frequency of Formal Publicly Funded PS/HM and other Service Types, Home Care Clients Receiving Any PS/HM Services, Billed Utilisation, by Assessment Group, Ontario FY 2016/17	90
Table 3-12 Receipt of HC Assessment within 182 Days of CA among Newly Admitted CA-Assessed LHIN Home Care Clients, by AUA, Ontario FY 2016/17	103
Table 3-13 Chi-Square Statistics for Differences between Time-to-Event Curves for Receipt of HC Assessment among Newly Admitted CA-Assessed LHIN Home Care Clients in CA+HC Group, Pairwise Comparisons of Adjacent AUA Levels, Ontario FY 2016/17	104
Table 3-14 Receipt of HC Assessment within 14 Days of CA among Newly Admitted CA-Assessed LHIN Home Care Clients, by AUA, Ontario FY 2016/17	104
Table 3-15 Chi-Square Statistics for Differences between Time-to-Event Curves for Receipt of HC Assessment among Newly Admitted CA-Assessed LHIN Home Care Clients in CA+HC Group, Pairwise Comparisons of Adjacent AUA Levels, Ontario FY 2016/17	106

Table 3-16 Average Number of Days to Receipt of HC Assessment among Newly Admitted CA-Assessed LHIN Home Care Clients in CA+HC Group, by AUA, Ontario FY 2016/17	106
Table 3-17 Distribution of MAPLe at Follow-up among Newly Admitted CA-Assessed LHIN Home Care Clients in CA+HC Group, by AUA at Intake, Ontario FY 2016/17	108
Table 3-18 Unadjusted Odds of Being in High or Very High MAPLe Level at Follow-up among Newly Admitted CA-Assessed LHIN Home Care Clients in CA+HC Group, by AUA at Intake, Ontario FY 2016/17	109
Table 3-19 Agreement Between Selected Need Characteristics Assessed at Time of CA and Time of HC among Newly Admitted CA-Assessed LHIN Home Care Clients in CA+HC Group, Ontario FY 2016/17	111
Table 3-20 Agreement Between Selected Need Characteristics Assessed at Time of CA and Time of HC among Newly Admitted CA-Assessed LHIN Home Care Clients in CA+HC Group, Stratified by Time to HC Assessment, Ontario FY 2016/17	111
Table 3-21 Agreement Between Selected Need Characteristics Assessed at Time of CA and Time of HC among Newly Admitted CA-Assessed LHIN Home Care Clients in CA+HC Group, Stratified by Type of Communication at Intake, Ontario FY 2016/17	112
Table 3-22 Receipt of Any Publicly Funded PS/HM Services after CA and HC Assessments, among Newly Admitted CA-Assessed LHIN Home Care Clients in CA+HC Group, Ontario FY 2016/17	119
Table 3-23 Receipt of Hours of Publicly Funded PS/HM Services after CA and HC Assessments, among Newly Admitted CA-Assessed LHIN Home Care Clients in CA+HC Clients, Ontario FY 2016/17	119
Table 3-24 Unadjusted and Adjusted Odds of Service Initiation (i.e., Clients Receiving No PS/HM after CA and Receiving Some PS/HM after HC), among Newly Admitted LHIN Home Care Clients in CA+HC Group, Ontario FY 2016/17	124
Table 3-25 Unadjusted and Adjusted Odds of Service Increase (i.e., Clients Receiving Some PS/HM Services after CA and Receiving More PS/HM Services after HC), among Newly Admitted LHIN Home Care Clients in CA+HC Group, Ontario FY 2016/17	127
Table 3-26 Unadjusted and Adjusted Odds of Service Decrease (i.e., Clients Receiving Some PS/HM Services after CA and Receiving Less PS/HM Services after HC), among Newly Admitted LHIN Home Care Clients in CA+HC Group, Ontario FY 2016/17	131
Table 3-27 Publicly Funded PS/HM Hours Received after CA and HC, among Newly Admitted LHIN Home Care Clients in CA+HC Group Receiving at Least 20 Fewer Hours after HC, Ontario FY 2016/17	133
Table 3-28 Billed Hours as a Percentage of Self-Reported Hours in the Last Seven Days, among Newly Admitted LHIN Home Care Clients in CA+HC Group, Ontario FY 2016/17	142
Table 3-29 Share of Monthly Informal and Formal (Publicly and Privately Funded) PS/HM Hours, among Newly Admitted LHIN Home Care Clients in CA+HC Group, Ontario FY 2016/17	143

Table 4-1 Definition of Expert-Defined and Data-Informed IADL-ADL Functional Hierarchy Levels.....	157
Table 4-2 Predisposing and Enabling Characteristics of HC-Assessed Clients, by First or Subsequent HC, Ontario FY 2016/17	159
Table 4-3 Need Characteristics of HC-Assessed Clients, by First or Subsequent HC, Ontario FY 2016/17	160
Table 4-4 Number of Days from Referral Date to HC Assessment Date among HC-Assessed Clients, Ontario FY 2016/17.....	161
Table 4-5 Median Monthly Informal Hours as a Proportion of Total Home Support Hours among HC-Assessed Clients, by PS Group and HC Assessment Number, Ontario FY 2016/17	163
Table 4-6 Performance of interRAI Scales and Algorithms in Explaining Publicly Funded and Total Home Support Hours among Clients Receiving Their First HC Assessments, Ontario FY 2016/17	164
Table 4-7 Performance of interRAI Scales and Algorithms in Explaining Publicly Funded and Total Home Support Hours among Clients Receiving Subsequent HC Assessments, Ontario FY 2016/17	165
Table 4-8 Comparison of RUG-III/HC and PS Algorithm in Explaining Monthly Formal Publicly Funded PS/HM Hours, by RUG Clinical Category, Ontario FY 2016/17.....	166
Table 4-9 Original Framework of Hours for the PS Algorithm Based on Ontario FY 2014/15 Data.....	175
Table 4-10 Updated Framework of Hours for the PS Algorithm Based on Ontario FY 2016/17 Data.....	176
Table 4-11 Percentage Change in Percentile Bands between Original and Updated Frameworks Based on Ontario FY 2014/15 and FY 2016/17 Data.....	177
Table 4-12 Proportion of HC-Assessed Clients Receiving Publicly Funded PS/HM Services within Defined Percentile Bands, by LHIN, Ontario FY 2016/17	178
Table 4-13 Proportion of HC-Assessed Clients Receiving Publicly Funded PS/HM Services Beyond Defined Percentile Bands, by LHIN, Ontario FY 2016/17	178
Table 5-1 Predisposing and Enabling Characteristics of CA-Assessed Clients, by Client Status, Ontario FY 2016/17	199
Table 5-2 Need Characteristics of CA-Assessed Clients, by Client Status, Ontario FY 2016/17	200
Table 5-3 Unadjusted Odds of Receipt of Any Publicly Funded PS/HM Services after CA among CA-Assessed Clients, by Client Status, Ontario FY 2016/17.....	203
Table 5-4 Unadjusted Estimates of Weekly Publicly Funded PS/HM Hours Received after CA among CA-Assessed Clients, by Client Status, Ontario FY 2016/17.....	205
Table 5-5 Performance Statistics across Candidate Trees for CA-Assessed Clients, Ontario April–December 2017.....	212

Table 5-6 Performance Statistics across Candidate Trees for CA-Assessed Clients, by Client Status, Ontario April–December 2017	213
Table 5-7 Performance Statistics across Candidate Trees for CA-Assessed Clients, Phone Only CAs, Ontario April–December 2017	213
Table 5-8 Performance Statistics across Candidate Trees for CA-Assessed Clients, Hospital (Inpatient) CAs, Ontario April–December 2017	214
Table 5-9 Performance Statistics across Candidate Trees for HC-Assessed Clients, Ontario FY 2016/17	214
Table 5-10 Distribution of PS Group by PS (CA) Group among CA- and HC-Assessed Clients, Ontario FY 2016/17	217
Table 5-11 Performance Statistics of PS (CA) Algorithm among CA-Assessed Clients, by LHIN, Ontario FY 2016/17	217
Table 6-1 Definition of PS/HM Quintiles Based on the Framework of Hours (FY 2014/15), in Monthly Publicly Funded PS/HM Hours.....	238
Table 6-2 Predisposing and Enabling Characteristics of HC-Assessed Clients, by Initial State, HNHB LHIN January 2013–December 2017.....	243
Table 6-3 Need Characteristics of HC-Assessed Clients, by Initial State, HNHB LHIN January 2013–December 2017	244
Table 6-4 Chi-Square Statistics for Variables in Multi-state Transition Model.....	248
Table 6-5 Adjusted Odds of State Transitions by Initial State and PS/HM Quintile, All PS Groups, HC-Assessed Clients, HNHB LHIN January 2013–December 2017, n=57,208.....	250
Table 6-6 Adjusted Odds of State Transitions by Initial State and PS/HM Quintile, PS Group 2, HC-Assessed Clients, HNHB LHIN January 2013–December 2017, n=18,877.....	252
Table 6-7 Adjusted Odds of State Transitions by Initial State and PS/HM Quintile, PS Group 3, HC-Assessed Clients, HNHB LHIN January 2013–December 2017, n=18,005.....	253
Table 6-8 Adjusted Odds of State Transitions by Initial State and PS/HM Quintile, PS Group 4, HC-Assessed Clients, HNHB LHIN January 2013–December 2017, n=6,242.....	254
Table 6-9 Adjusted Odds of State Transitions by Initial State and PS/HM Quintile, PS Group 5, HC-Assessed Clients, HNHB LHIN January 2013–December 2017, n=5,077.....	255
Table 6-10 Adjusted Odds of State Transitions by Initial State and PS/HM Quintile, PS Group 6, HC-Assessed Clients, HNHB LHIN January 2013–December 2017, n=2,883.....	256

LIST OF ABBREVIATIONS

ADL	Activity of Daily Living
AUA	Assessment Urgency Algorithm
CAP	Clinical Assessment Protocol
CCAC	Community Care Access Centre
CHESS	Changes in Health, End-stage disease, Signs and Symptoms Scale
CHRIS	Client Health and Related Information System
CPS	Cognitive Performance Scale
DAD	Discharge Abstract Database
HSSOntario	Health Shared Services Ontario
IADL	Instrumental Activity of Daily Living
interRAI CA	interRAI Contact Assessment
interRAI CHA	interRAI Community Health Assessment
interRAI HC	interRAI Home Care Assessment
LHIN	Local Health Integration Network
MAPLe	Method for Assigning Priority Levels
OACCAC	Ontario Association of Community Care Access Centres
PS/HM	Personal support and homemaking services
PS Algorithm	Personal Support Algorithm
PS (CA) Algorithm	Personal Support Algorithm for the Contact Assessment
RAI-HC	Resident Assessment Instrument for Home Care
RUG-III/HC	Resource Utilization Groups Version III for Home Care

CHAPTER 1: Introduction and Overview

1.1 Home and Community Care in Canada

Home and community care is a critical part of an effective health care system. The Canadian Home Care Association defines home and community care as “an array of services for people of all ages, provided in the home and community setting, that encompasses health promotion and teaching, rehabilitation, support and maintenance, social adaptation and integration, end-of-life care, and support for family caregivers” [1]. People seek home and community care to support recovery after hospital discharge, to manage chronic conditions, disabilities, or mental illnesses, to cope with life-limiting illnesses, among other reasons. In 2012, about 2.2 million or 8% of Canadians aged 15 and older received some form of care at home [2].

Broadly, the goal of home and community care is to enable people to live as independently as possible, in reasonably good health, and in sufficiently safe conditions. Being able to access home and community supports can mean delaying or avoiding institutional care and is a central part of policies intended to support aging-in-place. In most cases, individuals and governments share this preference to age in place. Most older adults want to live at home for as long as possible [3–5]. Preferring to stay at home is not merely a physical attachment, but is related to preserving one’s sense of self, beliefs, autonomy, belonging, and other symbolic meanings, and in turn, has been shown to confer a number of health and social benefits [4, 6].

At the health system level, there are various advantages to caring for people in the community rather than in institutions. The supply of hospital and long-term care spaces is exceedingly limited. In Ontario, many hospitals regularly operate at over 100% capacity. In 2016/17, 14.8%

of inpatient hospital days were spent waiting to receive care elsewhere, of which half were attributable to waiting for a long-term care bed [7]. The median time to be admitted into a long-term care home was 92 days from the hospital and 149 days from the community (31.4% and 12.9% longer than in the previous year, respectively) [7]. Currently, more than 26,000 Ontarians are on long-term care home waiting lists, and the gap is expected to widen over the next five years [8]. Meanwhile, an Ontario report concluded that as many as one in three older adults living in long-term care homes could have been supported in the community [9]. For some acutely ill patients, care at home may also replace the need for long inpatient stays for conditions such as heart failure or chronic obstructive pulmonary disease [10]. With access to appropriate home and community supports, the capacity issues faced by hospitals and long-term care homes might be greatly reduced. Additionally, institutional care is much more costly than community-based care. In Ontario, the average daily costs are estimated at \$842 for a hospital bed and \$126 for a long-term care bed, compared to \$42 for care at home [11]. Clearly, enabling earlier hospital discharges and delaying or avoiding institutionalisation through home and community care supports results in substantial efficiencies and cost savings for the health care system.

In Canada, the provinces and territories are responsible for the provision of home and community care services to its residents, with some exceptions. The federal government is directly responsible for providing home care services to serving members of the Canadian Forces, eligible veterans, First Nations living on reserves and Inuit in designated communities, and federal inmates [12]. Otherwise, the role played by the federal government is limited mostly to providing funding support through the Canada Health Transfer and Canada Social Transfer, estimated to account for 23% of provincial and territorial health budgets [13].

The federal government also enforces the *Canada Health Act* that stipulates that provinces and territories must provide insured persons with coverage of insured health services [14]. However, with the exception of two weeks of short-term acute home care, home and community care is not covered under public health insurance as a medically necessary service in the same way as physician and hospital-based services. Instead, home and community care is categorised as an “extended health service” and is not subject to the five principles of the Act [15]. Home and community care is funded and organised based on the terms and conditions of each province and territory. Most provinces and territories allocate their health budgets to regional health authorities that have primary responsibility for deciding on how to divide funding to specific health care services and programs. There are large jurisdictional differences in what services are available, how services are delivered, and to what degree services and populations are covered. These differences persist today despite the 2002 Romanow report calling for the expansion of the *Canada Health Act* to provide first-dollar coverage of home care services in priority areas that could form the basis of a national home care strategy [16].

As a direct result of variation in service mix and funding sources, it is difficult to measure and compare home and community care spending across Canada. In 2005, the Health Council of Canada estimated that 2–3% of Canadian adults received publicly funded home care and 2–5% received privately funded home care [17]. A Conference Board of Canada report estimated that, in 2010, provincial and territorial governments spent \$5.6 to 7.2 billion on public home care while households and insurance programs spent \$1.5 billion on private home care [18]. Another \$1.4 billion and \$0.4 billion were spent on public and private community care, respectively [18]. As a share of the total health budget, home and community care spending ranged from 0.9% in

Nunavut to 8.8% in New Brunswick [18]. In FY 2016/17, the Canadian Institute for Health Information estimated that provincial and territorial governments spent \$8.2 billion on home and community care [19]. While home and community care expenditures were not captured under a separate heading in the national data, the estimate was based on program-level spending data received from the provincial and territorial ministries.

There is a hidden cost of home and community care that is not captured by total spending estimates. Unlike many other health care sectors, most of home and community care is delivered by informal (i.e., unpaid) sources rather than formal (i.e., paid) sources. Informal care is provided by family members, friends, and neighbours and accounts for approximately 70 to 90% of the care at home [18, 20–22]. While 45% of caregivers spend less than four hours a week on caregiving activities, 31% spend 10 or more hours a week [22]. Two percent of caregivers spend 100 or more hours a week on caregiving activities [23]. Summed together, estimates place the economic value of informal caregiving in Canada between \$25 to \$72 billion annually, vastly surpassing the cost of formal services [22, 24].

There have been various theories about the interplay between formal and informal care [6]. The supplementary theory posits that the role of formal care is to supplement the efforts of informal caregivers while the substitution theory suggests that formal care replaces informal care. In general, Canadian studies have not found evidence to support the substitution theory in the context of publicly funded home care services [25–28]. Informal support networks provide the bulk of care and account for increasingly greater proportions of total care when more care is needed [20].

1.2 Home and Community Care in Ontario

In Ontario, the regional health authorities called Local Health Integration Networks (LHINs) plan, coordinate, integrate, and fund local health services. The 14 LHINs vary in geographic and population size, and have distinct population health needs and service delivery arrangements.

Under the *Local Health System Integration Act* [29], the provincial Minister of Health and Long-Term Care signs accountability agreements with each of the LHINs that set out funding amounts, mandatory services and standards, and expected health care and system outcomes. LHINs have responsibility for many but not all publicly funded health service providers, including hospitals, long-term care homes, community health centres, community mental health and addictions agencies, and community support services agencies. The LHINs sign accountability agreements with each health service provider. Prior to 2017, the LHINs signed accountability agreements with Community Care Access Centres (CCACs) that managed delivery of publicly funded home care services. With the passage of the *Patients First Act* [30], CCAC services and staff were transitioned into their local LHIN, meaning home care services became a direct responsibility of the LHIN.

Ontario's *Home Care and Community Services Act* [31] outlines four types of home and community care services. Community support services cover a wide variety of non-clinical supports that often have social or health promotion aims such as meal services, transportation services, adult day programs, and friendly visiting programs. Personal support (PS) services assist clients with Activities of Daily Living (ADLs) such as dressing, bathing, transferring, and other personal care activities. Homemaking (HM) services provide assistance with Instrumental Activities of Daily Living (IADLs) that are more complex tasks such as house cleaning, doing

laundry, and preparing meals. Professional services are delivered by regulated health professionals from a wide range of disciplines including nursing, occupational therapy, physiotherapy, social work, speech language pathology, and dietetics. Often seen in the literature, home support services refer to PS and HM services combined, and home health services is another term for professional services.

The *Canada Health Act* does not require the provinces and territories to offer a standard basket of home and community care services. Nevertheless, the provision of PS services, nursing, and some therapies are core services offered by all publicly funded home care programs [1]. For the most part, persons who are insured by their provincial or territorial health insurance plan and require assistance with ADLs are eligible to receive publicly funded PS services although co-payments and service limits may apply [1]. Most provinces and territories offer partial coverage of HM services with additional criteria. In Ontario, a client can only receive publicly funded HM services if the client also requires PS services, or if the caregiver requires HM support where the caregiver provides PS/HM help or the client requires constant supervision [1]. Clients in Ontario do not pay out-of-pocket fees for approved public PS/HM services [1]. Likewise, clients in Alberta and Manitoba do not pay direct fees for public PS/HM services [1]. Most other jurisdictions apply some form of means testing, so that clients who are below an income threshold or receiving income-tested government benefits (e.g., Old Age Security) do not pay direct fees [1]. Some provinces and territories such as New Brunswick and Quebec apply means testing to HM services only [1]. In British Columbia and Saskatchewan, monthly amounts paid toward PS and HM services in excess of \$300 and \$490, respectively, are waived [1]. Additionally, most provinces and territories set service limits. In Ontario, clients can receive up

to 120 hours of publicly funded PS/HM services in any 30-day period [32]. Clients at the end-of-life, waiting for long-term care placement, or in other time-limited exceptional circumstances may be exempted [32]. Other provinces and territories have set similar limits, often based on a maximum number of hours or dollars, and almost always in relation to the equivalent cost of non-professional care in an institution [1].

Although there are similarities in the types of services that are publicly funded, the service delivery models vary greatly by province or territory. The key difference is the degree to which services are publicly or privately coordinated or delivered. In Ontario, the 14 LHINs coordinate home care services, but service delivery is contracted out to private provider organisations that may be for-profit or not-for-profit. LHINs sign contracts with provider organisations (totalling about 160 provider organisations across the province), agreeing to purchase home care services at a negotiated rate [33, 34]. More information about each province or territory's eligibility criteria, direct fees and income testing, and service limits can be found in the Canadian Home Care Association's *Portraits of Home Care in Canada* [1] and the Levels of Care Expert Panel's *Thriving at Home* report [35].

In contrast, clients often pay at least some of the cost of community support services. Unlike “traditional” home care services that are managed by provincial and territorial home care programs, community support services are generally delivered by local not-for-profit agencies. Most community support services agencies were founded as charitable organisations in response to specific community needs [33]. There are over 800 community support services agencies in Ontario alone, but they are not dispersed evenly across the province [34]. Generally, the density of agencies and hence the availability and breadth of services is much higher in urban areas

compared to rural and northern regions. Agencies receive some operational funding from their respective LHINs with the remainder coming from fundraising, donations, client fees, and grants.

In essence, the home and community care sector can be viewed as two streams working in parallel to provide community-based medical and social services. Despite substantial overlap, home care programs have historically provided the bulk of medical services while community support services agencies offer a wider range of social services beyond personal care. Various groups have called for better integration of the home and community care sector [33, 35, 36]. Ontario's Expert Group on Home and Community Care recommended a lead agency model in which clients and families work with a single care coordinator for all care and services [33]. The concept of a lead agency was trialed through the Home and Community Care Collaborative in the Hamilton Niagara Haldimand Brant LHIN. Prospective clients can contact either the LHIN or any community support services agency, and under the coordinated intake process, the most appropriate provider would support the client to access the care they require. Clients with light care needs would be primarily supported by community support services agencies whereas clients with moderate to complex care needs would be primarily supported by the LHIN under a shared care model. Even if short-term needs arise, clients and families can expect coordinated and consistent care from their most appropriate provider. From a health system perspective, LHINs can focus on providing care to more complex clients and community support services agencies can strengthen their capacity to support clients who are relatively independent.

1.3 Personal Support Workers

This thesis focuses on formal PS/HM services that are provided by unregulated care providers who are known as personal support workers (a title often used in Ontario), home support workers, home health workers, health care aides, patient care aides, personal care attendants, health care assistants, or resident care workers [37, 38]. Although personal support workers provide much of direct client care across the health care system, there is limited knowledge about this “invisible” workforce and their work contexts [37, 39, 40]. Broadly speaking, personal support workers provide personal assistance and supportive services to clients. They provide these services as outlined in client care plans and work under the supervision of a regulated health professional or supervisor (or under the direction of the client in independent living environments) [41]. Personal support workers are not licensed by a regulatory body, meaning that they do not have a legally defined scope of practice, a protected title, mandatory education requirements, a set of professional practice standards, or a professional conduct review process [37]. With the convergence of aging-in-place policies and economic pressures, personal support workers are increasingly providing clinical care services (e.g., measuring blood pressure) and performing delegated acts (e.g., changing wound dressings) that were previously provided by regulated health professionals [42].

The size of the personal support worker workforce is relatively unknown. Estimates largely rely on provincial registries. In British Columbia, all personal support workers working in publicly funded long-term care homes must register with the BC Care Aide and Community Health Worker Registry. In 2018, Ontario relaunched the Personal Support Worker Registry of Ontario. At present, personal support workers in the home care sector may voluntarily sign up with the

registry although the registry website claims that mandatory registration will be rolled out after 2019. Alberta, Quebec, and Nova Scotia have voluntary registries. There are no registries of personal support workers in the rest of Canada. Current best estimates in Ontario come from a 2006 review of the *Regulated Health Professions Act* [41]. At the time, there were approximately 57,000 personal support workers employed in long-term care homes, 34,000 in home and community care, and 6,000 in hospitals. Subsequent surveys in Ontario and provinces in Western Canada have shown that personal support workers are predominantly (>90%) female and many are immigrants and visible minorities [43, 44].

No national education or training standards exist despite calls to establish a list of core competencies and educational requirements. Ontario introduced the Personal Support Worker Program Standard in 2014 [45]. Individuals who complete the course (typically eight months long) at an accredited institution receive the Personal Support Worker certificate. Personal support workers can also complete non-accredited training programs or receive on-the-job training. Neither completing the certificate course nor passing the National Association of Career Colleges examination is a prerequisite for employment in Ontario. While the *Long-Term Care Act* enforces minimum education standards for personal support workers employed in public long-term care homes, there is no corresponding requirement in the *Home and Community Care Act* for those working in community settings [37]. Thus, any minimum training requirements are set by employers.

At the same time, employers have expressed concerns about high turnover rates and insufficient supply of personal support workers to meet demand. In Ontario, community support services agencies and service provider organisations have been reporting shortages in the personal

support worker workforce for at least the past decade [46, 47]. Some of the shortage can be partly explained by greater client complexity leading to the need for time-specific services (e.g., to accommodate morning/evening routines, mealtimes) and clients living in more isolated rural communities [47]. Personal support workers themselves, especially those working in community-based settings, are concerned about erratic schedules, unrealistic time allocations, lack of equal participation in interdisciplinary teams, lack of performance feedback and opportunities for professional development, uncompetitive wages and benefits, and emotional burnout [37, 39, 43, 44, 48, 49]. Although many personal support workers enjoy their work and find it rewarding, the outcomes of their work may be challenging to demonstrate [50]. For clients with functional limitations or chronic health issues, PS/HM services are unlikely to return the client to a fully independent state, but they may help to maintain some level of independence, slow the rate of decline, or delay the need for institutional care (even if the client is eventually placed in long-term care). Thus, despite the importance of personal support workers, there may be limited means for members of this workforce to lead system-level conversations and advocate about their role in the health care system, adding to their overall “invisibility” [39, 51].

1.4 Personal Support/Homemaking Services

Formal PS/HM services represent the largest share of formal home care services. In 2010, the Conference Board of Canada estimated that formal PS/HM services accounted for \$3.2 billion in public spending and \$1.5 billion in private spending, compared to \$2.3–3.9 billion and \$25 million in public and private spending on formal home-based nursing and therapy services, respectively [18]. In 2015/16, Ontario’s home care clients received 29.1 million hours of publicly funded PS/HM services compared to approximately 8.4 million nursing visits and 1.8 million

therapy visits [52]. Moreover, between paid and unpaid help, the informal caregiving network is more likely to be involved in providing the same type of ADL/IADL-based care as paid help (e.g., transportation, homemaking, home maintenance, personal care) [53]. Clearly, the home and community care sector invests heavily into PS/HM services although substantial concern has been raised about whether this investment is distributed fairly among clients and families.

According to Section 22 of the *Home Care and Community Services Act*, Ontario's LHINs are responsible for (a) assessing the person's requirements; (b) determining the person's eligibility for the services that the person requires; and (c) developing a plan of service that sets out the amount of each service to be provided to each person who is determined to be eligible [31].

Although no explicit definition is provided, other parts of the Act (Section 1 and clauses 5 and 6 of Section 22) suggest that "requirements" refer to "a person's needs and preferences", including "the person's capacity, the person's impairment, the person's requirements for health care or community services," and "the person's preferences based on ethnic, spiritual, linguistic, familial, and cultural factors" [31]. Under *Ontario Regulation 386/99*, a client's service plan can include up to 120 hours of PS/HM services in any 30-day period [54].

However, a succession of Auditor General's reports have criticised the lack of provincially consistent methods for assessing need for PS/HM services and for linking the degree of need with the allocation of publicly funded PS/HM services [34, 55, 56]. Over time, each LHIN has developed their own processes for determining eligibility, priority, and provision of PS/HM services. Besides the use of local guidelines, differences between LHINs in the per-client funding amounts received from the Ministry of Health and Long-Term Care and the need to stay within annual budgets meant that LHINs were often unable to provide PS/HM services up to the

statutory maximum [34]. Notably, the regulation does not set service minimums either. Even if a client is eligible to receive PS/HM services, they may not actually receive the service (or only receive a fraction of the allocated service), attributable in part to a province-wide shortage of personal support workers [46, 47]. In addition to concerns that where a person lives plays a significant role in whether they receive publicly funded PS/HM services and the amount of service received regardless of the level of need [34, 55–58], there is a lack of transparency in how these services are allocated and used across the province.

In 2014, amendments to *Ontario Regulation 386/99* came into effect that enabled agencies other than LHINs, namely community support services agencies, to provide personal support services to more independent clients [32]. This amendment improved access to PS/HM services, although some issues such as the lack of a sustainable human health resource strategy and the absence of a common assessment and service planning framework across LHINs and community support services agencies became more pronounced.

1.4.1 Policy Context in Ontario

In response to these and other concerns related to the lack of system integration and accountability, Ontario’s Minister of Health and Long-Term Care appointed the Expert Group on Home and Community Care with a mandate to review the available evidence and consult clients, families, providers, and funders to identify strategies to address these issues [33]. Among the 16 recommendations outlined in the *Bringing Care Home* report included explicitly defining the available home and community care services (i.e., “a basket of services”) and clearly articulating the process for assessing eligibility for services. Based on these recommendations, the Ontario government released the *Patients First: A Roadmap to Strengthen Home and Community Care*

policy document [59]. One of the key goals identified was to improve client and caregiver experience while driving greater quality, consistency, and transparency in home care service delivery. Specifically, the roadmap proposed the creation of a Levels of Care framework that would provide an accessible way for the public to understand how needs are assessed and the services they can expect.

In August 2016, the Ministry of Health and Long-Term Care appointed the Levels of Care Expert Panel that was tasked with “provid[ing] evidence-informed policy recommendations and operational advice related to the design, implementation, and evaluation of a Levels of Care framework” [35]. The Expert Panel membership was comprised of care coordinators, service providers, physicians, nurse practitioners, researchers, and client and caregiver representatives with varied experiences of and insights into home and community care. The Expert Panel conducted reviews of the academic and grey literature, invited individual- and organisation-level submissions, hosted focus groups and workshops, and compared legislated hours of services across Canadian jurisdictions.

In their final report entitled *Thriving at Home*, the Expert Panel developed a Levels of Care Framework that would “identify and meet the functional needs of adults who require home and community care services for a longer period of time (i.e., for more than six months) and their caregivers” [35]. In essence, the framework outlines the key parts of assessment and care planning that clients and families can expect from the public home care system. The Levels of Care Framework is summarised in Table 1-1.

Table 1-1 Levels of Care Framework Proposed by the Levels of Care Expert Panel

Level of care	Functional need profile	Total home support hours per month
1	The person is independent in terms of ADLs but needs assistance with some IADLs. The person does not need PS services but may benefit from community support services such as assistance with transportation or home maintenance, as well as education, exercise, and socialisation programs.	No PS hours; HM or other community support services only
2	In addition to the needs at Level 1, the person needs assistance with some IADLs and early-loss ADLs such as bathing. Individuals at this level do not need assistance every day. They may also benefit from community support services and some assistive devices.	Up to 12 hours
3	In addition to the needs at Level 2, the person needs assistance with most IADLs and early-loss ADLs such as bathing and dressing. Individuals at this level may need assistance every day. They may also benefit from community support services, assistive devices, and caregiver coaching programs.	Up to 32 hours
4	In addition to the needs at Level 3, the person needs assistance with mid-loss ADLs such as transferring and toileting. Individuals at this level may need assistance once or twice per day. They may also benefit from community support services, assistive devices, caregiver respite, and caregiver coaching programs.	Up to 56 hours
5	In addition to the needs at Level 4, the person needs extensive assistance with early- and mid-loss ADLs, and may need assistance with late-loss ADLs such as eating. Individuals at this level may need assistance two or three times per day. They may also benefit from community support services, assistive devices, caregiver respite, and caregiver coaching programs.	Up to 84 hours
6	In addition to the needs at Level 5, the person needs extensive assistance with all ADLs, and may need two people to assist with transferring. Individuals at this level may be unable to leave their bed, or may spend extensive periods of time in a chair. They may need assistance three or more times per day. They may also benefit from community support services, assistive devices, caregiver respite, and caregiver coaching programs.	Up to 120 hours
7	The person needs extensive assistance with all IADLs and ADLs, and cannot be left alone for long periods of time. Individuals are experiencing exceptional circumstances, such as nearing end of life, awaiting crisis placement to long-term care, a short-term emergency, or a caregiver who is ill or hospitalised. They need frequency assistance throughout the day. They may also benefit from community support services, assistive devices, caregiver respite, and caregiver coaching programs.	More than 120 hours

Source: Levels of Care Expert Panel [35]

There are seven levels in the Levels of Care Framework [35]. Each level of care is associated with a functional need profile and total home support hours per month. The functional need profiles describe increasing degrees of IADL and ADL impairment and are largely based on the interRAI IADL-ADL Functional Hierarchy Scale [35]. Thus, a client's level of care is determined by their degree of IADL and ADL impairment. Within each level, a client's functional needs can be "modified" by social issues (e.g., living arrangement, family dynamics, housing stability), complex health issues (e.g., cognitive impairment, multi-morbidity, mental health conditions), and caregiver availability and capacity [35]. While the functional needs profiles for the two highest levels are the same, the highest level of care is intended to support clients nearing the end of life or those in time-limited exceptional circumstances who may need additional functional supports.

The Expert Panel noted a lack of pre-existing evidence about the relationship between the amount of PS/HM services and health outcomes [35]. In the absence of a strong evidence base, the total home support hours associated with each level of care were recommended by the panel members based on their expertise. Importantly, the Expert Panel stressed that assessment should be based on total functional needs, while care planning should be based on unmet functional needs [35]. In other words, a client's level of care should be specified independently of available formal and informal supports. When applying the assessment results to develop a care plan, the care coordinator should consider all current and possible sources of support. Where there is a difference between the client and family's needs and resources, publicly funded PS/HM services may help to address unmet functional needs. Other strategies could include referring to community support services and maximising use of assistive devices and technologies [35].

1.4.2 Personal Support Algorithm

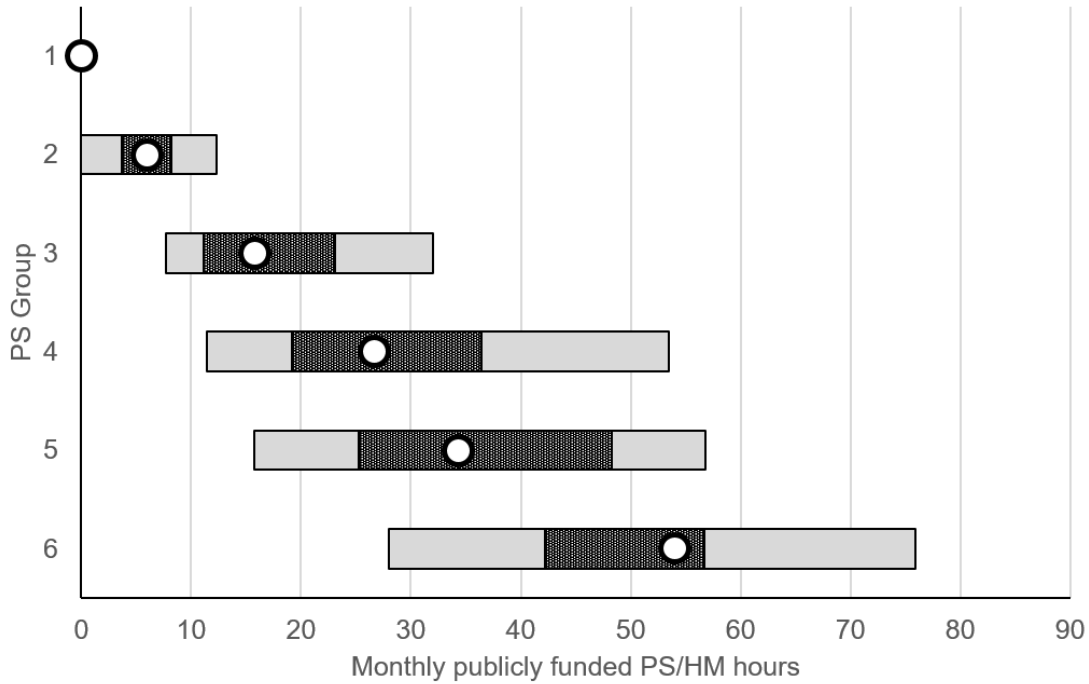
In parallel, there was a research effort to develop the Personal Support Algorithm led by interRAI Canada/University of Waterloo in collaboration with the Provincial Assessment Solution Working Group [60]. The working group was co-chaired by the Ontario Association of Community Care Access Centres (OACCAC; now Health Shared Services Ontario (HSSOntario)) and Hamilton Niagara Haldimand Brant Community Care Access Centre (CCAC; now LHIN). Members of the working group included OACCAC staff from Client Services, Sector Funding and Information Management, and Education Services, and a clinical lead from each of North West, Central East, Central, North Simcoe Muskoka, Toronto Central, and North East CCACs. The working group sought to develop an evidence-informed decision support tool to support care coordinators' decisions in allocating publicly funded PS/HM services. A series of meetings established the project's guiding principles, including “[client] needs for the purpose of resource allocation are clearly distinguishable”, “clinical decision-making is equitable and consistent”, and “guidelines reinforce the role of clinical expertise in decision-making”.

Working group members and care coordinators were surveyed for an initial list of need characteristics that were likely associated with need for PS/HM services. The characteristics generated by the group were cross-walked to the home care assessment (i.e. Resident Assessment Instrument for Home Care (RAI-HC)), and then tested against the receipt of any and the amount received of PS/HM services in a sample of Ontario long-stay home care clients. The final product was the PS Algorithm that classifies need for PS/HM services into six groups. The PS Algorithm explained 30.8% of variance in publicly funded PS/HM service use [60].

Similar to the Levels of Care Framework, the PS Algorithm is heavily influenced by a client's degree of IADL and ADL impairment [60]. However, the PS Algorithm includes other need characteristics, namely cognitive impairment, incontinence, unstable health patterns, communication difficulties, and caregiver distress. The Provincial Assessment Solution Working Group also sought to identify service guidelines for each PS Group, but approached the problem differently from the Levels of Care Expert Panel. Whereas the support hours proposed in the Levels of Care Framework are based on best guesses, the working group developed the Framework of Hours using the historical distribution of publicly funded PS/HM services.

The Framework of Hours is depicted in Figure 1-1. For each PS Group, the Framework of Hours provides the median and percentile bands around the median. The percentile bands convey the frequency at which care coordinators expect to allocate PS/HM services. Allocations are expected to be made most frequently within the 35th and 65th percentiles, occasionally between the 20th and 80th percentiles, and only in exceptional circumstances below the 20th or above the 80th percentiles. The intent of the Framework of Hours is to encourage service allocation toward a central value. At the same time, the percentile bands provide flexibility for care coordinators to adjust their allocation to take individual needs and circumstances into account.

Figure 1-1 Framework of Hours for the PS Algorithm



Note: Care coordinators would expect to allocate publicly funded PS/HM services toward the median (represented by the dots). Allocations are expected to be made most frequently within the 35th and 65th percentiles (represented by the patterned bars), occasionally between the 20th and 80th percentiles (represented by the solid bars), and only in exceptional circumstances below the 20th or above the 80th percentiles.

Adapted from Sinn et al. [60]

With support from OACCAC, the PS Algorithm was piloted from June to July 2015 with promising results. Twenty-eight care coordinators across six CCACs (Hamilton Niagara Haldimand Brant, Mississauga Halton, Central, Central East, Champlain, North West) participated in the pilot. These CCACs reflected the diversity of urban and rural geographies and care coordinator practices. As well, two of the CCACs (namely, Mississauga Halton and Champlain) that tested the algorithm had not been part of its development. During the pilot, care coordinators completed a home care assessment and followed their usual practice to create the client’s care plan, including the allocation of publicly funded PS/HM hours. Soon after signing off on the assessment, the care coordinator received an online survey along with the PS

Algorithm group and the suggested hours for that group (i.e., lower bound, median, upper bound). The survey results showed that 93.1% of care coordinators thought that the suggested hours were clinically appropriate to meet the client's needs and that their actual allocation of PS/HM hours fell within the suggested range in 89.1% of cases [60]. Care coordinators and managers involved in the pilot were invited to talk about their experiences and suggestions using the algorithm. In general, participants thought the algorithm and guidelines aligned well with their clinical decision-making processes and organisational practices.

In 2016, the interRAI Instrument and System Development Committee endorsed the PS Algorithm. As an official interRAI algorithm, the Canadian Institute for Health Information maintains data standards and supports the PS Algorithm within the Integrated interRAI Reporting System (IRRS).

1.5 Thesis Overview

In 2018, nearly all LHINs adopted the PS Algorithm as a common indicator for need for PS/HM services. However, concerns about transparency and equity of service allocation persist for two main reasons. First, the LHINs are not required to adhere to the Framework of Hours. Even if the LHINs measure PS/HM need in the same way, the Framework of Hours is the key to standardising the distribution of public PS/HM resources across the province. To varying degrees, LHINs may lack the resources or are otherwise hesitant to implement the Framework of Hours. Some LHINs that may have historically received less per-client funding may find it difficult to increase services without more funding. Other LHINs may have to reduce services to match the Framework of Hours. Also, there may be hesitancy to implement service guidelines that are based on the status quo. As noted by the Expert Panel, the lack of evidence supporting

the “right” level of services is a major barrier. LHINs need to justify to clients, families, providers, and funders that updating their PS/HM allocation policies to align with the Framework of Hours will promote positive client and family outcomes and avoid negative outcomes.

Second, neither the Expert Panel’s report nor the PS Algorithm apply to the full home care episode (i.e., from home care intake to discharge). In Ontario, most home care clients are briefly assessed at intake using the interRAI Contact Assessment (CA). Based on the CA, the care coordinator puts a short-term service plan in place. Clients expected to require long-term home care services (i.e., long-stay clients) are later assessed with the more comprehensive interRAI Home Care (HC) assessment that informs a complete service plan that addresses all their identified needs and preferences. Provincial reassessment guidelines state that long-stay clients should receive an HC assessment every six to 12 months (or sooner if the client undergoes a significant change in health status) to ensure care plans are up-to-date. Appropriately, the Expert Panel focused on the long-stay client population since they are responsible for the use of 90% of publicly funded PS/HM services [35]. However, both the proposed Levels of Care Framework and PS Algorithm focus on the HC assessment, that is, these tools do not provide decision support around the initial service plan after the CA.

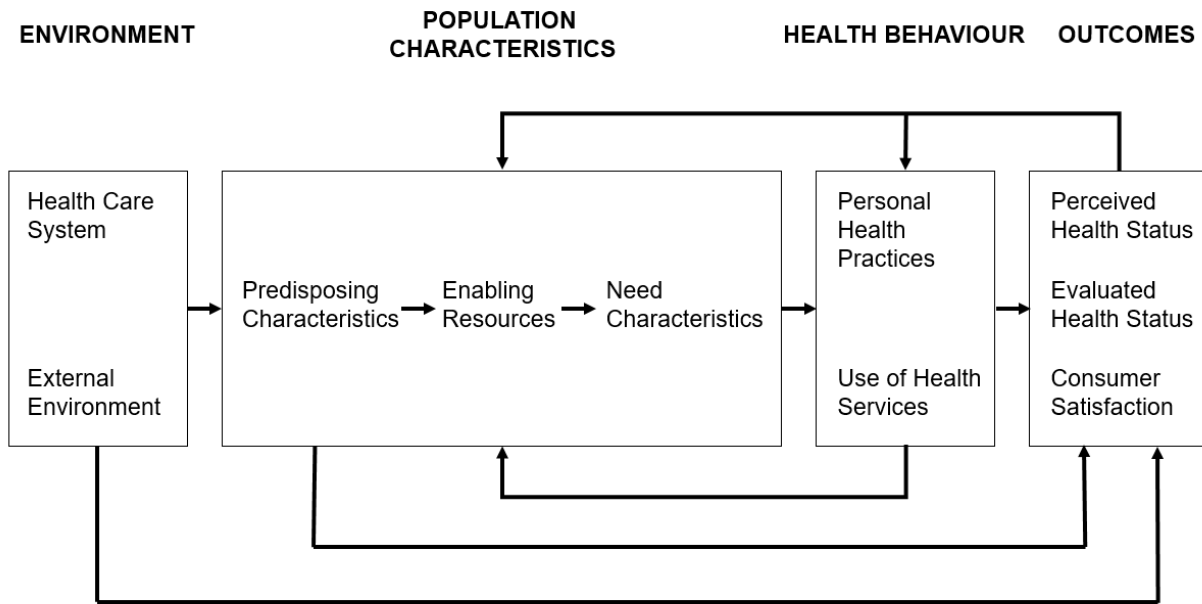
Following the 2015 Auditor General’s report, there has been substantial efforts to make the allocation of publicly funded PS/HM services more transparent and equitable across Ontario. Building on these efforts, the goal of this thesis is to address the aforementioned challenges by developing and refining decision support tools to guide the allocation of publicly funded PS/HM services and defining PS/HM-sensitive outcomes.

This thesis is comprised of four studies. The first study provides a comprehensive description of the characteristics and service use patterns fundamental to understanding the population of public home and community care recipients in Ontario. The second study compares the predictive performance of the PS Algorithm with that of other scales and algorithms and also tests the relevance of additional modifiers that were raised by the Levels of Care Expert Panel. In the third study, a decision support algorithm for classifying need for PS/HM services after the CA is developed and validated. The fourth study characterises the relationship between the quantity of publicly funded PS/HM services and client and caregiver outcomes.

1.6 Andersen-Newman Service Utilisation Model: Theoretical Framework

This thesis draws upon the Andersen-Newman Service Utilisation Model as a theoretical framework to inform this research (Figure 1-2). Introduced in the 1960s, the model was initially developed to explain disparities in access to health care, define and measure equitable access to health care, and serve as a framework for developing policies to promote equitable access [61]. Although the model has evolved over time, its central premise is a person's health service use depends on three types of individual-level determinants: predisposing, enabling, and need characteristics [61–63].

Figure 1-2 Andersen-Newman Service Utilisation Model



Adapted from Andersen & Newman, 1995

Predisposing characteristics are socio-cultural or biological characteristics of a person that increase or decrease their likelihood of seeking health care but are not directly responsible for health service use [63]. Such characteristics include demographics (e.g., age, sex), social structures (e.g., marital status, education level), and health-related attitudes and beliefs (e.g., about health or treatment efficacy). Predisposing characteristics alone are not a sufficient cause for seeking health care but they may be associated with need characteristics (e.g., increasing age is generally associated with a greater number of chronic conditions).

Enabling resources refer to factors that facilitate or impede access to health services and describe the extent to which a person is able to access health services. Enabling characteristics can be measured by family resources (e.g., income, public or private health insurance coverage) or

community resources (e.g., neighbourhood, rurality). It is important that the person has the knowledge and means to access health services in order to use them.

Of the three categories of individual-level determinants, need characteristics represent the most proximal cause for health service use. Even when a person is predisposed and has the means to use services, the person is unlikely to use health services without perceiving a need. In the case of formal health care, health service use is often preceded by need that is perceived by the individual or family and then evaluated by a health professional.

Over time, components have been expanded and added to the original model. The role of individual-level determinants on an individual's health service use is still central to the Andersen-Newman model; however, factors beyond the individual are also recognised.

Depending on the exact model, these factors are called environmental or societal factors that encompass the external environment and health care system or contextual factors that are measured at the health organisation, provider, and community (i.e., aggregate) level.

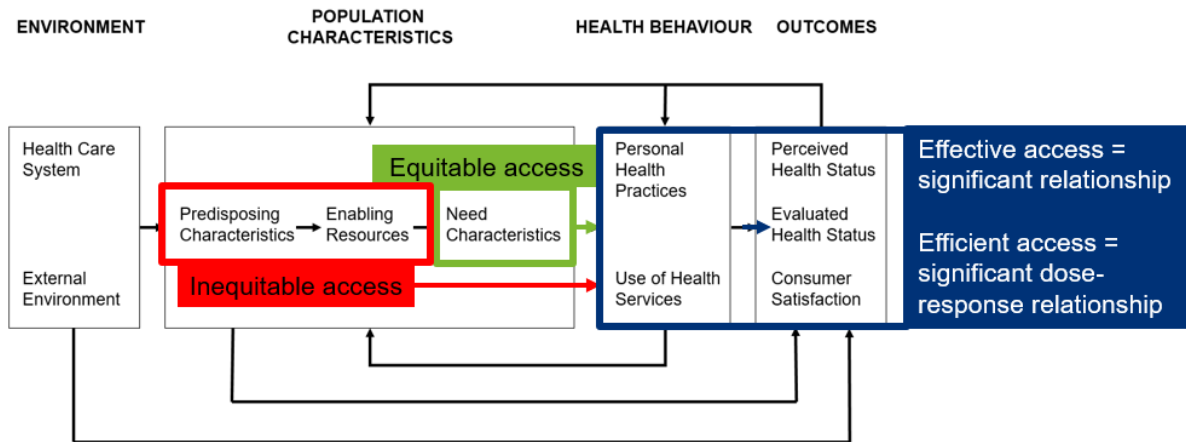
Additionally, perceived health, evaluated health (i.e., by a health professional), and consumer satisfaction were added as health status outcomes to the model.

This thesis adopts Andersen's view of equity pertaining to equitable access to health services.

According to Andersen [64], "equitable access" occurs when demographic and need characteristics account for most of the variance in health service use. In contrast, "inequitable access" occurs when social structures, health-related attitudes and beliefs, and enabling characteristics are predominant. To support the goal of equitable allocation of publicly funded PS/HM services, only need characteristics are included in the algorithms in Chapter 4 and Chapter 5. Two additional measures of access accompany the Andersen-Newman model:

“effective access” occurs when health service use improves health status (or consumer satisfaction) and “efficient access” occurs when the level of health status (or consumer satisfaction) improves relative to the amount of services used [62]. To test for effective and efficient access, Chapter 6 examines the relationship between publicly funded PS/HM service use and client and caregiver outcomes. Figure 1-3 illustrates how these definitions apply to the Andersen-Newman model.

Figure 1-3 Definitions of Access within the Andersen-Newman Service Utilisation Model



Adapted from Andersen & Newman, 1995

Studies of health service use frequently reference the Andersen-Newman model, including some studies of home care services (examples include Murphy et al. [65], Hammar et al. [66], Sun et al. [67], and Penning et al. [68]). In applying the Andersen-Newman model to this thesis, it was important to carefully consider the characteristics that describe the availability and capacity of the informal caregiving network. Some researchers view characteristics such as marital status as predisposing factors because they influence an individual’s tendency to seek health services. Others believe the same characteristics may influence the individual’s health service use directly. Their dual nature is observed in the way that the caregiving literature inconsistently

conceptualises such characteristics within the Andersen-Newman model. For instance, marital status has been classified as a predisposing [69, 70] or enabling [71] factor, living alone as a predisposing [72] or enabling [73, 74] factor, and time spent on caregiving as an enabling/need [75, 76] or need [69, 71] factor. Meanwhile, the concept of caregiver distress is consistently viewed as a need characteristic [70, 72, 77, 78].

Bass and Noelker [78] were one of the first to suggest that studies of home care service use should expand the Andersen-Newman model to include the client-caregiver dyad. In Ontario, extending the definition of “client” to include the family was a key recommendation of the Expert Group on Home and Community Care [33]. Similarly, it is the position of this thesis that need characteristics of both the client and caregiver should explain use of PS/HM services. This thesis views marital/relationship status and the client-caregiver relationship as predisposing characteristics and the presence of a live-in caregiver as an enabling characteristic since the latter more proximally describes the informal resources available to the individual. Further, caregiver distress is considered a key indicator of caregiver need that is consistent with other caregiving studies and reports.

1.7 Health Care Need

The Andersen-Newman model defined need as characteristics other than those of the predisposing or enabling type that, when perceived by an individual or evaluated by a health professional, would motivate the individual to use health services. However, the concept of need underlying these need characteristics is not explicitly stated. This section briefly reviews the major views on needs and adopts a working concept of need used in the thesis.

1.7.1 Properties of Need

According to McKillip [79], needs are problems that can be solved. Needs are possessed by individuals or a group of individuals (i.e., target group) in a certain set of circumstances where an expectation is violated. Liss [80] views this violation as a difference between the person's actual state (i.e., physical, mental, social, or other type of state) and the end state (also called the goal of need). The object of need is required to move from the actual state to the end state [80]. The goal is the justifying component of need that distinguishes needs from wants that are characterised by less vital goals [80].

Need is inherently a value-laden concept [79, 80]. Values play a large role in determining the goal of need [80]. Clients, family members, and care coordinators may have conflicting views about the end state and assign different weights to priorities and risks. They may also disagree on the object of need, either over the evidence demonstrating the effectiveness of the intervention or the choice of the intervention from alternatives [80].

1.7.2 Views on Health Care Need

Most views on health care need can be classified into one of four categories. The ill health or poor initial state interpretation was first proposed by Donabedian [81] who described need as "some disturbance in health and well-being...that require[s] medical care services". Need is based on the person's actual state alone, in other words, neither the object nor goal of need are relevant [82]. The degree of need is proportional to the degree of ill health, and this process of determining need is independent of whether an acceptable intervention or sufficient resources exist [80].

In contrast, the supply view posits a second criterion, that there exists an effective or acceptable intervention to meet the need. The emphasis is on the object of need. Acheson [83] asserted that it must be possible to improve a person's health state and that the cost of doing so is reasonable. Similarly, Culyer [84] argued that there should be empirical evidence to demonstrate that the intervention can be reasonably expected to achieve some benefits. The key difference between the ill health and supply interpretations is that the latter does not acknowledge the existence of a need if there is no acceptable intervention [80]. If the object and goal of need are not related, then the person does not need X to achieve Y. Need for health and need for health care are synonymous in the ill health interpretation, but conceptually distinct in the supply interpretation.

According to the normal functioning range interpretation of need, the intervention must improve the person's health such that the person's end state is above a minimum threshold. Daniels [85] refers to this threshold as the person's ability to construct and live their life plans. According to Liss [80], a person who "has an ability, given reasonable circumstances, to realise all the goals necessary for his minimal happiness...that would be considered possible...within a reasonable future" would have achieved the minimal health state. Notably, the end state is person-specific, meaning that it is chosen by the person and may be restricted by the person's current conditions [80]. For instance, a client recovering from delirium would expect to return to complete health. In contrast, a client with dementia would likely seek health care services to maximise quality of life since no cure for dementia is available, at least in the near future.

The final view on need is the significant gain interpretation. This interpretation focuses on the magnitude of benefit from the intervention, that is, the difference between the actual state and the end state [82]. A given intervention is needed if the absolute or relative capacity to benefit

exceeds a minimum threshold value [82]. The implication of the significant gain criterion is that the needs of a person in poorer health may be lower than that of a person in better health if the latter person stands to gain more from the intervention.

As argued by Hasman et al. [82], these views highlight different features of the concept of health care need and can be combined. A client requires PS/HM services because they are unable to perform activities needed to live independently and safely in the community (ill health interpretation) and PS/HM services assist the client and family to perform these activities (supply interpretation). The goal of PS/HM services may be viewed as helping the client to remain as independent for as long as possible (normal functioning range interpretation) or to minimise the risks associated with functional decline, loss of independence, and institutionalisation if the services were not available (significant gain interpretation). In other words, clients who are unable to perform activities needed to live independently and safely in the community (actual state) have a need for PS/HM services (object of need) in order to live independently and safely in the community (goal of need).

1.7.3 Health Care Need and Health Service Use

Analysing health service use is one method of estimating health care need [79]. The assumptions underlying this method are that greater health care needs precede greater health service use, and that individuals with similar needs use health services to a similar extent. For the most part, public PS/HM service use can be expected to meet these assumptions since care coordinators serve as the gatekeepers within the care coordination model [86]. Not only are care coordinators expected to provide services to optimise each client and family's health and well-being, but they are responsible for distributing these services equitably across all clients and families [86]. When

analysing public PS/HM service use, the absolute allocation of PS/HM services will vary due to differences between LHIN guidelines and care coordinator behaviours that may arise from differences in training and experience. Nevertheless, so long as care coordinators allocate services consistently and rationally within their caseloads, the relative differences in public PS/HM service use averaged across all clients should identify those with greater or lesser assessed needs.

There are two important caveats to this method. First, service use may be unrelated to need, and second, service non-use may also indicate need [79]. Such situations may arise because of low awareness of services, low cultural acceptability of services, and other barriers that may be physical or financial in nature [79]. Although there is evidence that these non-need factors influence service use (for example, Chang & Hirdes [87] found that the presence of a language barrier (via the need for an interpreter) was associated with higher levels of caregiver distress among Korean and Chinese Canadian home care clients), these issues may be more appropriately described as problems with equal access rather than equitable distribution of services (see Section 1.7.4 for a more detailed discussion). As well, there may be groups of clients whose needs are under-recognised in current guidelines. Despite these limitations, current service use patterns will explain differences in needs for most clients and will be useful for constructing decision support tools to guide future allocation. Hypotheses about underserved populations and unmet needs can be tested and used to update these decision support tools.

1.7.4 Equity

According to Culyer [88], a health care system that is equally accessible means that every potential client has the opportunity to have their needs assessed [88]. Any barriers that prevent or deter such assessment creates inequity [88]. Once the client's needs are known, however, further access depends on the assessed needs [88]. In other words, an equitable health care system features equal access and equitable distribution.

Providing more services to a particular client group has opportunity costs in terms of reducing the available resources to meet the needs of other clients [84]. Although care coordinators are asked to distribute services equitably across the population, medical ethics that were devised for use at the individual level provide limited support for decisions at the population level [86, 88]. In the absence of criteria to guide priority setting, it would be unrealistic to assume care coordinators can objectively judge the strength of their claims against the claims of other care coordinators also advocating on behalf of their clients [88].

Recalling that the moral significance of health care need is in its pivotal role to achieving a person's vital goals, then it should follow that the equitable distribution of health resources should promote the equitable distribution of health (e.g., life expectancy, quality of life) [88]. Notably, it does not mean that every person has a basic right to have all of their needs met [85]. In the context of limited resources, it means that the public health care system is designed to protect their equal opportunity to achieve their vital goals [85]. Thus, there will be some unmet needs because some clients may not receive any services and others may not receive all the services they need [88].

A process for selecting and grading needs is required, but the solution is neither obvious nor straightforward. Distribution according to ill health may exacerbate health inequities insofar as substantial resources may be allocated to those with the lowest capacity to benefit [88].

Distribution according to capacity to benefit may favour healthier clients to the disadvantage to less healthy clients [88]. Many other theories exist such as utilitarianism that would distribute resources to achieve the greatest good in the most number of people.

There is no single theory of equity, and this thesis does not impose a particular view of equitable distribution. The values upon which equitable distribution rest belong in the purview of policy-makers, in consultation with front-line clinicians, clients and families, and the general public.

What this thesis seeks to achieve is to characterise need, and in particular, provide empirical evidence substantiating the link between need for PS/HM services and resultant outcomes. By bringing together research and public policy, it is the hope that greater transparency in the measurement of need for PS/HM services will stimulate conversation and action on policies and priorities that may promote equitable distribution.

CHAPTER 2: Literature Review

2.1 Introduction

A literature review was conducted to compile the available literature on: 1) the determinants of PS/HM service allocation or utilisation and to discuss the relevance of predisposing, enabling, and need characteristics, and 2) the outcomes of PS/HM service allocation or utilisation.

2.2 Search Strategy

A single search strategy was used to retrieve relevant studies. Studies were identified through keyword searches of Medline, Embase, and CINAHL databases. The search strategy consisted of three parts: PS/HM services AND home and community setting AND (utilisation OR outcomes). Keywords used to search for “PS/HM services” were adapted from a scoping review on the health care aide workforce literature by Hewko et al. [39], including common titles such as personal support worker and nursing attendant as well as combinations of keywords such as unregistered/unregulated AND worker/assistant. Additional job titles that are used in Canada such as personal care aide and home health aide were added to the search strategy. Studies that were published before 1980 or were not written in English were excluded. A total of 561 articles from Medline, 8,473 studies from Embase, and 775 articles from CINAHL were retrieved. The full search strategy can be found in Appendices A.1 and A.2.

After removing 988 duplicates, the titles and abstracts of 8,821 articles were screened. The most common reasons for exclusion were that PS/HM services were not the focus of the article, provision or outcomes of provision of PS/HM services were not the focus of the article, and the setting was not in the community. The full texts of 127 studies (and any relevant citations that

were found in their reference lists) were reviewed, leading to 45 studies on the determinants and 27 articles on the outcomes included in their respective reviews.

2.3 Literature on the Determinants of PS/HM Service Allocation or Utilisation

This section summarises the results of 45 studies on the determinants of PS/HM service allocation or utilisation. A table summarising the details of each study, including the sample, measurement of PS/HM use, key findings, and limitations can be found in Appendix A.3.

2.3.1 Measures of PS/HM Service Allocation or Utilisation

In approximately half of all studies, the dependent variable was receipt of any PS/HM services [65, 66, 89–113]. Eight studies examined hours of PS/HM services [114–121], one study examined the change in hours between two periods [122], and two studies examined the number of PS/HM visits [123, 124]. Four studies defined the cost of PS/HM services as the dependent variable [125–128]. Rather than receipt of services, one study examined the likelihood of reporting unmet needs [129]. While most studies considered the sum of PS/HM services, some studies modelled the receipt of PS and HM services separately [97–99, 105, 106, 108, 111].

Most studies relied on client or caregiver self-reported PS/HM service use with recall periods ranging from the past week to the past year [65, 66, 89–96, 98, 99, 101–114, 116, 118, 119, 122, 126–128]. A small number of studies accessed the client's care plan, service records, or claims information directly [97, 100, 115, 117, 120, 123–125]. Although nearly all self-reported measures represented PS/HM services received from any paid source, it was not always clear whether the PS/HM measure reflected publicly or privately funded services, or both. The proportion of persons using PS/HM services varied greatly depending on the sample, ranging

from 6%–16% in the general community-dwelling population [65, 91, 101, 102, 104, 107, 109] to 62–76% among persons enrolled in a home care or other enhanced community program [66, 97, 124, 125].

2.3.2 Predisposing Characteristics

Approximately half of all studies explored client age and sex. Overall, increasing age was positively associated with receiving PS/HM services [65, 91, 100, 104, 114, 119, 127, 129], especially among studies that focused on PS services only [90, 97–99, 107, 110]. For instance, Ranhoff & Laake [107] found that every 10-year increase in age doubled the odds of receiving PS services. In contrast, many studies found no association between age and HM service use [93, 94, 97–99, 105, 111, 113, 122, 128]. Only one study found a negative association with age [121], where persons younger than 20 received more ADL help than persons over the age of 20, although the study population was persons receiving personal assistance under Sweden’s disability policy (rather than home and community care policy). Five studies found a positive relationship between female sex and PS/HM services, but two studies were based on bivariate results only [95, 112]. In the other three studies, other variables in the multivariable models were substantially more influential than sex [65, 91, 95]. Two studies found a positive relationship between male sex and PS/HM services, but again, the effects were small [104, 113]. In contrast, sex was not significantly associated with PS/HM service use in 15 studies [65, 66, 90, 93, 94, 97, 98, 106, 107, 119, 121–123, 128, 130].

Most studies found no significant association with client ethnicity, education, or immigrant status; however, the effects were large when there were exceptions. In the US, Hasche et al. [97] found that being Caucasian reduced the likelihood of receiving PS services from a community

program (OR=0.40) while Scharlach et al. [110] found that being non-Caucasian reduced the likelihood of receiving PS services from any source (OR=0.44). Freedman et al. [122] found that having more than a high school education was associated with receiving more PS/HM services among older unmarried Americans. Two studies from Germany and Spain found strong negative associations between education level and receipt of HM services [119, 129]. In Canada, Penning [106] found that each additional year of education increased the odds of receiving any HM services among persons with a diagnosis of dementia (OR=1.09). On the other hand, a more nationally representative study of community-dwelling Canadians did not find an association between education level and receipt of publicly funded PS/HM services; instead, receipt was negatively associated with immigrant status (OR=0.55) [104]. Overall, there is some evidence that the above characteristics related to social status may influence HM services. The few studies that examined the client's marital status [98, 112, 119, 125, 127] or the nature of the client–caregiver relationship [89, 106, 110] were inconclusive.

A handful of studies explored the informal caregiver's predisposing characteristics, but no consistent associations were found. In Lévesque et al. [103], caregivers over the age of 70 had four times greater odds of using PS/HM services. Beeber et al. [89] found that more years of education was associated with belonging in a group with high probability of using PS/HM services (multinomial OR=1.12). Other studies of caregivers in the general community-dwelling population did not find associations with caregiver age, sex, or education [98, 99, 110]. There was mixed evidence on the effect of the caregiver's employment status. Two studies found a positive association between either full-time employment [110] or hours of employment [114] and PS/HM service use. One study of the general community-dwelling population found that

paid employment was negatively associated with receiving PS services (OR=0.33) but was unrelated to receiving HM services [98].

2.3.3 Enabling Characteristics

Living arrangement was the most frequently studied enabling characteristic. All studies examining living arrangement compared the effect of living alone with living with others, and some studies further classified “others” to differentiate between clients living with their spouse/partner, other relatives, or other non-relatives. There was strong evidence that living alone was associated with greater PS/HM service use with most odds ratios above 1.50 [65, 91, 94, 106, 107, 129]. Additionally, there was strong evidence that living with others (regardless of the identity of “others”) was negatively associated with PS/HM service use with most odds ratios below 0.50 [90, 98, 99, 104, 113, 128].

There may be some evidence to suggest that persons with lower income or socioeconomic status are more likely to receive PS/HM services. In a Canadian study, being in a high income bracket halved the odds of receiving publicly funded PS/HM services [104]. Participants of the national Long-Term Care Channeling Demonstration Project (US) with incomes \leq \$1000 had higher PS/HM costs [127]. After age and health status, having a low income was the strongest predictor of receiving PS/HM services in one region of the UK (OR=10.38) [91]. However, Otero et al. [129] found having a low income significantly increased the odds of reporting both unmet daily (i.e., ADL) and unmet weekly (i.e., IADL) needs by four-fold. Other studies did not find a significant association between income, socioeconomic status, or insurance status and receipt of PS/HM services [89, 90, 93, 94, 98, 111, 122, 123].

Results for urban/rural areas were mixed. In Ontario, fewer clients living in the most urban or most rural areas received publicly funded PS services [102]. Canadians with a diagnosis of dementia were more likely to receive PS services if they lived in non-urban areas (OR=4.57) but no significant association was observed with HM services [106]. Among Medicare recipients living in medically underserved areas in New York, urban recipients received more weekly hours of PS services (mean hours=0.7 (urban) vs. 0.4 (non-urban)) but fewer weekly hours of HM services (mean hours=4.4 (urban) vs. 7.1 (non-urban)) [108]. Other studies found no differences between urban and rural areas [89, 97, 106].

There may be also some evidence to suggest that clients receiving other home care services are more likely to receive PS/HM services. Out of three studies examining home nursing, two studies found that clients receiving PS/HM services were likely to be receiving nursing services [66] and more hours of direct nursing care [100]. In the third study, the number of PS visits was not associated with the number of HM or nursing visits [123]. Across the general community-dwelling population, the receipt of publicly funded professional home care services greatly increased the odds of receiving publicly funded PS/HM services (OR=13.71) [104].

2.3.4 Need Characteristics

Nearly all studies included at least one measure of physical function, and this measure often had one of the strongest associations with the dependent variable. Out of 16 studies examining ADL impairment, 14 studies reported a positive association with PS/HM service use. Three studies tested the presence of any ADL impairment, where the increased odds associated with ADL impairment ranged from 1.35 among home and community care populations [89] to 56.26 in the general population [98]. Eleven studies tested the degree of ADL impairment through a count of

limitations or the use of hierarchical definitions or scales [104, 106, 113–115, 122–125, 127, 130]. In the Canadian National Population Health Survey from 1994/95 to 2010/11, the odds of receiving PS/HM services increased exponentially with the degree of ADL dependence from 3.87 among persons with low dependence (compared to no dependence) to 36.39 among persons with high dependence [104]. Analysis of the Long-Term Care Channeling Demonstration Project (US) showed that persons impaired in all ADLs doubled the daily cost of PS/HM services compared to persons who were impaired in IADLs but not ADLs [127]. Across 11 European countries, the median PS/HM hours increased steadily with the ADL Hierarchy Scale from 1.9 hours/week for no impairment to 4.1 hours/week for severe impairment [115].

Seven out of 10 studies found a positive association with IADL impairment [65, 94, 96, 98, 107, 119, 122]. Forbes et al. [94] found that needing help with normal housework was associated with 6.36 times greater odds of using PS/HM services. Among clients with a disability, Murphy et al. [65] found that each additional area of IADL impairment was associated with 1.5 times greater odds of using PS/HM services. When IADL impairment was not significant, ADL impairment had already been entered into the explanatory models [98, 106, 123, 125]. Three studies tested combined variables representing IADL and ADL impairment that were found to be positively associated with PS [111] and PS/HM service use [66, 99]. Other manifestations of physical function such as mobility [90, 93, 112, 124], chronic disability [104, 126, 128], and frailty [101] were consistently associated with greater PS/HM service use although the associations were not nearly as strong as observed with ADL and IADL impairment.

For the most part, co/multi-morbidity (either presence of any or number of chronic conditions) was weakly positively associated [97, 123] or not associated [66, 89, 104, 106, 113, 119] with

PS/HM service use. One exception was the finding that community-dwelling Norwegians with any chronic health problems were nearly four times more likely to receive PS services [107]. Studies of cognitive impairment suggested associations in either direction or no association at all. However, many study methods restricted the population's variability of cognitive status that may have made significant differences more difficult to detect. A number of studies enrolled or excluded participants based on the presence of moderate or severe cognitive impairment or dementia diagnosis [89, 94, 99, 103, 105, 105, 106, 108, 111, 113, 114, 127]. In the general older adult population, dementia and at least moderate cognitive impairment were associated with greater odds (OR=4.22) of receiving PS/HM services in one study [98] but lesser odds (OR=0.7) in another study [93]. Two other studies of the general population did not produce significant associations [90, 104]. Among persons diagnosed with dementia, the degree of cognitive impairment predicted significantly greater odds (OR=1.05) of receiving PS services in one study [111] but lesser odds (OR=0.74) in another study [105]. Neither study found a significant association with degree of cognitive impairment and receiving HM services. In contrast, Penning [106] found that severe cognitive impairment was weakly negatively associated with receiving HM services (OR=0.97).

Several studies investigated the person's mental health. Depression and depressive symptoms were the most commonly investigated variables. Most study populations that were representative of the general older population found no associations between depressive symptoms and PS/HM services [96, 98, 107, 129]. Otero et al. [129] found that persons with depression were less likely to report unmet daily (i.e., ADL) needs. In contrast, studies involving specific populations tended to find positive associations with depressive symptoms, namely among persons with functional

impairment (OR=2.3) [65], persons with a dementia diagnosis (OR=1.60) [113], and home care clients (history of depression; OR=1.28) [130]. Needing help with psychosocial well-being also doubled the odds of receiving PS/HM services among home care clients who had been recently hospitalised [66]. Another study found that depression did not differentiate between new home care clients receiving either PS or HM services; however, this study was relatively small and prevalence of service use was quite high [97]. In a study of Quebec caregivers caring for a person with dementia, the frequency of dysfunctional behaviours was associated with greater likelihood of using PS/HM (OR=3.54) and respite services (OR=2.90) [103]. Other studies did not find significant associations with either behavioural or psychotic symptoms [89, 105, 111, 113].

Other measures of the client's health status for which there was some supporting evidence of a positive association with PS/HM services were visual impairment [91, 93, 112], bladder and bowel incontinence [99, 125], and hospitalisation [65, 94, 112]. Excluding the study reporting bivariate results only, the presence of visual impairment was associated with a doubling of odds of receiving PS/HM services [91, 93]. Baker et al. [125] found that bladder and bowel incontinence were associated with increased PS/HM service use over an 18-month period. Having at least one or two recent hospital stays was associated with greater odds of receiving PS/HM services [65, 94, 112]. Measures for which there were too few studies or the weight of evidence suggested no association were falls [112], hearing impairment [91, 107, 112], self-reported health [65, 94, 98, 106, 112, 129], polypharmacy [65, 66, 97], musculoskeletal conditions [91], respiratory conditions [91, 104], cardiovascular conditions [91, 104, 112, 118, 127], and cancer [112, 127].

Time to death emerged as a key driver of service intensity that is unique to persons receiving home-based palliative care. Several studies, including two studies in Ontario, described a U-shaped pattern to PS/HM use that is most intensive during the first days in the episode and for the last few weeks or days prior to death [67, 131, 132]. Proximity to death predicted both the likelihood of receiving and the amount of PS/HM services across the studies. Among Ontario clients who were admitted to end-of-life home care and died within six months, weekly PS/HM service use was fairly consistent from 12 to four weeks before death and increased quickly in the last month prior to death [120]. Similarly, in an assessment of overall care plan eligibility, case managers assessed more generous care plans for persons with a terminal illness [130].

Only four studies investigated factors describing the caregiver's needs. Presence of caregiver burden was significantly associated with greater likelihood of receiving PS services among persons without cognitive impairment (OR=1.11) [98] and persons with dementia (OR=1.22) [105]. Neither study found an association between caregiver burden and receipt of HM services. In another study of caregivers caring for persons with a dementia diagnosis, there was no relationship between caregiver burden and either PS or HM services [106]. Two studies found a weak positive relationship between the caregiver's co/multi-morbidity and likelihood of receiving HM services (OR=1.22) [98] and belonging in a class with high probability of using PS/HM services (multinomial OR=1.09) [89]. Pedlar & Biegel [105] found that the caregiver's physical functioning was associated with receipt of HM services (OR=1.41) but not PS services.

2.3.5 Summary

In the literature, PS/HM service use is consistently associated with older age, living alone, and functional impairment and consistently not associated with sex and ethnicity. In general, the above relationships hold across time and geography (including Canada, USA, UK, Germany, Finland, Ireland, and Norway). There is some evidence pointing to greater PS/HM service use among persons with low socioeconomic status, depressive symptoms, bladder and bowel incontinence, and proximity to death. Mixed results were observed with urban/rural areas, co/multi-morbidity, cognitive impairment, self-reported health, and recent hospitalisation.

Common methodological limitations were related to the study sample, data collection methods, and measurement of dependent and independent variables. Many studies had small sample sizes (<1000 participants) and findings that could not be generalised beyond specific geographic or client populations. Most studies employed mailed questionnaires or interviews, but this method of recruitment and data collection often under-represents persons with cognitive impairment.

While characteristics about the person, caregiver, or family situation may be readily answered, the accuracy of self-reported service use such as the type, amount, and source of help received (especially if the respondent is asked about “average” utilisation) may vary widely between respondents. As well, recall periods ranged from the past week to the past year. Many studies investigated the general community-dwelling population, but it is likely that the identified factors describe the likelihood of receiving home and community services in general rather than specific factors that differentiate between use of PS/HM and other home-based services. Independent variables were often represented as dichotomous variables although many health status indicators

exist on a continuum. Finally, studies often focused on physical functioning and did not or could not explore relationships with other clinical indicators of need.

In summary, the literature review identifies important determinants and potential enabling and need factors warranting further exploration. A final observation is that many studies employed descriptive and other traditional statistical methods to uncover the relationships between factors and PS/HM service use; however, guidance on how to bring together disparate factors particularly within care coordinators' decision-making processes about allocating PS/HM services was absent.

2.4 Literature on the Outcomes of PS/HM Service Allocation or Utilisation

This section summarises the results of 37 studies on the outcomes of PS/HM service allocation or utilisation. A table summarising the details of each study, including the sample, variable measurement, type of analysis, key findings, and limitations can be found in Appendix A.4.

2.4.1 Mortality

Across nine studies examining receipt of PS/HM services and mortality, two studies found significant positive associations [133, 134], two studies found significant negative associations [135, 136], and five studies did not find significant associations [137–141]. Only three studies included at least 1000 clients and the results were highly variable. The largest study was conducted by the Health Services Utilization and Research Commission in Saskatchewan that sought to determine the effectiveness of community-based support services for light-care populations (i.e., excluding post-acute care and home care for the purpose of delaying LTC placement) [134]. Compared to persons not receiving PS/HM services, persons either receiving a

“low” (<2.75 hours/month) or “high” (≥ 5.70 hours/month) amount of PS/HM services were significantly more likely to die sooner than persons receiving a “moderate” amount (HR=1.2 and 1.1, respectively). However, the authors were unable to adjust for functional status beyond health status and use of other home care services. In British Columbia, Hollander & Tessaro [137] studied the impact of a policy that severely cut service for low-level home care clients in the mid-1990s. Three years after the cuts, the mortality rate was 21.6% in the Health Units that instituted the policy and 14.5% in the Health Units that did not introduce the policy. Although the authors did not report any test statistics, the chi-square statistic would have been highly significant ($p < .0001$). Using a case-control approach, Gené-Badia et al. [136] found that 35.9% of older home care clients who died had used PS/HM services in the previous year compared to 40.2% of surviving clients but the chi-square statistic was not significant.

The sample sizes of other studies ranged from 38 [141] to 617 [135]. Albert et al. [135] found that receipt of any PS/HM services was associated with lower odds of dying earlier (HR=0.59 (95% CI: 0.40–0.89)) although the effect was only observed for clients with ADL impairment. Receiving more PS/HM services was also associated with lower odds of dying earlier when the amount was grouped as 0 hours/week, 1–19 hours/week, and 20 hours/week (HR=0.75 (95% CI: 0.59–0.95)), but not as a continuous variable. Among clients receiving home-based palliative care services, clients in the highest tertile of PS/HM cost had 2.26 times greater odds of dying at home than in an institution [133]. The remaining studies did not observe significant associations for any death [138, 139, 141] or home death [140].

2.4.2 Institutionalisation

Avoiding or delaying institutionalisation was the second most commonly studied outcome of PS/HM service use. Four studies found significant negative associations [139, 141–143], one study found significant positive associations [134], and one study did not find significant associations [138]. In Sands et al. [142], every five-hour increase in monthly PS hours and HM hours was associated with lower odds of long-term care admission at any time point within two years (PS: HR=0.95 (95% CI: 0.92–0.98) and HM: HR=0.87 (95% CI: 0.77–0.99)). Although their analyses adjusted for a number of predisposing, enabling, and need characteristics and treated death as a competing risk, they did not account for the presence of informal care or changes in the client's health status after the initial assessment.

Three studies examined the proportion of institutionalised clients after a defined period. Hollander & Tessaro [137] observed that 15.0% of low-level clients whose PS/HM services were not severely cut had been admitted to long-term care after three years compared to 37.9% of low-level clients whose services were severely cut ($p<.0001$). In Hughes et al. [139], 13.2% of clients receiving PS/HM services in the intervention group were admitted to long-term care after nine months compared to 22.8% of clients receiving home-delivered meals living in the same area ($p<.01$). Among clients with a dementia diagnosis, Riordan & Bennett [141] found that receipt of an augmented home support service (in addition to standard home support services) was associated with fewer institutionalised clients after six and 12 months ($p<.05$), but not after 18 months. At the state level, Thomas [143] concluded that every 1% increase in the population aged 65 and older and receiving PS/HM services was associated with a 0.8% decrease in the

proportion of low-care long-term care residents. Only Sands et al. [142] adjusted for any client-level characteristics that may have been associated with institutionalisation.

2.4.3 Hospitalisation

Only one out of six studies found a significant association between PS/HM service use and hospitalisation that was operationalised as hospital (re)admission or hospital length of stay. After adjusting for previous emergency department visits and hospitalisations, Xu et al. [144] found that clients receiving five PS hours/month (i.e., 75th percentile among those enrolled in the Aged and Disabled Waiver program) had lower odds of being hospitalised (HR=0.46 (95% CI: 0.38–0.57) compared to those receiving no PS services. However, the magnitude of the relationship decreased over time. By 14 months after enrollment, the hazard ratio was 0.88 and became non-significant thereafter. Similar findings were observed with HM services. The hazard ratio for hospitalisation among clients receiving two HM hours/week was 0.52 (95% CI: 0.44–0.63) during the month of enrollment but became non-significant after 13 months.

In other studies, most samples were either not comparable at baseline or not representative of home care clients in general. For instance, the intervention and control groups in Hughes et al. [139] differed by ADL status, home care use, and unmet need for medical care among other demographic and functional health status measures at baseline. Contandriopoulos et al. [145] compared two cross-sectional groups of home care clients on service before and after the introduction of a home aide program, but only on demographics and service use characteristics. Meanwhile, clients with cognitive impairment were excluded from the studies by Chambers et al. [138] and Dellasega & Fisher [116].

2.4.4 Total Health Service Cost

Three studies examined total health service cost. PS/HM service use was significantly associated with lower health service costs in the two studies that tested for significant associations.

Hollander & Tessaro [137] included annual costs incurred by government for hospital services, physician services, long-term care and chronic care facilities, home care including adult day care, and pharmaceuticals. Total health service cost did not differ between groups within the first year of service cuts. However, clients whose services were not cut contributed lower costs after two years (\$6,771 vs. \$9,654, $p < .001$) and this difference increased after the third year (\$7,807 vs. \$11,903, $p < .001$). Markle-Reid et al. [146] captured the annual societal cost of all health and social services, including private and indirect costs. The amount of PS/HM services was significantly associated with total cost ($p = .02$). Clients receiving some PS/HM services (i.e., < 1 hour/week) incurred the highest cost (\$19,328), clients receiving more PS/HM services (i.e., > 1 hour/week) incurred the second highest cost (\$16,563), and clients not receiving PS/HM services incurred the lowest cost (\$8,249). Neither study adjusted for baseline health status.

2.4.5 Client Health

Results describing the relationship between PS/HM service use and client health were mixed. Of studies that examined the client's physical health, one study found significant positive associations [147], two studies found significant negative associations [139, 146], and two studies did not observe any significant associations [148, 149]. Hansen et al. [148] did not find a significant relationship between the number of home help visits and change in functional incapacity. In Japan, clients receiving publicly funded home care are assigned to one of six care needs levels. Kato et al. [149] did not detect any association between receipt of home help and

either improving/maintaining or deteriorating in care needs level after 11 months. In an updated study with a larger sample and some covariate adjustment, receipt of home help or bathing among lower needs clients was associated with 2.59 times greater odds of either maintaining or improving in care needs level after two years [147].

On the contrary, Hughes et al. [139] found that clients receiving PS/HM services in the intervention group reported significantly poorer perceived ADL capacity ($p < .01$) and poorer perceived incontinence ($p = 0.02$) after nine months. Markle-Reid et al. [146] compared average change scores in the Medical Outcome Study Short Form (SF-36) Health Survey from baseline to six months. Greater improvement in physical functioning was observed among clients receiving less PS/HM service. Compared to only a 16.8% improvement among clients receiving >1 hour/week, 50.5% improved among those who did not use PS/HM services. No statistically significant differences were observed across the other seven dimensions of the SF-36. However, the analyses did not adjust for the reason for referral or other measures that might explain the client's propensity to improve in health status and excluded clients lost to follow-up (notably, 46% were discharged due to death).

Three studies found significant positive associations between PS/HM use and client mental health, although outcome measures varied greatly and observed associations were modest. In Markle-Reid et al. [146], receipt of >1 hour/week was associated with greater use of active behavioural coping (in response to stressors) after six months, compared to clients receiving <1 hour/week or no PS/HM services ($p = .002$). The amount of PS/HM was not associated with either change in depression symptoms or perceived social support. Chambers et al. [138] found that a 10% increase in home-based social services was associated with improved morale after one year

($p < .05$), but social services did not contribute toward the prediction of social functioning or cognitive status. Barnay & Juin [150] found that each additional hour of PS/HM service per week was associated with a 1.8-point increase in the Mental Health Inventory (MHI-5) that is a measure of general mental health ranging from 0 to 100 ($p < .05$). In the same study, the amount of PS/HM was not significantly associated with self-reported depression. In other studies, neither cognitive status [116] nor perceived mental health [139] was associated with PS/HM service use.

2.4.6 Caregiver Health

None of three studies found a significant association between PS/HM service use and caregiver health. In Sussman & Regehr [151], there was no significant difference in caregiver distress measured using the Zarit Burden Inventory between clients using and not using HM services. Hooyman et al. [152] examined the impact of a policy change where households with incomes greater than 30% but less than 50% of the median income were no longer eligible for publicly funded HM services. The type, frequency, and duration of informal caregiving and caregiver distress did not significantly differ between clients whose services were and were not terminated. However, the authors did not report the amount of HM services previously used by the clients. In Riordan & Bennett [141], receipt of an augmented home support service was not associated with any of three caregiver health measures. Notably, study samples were quite small ($n < 100$) and sampling methods meant that the results could not be generalised to the general caregiver population.

2.4.7 Summary

The existing literature on outcomes associated with PS/HM service use is typically limited by small sample sizes, self-reported measures, insufficient covariate adjustment, and narrow definition of outcomes. Most studies ranged from 100 to 1000 participants and relied on self-reported measures of independent and dependent variables. Of 26 quantitative studies retrieved, over half of the studies did not adjust for baseline health status, informal care use, or other formal care use. Overall, the evidence behind PS/HM use and single adverse events (i.e., mortality, institutionalisation, hospitalisation) is highly mixed and inconclusive. In the two studies that examined total health service use, PS/HM use was significantly negatively associated with total cost, suggesting that examination of health service use one at a time may fail to detect differential outcomes. Moreover, health service use represents one facet of health status, but does not provide a comprehensive picture of client or caregiver well-being. A minority of studies examined the client's physical or mental health. In two studies, greater PS/HM use was associated with poorer actual or subjective functional status, but the studies did not investigate the reasons for loss to follow-up as a separate outcome. Only three studies examined caregiver-related outcomes. The absence of caregiver-related outcomes was surprising given the trend toward family-centred (i.e., not just client-centred) care and the fact that family and friends provide the vast majority of care to enable their loved ones to remain at home safely.

CHAPTER 3: Who is assessed with the interRAI Contact Assessment, Home Care, and Community Health Assessment and who receives publicly funded home and community care services in Ontario?

3.1 Introduction

In 2016, the proportion of seniors (16.9%) exceeded that of children (16.6%) for the first time in the history of the Canadian census [153]. By 2041, a quarter of the Canadian population will be 65 years and older [154]. As the population ages, demand for home and community care will increase concurrently. Between 2009 and 2015, 22% more clients accessed Ontario's publicly funded home care services [34]. Given these projections, it is vitally important to design programs that will rationally and equitably meet future needs of the population [155]. At the centre of any needs-based program is an effective assessment system. Assessment of the individual is needed to measure needs, track health outcomes, and guide decisions on how to allocate program resources. At the aggregate level, assessments are used to measure quality and value of care and highlight areas for program improvement. Additionally, it is important that the assessment process itself is streamlined, sensible, and actionable.

interRAI is an international not-for-profit collaboration founded on the vision that “collecting accurate information in a common format within and across service sectors and countries enhances both the well-being of frail persons and the efficient and equitable distribution of public resources” [156, 157]. interRAI assessment instruments cover all parts of the health care system, and when used together, form a fully integrated assessment system [158]. Three assessment systems focus on the general home and community care population: interRAI Home Care (HC), interRAI Community Health Assessment (CHA), and interRAI Contact Assessment

(CA). The HC and CHA were developed for use with adults in home and community-based settings and share many of the core questions [159, 160]. The CHA differs from the HC such that only CHA-assessed persons indicating specific needs receive one or more of four supplements in addition to the core assessment. Completing both the core CHA and Functional Supplement is basically equivalent to the HC. The HC and CHA are comprehensive assessments and provide clinical scales and care planning protocols. The CA is much briefer, designed for screening home care clients at program intake [161]. It records basic clinical information and produces decision support tools regarding the need for more comprehensive assessment and urgency for providing nursing and rehabilitation services.

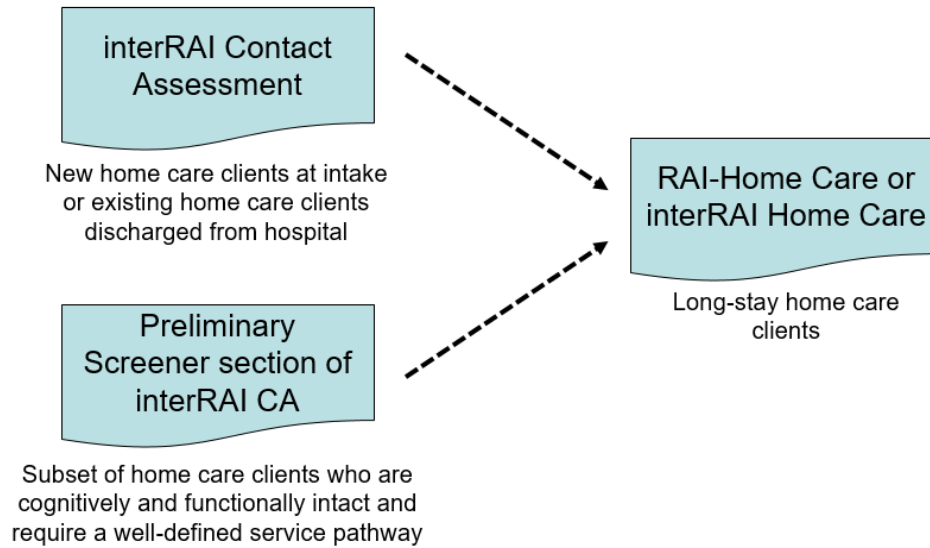
Across Canada, every province and territory has implemented at least one interRAI assessment system [162]. The HC is mandated across Ontario, British Columbia, Alberta, Saskatchewan, Winnipeg Regional Health Authority (one of five regional health authorities in Manitoba), Nova Scotia, Newfoundland, and Yukon. The CHA is mandated across Ontario, Prince Edward Island, and parts of New Brunswick. The CA is mandated across Ontario and three zones in Alberta, and pilot projects with the CA are underway in Saskatchewan and Manitoba. Participating provincial and territorial ministries of health and regional organisations regularly submit CA and/or HC data to the Canadian Institute for Health Information. The Home Care Reporting System produces organisation, provincial/territorial, and national-level reports about health system performance and quality. In contrast, the Canadian Institute for Health Information does not currently support a national reporting system for the CHA. In Ontario, community support service agencies completing the CHA may choose to upload their assessments to the Integrated

Assessment Record that is managed by Community Care Information Management [163].

Agencies that upload to the Integrated Assessment Record receive an agency-level report.

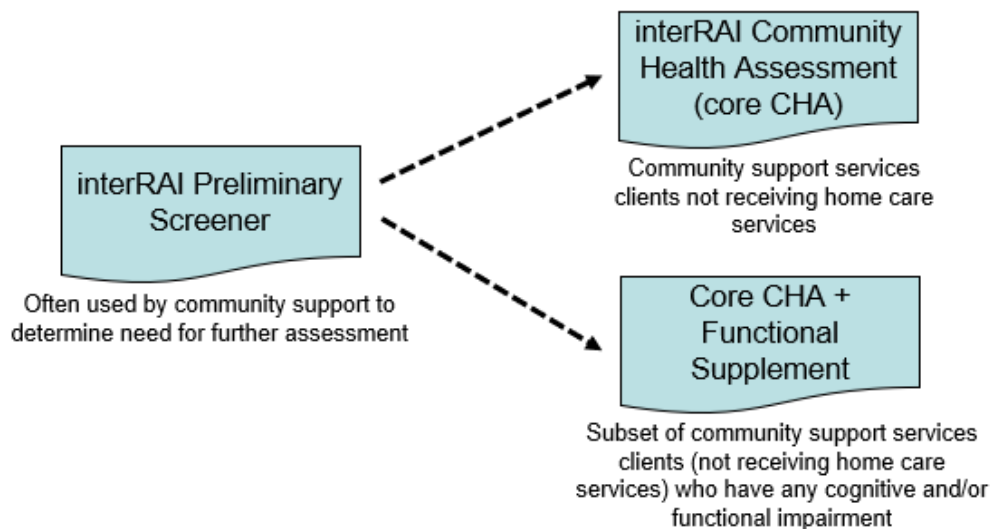
Notably, Ontario is the sole province that has implemented all three assessments. The following figures briefly describe the assessed populations. Figure 3-1 depicts Ontario's stepped approach to home care assessment, where clients are first assessed with the CA and some clients are later assessed with the HC. The CA is used when a prospective client is referred for home care services, and in most cases, when an existing home care client returns home after hospital discharge. At first, only the Preliminary Screener section of the CA is completed. If the client does not have any issues with cognition, physical functioning, shortness of breath, self-reported health, or unstable conditions and requires a well-defined service pathway (e.g., suctioning), the assessor skips the remaining questions and orders the services accordingly (i.e., early triage CA). Otherwise, the assessor completes the rest of the CA (i.e., full CA). Clients expected to remain on home care service for 60 days or longer receive the HC assessment with most clients being reassessed every six to 12 months.

Figure 3-1 interRAI Assessments and Assessed Populations in Home Care in Ontario



In Figure 3-2, clients receiving support solely from community support service agencies are assessed with the CHA. Clients receiving support from both home care and community support sources are assessed with the HC and therefore do not receive the CHA. Many agencies also employ the interRAI Preliminary Screener to assess a prospective client's need for further assessment. The Preliminary Screener is identical to the Preliminary Screener section in the CA with the addition of three questions. Clients indicating some level of need and requiring some type of clinical support are assessed with the CHA, and only those indicating issues with cognitive or physical functioning receive the Functional Supplement. CHA reassessments generally occur every 12 months.

Figure 3-2 *interRAI Assessments and Assessed Populations in Community Care in Ontario*



To date, published work based on interRAI data on home and community care has focused on the HC-assessed population. In December 2018, a Scopus search returned 179 publications on the HC, CHA, and CA. Six papers were published on the CHA [60, 163–167], four were published on the CA [168–171], and the remaining were published exclusively on the HC. Many of these studies were conducted with Ontario data; however, the possibilities for better understanding the home and community sector remain untapped. First, although the CA is widely used in Ontario’s publicly funded home care system, no data have been published about the general home care population. Most research papers and reports focus on long-stay home care clients despite the vital role that home care plays in supporting clients with short-term acute needs, especially those returning home after hospital discharge. Even among published studies involving the CA, the CA-assessed population is not well described. Cheng et al. [169] used the distribution of CA-assessed clients with any ADL impairment, any cognitive impairment, and recent falls to create a frequency-matched HC sample. Bucek [172] used the CA to describe the

profile and use of rehabilitation services among home care clients with a previous hospitalisation due to stroke in a single region in Ontario. Dwyer [173] briefly described the profiles of home care clients who were assessed with the CA only and both the CA and HC. Clients receiving both assessments were more likely to be older and female, have unstable health patterns, have some degree of cognitive or ADL impairment, and report poor health and depressive symptoms. However, these data were collected prior to the provincial implementation of the CA. Second, there was been little research into Ontario's stepped approach to home care assessment. In 2006, interRAI and the Ontario Ministry of Health and Long-Term Care developed the CA as a general needs assessment. No evaluation seems to have been conducted in the past decade. Linking the CA and HC would provide insight into the utility of a stepped approach that if proven effective would form the evidence base for adopting the same assessment approach in other Canadian and international jurisdictions. Finally, having implemented all three assessments, Ontario is uniquely positioned to present a broad picture of clients accessing publicly funded home and community care services.

3.2 Objectives

With access to census-level CA and HC data and a substantial number of CHAs, the goal of this chapter is to describe the recipients of public home and community care in Ontario. Given the lack of published evidence on the CA and CHA, the primary objective is to describe the profiles of clients assessed with the CA and CHA and draw comparisons with the profile of long-stay home care clients assessed with the HC.

During the data exploration phase, additional questions were raised about the relationship between the CA and HC and the quality of the service data. Some of these analyses were added

to this chapter because they may be of interest to data custodians and researchers seeking to work with the home care assessment and service data.

This chapter is presented as a series of sub-chapters, one for each of the following objectives:

1. Describe the predisposing, enabling, need, and service use characteristics of public home and community care clients in Ontario → sub-chapter 3A
2. Examine the relationship between the CA and HC assessments in Ontario, namely the relationship between the Assessment Urgency Algorithm and receipt of HC assessment and associations between selected need characteristics → sub-chapter 3B
3. Identify predisposing, enabling, and need characteristics that predict receipt of greater or lesser amounts of publicly funded PS/HM services between the CA and HC among home care clients in Ontario → sub-chapter 3C
4. Compare the self-reported and billed formal care data and comment on the integrity of the self-reported formal care data in the HC assessments in Ontario → sub-chapter 3D

The same data sources and samples are used across all sub-chapters.

3.3 Data Sources

3.3.1 Health Shared Services Ontario Data

Client-level assessment and administrative data were sent by HSSOntario to the University of Waterloo through agreements between these two organisations. HSSOntario is a government agency that supports the 14 LHINs in part by managing the Client Health and Related Information System (CHRIS). Through the CHRIS suite of applications and associated portals, LHINs keep track of referrals, complete clinical assessments, create and update service plans,

order and bill for home care services and medical equipment/supplies, and apply for long-term care placement, among other functions. Any changes made in CHRIS at the local LHIN level can be immediately accessed in real-time by HSSOntario. As well, each LHIN regularly checks for congruency between local and provincial reports and notifies HSSOntario of any discrepancies. The frequent and detailed checks in addition to the use of CHRIS data for managing home care service delivery mean that these data can be expected to be complete and trustworthy. All data were anonymised by HSSOntario prior to transfer to the University of Waterloo although a real-world linking field (client number) was generated to allow merging of the data tables. Use of these data was approved by the University of Waterloo's Office of Research Ethics (ORE# 18228). Previous studies have also used data from the CHRIS system to examine client characteristics, service utilisation, and referral patterns (examples include Poss et al. [174], Sinn et al. [60], Betini et al. [175], and Salam-White et al. [176]).

The following data tables are used in this study:

- Home care referrals: Each row contains a unique referral. All referrals made to the LHIN are captured in this table even if the person was not admitted. Selected data columns include age, sex, forward sortation area of the postal code, LHIN administrative region, referral date, referral source, referral decision, admission date, Service Recipient Code at admission, discharge date, and discharge reason.
- interRAI CA assessments: Each row contains a unique assessment. All CAs (full CA or Preliminary Screener only) are captured in this table. The data columns include assessment date, and all interRAI CA items, outcome scales, and algorithms. Preliminary Screeners account for approximately 20% of interRAI CA records each year.

- **RAI-HC assessments:** Each row contains a unique assessment. All HCs are captured in this table. The data columns include assessment date, and all HC items, outcome scales, and algorithms. There is a section on formal care utilisation that represents the client's self-reported service use from all sources (i.e., publicly or privately funded) as well as hours of informal care received in the previous week. In this study, hospital versions (i.e., HCs completed in hospital as part of a long-term care application) were excluded from analysis.
- **Billed services:** Each row contains a unique home care service visit. The dataset consists of all services that were paid from the LHIN to service provider agencies, the sum of which represents all publicly funded home care services. Selected data columns include visit date, care location type, service type, and units of service provided (hours or visits). Only personal support services and shift nursing are reported in hours. All other service types are counted by the number of visits.

3.3.2 Ontario Ministry of Health and Long-Term Care Data

A database of interRAI CHAs completed between June 2013 and May 2016 was sent from the Ontario Ministry of Health and Long-Term Care to the University of Waterloo. Community support services agencies in Ontario are not required to complete a standardised assessment if their services are limited to non-clinical supports or if the client has already received a standardised assessment (i.e., HC assessment). Thus, this database represents a subset of community support services agencies that routinely and voluntarily upload their assessments to the Integrated Assessment Record. All data were anonymised by the Ministry prior to transfer to

the University of Waterloo. Use of these data was approved by the University of Waterloo's Office of Research Ethics (ORE# 19917).

The following data tables are used in this study:

- interRAI CHA assessments: Each row contains a unique assessment. The data columns include age, sex, forward sortation area of the postal code, agency identifier (anonymised), assessment date, and all interRAI CHA items, outcome scales, and algorithms. A CHA record may contain the core CHA only or the CHA+Functional Supplement. The CHA+Functional Supplement assessments account for approximately 70% of total interRAI CHAs in each year.

3.4 Samples

3.4.1 Home Care Sample

All Ontario adult (age ≥ 18 years) home care referrals that were initiated between April 1, 2016 and March 31, 2017 and subsequently admitted were retrieved. Referrals without a valid client number or referral start date were deleted. If a client had overlapping referrals, the referral start date was reset to the earliest referral start date and the discharge date (if discharged) was reset to the latest discharge date. The home care episode refers to the length of time between the referral start date and the discharge date. If a client had multiple non-overlapping referrals within the year, only the first referral was retained. At admission, Ontario adult home care clients are assigned a Service Recipient Code (SRC) based on the overall service goal and the types of services they need. Only referrals assigned to one of the following four SRCs were retained: 91 Acute (provide short-term education, care, or support to aid in recovery from illness or injury),

92 Rehabilitation (optimise functional status and facilitate social integration and independence for those with short-term activity limitations), 93 Maintenance (prevent or minimise decline in functional status and maintain independence for those with stable chronic conditions), and 94 Long-term Supportive (preserve functional status and independence and delay institutionalisation for those with progressive decline) [177]. Referrals associated with other SRCs such as Long-Term Care Placement and End of Life were excluded.

Prior to linking, clients residing in a long-term care home or hospital were deleted. Referrals were linked to the assessment databases using the client number. The initial assessment was determined based on the first assessment in the home care episode. For each CA, the CA must have been initiated while the referral was active, between one day before the referral start date and up to 14 days after the referral start date (but not after the discharge date). For each HC, the HC must have been initiated while the referral was active, between one day before the referral start date and up to 182 days after the referral start date (but not after the discharge date). If both a qualifying CA and HC could be retrieved for a given referral, the earlier assessment was identified as the initial assessment. Referrals for which no initial assessment could be identified were dropped from the sample. Additionally, referrals that had a CA as the initial assessment were linked to the first subsequent HC assessment that was initiated within 182 days of the CA assessment date, where available.

3.4.2 Community Care Sample

All CHA assessments completed between April 1, 2015 and March 31, 2016 were retrieved. Assessments without a valid client number or assessment date were deleted. If a client had more than one assessment within the year, only the first assessment was retained.

SUB-CHAPTER 3A

3A.1 Objectives

The objective of this sub-chapter is to describe the predisposing, enabling, need, and service use characteristics of Ontario’s public home and community care clients assessed with the CA, HC, and CHA.

3A.2 Variables of Interest

3A.2.1 Assessment Groups

Assessment groups were defined by the type(s) of assessment received. Home care clients were classified into one of three groups: “CA+HC” are clients who were first assessed with CA and subsequently assessed with HC, “CA only” are clients who were first assessed with CA (and not subsequently assessed with HC), and “HC only” are clients who were first assessed with HC without previously receiving a CA within the same home care episode. All CHA-assessed clients were classified into the “CHA” group.

3A.2.2 Predisposing Characteristics

Predisposing characteristics were drawn from the assessments. *Age at the time of assessment* was calculated by taking the difference between the birth date and assessment reference date and collapsed into five groups (18–44, 45–64, 65–74, 75–84, 85+). *Sex* is reported as a binary variable (female, not female). There were 12 cases in which sex was reported as “other” or “unknown” and were counted in the “not female” category. *Marital status* was collapsed into four categories (married, divorced/separated/widowed, never married, other). Being in a

common-law relationship was an additional response option in the CHA that was reported under the “married” category.

3A.2.3 Enabling Characteristics

The following enabling characteristics were drawn from the assessments, except for Local Health Integration Network that came from the referral dataset. *Caregiver status* was used to identify whether the client has a co-residing informal caregiver and was reported using three categories (caregiver lives with client, caregiver does not live with client, no caregiver). *Living arrangement at the time of referral* describes the people with whom the client lives and was collapsed into five groups (lives alone, lives with spouse, lives with child/child-in-law, lives with other relatives, lives with non-relatives). *Residential location at the time of referral* describes the type of dwelling in which the client lives and was collapsed into three groups (private home/apartment, board and care/assisted living/ group home, other). *Local Health Integration Network* was a variable provided by HSSOntario based on geographic boundaries established by the Ministry of Health and Long-Term Care and identified the LHIN region in which the client lives.

Additional enabling characteristics were available for the home care sample only, and were drawn predominantly from the referral dataset. In practice, care coordinators use drop-down lists to enter referral source, Service Recipient Code (SRC), and discharge reason for each client. *Referral source* was collapsed into five categories (hospital (inpatient), hospital (outpatient), other health professional, other health/social/education services organisation, other individual or self). Referrals received from long-term care homes and other LHINs were included in the “other health/social/education services organisation” category. *SRC at admission* is the first SRC that

was applied to the client's home care episode and represents the service goal at the time of admission (Acute, Rehabilitation, Maintenance, Long-term Supportive). *Type of communication at intake* combines care coordinators' responses on three items on the CA about how the assessment was completed (phone only, in-person only, other/multiple methods). *Discharge reason* was collapsed into seven categories. "Service plan complete" means that the client's service goals were met and home care services were no longer required. "Hospitalised >14 days" refers to clients who were admitted to hospital for longer than 14 days that would lead the care coordinator to close the existing home care file according to LHIN standard policy. "Died" includes both clients who died in the community and those who died in hospital within 14 days of hospital admission. Other discharge categories included clients admitted to long-term care, transferred to a community service agency, transferred to another LHIN, or clients requesting to discontinue home care services for a period longer than 30 days. *Length of stay* was calculated by taking the difference between the admission and discharge dates and collapsed into five groups (0 to 1 month, 1 to 2 months, 2 to 6 months, 6 to 12 months, 12+ months). For clients assessed with both the CA and HC, *time to HC assessment* was calculated by taking the difference between the CA and HC assessment dates.

3A.2.4 Need Characteristics

Need characteristics were drawn from the assessments. Items appearing in multiple interRAI assessments share the same clinical concepts and definitions; thus, the items can be directly compared across the CA, HC, and CHA. Table 3-1 lists the sections and number of items across the three assessments.

Table 3-1 Clinical Sections and Number of Items in interRAI CA, HC, and CHA

Section	interRAI CA	interRAI HC	interRAI CHA (Functional Supplement)
Cognition	2	9	3 (6)
Communication	1	4	4 (0)
Mood and behaviour	1	20	12 (8)
Psychosocial well-being	1	12	11 (1)
Physical functioning	9	37	28 (9)
Continence	0	4	1 (3)
Disease diagnoses	5	26	19 (7)
Health conditions	12	36	26 (10)
Oral and nutritional status	3	15	6 (11)
Skin condition	2	7	0 (7)
Medication	0	12	11 (1)
Treatments and procedures	6	41	11 (30)
Social supports	5	13	0 (12)
Environmental assessment	0	10	1 (9)
Discharge potential	0	5	0 (5)

Source: interRAI CA assessment instrument; interRAI HC assessment instrument, interRAI CHA assessment instrument, interRAI Functional Supplement assessment instrument [159–161]

Some differences exist between assessments. In terms of the observation period, assessors generally code for the last 24 hours in the CA and for the last three days in the HC and CHA. As a brief instrument, the CA often uses a more simplified response set than either the HC or CHA. Where the response sets differ, this analysis collapsed the additional responses in the HC and CHA to match the CA response set. As well, some items are not part of the Preliminary Screener or core CHA and were reported as “not assessed”. *Cognitive skills for daily decision-making* describes the client’s ability to make decisions regarding ADLs. Cognitive impairment is present if the client has any difficulty making reasonable and safe decisions in new or routine situations. *Personal hygiene/dressing lower body/bathing self-performance* describes the client’s performance of these ADLs. ADL impairment is present if the client received any supervision, cueing, or physical assistance during the activity, or if the client did not perform the activity during the observation period. *Meal preparation/ordinary housework/managing medications*

capacity describes the client's ability to perform these IADLs. IADL impairment is present if the client is presumed to require at least supervision, cueing, or physical assistance during the activity. *Decline in cognitive status and decline in ADL status* reflects poorer functioning as compared to the client's cognitive or functional status three months ago from the perspective of the client, family, or assessor. *Dyspnea* indicates shortness of breath while performing activities or at rest. *Poor self-rated health* is captured by the client's response to the question "in general, how would you rate your health". *Unstable cognitive/ADL/mood/behaviour patterns* refers to unstable or fluctuating care needs attributable to the client's health condition. *Chest pain, falls, and pressure ulcers* are also reported. The *Changes in Health, End-stage disease, Signs and Symptoms Scale (CHESS)* is a measure of health instability that is based on a count of decline in cognitive status, decline in ADL status, symptoms such as dehydration and weight loss, and clinician ratings of less than six months to live [178]. High CHESS has been shown to predict mortality, health service use, and caregiver distress among home care clients [178–180]. In this study, high to very high health instability corresponded to CHESS scores of 4 or 5. *Caregiver distress* is based on a combination of two or three items depending on the availability in each assessment: 1) "informal helper(s) is unable to continue in caring activities" (HC, CHA); 2) "primary informal helper expresses feelings of distress, anger, or depression" (HC, CHA, CA); 3) "family or close friends report feeling overwhelmed by person's illness" (CHA, CA). The presence of caregiver distress was indicated by an affirmative response to any of the above questions.

3A.2.5 Formal and Informal Care

Information about formal and informal home and community care utilisation was summarised from the assessments and billed services dataset. In general, two types of variables were created for each type of care, indicating if any care was received and the average amount of care received. Weekly utilisation values were very small for some services; therefore, monthly utilisation values are reported to aid in interpretation. A month is defined as four weeks that is consistent with the *Thriving at Home* report [23].

- *Monthly informal support hours* were derived from the HC and Functional Supplement. The HC item is the “hours of informal help (instrumental and personal activities of daily living) received over the last seven days” and this value was multiplied by 4 to generate monthly utilisation. The Functional Supplement item is the “hours of informal care and active monitoring (instrumental and personal activities of daily living) in the last three days” and this value was multiplied by 28/3 to generate monthly utilisation.
- *Monthly formal (publicly and privately funded) hours* were derived from the HC and Functional Supplement. The HC item is the “hours and minutes (rounded to even 10 minutes) of formal care (care or care management) in the last seven days”. The minutes were divided by 60 and summed with the hours, and this sum was multiplied by 4 to generate monthly utilisation. The Functional Supplement item is the “minutes of formal care in the last seven days” and this value was multiplied by 4 to generate monthly utilisation. The following types of care were included: personal support/homemaking (sum of home health aides and homemaking services), nursing, physiotherapy, occupational therapy, speech language pathology, and meals program.

- *Monthly formal (publicly funded) hours* were derived from the billed services dataset containing all home care service visits. For each client, the services that were received up to 28 days after the CA assessment date and/or up to 84 days after the HC assessment date were retained. If the client received a subsequent assessment or was discharged within the observation period, only the services received up to the follow-up assessment or discharge date were retained. The quantity of home care services was summed for each service type. Quantity was measured in number of visits for all service types except for personal support/homemaking and shift nursing that were measured in number of hours. Thus, the quantity of nursing is somewhat ambiguous because the sum consists of both visits and hours. The following service types were included: personal support/homemaking (sum of personal services, homemaking services, combined personal services and homemaking services, respite), nursing (sum of shift nursing, visiting nursing, and rapid response nursing), physiotherapy, occupational therapy, speech language pathology, nutrition/dietetic, social work, and other (e.g., respiratory services, psychology, mental health and addiction services). Case management and placement services are also captured in the billed services dataset; however, these hours were excluded from the analysis. To calculate monthly utilisation, the sum of each service type was divided by the number of service days (i.e., difference in days between the first and last visit) and multiplied by 28.

3A.3 Analysis Plan

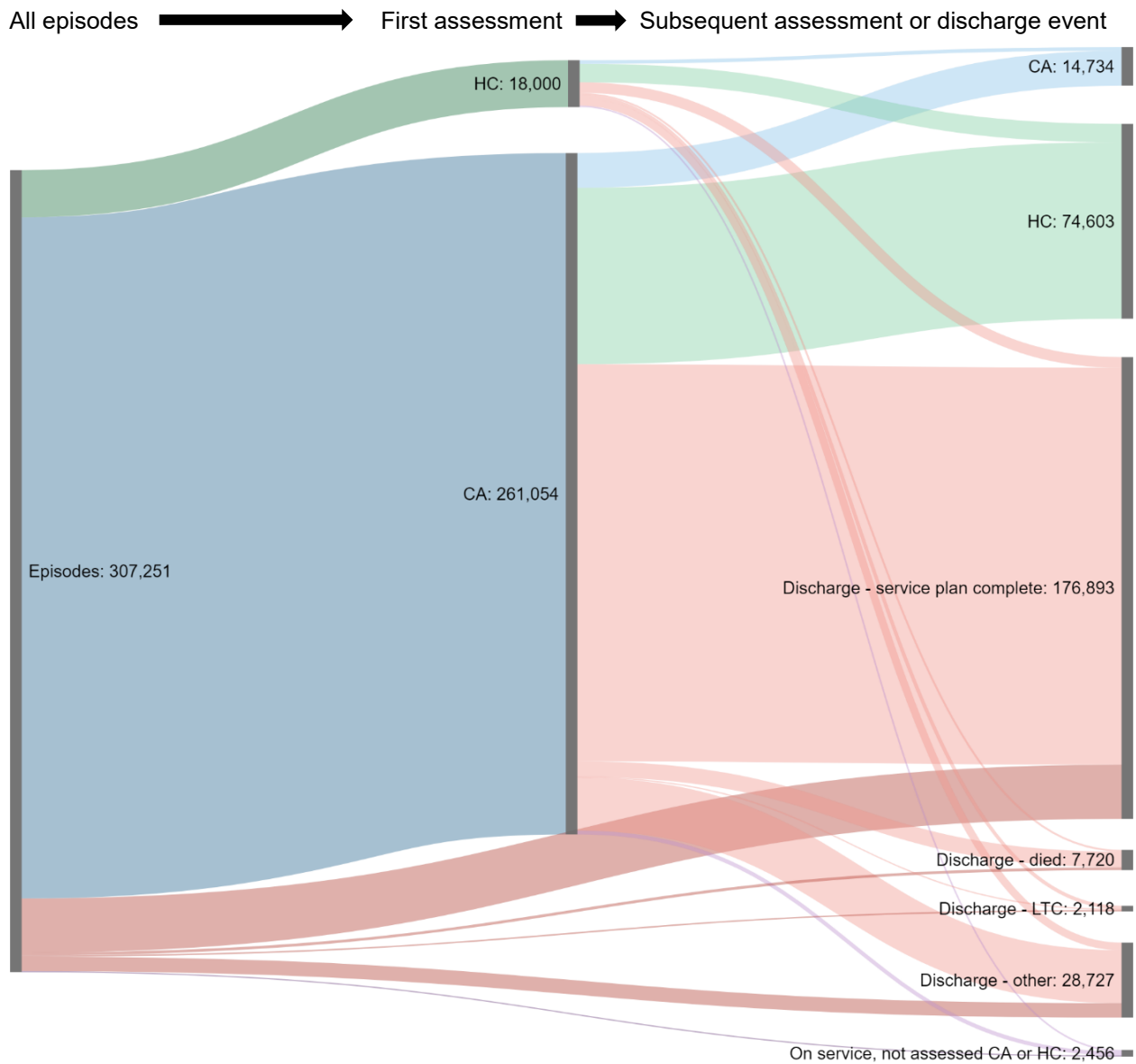
Predisposing, enabling, and need characteristics and likelihood to receive formal and informal care were summarised in frequency tables and compared using chi-square tests across assessment groups. The reference group was the CA+HC group. Since the CA+HC group was assessed at two different time points, some results were further stratified by the CA or HC. Distributions of the amount received of formal and informal care were compared using Kruskal-Wallis tests. All analyses were done using SAS 9.4.

3A.4 Results

In Ontario FY 2016/17, 307,251 unique clients were admitted to the publicly funded home care program under SRCs 91, 92, 93, and 94.

Figure 3-3 illustrates the flow of all admitted home care clients before any restrictions were placed on the sample. Of all clients, 90.8% (279,054) had a linkable CA or HC assessment and 9.2% (28,197) did not. Compared to clients with a linkable assessment, clients without an assessment were significantly more likely to be younger than 65 years (40.7% vs. 35.2%). The proportion of females was not significantly different. Clients without an assessment were significantly more likely to be in SRC 91 (47.9% vs. 44.7%) and SRC 92 (30.8% vs. 22.4%), more likely referred by long-term care (5.0% vs. 1.0%) and less likely referred by a hospital inpatient unit (32.7% vs. 39.4%), more likely to be discharged as service plan complete (72.8% vs. 66.9%) or other reasons (5.8% vs. 2.3%), and less likely to stay on home care service for longer than 60 days (38.0% vs. 49.4%). About three-quarters of these clients were discharged as service plan complete whereas 400 clients continued to be on service without a CA or HC assessment (i.e., not discharged and not reassessed).

Figure 3-3 New LHIN Home Care Referrals and Subsequent Assessment or Discharge Events, Unique Clients Admitted as SRC 91/92/93/94, Ontario FY 2016/17, n=307,251



To better represent initial assessments on newly referred clients, this analysis counted only CAs initiated within 14 days and HCs initiated within 182 days of the referral. As a result, the percentage of clients with a linkable CA or HC assessment dropped from 90.8% to 87.4%. In total, this analysis included 268,667 unique home care clients from FY 16/17 and 15,307 unique

community care clients from FY 15/16. Among clients with an initial CA assessment, the time between referral and assessment was 3.5 ± 10.7 days (mean \pm SD), 1 day (median), and 16 days (95th percentile). Among clients with an initial HC assessment, the time between referral and assessment was 35.1 ± 60.4 days (mean \pm SD), 16 days (median), and 143 days (95th percentile).

Table 3-2 shows the distribution of clients by the assessment groups. Nearly two-thirds (65.4%) of home care clients were assessed with the CA only. About one-quarter (26.1%) of home care clients were assessed with both the CA and HC. Only 8.5% of home care clients were assessed with the HC only. There were 66,060 early triage CAs, accounting for 26.8% of all CAs. Early triage CAs were most often completed for clients in the CA only group (i.e., clients who were not subsequently assessed with the HC), accounting for 36.2% of CAs in the CA only group. In comparison, early triage CAs accounted for just 3.4% of CAs in the CA+HC group. The CHA group consisted of 4,204 core CHAs, and 11,103 CHAs with a completed Functional Supplement.

Table 3-2 Classification of Home and Community Care Clients based on Type of Assessment, Ontario FY 2016/17 and FY 2015/16, n=268,667

Assessment group	n	Proportion of home care clients, %	Type of CA, %	
			Full CAs	Early triage CAs
CA+HC	70,023	26.1	96.6	3.4
CA only	175,732	65.4	63.8	36.2
HC only	22,912	8.5	--	--
CHA	15,307	--	--	--

3A.4.1 Group Characteristics

Table 3-3 describes the predisposing characteristics of each assessment group. Clients in the CA only group were significantly more likely to be younger and not female compared to other groups. About half of the CA only group were 65 years or older whereas over 80% were 65 years or older in the other groups. Clients in the CHA group were significantly less likely to be married or in a common-law relationship.

Table 3-3 Predisposing Characteristics of Home and Community Care Clients, by Assessment Group, Ontario FY 2016/17 and FY 2015/16

% (n)	CA+HC n=70,023	CA only n=175,732	HC only n=22,912	CHA (with and without FS) n=15,307
Age				
18 to 44 years	2.6 (1,840)	15.0 (26,388)	2.4 (542)	4.0 (609)
45 to 64 years	13.4 (9,397)	31.4 (55,226)	10.1 (2,303)	12.3 (1,875)
65 to 74 years	18.0 (12,625)	23.0 (40,429)	14.5 (3,315)	17.3 (2,654)
75 to 84 years	32.6 (22,826)	19.6 (34,467)	33.5 (7,667)	31.0 (4,749)
85+ years	33.3 (23,335)	10.9 (19,222)	39.7 (9,085)	35.4 (5,420)
Sex				
Female	59.4 (41,609)	50.6 (88,962)	61.9 (14,175)	67.7 (10,369)
Not female	40.6 (28,414)	49.4 (86,759)	38.1 (8,737)	32.3 (4,938)
Marital status				
Married	41.4 (29,007)	n/a	39.0 (8,927)	25.8 (3,953)
Divorced/Separated/Widowed	48.4 (33,910)	n/a	50.7 (11,615)	57.7 (8,839)
Never married	7.9 (5,551)	n/a	8.6 (1,966)	15.5 (2,365)
Other	2.2 (1,552)	n/a	1.8 (404)	1.0 (150)

*Not assessed for clients meeting early triage criteria; **Not assessed for clients receiving core CHA only

- Chi-square test: All results were significant at $p < .0001$ unless otherwise noted.
- Missing data were noted, unless missing observations counted for <1% of the group.

Table 3-4 describes the enabling characteristics of home and community care clients. Across all groups, clients often identified a primary informal caregiver, although it was more common for CHA-assessed clients and caregivers to live apart. Additionally, CHA-assessed clients were significantly more likely to live alone and less likely to live with family members compared to

other groups. Living in a private dwelling was common across all groups, especially among the CA only group. Clients living in Central Ontario or Metropolitan Toronto accounted for about half of each assessment group. Fewer individuals in the CHA group lived in Southwestern Ontario although the CHAs in this sample account for a non-representative portion of all completed CHAs in the province. At the LHIN-level, most LHINs posted similar percentages of home care clients in the CA+HC and CA only groups. Combined, one-third of clients in the HC only group were assessed in either Hamilton Niagara Haldimand Brant or Toronto Central LHIN.

Table 3-5 describes the enabling characteristics of home care clients only. Home care clients are frequently referred from hospital. Although clients in the CA only group were most likely to have been referred from hospital, those in the CA+HC group were most likely to have been referred as a hospital inpatient. Clients in the HC only group were also frequently referred by other health or social services organisations, family or friends, and themselves. A clear pattern emerged by admission SRC, where most clients in the CA only group were classified as Acute or Rehabilitation and most clients in the CA+HC and HC only groups were classified as Maintenance or Long-term Supportive. Still, about a quarter (27.9%) of clients in the CA+HC group were admitted under Acute or Rehabilitation, although their SRC may have changed during the home care episode. The majority of CAs were completed over the phone, with the remainder being completed using other methods. Among discharged clients, the most common reason for discharge was having met the goals of the service plan and no longer requiring home care services. Clients in the CA+HC and HC only groups were also often admitted to hospital or long-term care or died during the home care episode. Clients in the CA only group often had the shortest home care episodes with only 1.5% of discharged episodes exceeding one year.

Table 3-4 Enabling Characteristics of Home and Community Care Clients, by Assessment Group, Ontario FY 2016/17 and FY 2015/16

<i>% (n)</i>	CA+HC n=70,023	CA only n=175,732	HC only n=22,912	CHA (with and without FS) n=15,307
Caregiver status				
Caregiver lives with client	57.1 (39,957)	40.3 (70,825)	53.4 (12,237)	25.4 (3,884)
Caregiver does not live with client	39.3 (27,538)	19.9 (34,944)	42.7 (9,780)	39.7 (6,073)
No caregiver	3.6 (2,528)	3.0 (5,274)	3.9 (895)	7.3 (1,123)
Not assessed	-- (0)	*36.2 (63,658)	-- (0)	**27.5 (4,204)
Living arrangement				
Lives alone	34.9 (24,467)	24.1 (42,297)	34.0 (7,784)	60.3 (9,229)
Lives with spouse	39.6 (27,716)	55.7 (97,892)	37.1 (8,489)	23.5 (3,590)
Lives with child/child-in-law	13.2 (9,233)	7.8 (13,761)	14.2 (3,252)	8.6 (1,323)
Lives with other relatives	4.1 (2,902)	7.4 (12,925)	7.6 (1,731)	3.5 (540)
Lives with non-relatives	8.2 (5,705)	5.0 (8,857)	6.8 (1,566)	4.1 (625)
Residential location				
Private home/apartment	87.2 (61,073)	94.5 (166,145)	87.8 (20,124)	81.0 (12,403)
Board and care/assisted living/ group home	12.2 (8,552)	5.0 (8,743)	10.1 (2,308)	18.5 (2,833)
Other	0.6 (398)	0.5 (844)	1.7 (390)	0.5 (71)
Local Health Integration Network				
Central East	12.0 (8,420)	10.4 (18,316)	13.3 (3,041)	9.7 (1,477)
Central	11.7 (8,163)	8.7 (15,286)	13.6 (3,118)	13.3 (2,034)
Champlain	7.6 (5,288)	10.0 (17,529)	6.2 (1,424)	13.2 (2,020)
Central West	3.9 (2,762)	5.3 (9,322)	2.0 (460)	2.1 (322)
Erie St. Clair	5.2 (3,668)	7.4 (13,046)	3.3 (761)	1.3 (205)
Hamilton Niagara Haldimand Brant	13.7 (9,561)	13.3 (23,296)	22.0 (5,032)	7.4 (1,129)
Mississauga Halton	6.7 (4,667)	7.1 (12,513)	8.1 (1,860)	11.4 (1,749)
North East	6.7 (4,695)	5.9 (10,417)	2.5 (580)	7.9 (1,214)
North Simcoe Muskoka	4.0 (2,825)	3.7 (6,496)	4.7 (1,081)	3.2 (484)
North West	2.1 (1,438)	2.6 (4,542)	0.7 (163)	2.7 (409)
South East	6.4 (4,467)	5.4 (9,480)	1.6 (360)	8.0 (1,229)
South West	7.2 (5,032)	7.7 (13,550)	8.7 (1,981)	4.0 (609)
Toronto Central	5.9 (4,128)	6.7 (11,792)	10.4 (2,385)	15.7 (2,396)
Waterloo Wellington	7.0 (4,909)	5.8 (10,147)	2.9 (666)	0.2 (30)

*Not assessed for clients meeting early triage criteria; **Not assessed for clients receiving core CHA only

- Chi-square test: All results were significant at $p < .0001$ unless otherwise noted.
- Missing data were noted, unless missing observations counted for $< 1\%$ of the group.

Table 3-5 Enabling Characteristics of Home Care Clients, by Assessment Group, Ontario FY 2016/17

% (n)	CA+HC n=70,023	CA only n=175,732	HC only n=22,912	CHA (with and without FS) n=15,307
Referral source				
Hospital (inpatient)	44.4 (31,061)	39.7 (69,685)	25.4 (5,816)	n/a
Hospital (outpatient)	13.7 (9,565)	30.9 (54,374)	4.6 (1,062)	n/a
Other health professional	15.3 (10,700)	15.5 (27,177)	17.0 (3,884)	n/a
Other health/social/education services organisation	11.5 (8,023)	9.5 (16,628)	18.4 (4,212)	n/a
Other individual or self	15.2 (10,674)	4.5 (7,868)	34.7 (7,938)	n/a
Service Recipient Code at admission				
Acute (91)	10.9 (7,614)	64.1 (112,699)	3.0 (695)	n/a
Rehabilitation (92)	17.0 (11,918)	25.6 (44,982)	9.1 (2,087)	n/a
Maintenance (93)	42.5 (29,791)	6.0 (10,612)	44.3 (10,150)	n/a
Long-term Supportive (94)	29.6 (20,700)	4.2 (7,439)	43.6 (9,980)	n/a
Type of communication at intake				
Phone only	59.1 (41,364)	68.6 (120,508)	n/a	n/a
In-person only	8.0 (5,572)	5.4 (9,512)	n/a	n/a
Other/multiple methods	33.0 (23,087)	26.0 (45,712)	n/a	n/a
Discharge reason (among discharged clients)				
Service plan complete	46.2 (25,639)	85.0 (146,739)	38.7 (6,857)	n/a
Hospitalised >14 days	16.4 (9,079)	3.1 (5,316)	13.8 (2,451)	n/a
Died	13.1 (7,271)	4.1 (6,991)	10.0 (1,776)	n/a
Admitted to long-term care	8.4 (4,631)	0.2 (253)	19.3 (3,417)	n/a
Needs met by community service agency	1.9 (1,049)	1.2 (2,131)	2.9 (505)	n/a
Other	15.4 (10,811)	6.4 (11,302)	17.8 (1,322)	n/a
Length of stay (among discharged clients)				
0 to 1 month	12.0 (6,666)	41.1 (71,021)	10.8 (1,907)	n/a
1 to 2 months	16.5 (9,172)	25.3 (43,736)	15.2 (2,690)	n/a
2 to 6 months	38.7 (21,474)	26.6 (45,885)	38.3 (6,800)	n/a
6 to 12 months	21.1 (11,690)	5.5 (9,471)	22.6 (4,014)	n/a
12+ months	11.6 (6,442)	1.5 (2,610)	13.0 (2,307)	n/a

- Chi-square test: All results were significant at p<.0001 unless otherwise noted.
- Missing data were noted, unless missing observations counted for <1% of the group.

Table 3-6 describes the need characteristics of each assessment group. Any clinical items that were not assessed in the Preliminary Section of the CA or Functional Supplement of the CHA are noted in the table. In general, the assessment groups reflect a pattern of increasing care needs in the following order: CA only, CHA, CA+HC, and HC only. Clients in the CA only group reported the fewest clinical issues across nearly every item. CA-assessed clients having any cognitive or functional impairment were often subsequently assessed with the HC. For instance, only 6.0% of the CA only group had any difficulty with cognitive skills for daily decision-making compared to 32.1% of those who were later assessed with the HC. The CA only and CHA groups shared similar proportions of clients reporting recent ADL decline, unstable health patterns, pressure ulcers, and falls, although the CHA group showed significantly greater needs in other areas such as cognitive and functional status. The CA+HC group showed significantly greater needs than the CHA group in every clinical area except dyspnea. Within the CA+HC group, the detection of care needs improved at the time of the HC, especially cognitive status, IADL performance, and self-rated health. Most clients in the CHA, CA+HC, and HC only groups required assistance in bathing, meal preparation, and ordinary housework. As well, many clients in the HC only group were impaired in cognitive skills and required assistance with managing medications. The frequencies of some acute issues such as chest pain and pressure ulcers were less variable. A small proportion of each assessment group had a CHES level consistent with high to very high health instability. Caregiver distress was frequently reported among the CA+HC and HC only groups. Although caregiver distress items were not assessed in either the Preliminary Screener or core CHA, the issue of caregivers experiencing distress was still more prevalent than clients indicating poor self-reported health in the CA only and CHA groups.

Table 3-6 Need Characteristics of Home and Community Care Clients, by Assessment Group, Ontario FY 2016/17 and FY 2015/16

% (n)	CA+HC		CA only n=175,732	HC only n=22,912	CHA (with and without FS) n=15,307
	At time of CA n=70,023	At time of HC n=70,023			
Cognitive skills for daily decision-making					
Modified independent or any impairment	32.1 (22,480)	58.7 (41,108)	6.0 (10,580)	73.0 (16,719)	38.6 (5,901)
Independent	67.9 (47,543)	41.3 (28,915)	94.0 (165,152)	27.0 (6,193)	61.5 (9,406)
Personal hygiene self-performance					
Supervision or any physical assistance	31.9 (22,330)	35.7 (25,009)	7.5 (13,210)	43.6 (9,989)	22.3 (3,419)
Independent or set-up help only	68.1 (47,693)	64.3 (45,014)	92.5 (162,522)	56.4 (12,923)	77.7 (11,888)
Dressing lower body self-performance					
Supervision or any physical assistance	49.6 (34,699)	50.9 (35,645)	16.4 (28,836)	54.5 (12,487)	29.3 (4,482)
Independent or set-up help only	50.5 (35,324)	49.1 (34,378)	83.6 (146,896)	45.5 (10,425)	70.7 (10,825)
Bathing self-performance					
Supervision or any physical assistance	68.7 (48,104)	72.4 (50,683)	23.7 (41,695)	75.3 (17,262)	56.1 (8,594)
Independent or set-up help only	31.3 (21,919)	27.6 (19,340)	76.3 (134,037)	24.7 (5,650)	43.9 (6,713)
Meal preparation capacity					
Supervision or any physical assistance	74.8 (52,403)	91.2 (63,872)	34.9 (61,254)	94.1 (21,565)	60.7 (9,288)
Independent or set-up help only	21.5 (15,032)	8.8 (6,151)	28.3 (49,789)	5.9 (1,347)	39.3 (6,019)
Not assessed	*3.4 (2,402)	-- (0)	*36.2 (63,658)	-- (0)	-- (0)
Ordinary housework capacity					
Supervision or any physical assistance	84.8 (59,408)	95.7 (66,995)	44.0 (77,266)	97.0 (22,213)	82.5 (12,633)
Independent or set-up help only	11.5 (8,027)	4.3 (3,028)	19.2 (33,777)	3.1 (699)	17.5 (2,674)
Not assessed	*3.4 (2,402)	-- (0)	*36.2 (63,658)	-- (0)	-- (0)
Managing medications capacity					
Supervision or any physical assistance	45.5 (31,847)	59.3 (41,494)	12.2 (21,501)	70.3 (16,105)	39.1 (5,984)
Independent or set-up help only	50.8 (35,588)	40.7 (28,529)	51.0 (89,542)	29.7 (6,807)	60.9 (9,323)
Not assessed	*3.4 (2,402)	-- (0)	*36.2 (63,658)	-- (0)	-- (0)

*Not assessed for clients meeting early triage criteria; **Not assessed for clients receiving core CHA only

- Chi-square test: All results were significant at $p < .0001$ unless otherwise noted.
- For significance testing, the CA within the CA+HC assessment group was used as the reference group against which the CA only group was compared. The HC within the CA+HC assessment group was used as the reference group against which the HC only and CHA groups were compared.
- Missing data were noted, unless missing observations counted for <1% of the group.

Table 3-6 Continued

% (n)	CA+HC		CA only n=175,732	HC only n=22,912	CHA (with and without FS) n=15,307	
	At time of CA n=70,023	At time of HC n=70,023				
Cognitive decline in last 90 days	Yes	24.3 (16,984)	26.7 (18,719)	3.9 (6,858)	36.2 (8,285)	13.6 (2,084)
	No	72.1 (50,453)	73.3 (51,304)	59.3 (104,188)	63.8 (14,627)	86.4 (13,223)
	Not assessed	*3.4 (2,402)	-- (0)	*36.2 (63,658)	-- (0)	-- (0)
Functional decline in last 90 days	Yes	71.1 (49,748)	69.6 (48,712)	33.8 (59,457)	65.9 (15,100)	18.9 (2,899)
	No	25.3 (17,689)	30.4 (21,311)	29.4 (51,589)	34.1 (7,812)	81.1 (12,408)
	Not assessed	*3.4 (2,402)	-- (0)	*36.2 (63,658)	-- (0)	-- (0)
Dyspnea	Yes	45.0 (31,539)	34.7 (24,269)	22.0 (38,569)	29.3 (6,712)	n.s. 35.7 (5,468)
	No	55.0 (38,484)	65.3 (45,754)	78.1 (137,163)	70.7 (16,200)	n.s. 64.3 (9,839)
Poor self-rated health	Yes	11.7 (8,169)	30.4 (21,309)	4.7 (8,307)	27.4 (6,269)	13.0 (1,990)
	No	88.3 (61,854)	69.6 (48,714)	95.3 (167,425)	72.6 (16,643)	87.0 (13,317)
Unstable or fluctuating cognitive/ADL/mood/ behaviour patterns	Yes	68.9 (48,212)	58.4 (40,860)	27.7 (48,602)	64.8 (14,854)	29.1 (4,457)
	No	31.2 (21,811)	41.7 (29,163)	72.3 (127,130)	35.2 (8,058)	70.9 (10,850)
Chest pain	Yes	4.0 (2,809)	5.3 (3,688)	2.0 (3,531)	4.1 (946)	3.3 (508)
	No	92.3 (64,626)	94.7 (66,335)	61.2 (107,512)	95.9 (21,966)	96.7 (14,799)
	Not assessed	*3.4 (2,402)	-- (0)	*36.2 (63,658)	-- (0)	-- (0)

*Not assessed for clients meeting early triage criteria; **Not assessed for clients receiving core CHA only

- Chi-square test: All results were significant at $p < .0001$ unless otherwise noted.
- For significance testing, the CA within the CA+HC assessment group was used as the reference group against which the CA only group was compared. The HC within the CA+HC assessment group was used as the reference group against which the HC only and CHA groups were compared.
- Missing data were noted, unless missing observations counted for $<1\%$ of the group.

Table 3-6 Continued

% (n)	CA+HC		CA only n=175,732	HC only n=22,912	CHA (with and without FS) n=15,307
	At time of CA n=70,023	At time of HC n=70,023			
Fall(s) in last 90 days					
Yes	46.4 (32,492)	50.6 (35,451)	16.1 (28,275)	46.0 (10,530)	9.6 (1,462)
No	49.9 (34,945)	49.4 (34,572)	47.1 (82,771)	54.0 (12,382)	77.5 (11,866)
Not assessed or missing	*3.4 (2,402)	-- (0)	*36.2 (63,658)	-- (0)	12.9 (1,979)
Pressure ulcer(s)					
Yes	6.0 (4,223)	5.2 (3,616)	3.4 (5,984)	4.4 (1,011)	2.9 (448)
No	90.3 (63,214)	94.8 (66,407)	59.8 (105,062)	95.6 (21,901)	69.6 (10,648)
Not assessed	*3.4 (2,402)	-- (0)	*36.2 (63,658)	-- (0)	**27.5 (4,204)
Changes in Health, End-stage disease, Signs and Symptoms Scale					
High to very high health instability (4-5)	7.9 (5,522)	7.4 (5,174)	1.9 (3,286)	n.s. 7.1 (1,626)	1.9 (292)
No to moderate health instability (0-3)	88.4 (61,913)	92.6 (64,849)	61.3 (107,757)	n.s. 92.9 (21,286)	68.7 (10,517)
Not assessed	*3.4 (2,402)	-- (0)	*36.2 (63,658)	-- (0)	**27.5 (4,204)
Caregiver distress					
Yes	38.3 (26,785)	34.7 (24,319)	8.3 (14,589)	44.9 (10,282)	14.1 (2,154)
No	58.1 (40,652)	65.3 (45,704)	54.9 (96,457)	55.1 (12,630)	58.3 (8,923)
Not assessed	*3.4 (2,402)	-- (0)	*36.2 (63,658)	-- (0)	**27.5 (4,204)

*Not assessed for clients meeting early triage criteria; **Not assessed for clients receiving core CHA only

- Chi-square test: All results were significant at $p < .0001$ unless otherwise noted.
- For significance testing, the CA within the CA+HC assessment group was used as the reference group against which the CA only group was compared. The HC within the CA+HC assessment group was used as the reference group against which the HC only and CHA groups were compared.
- Missing data were noted, unless missing observations counted for $< 1\%$ of the group.

3A.4.2 Self-Reported Informal Care Received Prior to Assessment

Table 3-7 summarises the proportion of clients receiving any informal support in the week before assessment. About 95% of HC-assessed clients reported receiving help from family, friends, or neighbours in the previous week, and this proportion was not significantly different between the CA+HC and HC only groups. In contrast, about two-thirds of clients receiving the CHA+Functional Supplement reported receiving help from an informal caregiver. Across assessment groups, informal caregivers were more likely to provide help with IADLs than ADLs.

Figure 3-4 depicts the distribution of self-reported informal support hours in the previous week, extrapolated to a monthly utilisation. All distributions were characterised by high dispersion and right skewness, especially within the CHA group. Among all clients, the median value for informal support hours was 56 hours/month (i.e., 14 hours/week) in both the CA+HC group and HC only groups. The median value in the CHA group was 28 hours/month (i.e., 7 hours/week). The mean (95% CI) monthly informal support hours were 74.6 (74.0–75.2) in the CA+HC group, 78.9 (77.8–80.1) in the HC only group, and 87.7 (84.8–90.6) in the CHA group. All group distributions were significantly different from each other according to Kruskal-Wallis tests (HC only vs. CA+HC: $\chi^2=10.0$, $p=.0016$; CHA vs. CA+HC: $\chi^2=1493.3$, $p<.0001$).

Among clients receiving any informal support, all groups shared the same median value for informal support hours that was 56 hours/month. The mean (95% CI) monthly informal support hours were 78.7 (78.0–79.3) in the CA+HC group, 83.5 (82.4–84.7) in the HC only group, and 130.7 (126.7–134.6) in the CHA group. All group distributions were significantly different from

each other according to Kruskal-Wallis tests (HC only vs. CA+HC: $\chi^2=18.7$, $p<.0001$; CHA vs. CA+HC: $\chi^2=122.6$, $p<.0001$).

Table 3-7 Receipt of Informal Support among Home and Community Care Clients, Self-Reported Utilisation, by Assessment Group, Ontario FY 2016/17 and FY 2015/16

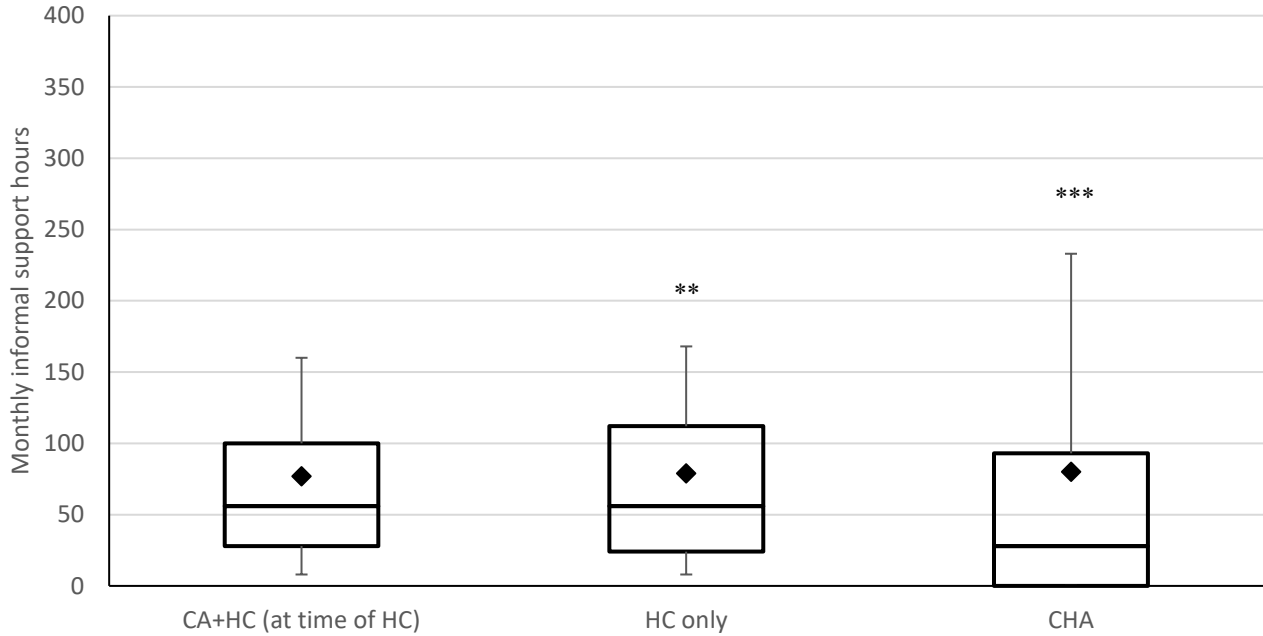
% (n)		CA+HC		*CA only n=175,732	**HC only n=22,912	***CHA (with FS) n=11,103
		*At time of CA n=70,023	**At time of HC n=70,023			
Any informal support		n/a	94.9 (66,426)	n/a	n.s. 94.5 (21,652)	66.9 (7,422)
Area of help	ADL care	n/a	43.1 (30,197)	n/a	42.8 (9,496)	34.2 (3,794)
	IADL care	n/a	89.2 (62,450)	n/a	88.5 (20,287)	62.1 (6,889)
	Advice or emotional support	n/a	92.5 (64,758)	n/a	92.4 (21,162)	n/a

*Not assessed in CA; **Received in last 7 days before HC; *** Received in last 7 days before CHA

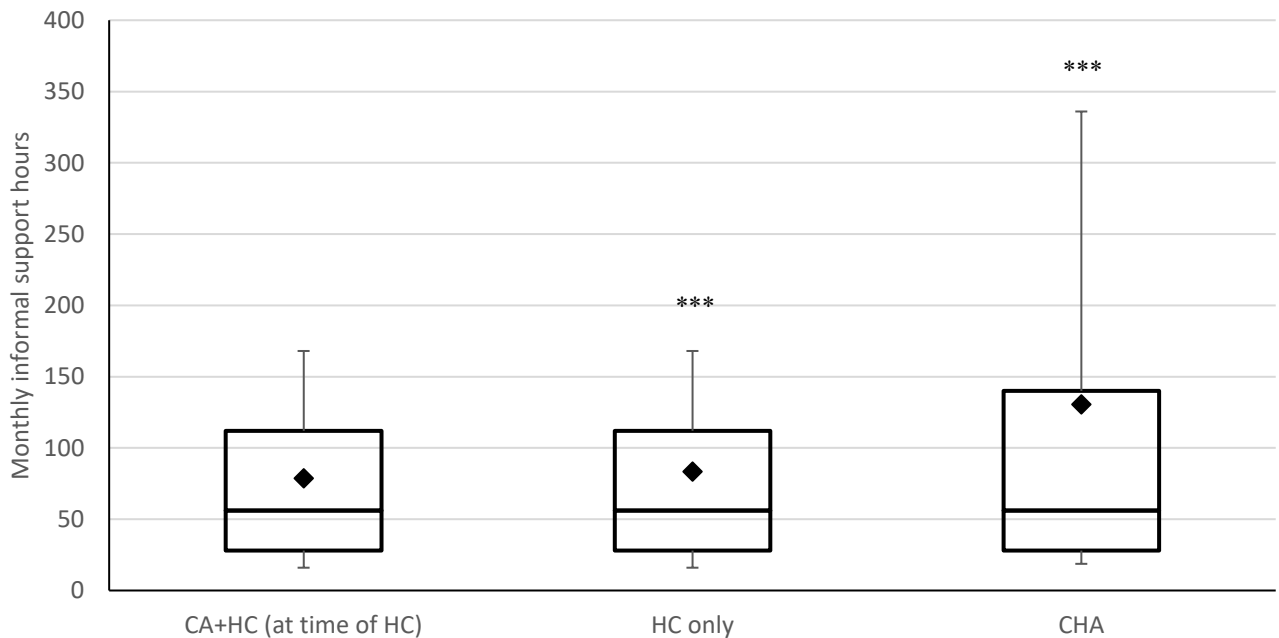
- Chi-square test: All results were significant at $p < .0001$ unless otherwise noted.
- For significance testing, the HC within CA+HC assessment group was used as the reference group against which all other columns were compared.

Figure 3-4 Distribution of Monthly Informal Support Hours among Home and Community Care Clients, Self-Reported Utilisation, by Assessment Group, Ontario FY 2016/17 and FY 2015/16

a) Among all clients



b) Among clients receiving informal support only



Kruskal-Wallis test: *p<.05, **p<.001, ***p<.0001

- The box depicts the 25th (bottom), 50th (centre line), and 75th (top) percentiles. The whiskers depict the 10th (bottom) and 90th (top) percentiles. The diamond represents the mean.

3A.4.3 Self-Reported Formal Care Received Prior to Assessment

Table 3-8 summarises the proportion of clients receiving any formal (i.e., public and privately funded) home and community care services in the week before assessment. Personal support and homemaking (PS/HM) services were the most common type of formal care received. About half of home care and one-quarter of community care clients reported any formal PS/HM visits in the previous week. Clients in the CA+HC group were about 1.5 times more likely to receive nursing or therapy services than clients in the HC only group. Receipt of nursing or therapy services was rare among the CHA+Functional Supplement group.

Figure 3-5 depicts the distribution of self-reported formal PS/HM hours in the previous week, extrapolated to a monthly utilisation. Each of the assessment groups displayed a considerably right-skewed distribution for which the mean values approached or exceeded the 75th percentile. Among all clients, the mean (95% CI) and median monthly formal PS/HM hours were 16.1 (15.8–16.5) and 4.0 in the CA+HC group, 23.5 (22.5–24.4) and 0.0 in the HC only group, and 14.1 (12.6–15.6) and 0.0 in the CHA group. Only the CHA distribution was significantly different from that of the CA+HC group ($\chi^2=563.4$, $p<.0001$).

Among clients receiving any formal PS/HM, the mean (95% CI) and median monthly formal PS/HM hours were 31.4 (30.8–32.1) and 14.0 in the CA+HC group, 49.3 (47.3–51.2) and 20.0 in the HC only group, and 39.3 (35.3–43.3) and 20.0 in the CHA group. All group distributions and were significantly different from each other according to Kruskal-Wallis tests (HC only vs. CA+HC: $\chi^2=348.0$, $p<.0001$; CHA vs. CA+HC: $\chi^2=177.7$, $p<.0001$).

Table 3-8 Receipt of Formal (Public and Privately Funded) Care among Home and Community Care Clients, Self-Reported Utilisation, by Assessment Group, Ontario FY 2016/17 and FY 2015/16

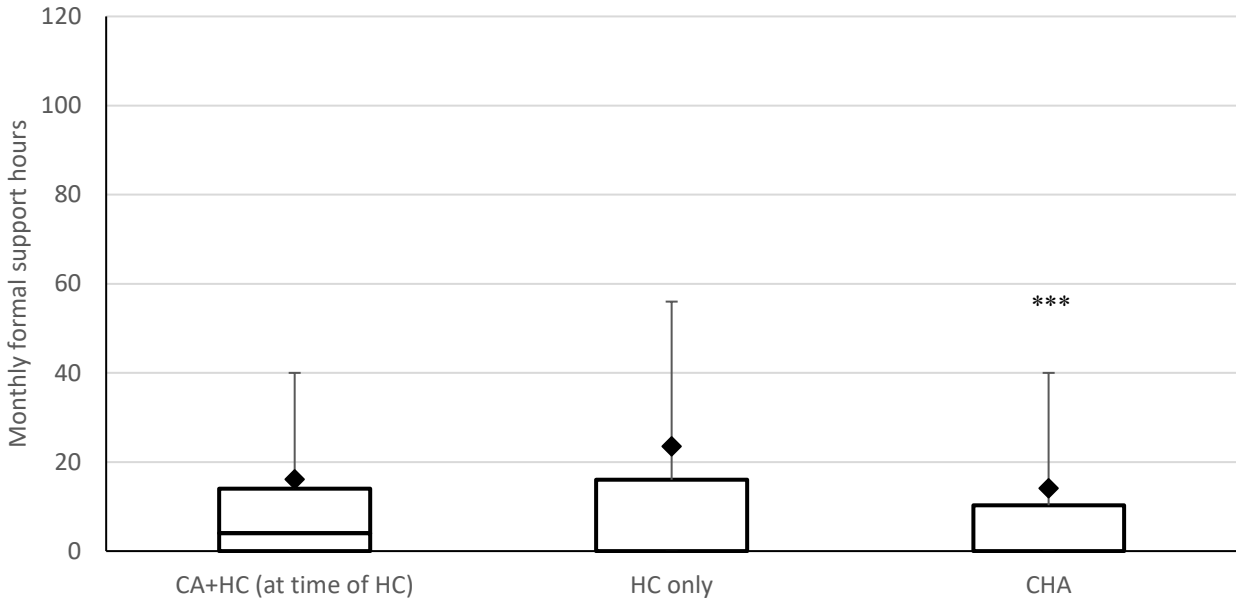
% (n)	CA+HC		*CA only n=175,732	**HC only n=22,912	***CHA (with FS) n=11,103
	*At time of CA n=70,023	**At time of HC n=70,023			
Any personal support/homemaking visit	n/a	51.3 (35,911)	n/a	47.7 (10,918)	26.0 (3,985)
Any nursing visit	n/a	33.4 (23,361)	n/a	18.4 (4,211)	2.4 (363)
Any physiotherapy visit	n/a	24.7 (17,272)	n/a	16.1 (3,687)	2.2 (341)
Any occupational therapy visit	n/a	35.8 (25,089)	n/a	22.9 (5,247)	0.6 (97)
Any speech language pathology visit	n/a	2.0 (1,374)	n/a	1.3 (308)	0.2 (24)
Any meals program	n/a	11.0 (7,724)	n/a	13.9 (3,180)	3.2 (496)

*Not assessed in CA; **Received in last 7 days before HC; *** Received in last 7 days before CHA

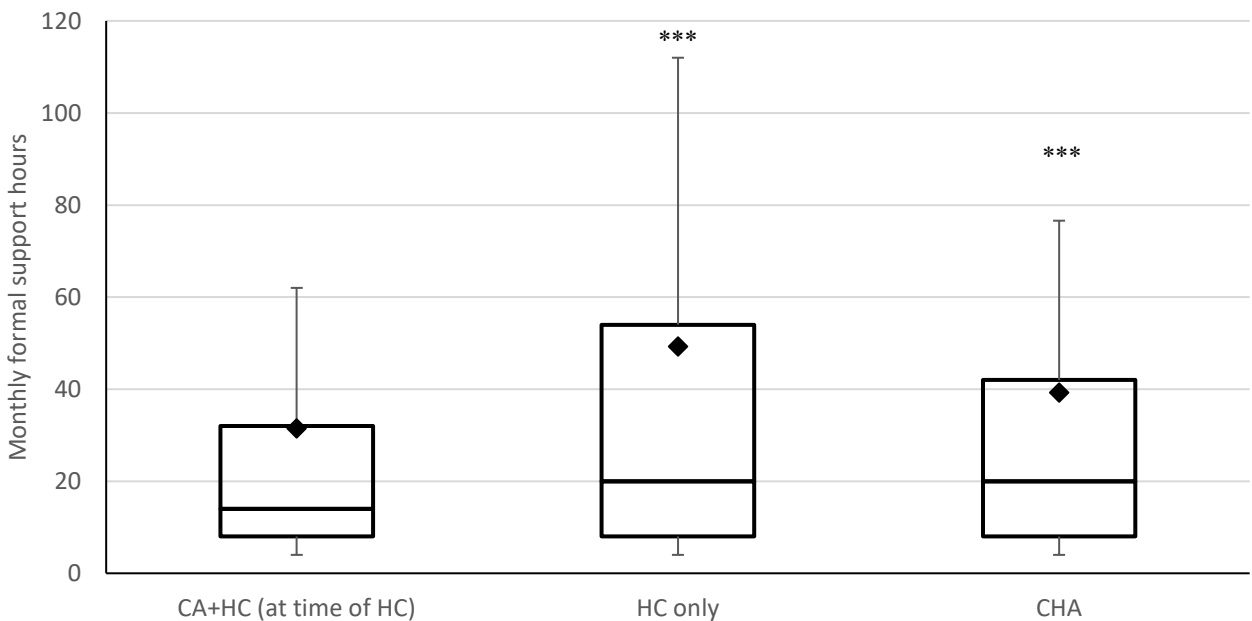
- Chi-square test: All results were significant at $p < .0001$ unless otherwise noted.
- For significance testing, the HC within CA+HC assessment group was used as the reference group against which all other columns were compared.

Figure 3-5 Distribution of Monthly Formal (Publicly and Privately Funded) PS/HM Hours among Home and Community Care Clients, Self-Reported Utilisation, by Assessment Group, Ontario FY 2016/17 and FY 2015/16

a) Among all clients



b) Among clients receiving formal (publicly and privately funded) PS/HM only



Kruskal-Wallis test: *p<.05, **p<.001, ***p<.0001

- The box depicts the 25th (bottom), 50th (centre line), and 75th (top) percentiles. The whiskers depict the 10th (bottom) and 90th (top) percentiles. The diamond represents the mean.

3A.4.4 Billed Formal Care Received After Assessment

Table 3-9 describes the proportion of clients receiving publicly funded care after their assessment. Clients in the CA only group were significantly more likely to receive any publicly funded services although most home care clients received at least one home service visit after their assessment. For clients in the CA+HC group, at the time of CA, the most frequently utilised publicly funded services were occupational therapy, nursing, and PS/HM. Among HC-assessed clients, the most frequently utilised publicly funded services were PS/HM, occupational therapy, and physiotherapy, irrespective of whether they assessed previously with the CA. In contrast, nursing and physiotherapy were the most common services received by the CA only group and PS/HM visits were relatively rare. When comparing publicly funded services received by the CA+HC group, significantly more clients received PS/HM, physiotherapy, speech language pathology, dietetic, and social work services after the HC compared to after the CA.

Table 3-10 describes the frequency of co-occurring service types. Over four-fifths of the CA only group received one service type, doubling the proportion of any other group. HC-assessed clients were significantly more likely to receive three or more service types. Table 3-11 shows that PS/HM services were frequently delivered in conjunction with nursing and other service types. Approximately one-third of the HC only group received PS/HM as a single service.

Table 3-9 Receipt of Formal Publicly Funded Care among Home Care Clients, Billed Utilisation, by Assessment Group, Ontario FY 2016/17

% (n)	CA+HC		*CA only n=175,732	**HC only n=22,912	***CHA
	*At time of CA n=70,023	**At time of HC n=70,023			
Any personal support/homemaking visit	32.7 (22,878)	48.7 (34,088)	4.0 (6,943)	53.3 (12,202)	n/a
Any nursing visit	37.0 (25,889)	30.1 (21,051)	69.6 (122,386)	20.2 (4,638)	n/a
Any physiotherapy visit	23.5 (16,460)	31.3 (21,917)	18.4 (32,265)	26.8 (6,149)	n/a
Any occupational therapy visit	40.7 (28,528)	36.0 (25,183)	15.6 (27,479)	37.1 (8,510)	n/a
Any speech language pathology visit	2.0 (1,367)	2.8 (1,991)	1.2 (2,045)	n.s. 2.8 (648)	n/a
Any dietetic visit	1.9 (1,338)	3.7 (2,598)	0.9 (1,489)	2.7 (621)	n/a
Any social work visit	1.7 (1,175)	4.6 (3,200)	0.5 (810)	3.9 (884)	n/a
Any home service visit	79.6 (55,766)	78.7 (55,078)	94.3 (165,722)	n.s. 78.8 (18,048)	n/a

*Received up to 4 weeks after CA; **Received up to 12 weeks after HC; ***No billed services data available

- Chi-square test: All results were significant at $p < .0001$ unless otherwise noted.
- For significance testing, the CA within the CA+HC assessment group was used as the reference group against which the CA only group was compared. The HC within the CA+HC assessment group was used as the reference group against which the HC only was compared.

Table 3-10 Frequency of Formal Publicly Funded Service Types among Home Care Clients, Billed Utilisation, by Assessment Group, Ontario FY 2016/17

% (n)	CA+HC		*CA only n=175,732	**HC only n=22,912	***CHA
	*At time of CA n=70,023	**At time of HC n=70,023			
No services	20.4 (14,257)	21.3 (14,945)	5.7 (10,010)	21.2 (4,864)	n/a
1 service type	38.4 (26,913)	28.9 (20,241)	81.7 (143,536)	35.4 (8,107)	n/a
2 service types	25.2 (17,614)	26.2 (18,320)	9.4 (16,572)	24.0 (5,499)	n/a
3+ service types	16.1 (11,239)	23.6 (16,517)	3.2 (5,614)	19.4 (4,442)	n/a

*Received up to 4 weeks after CA; **Received up to 12 weeks after HC; ***No billed services data available

- Chi-square test: All results were significant at $p < .0001$ unless otherwise noted.
- For significance testing, the CA within the CA+HC assessment group was used as the reference group against which the CA only group was compared. The HC within the CA+HC assessment group was used as the reference group against which the HC only was compared.

Table 3-11 Frequency of Formal Publicly Funded PS/HM and other Service Types, Home Care Clients Receiving Any PS/HM Services, Billed Utilisation, by Assessment Group, Ontario FY 2016/17

% (n)	CA+HC		*CA only n=6,943	**HC only n=12,202	***CHA
	*At time of CA n=22,878	**At time of HC n=34,088			
Personal support only	18.6 (4,262)	23.3 (7,944)	15.3 (1,061)	33.2 (4,054)	n/a
Personal support + nursing only	7.1 (1,628)	7.4 (2,537)	12.1 (839)	5.4 (656)	n/a
Personal support + other only	51.9 (11,866)	43.7 (14,893)	37.8 (2,623)	42.1 (5,134)	n/a
Personal support + nursing + other	22.4 (5,122)	25.6 (8,714)	34.9 (2,420)	19.3 (2,358)	n/a

*Received up to 4 weeks after CA; **Received up to 12 weeks after HC; ***No billed services data available

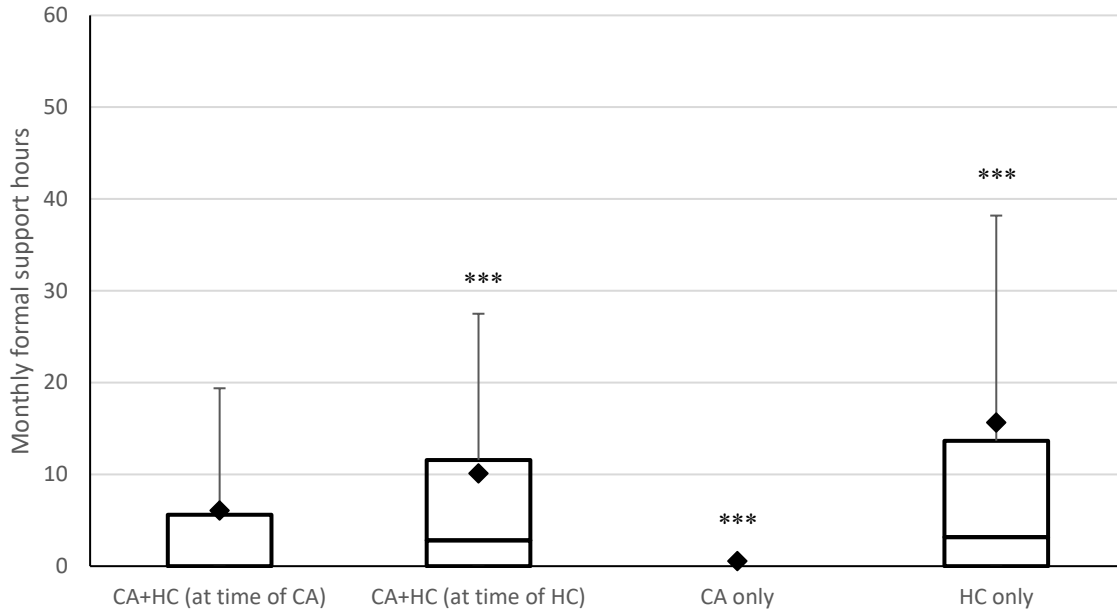
- Chi-square test: All results were significant at $p < .0001$ unless otherwise noted.
- For significance testing, the CA within the CA+HC assessment group was used as the reference group against which the CA only group was compared. The HC within the CA+HC assessment group was used as the reference group against which the HC only was compared.

Figure 3-6 depicts the distribution of formal publicly funded PS/HM hours in the previous week, extrapolated to a monthly utilisation. All distributions were characterised by high dispersion and right skewness. Among all clients, the median monthly hours were 0.0 in the CA-assessed groups and 2.8 and 3.2 in the HC-assessed groups. In the CA+HC group, the mean (95% CI) monthly hours were 6.1 (5.9–6.2) and 10.1 (9.9–10.3) at the time of CA and HC, respectively. The mean (95% CI) monthly hours were 0.5 (0.5–0.6) in the CA only group and 15.6 (15.1–16.2) in the HC only group. All group distributions were significantly different from each other according to Kruskal-Wallis tests (CA only vs. CA+HC (at time of CA): $\chi^2=41285.2$, $p<.0001$; HC only vs. CA+HC (at time of HC): $\chi^2=51.5$, $p<.0001$; CA+HC (at time of HC) vs. CA+HC (at time of CA): $\chi^2=5415.4$, $p<.0001$).

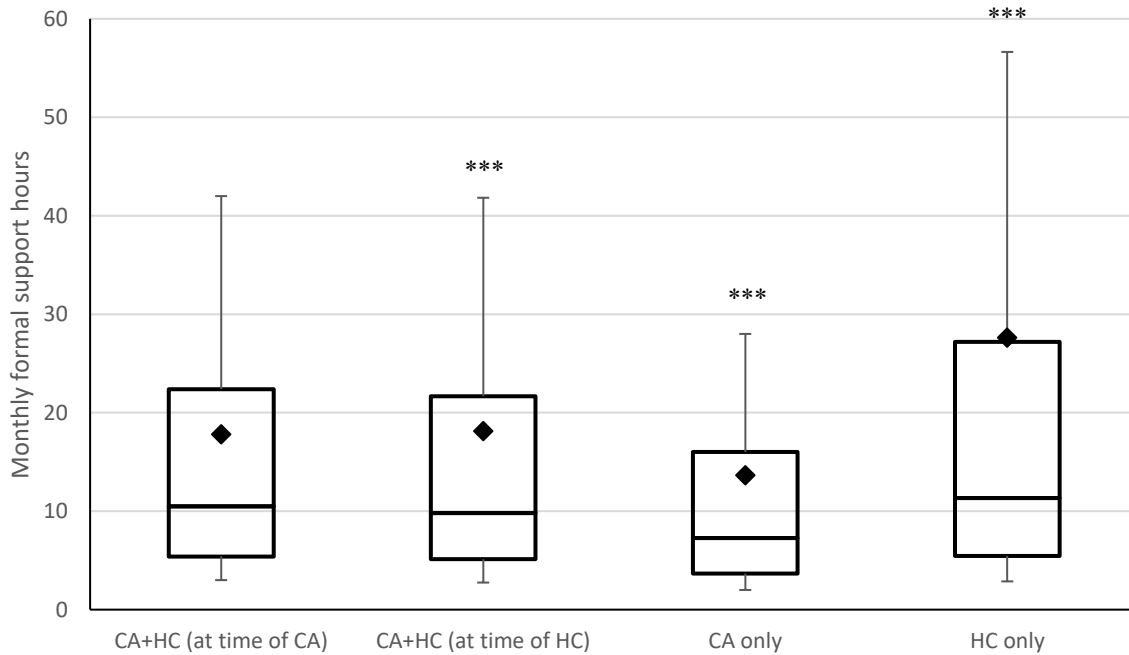
Among clients receiving any publicly funded PS/HM after the CA, the mean (95% CI) and median monthly hours were 17.8 (17.5–18.1) and 10.5 in the CA+HC group and 13.6 (13.1–14.2) and 7.3 in the CA only group. Among clients receiving any publicly funded PS/HM after the HC, the mean (95% CI) and median monthly hours were 18.1 (17.8–18.4) and 9.8 in the CA+HC group and 27.6 (26.7–28.6) and 11.3 in the HC only group. All group distributions were significantly different from each other according to Kruskal-Wallis tests (CA only vs. CA+HC (at time of CA): $\chi^2=600.8$, $p<.0001$; HC only vs. CA+HC (at time of HC): $\chi^2=136.5$, $p<.0001$); CA+HC (at time of HC) vs. CA+HC (at time of CA): $\chi^2=16.2$, $p<.0001$). Given that the distributions of publicly funded PS/HM hours were comparable within the CA+HC group, rejecting the null hypothesis of Kruskal-Wallis test can also be interpreted to signify significantly different median values at the time of CA and HC.

Figure 3-6 Distribution of Monthly Formal Publicly Funded PS/HM Hours among Home Care Clients, Billed Utilisation, by Assessment Group, Ontario FY 2016/17

a) Among all clients



b) Among clients receiving publicly funded PS/HM only



Kruskal-Wallis test: * $p < .05$, ** $p < .001$, *** $p < .0001$

- The box depicts the 25th (bottom), 50th (centre line), and 75th (top) percentiles. The whiskers depict the 10th (bottom) and 90th (top) percentiles. The diamond represents the mean.

3A.5 Discussion

Unique client profiles and service use patterns emerged among Ontario's public home and community care clients assessed with the CA, HC, and CHA. Whereas previous studies have mostly focused on the long-stay home care population, this study demonstrates the value of linking information from the interRAI CA and CHA to represent clients served in this sector more broadly.

Long-stay home care clients are mostly represented by clients receiving both a CA and HC. Consistent with previous studies of long-stay home care (examples include Doran et al. [181], Poss et al. [182], Vu et al. [183], and Mondor et al. [184]), clients in this group are generally older, require help in multiple areas of functioning, and receive support services with the primary goal of maintaining independence or minimising decline. In comparison, clients assessed with the CA only tend to be acute or rehabilitative clients, often do not have very complex or long-term needs, and are more likely to use a single nursing or therapy service. Clients initially assessed with the HC have the highest needs and service use. Some LHINs contribute disproportionately to the HC only group, so this group likely represents LHIN-specific programs to support clients who are designated alternate level of care in hospital or other special arrangements to support the needs of the most complex clients. Based on current assessment policies, CHA-assessed clients can be understood to be individuals whose needs are met by a community support service organisation. Like HC-assessed clients, CHA-assessed clients are older but also more likely to live alone. Although their needs are driven by IADL impairment, many CHA-assessed clients also report some ADL or cognitive impairment. While the assessment groups permit classification of the home and community care population around

similar need characteristics, none of the need characteristics are always present or absent in any of the assessment groups. For instance, although CHA-assessed clients can be generally described as a stable client population with moderate physical or cognitive impairments, a small percentage experience acute issues such as chest pain, pressure ulcers, or health instability.

There is wide variability in the receipt of formal and informal care. In general, CHA-assessed clients are less likely to receive any formal or informal care compared to HC-assessed clients. However, the distributions of care hours are more similar when restricting the analyses to clients receiving any services, indicating substantial overlap between populations served by home care and community support service agencies. Informal caregivers of both HC- and CHA-assessed clients spend on average 56 hours/month (i.e., 14 hours/week) providing support. The 90th percentile of monthly informal support hours is noticeably higher among caregivers of clients assessed with the CHA (336 hours/week vs. 168 hours/week). Thus, while the general CHA-assessed population has lighter care needs and are less likely to require support, there is a subset of caregivers providing much more informal care than most caregivers of home care clients. This finding is notable because LHINs provide publicly funded respite services, and in FY 2017/18, the Ontario government invested an additional \$20 million to increase access to respite services for caregivers of home care clients [185]. In contrast, caregiver respite services accessed through community support services agencies are usually subject to some level of co-payment.

The question of equity arises if the method of accessing public caregiver resources (i.e., through the LHIN or a community support service agency) creates advantages or disadvantages. Under the lead agency model recommended in the *Bringing Care Home* report [33], a coordinated intake process would mean that clients and families can expect the same access to services,

whether they initially make contact through the LHIN or a community support service agency. As well, it is important to recognise that the client and family dyad is the recipient of home and community care. Assessment of both client and caregiver needs is needed, so that the appropriate lead agency is identified that can serve the needs of both the client and caregiver.

Clearly defining the eligibility criteria and available services for caregivers will be an important part of increasing consistency and transparency in the home and community care sector.

Conceptually speaking, there are two ways to allocate caregiver respite services. Under the current system, publicly funded respite is predicated on client need (i.e., the client's needs are high enough that they receive LHIN services) and allocated based on caregiver need. Another approach would define eligibility and allocation based on caregiver need regardless of client need. This approach would be in line with a shared care model in which the client could receive PS/HM or other services from the community support service agency while the caregiver receives respite services from the LHIN. In the absence of economic analyses, there is an immediate need to increase public awareness of available caregiver services. Future research should consider the public and private cost implications of either approach to inform policy directions.

To date, only one study has examined Ontario's general home care population (rather than the long-stay home care population). Dwyer et al. [173] classified home care assessments from 2006 to 2008 and found that 84.9% of clients received the CA only and 15.1% received both the CA and HC. In this study, 65.4% of home care clients received the CA only and 26.1% received both the CA and HC (the percentages do not add up to 100% because some newly admitted clients did not receive the CA within two weeks of admission). Since the CA was not mandated across

Ontario until 2010, the present chapter may be more representative of the general CA-assessed population. Nevertheless, the main conclusion in both studies is that clients assessed with the CA only are quite different from clients later assessed with the HC. As well, health system trends likely increased the differences between these client populations over the last decade. With hospitals facing increasing pressures to discharge patients earlier, clients receiving the CA only mostly represent an acute population. In contrast, aging-at-home policies, low supply of long-term care beds, and a shift of lower need clients to community support service agencies mean that HC-assessed clients represent an increasingly complex population with chronic needs.

Overall, this study demonstrates the importance of matching the appropriate data sources to represent the population of interest, and in a sector as varied as the home and community care sector, acknowledging any local practices that may include or exclude certain clients. During the dataset construction process, it was important to visualise the flow of clients through key assessment and discharge milestones. In this study, 65.4% of the home care population was assessed with the CA only. In other words, it is important to note that much of public reporting and existing research that draw on HC data represents just one-third of the total home care population. As well, the process challenged the assumption that all clients are assessed with the CA at the point of home care intake. While 85.0% of clients are assessed with the CA after admission, 5.6% are initially assessed with the HC and most of the remaining 9.4% of clients are discharged without receiving either assessment. Some clients may have been transferred to a specialised caseload and assessed with the interRAI Palliative Care or the interRAI Community Mental Health assessments instead. Other clients may have been assessed in hospital using a non-standardised instrument other than the interRAI suite that was not readily available for

research use. The implication is that while the CA accounts for the vast majority of intake home care assessments, it may be necessary to include the HC and other assessments to have full coverage of the intended study population.

Additionally, the finding that two LHINs account for one-third of initial HC assessments highlights the importance of considering LHIN-specific assessment policies. For example, since 2014, the Hamilton Niagara Haldimand Brant LHIN has invested in its Transitional Care Program that offers more intensive home care in retirement homes and assisted living facilities to reduce hospital alternate level of care rates [186]. Clients in the Transitional Care Program who are assessed with the HC do not represent the average long-stay home care client across the province. Although CA and HC assessments are implemented province-wide, use of provincial home care data either to study the home care sector in general or otherwise draw comparisons across LHINs must consider local assessment practices.

3A.5.1 Strengths

The use of census-level assessment and administrative data means that these results are generalisable across Ontario's publicly funded home care population that is novel especially with the CA-assessed population. Where most studies have focused on the HC-assessed population, this study used both CA and HC data that increases coverage of the publicly funded home care population by approximately 200% (by our estimate). Since these assessments are standardised and multiple processes are in place to ensure data quality, the assessment data were mostly complete, except for a small number of items that by design are not asked across all assessments.

3A.5.2 Limitations

Unlike the home care assessments, the CHAs used in this study are likely not representative of all CHAs completed in Ontario. Community support service clients receiving non-clinical supports and those clients receiving concurrent home care services are not regularly assessed with the CHA. The community support service client population is quite heterogeneous, reflecting the diversity of community support service programs ranging from meal preparation or delivery to PS/HM services. Although the CHA-assessed sample may not represent all clients in this sector, the findings support the overall conclusion that community support service clients have a range of health needs, sometimes at a similar level to home care clients. In this study, it was not possible to link the CHAs to the home care assessments. Future work should seek to identify the subset of home care clients also receiving community support services.

SUB-CHAPTER 3B

3B.1 Objectives

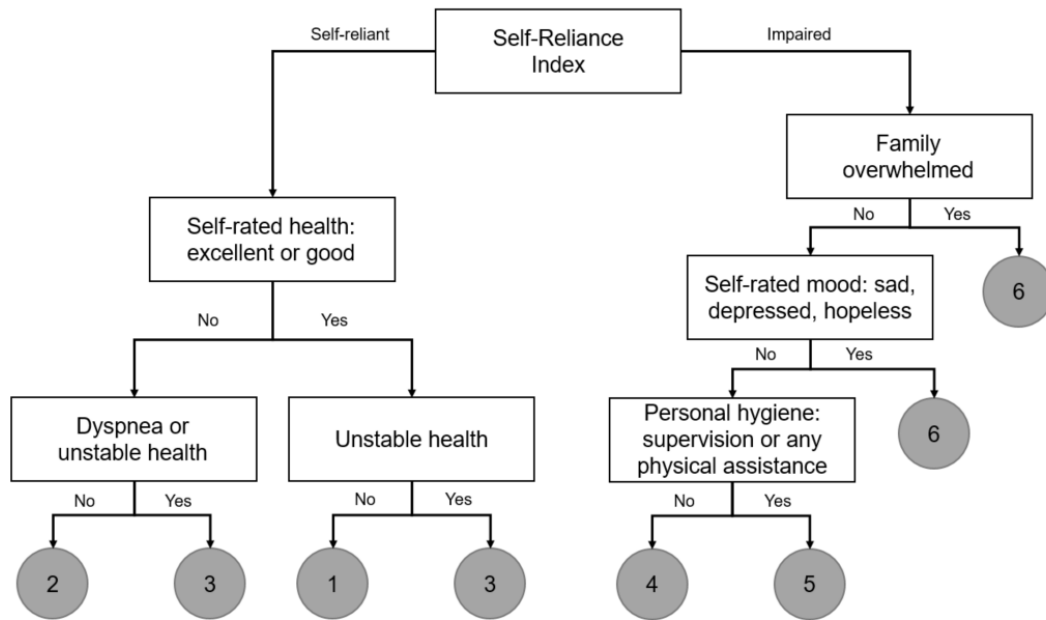
The objective of this sub-chapter is to examine the relationship between the CA and HC assessments in Ontario. This sub-chapter presents analyses related to the relationship between the Assessment Urgency Algorithm and receipt of HC assessment, the relationship between the Assessment Urgency Algorithm and Method for Assigning Priority Levels algorithm, and the associations between selected need characteristics recorded in these two assessments.

3B.2 Scales of Interest

3B.2.1 Assessment Urgency Algorithm

The Assessment Urgency Algorithm (AUA) is a risk screening tool calculated from the CA (Figure 3-7). The AUA ranges from 1 to 6, where higher scores indicate greater need and priority for a comprehensive follow-up assessment [161]. The Self-Reliance Index (SRI) is the backbone of the AUA and is based on five items representing cognitive and physical functioning (cognitive skills for daily decision-making, bathing self-performance, personal hygiene self-performance, dressing lower body self-performance, locomotion self-performance). A client who is impaired in any of the five items is considered to be “impaired” in self-reliance and will receive an AUA score of 4–6 depending on other indicators of personal and family coping. In contrast, a client who is “self-reliant” (i.e., independent in cognitive and physical functioning) will receive an AUA score of 1–3 depending on items relating to dyspnea, unstable health patterns, and self-rated health.

Figure 3-7 Schematic of the Assessment Urgency Algorithm



Adapted from interRAI CA assessment instrument [161]

3B.2.2 Method for Assigning Priority Levels

The Method for Assigning Priority Levels (MAPLe) algorithm is calculated from the HC. The MAPLe algorithm is intended to inform home care resource allocation and prioritisation decisions by care coordinators [187]. There are five MAPLe levels, ranging from low (1) to very high (5). Each increase in MAPLe level is associated with substantial increases in risk of long-term care placement, caregiver distress, and client or caregiver ratings of being better off elsewhere [181, 187, 188]. Clients in the highest MAPLe level have at least one of the following: cognitive impairment, ADL impairment, wandering, other behavioural symptoms, recent fall(s), or a cluster of characteristics that are known to be associated with institutionalisation.

3B.3 Analysis Plan

Time to HC assessment was modelled using cumulative incidence competing risk and Kaplan-Meier methods, the former in the presence of discharge due to death, long-term care placement, or hospitalisation as competing risks. Differences between strata were tested using generalised Wilcoxon tests with the Sidak adjustment for multiple comparisons. Agreement between assessment scales and items was summarised in frequency tables and compared using percent agreement and Cohen's kappa statistic. All analyses were done using SAS 9.4.

3B.4 Results

In Ontario FY 2016/17, a total of 245,755 CAs were completed for unique clients who were newly admitted to the publicly funded home care program under SRCs 91, 92, 93, and 94.

3B.4.1 Relationship between AUA and Time to HC Assessment

Figure 3-8 shows the distribution of CA-assessed clients based on the AUA. One-third (34.9%) of clients were in the lowest AUA level. Nearly one-quarter of clients (23.7%) were in the two highest AUA levels that represent the highest need and priority for a comprehensive follow-up assessment. Values for the AUA was missing for 0.9% (2,161) of clients.

Figure 3-8 Distribution of AUA among Newly Admitted CA-Assessed LHIN Home Care Clients, Ontario FY 2016/17

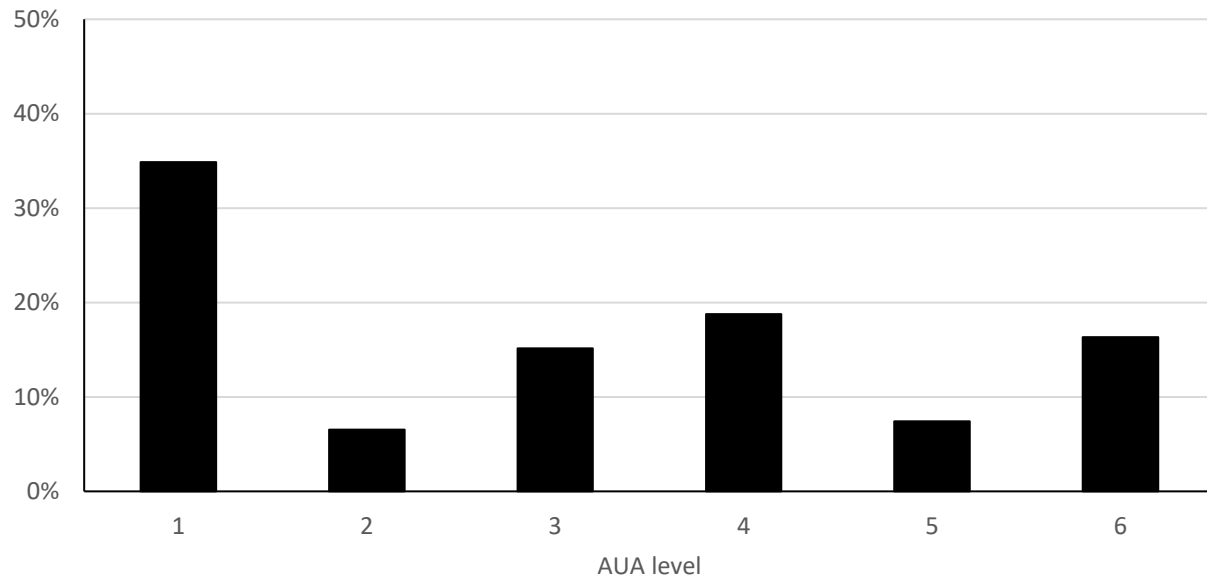


Table 3-12 shows the percentage of CA-assessed clients receiving an HC assessment within 182 days of the CA assessment. The table also illustrates the percentage of clients who died, were admitted to LTC, or were hospitalised for whom assessment may not have been possible. In each AUA level, a greater proportion of clients were subsequently assessed with the HC, ranging from 4.9% of clients in level 1 to 66.5% of clients in level 6 ($\chi^2=61612.7$, $p<.0001$). Clients meeting the criteria for competing events also increased at each AUA level, ranging from 1.5% of clients in level 1 to 6.9% of clients in level 6 ($\chi^2=2947.7$, $p<.0001$).

Table 3-12 Receipt of HC Assessment within 182 Days of CA among Newly Admitted CA-Assessed LHIN Home Care Clients, by AUA, Ontario FY 2016/17

Row % (n)		Event of interest: assessed with HC within 182 days	Competing risk: died, admitted to LTC, or hospitalised within 182 days	Censored: not assessed with HC within 182 days
AUA				
1	Lowest	4.9 (4,194)	1.5 (1,261)	93.6 (80,245)
2		13.5 (2,165)	3.6 (577)	83.0 (13,343)
3		24.5 (9,136)	6.1 (2,279)	69.4 (25,838)
4		37.7 (17,404)	4.1 (1,898)	58.2 (26,859)
5		53.8 (9,806)	6.3 (1,151)	39.9 (7,286)
6	Highest	66.5 (26,705)	6.9 (2,774)	26.6 (10,673)

Figure 3-9 illustrates the time-to-event curve for receipt of HC assessment up to 182 days. At any given time, clients in higher AUA levels were more likely to receive an HC assessment. Although the proportional hazards assumption was not met, the time-to-event curves did not cross, so the generalised Wilcoxon test was appropriate.

Figure 3-9 Time-to-Event Curve for Receipt of HC Assessment among Newly Admitted CA-Assessed LHIN Home Care Clients, by AUA, Ontario FY 2016/17

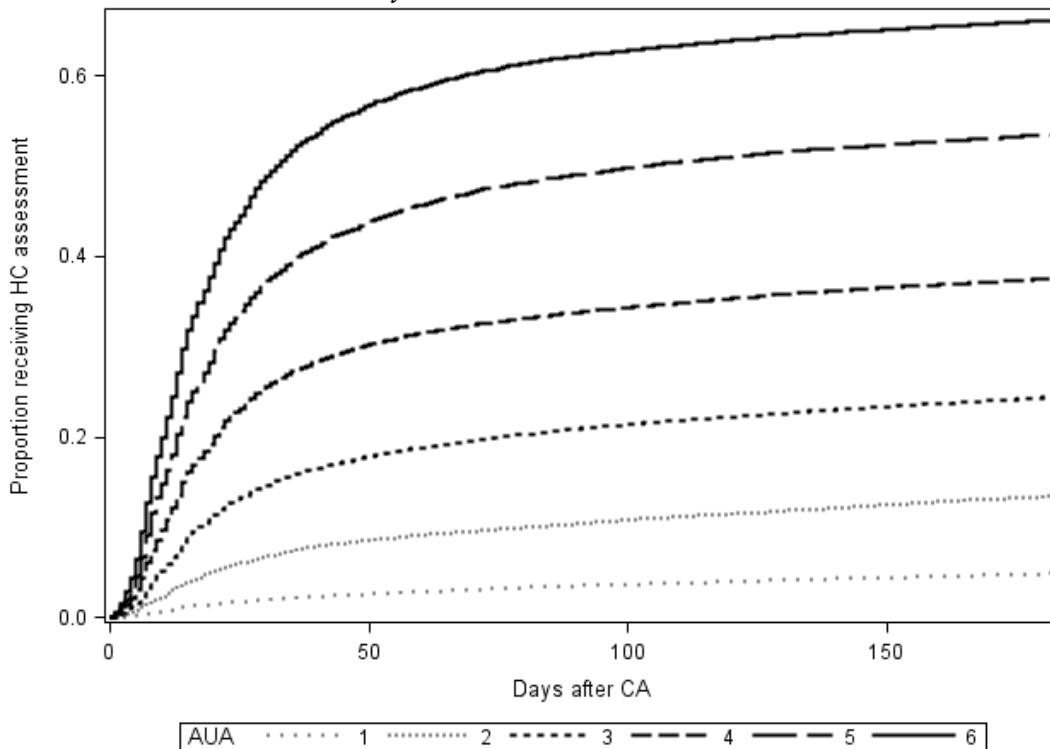


Table 3-13 shows the chi-square statistics for the pairwise comparisons between adjacent AUA levels. All pairwise comparisons except between AUA 2 and 3 were significant ($p < .0001$).

Table 3-13 Chi-Square Statistics for Differences between Time-to-Event Curves for Receipt of HC Assessment among Newly Admitted CA-Assessed LHIN Home Care Clients in CA+HC Group, Pairwise Comparisons of Adjacent AUA Levels, Ontario FY 2016/17

AUA pair	Chi-square statistic
1 vs. 2	11809.4 ***
2 vs. 3	0.07 $p=0.80$
3 vs. 4	1824.9 ***
4 vs. 5	45.9 ***
5 vs. 6	10250.3 ***

Wilcoxon test: * $p < .05$, ** $p < .001$, *** $p < .0001$

In Table 3-14, the observation was shortened to 14 days to investigate priority for receiving an HC assessment. Higher AUA levels were associated with fewer days between the CA and HC ($\chi^2=26993.0$, $p < .0001$). At 14 days post-CA assessment, nearly one-third (30.1%) of clients in AUA 6 received an HC assessment compared to just 1.1% of clients in AUA 1.

Table 3-14 Receipt of HC Assessment within 14 Days of CA among Newly Admitted CA-Assessed LHIN Home Care Clients, by AUA, Ontario FY 2016/17

Row % (n)	Event of interest: assessed with HC within 14 days	Competing risk: died, admitted to LTC, or hospitalised within 14 days	Censored: not assessed with HC within 14 days
AUA			
1 Lowest	1.1 (949)	0.1 (79)	98.8 (84,672)
2	3.7 (601)	0.2 (25)	96.1 (15,459)
3	8.3 (3,102)	0.5 (188)	91.2 (33,963)
4	15.0 (6,943)	0.5 (228)	84.5 (38,990)
5	22.4 (4,084)	1.3 (242)	76.3 (13,917)
6 Highest	30.1 (12,096)	1.3 (540)	68.5 (27,516)

In Figure 3-10, the same time to HC assessment analysis was repeated for the CA+HC group, in other words, for clients who were subsequently assessed with an HC assessment. Within this group, there was still clear differentiation in time to HC assessment by each AUA level. Among clients receiving an HC assessment, those in higher AUA levels were more likely to be assessed sooner. Again, the proportional hazards assumption was not met although the time-to-event curves did not cross.

Figure 3-10 Time-to-Event Curve for Receipt of HC Assessment among Newly Admitted CA-Assessed LHIN Home Care Clients in CA+HC Group, by AUA, Ontario FY 2016/17

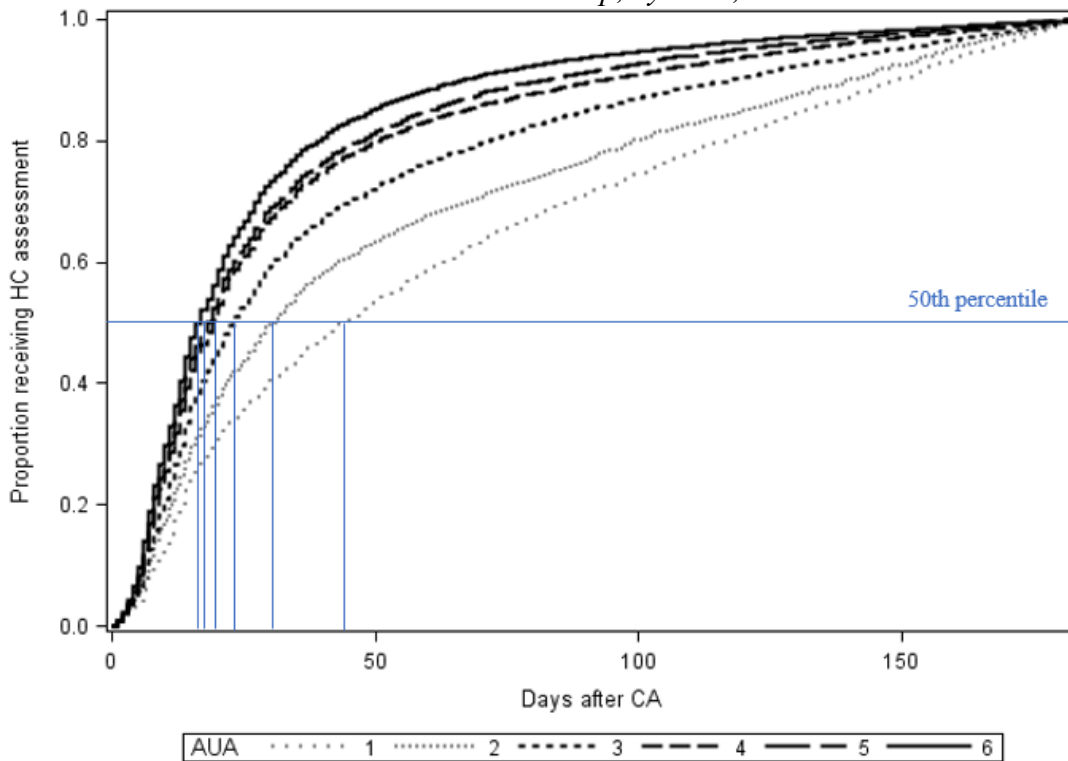


Table 3-15 shows the chi-square statistics for the pairwise comparisons between adjacent AUA levels. All pairwise comparisons except between AUA 4 and 5 were significant according to the generalised Wilcoxon tests ($p < .0001$).

Table 3-15 Chi-Square Statistics for Differences between Time-to-Event Curves for Receipt of HC Assessment among Newly Admitted CA-Assessed LHIN Home Care Clients in CA+HC Group, Pairwise Comparisons of Adjacent AUA Levels, Ontario FY 2016/17

AUA pair	Chi-square statistic	
1 vs. 2	340.8	***
2 vs. 3	55.8	***
3 vs. 4	108.8	***
4 vs. 5	7.5	p=0.09
5 vs. 6	422.2	***

Wilcoxon test: * $p < .05$, ** $p < .001$, *** $p < .0001$

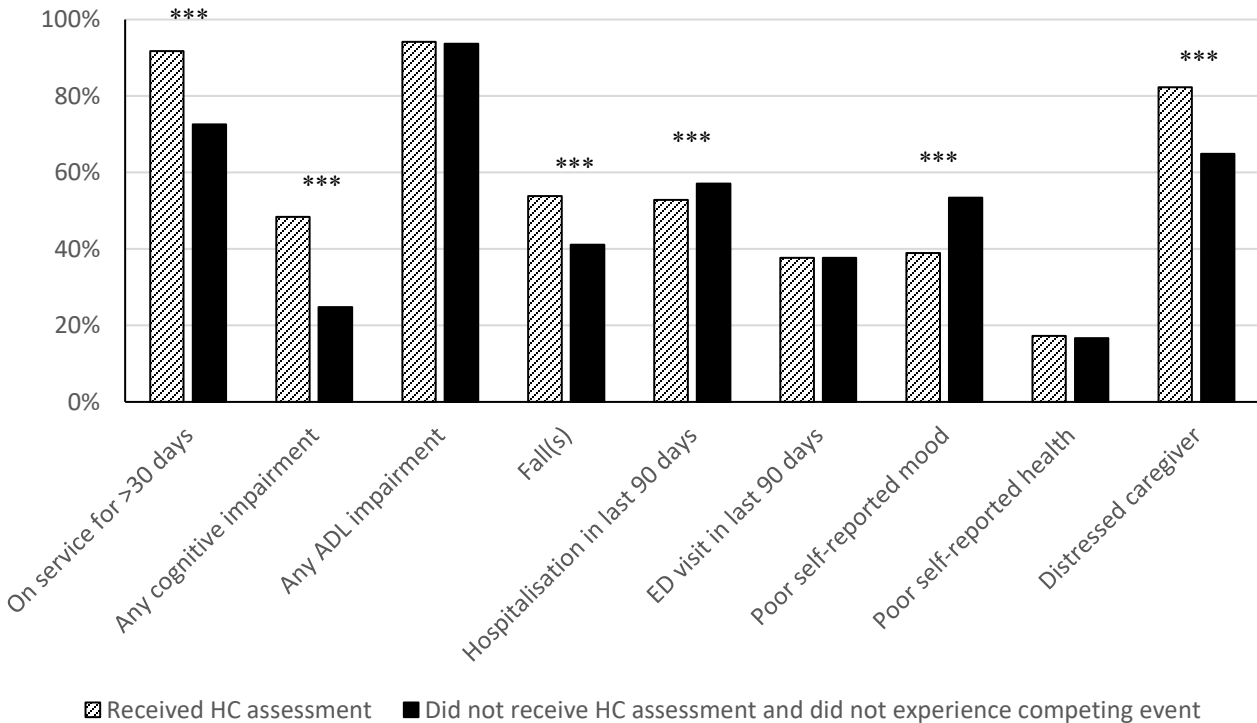
Table 3-16 compares the average number of days between the CA and HC. Each increase in AUA level was associated with a shorter time to HC assessment. The median time to HC assessment was 43 days in AUA 1 and 16 days in AUA 6. Nine in 10 clients in AUA 6 who received an HC assessment were assessed within 65 days.

Table 3-16 Average Number of Days to Receipt of HC Assessment among Newly Admitted CA-Assessed LHIN Home Care Clients in CA+HC Group, by AUA, Ontario FY 2016/17

AUA		Number of days between CA and HC	
		Median	90th percentile
1	Lowest	43	148
2		30	139
3		22	115
4		19	91
5		18	80
6	Highest	16	65

Figure 3-11 compares selected need characteristics of clients in AUA 6 who were assessed with the HC and not assessed with the HC (and had not died, been admitted to LTC, or hospitalised) within 182 days. There were no significant between-group differences in the rates of any ADL impairment or recent ED visit. Significantly more clients who were assessed with the HC were on service for longer than month and had any cognitive impairment, recent fall, or distressed caregiver although the proportions were not negligible among clients not assessed with the HC. For instance, 24.8% had any cognitive impairment and 64.9% had a distressed caregiver. The proportion of clients who indicated they had felt sad, depressed, or hopeless was higher among clients who were not subsequently assessed (53.4% vs. 38.9%).

Figure 3-11 Selected Need Characteristics among Newly Admitted CA-Assessed LHIN Home Care Clients in AUA 6, Ontario FY 2016/17



Chi-square test: *p<.05, **p<.001, ***p<.0001

3B.4.2 Relationship between AUA and MAPLe

In Table 3-17, a client’s AUA level assessed at intake was associated with their MAPLe level assessed at follow-up. Clients in AUA 1 and 2 were significantly more likely to be assessed into low or mild MAPLe levels ($\chi^2=5993.5$, $p<.0001$). Clients in AUA 5 and 6 were significantly more likely to be assessed into high or very high MAPLe levels ($\chi^2=1470.7$, $p<.0001$). There was a significant trend in which clients in the middle AUA levels were more likely to be assessed into the moderate MAPLe level ($\chi^2=811.5$, $p<.0001$).

Table 3-17 Distribution of MAPLe at Follow-up among Newly Admitted CA-Assessed LHIN Home Care Clients in CA+HC Group, by AUA at Intake, Ontario FY 2016/17

Row % (n)	AUA at time of CA	MAPLe at time of HC(s)		
		Low or mild (MAPLe 1 or 2)	Moderate (MAPLe 3)	High or very high (MAPLe 4 or 5)
1	Lowest	41.8 (1,056)	25.0 (631)	33.2 (837)
2		38.8 (800)	26.0 (535)	35.3 (727)
3		37.8 (3,374)	24.3 (2,170)	38.0 (3,391)
4		18.6 (3,232)	37.2 (6,474)	44.2 (7,698)
5		8.2 (804)	40.8 (4,002)	51.0 (5,000)
6	Highest	9.5 (2,547)	34.9 (9,307)	55.6 (14,851)

Table 3-18 shows the unadjusted odds of being assessed into high or very high MAPLe levels at follow-up. Compared to AUA 1 or 2, being in AUA 5 and 6 doubled the odds of being assessed into the highest MAPLe levels. Clients in AUA 3 and 4 were also at significantly greater odds of being assessed into the highest MAPLe levels. Using the un-collapsed AUA levels, the overall area under the curve predicting high or very high MAPLe was 0.58.

Table 3-18 Unadjusted Odds of Being in High or Very High MAPLe Level at Follow-up among Newly Admitted CA-Assessed LHIN Home Care Clients in CA+HC Group, by AUA at Intake, Ontario FY 2016/17

AUA at time of CA	Odds ratio (95% CI) of high or very high MAPLe level
1 Lowest	Reference
2	n.s. 1.10 (0.97–1.24)
3	1.23 (1.12–1.35)
4	1.60 (1.46–1.75)
5	2.10 (1.91–2.30)
6 Highest	2.53 (2.32–2.75)

3B.4.3 Selected Need Characteristics Assessed at Time of CA and Time of HC

Table 3-19 presents the agreement between selected need characteristics assessed at the time of CA and time of HC within the CA+HC group. Items representing cognitive status, ADL status, and caregiver distress were chosen since they are known to strongly influence decisions related to home care service eligibility and allocation. In general, there was fair to moderate agreement between assessments. Greater agreement was observed among the ADL items compared to the other measures.

The highest agreement was observed for bathing self-performance. Percent agreement was 76.6% and the kappa statistic (0.44) was consistent with moderate agreement. Among clients assessed as impaired in bathing self-performance at the time of CA, 85.6% were also assessed as impaired at the time of HC. Among clients assessed as independent in bathing self-performance at the time of CA, 56.7% were also independent at the time of HC. Yet the remaining 43.3% of clients were found to require supervision or greater assistance at the time of HC. Assuming the more comprehensive HC reflected the client’s true status, there may have been under-detection of need for assistance with bathing at the time of CA. Similar results were observed for dressing

lower body self-performance. While the values for percent agreement were comparable for personal hygiene and locomotion, the kappa statistics were lower, mostly attributable to fewer clients continuing to be assessed as impaired in these activities on the HC.

Percent agreement in the cognition item was 64.8% and the kappa statistic (0.34) was consistent with fair agreement. Among clients assessed as impaired in cognition at the time of CA, 86.7% were also assessed as impaired at the time of HC. However, among clients assessed as independent in cognition at the time of CA, nearly half (45.5%) were assessed as impaired at the time of HC. Thus, most of the disagreement could be attributed to under-detecting impairment at the time of CA.

The lowest agreement was observed for caregiver distress. The kappa statistic (0.23) represented the lower bound of fair agreement. At least half (51.5%) of caregivers who expressed feeling distressed/overwhelmed or depressed at the time of CA did not report these symptoms at the time of HC. Conversely, 26.2% of caregivers who did not express feelings of distress, anger, or depression at the time of CA reported these symptoms at the time of HC.

Table 3-19 Agreement Between Selected Need Characteristics Assessed at Time of CA and Time of HC among Newly Admitted CA-Assessed LHIN Home Care Clients in CA+HC Group, Ontario FY 2016/17

Need characteristic	Row % Status at CA	Status at HC		Percent agreement, % (n)	Simple kappa (95% CI)
		Independent/No	Impaired/Yes		
Cognitive skills for daily decision-making	Independent	54.5%	45.5%	64.8% (45,403)	0.34 (0.33–0.34)
	Impaired	13.3%	86.7%		
Personal hygiene self-performance	Independent	75.1%	24.9%	70.0% (48,982)	0.33 (0.32–0.34)
	Impaired	41.1%	58.9%		
Locomotion self-performance	Independent	82.3%	17.7%	71.2% (49,840)	0.31 (0.30–0.32)
	Impaired	52.4%	47.6%		
Dressing lower body self-performance	Independent	69.5%	30.5%	70.6% (49,408)	0.41 (0.40–0.42)
	Impaired	28.3%	71.7%		
Bathing self-performance	Independent	56.7%	43.3%	76.6% (53,624)	0.44 (0.43–0.45)
	Impaired	14.4%	85.6%		
Caregiver distress	No	73.8%	26.2%	61.4% (43,002)	0.23 (0.22–0.24)
	Yes	51.5%	48.5%		

Table 3-20 presents the kappa statistics stratified by the time of HC assessment. The kappa statistics were consistently negatively associated with the number of days between the CA and HC assessments. The confidence intervals for assessments done at least 31 days apart did not overlap with those completed within 14 days, indicating significantly greater agreement between need characteristics when the two assessments were done in close proximity.

Table 3-20 Agreement Between Selected Need Characteristics Assessed at Time of CA and Time of HC among Newly Admitted CA-Assessed LHIN Home Care Clients in CA+HC Group, Stratified by Time to HC Assessment, Ontario FY 2016/17

Need characteristic	Number of days between CA and HC		
	0 to 14 days n=28,019	15 to 30 days n=19,157	31+ days n=22,847
Cognitive skills for daily decision-making	0.36 (0.35–0.37)	0.35 (0.34–0.36)	0.30 (0.29–0.31)
Personal hygiene self-performance	0.34 (0.33–0.35)	0.34 (0.33–0.36)	0.30 (0.28–0.31)
Locomotion self-performance	0.35 (0.34–0.36)	0.30 (0.29–0.32)	0.25 (0.24–0.28)
Dressing lower body self-performance	0.44 (0.43–0.45)	0.43 (0.42–0.44)	0.35 (0.34–0.36)
Bathing self-performance	0.49 (0.47–0.50)	0.45 (0.44–0.47)	0.37 (0.36–0.38)
Caregiver distress	0.25 (0.24–0.26)	0.24 (0.23–0.25)	0.17 (0.16–0.19)

Table 3-21 presents the kappa statistics stratified by the type of communication at intake. In general, the level of agreement did not significantly differ by the mode of communication, except for slight but significant differences in caregiver distress and locomotion self-performance.

Kappa statistics were higher for caregiver distress and lower for locomotion self-performance when the CA assessment was completed over the phone only.

Table 3-21 Agreement Between Selected Need Characteristics Assessed at Time of CA and Time of HC among Newly Admitted CA-Assessed LHIN Home Care Clients in CA+HC Group, Stratified by Type of Communication at Intake, Ontario FY 2016/17

Simple kappa (95% CI) Need characteristic	Type of communication of intake	
	Phone only n=41,365	Other methods n=28,658
Cognitive skills for daily decision-making	0.35 (0.34–0.35)	0.33 (0.32–0.34)
Personal hygiene self-performance	0.32 (0.31–0.33)	0.34 (0.32–0.35)
Locomotion self-performance	0.28 (0.27–0.29)	0.32 (0.31–0.33)
Dressing lower body self-performance	0.40 (0.39–0.40)	0.42 (0.40–0.43)
Bathing self-performance	0.43 (0.42–0.44)	0.43 (0.42–0.45)
Caregiver distress	0.25 (0.24–0.26)	0.20 (0.19–0.21)

3B.5 Discussion

The CA plays an important screening and triaging role within the process of home care assessment in Ontario. Higher AUA levels are strongly associated with greater likelihood of receiving an HC assessment and shorter time to HC assessment. The AUA calculated from the CA is moderately positively correlated with the MAPLe algorithm from the HC. In Ontario, LHINs use the MAPLe algorithm to guide client-level decisions related to priority for service delivery in the community and eligibility and priority for long-term care placement. Correlation between the AUA and MAPLe suggests that the AUA is a useful indicator for identifying clients at the greatest risk of long-term care placement, caregiver distress, or being rated as better off living elsewhere [187]. Thus, a similar approach is used at the point of intake and throughout the

home care episode to identify clients who are likely to benefit from long-stay home care services. Overall, these findings provide strong evidence that the CA and HC function together as an efficient assessment system that forms the backbone of the public home care sector.

Since the AUA was designed to be an indicator of need and priority for a comprehensive follow-up assessment, the finding that higher AUA levels are associated with greater likelihood of being subsequently assessed with the HC is expected. However, not all clients with high AUA levels are subsequently assessed. In this study, only 66.5% of clients in AUA 6 received an HC assessment within 182 days. Some of these clients may have been discharged for urgent or acute reasons, but only 6.9% died or were admitted to long-term care or hospital before an assessment could take place. Put another way, about a quarter of clients in AUA 6 did not receive a follow-up HC assessment within six months, even though they theoretically could have. Their CAs suggest various clinical areas that would benefit from more comprehensive assessment and possible involvement of other health professionals, including cognitive or ADL impairment, recent falls, recent acute service use, poor self-reported health or mood, and caregiver distress. In addition, only 22.4% and 30.1% of clients in AUA 5 and 6 were assessed with the HC within 14 days. Given that the highest AUA levels identify clients with some degree of functional need and possible issues with personal or family coping, it seems sensible that these clients should receive a comprehensive assessment to identify their needs more fully and to ensure the appropriate services are in place to meet their needs.

Although clinical status recorded at intake is often related to clinical status at follow-up, the kappa statistics between clinical characteristics do not exceed Landis & Koch's [189] benchmarks for moderate agreement. Many factors explain why there would be an upper limit to

the strength of agreement. First, the CA and HC assessments are completed at different time points. Disagreement between clinical items may reflect actual changes in the client's and caregiver's health. The health status of home care clients may change rapidly, especially for those recently in hospital. For instance, a client may have had limited range of motion and required help with dressing themselves while in hospital but made large functional gains shortly after discharge. Sensitivity analyses showed that the information recorded in the CA and HC is more consistent when the HC is done sooner after the CA. Second, the CA has a much shorter lookback period than the HC, and thus may not capture fluctuations in health status. Another client may have developed delirium during their hospital stay but was assessed during a period of no symptoms and these changes were not detected until the client returned home. Third, the CA covers most clinical domains but often with a single question and response sets are simplified to allow for completion by a non-health professional or self-report (if the assessment is done over the phone). Although this format reduces assessment time at intake, the CA does not take the place of a care coordinator visiting clients in their homes to fully assess their needs and preferences. Lower levels of agreement are observed for the items representing cognitive status and caregiver distress, likely because the nature of these needs are difficult to accurately determine over the phone or when time is limited. Comprehensive assessment will be more sensitive to these types of clinical needs than the brief screener.

In short, the CA helps to identify clients who would most benefit from subsequent assessment, but is not in itself a substitute for the HC. The CA is designed such that some precision is sacrificed in exchange for reducing assessment burden and thus can be used to reasonably screen all prospective home care clients. Without the CA, completing an HC assessment on all eligible

clients would be an inefficient use of resources and would likely delay timely comprehensive assessment for clients in greatest need. At intake, only the most essential information at the time of intake is recorded to support decisions about short-term planning. Regardless, the most appropriate service plan put in place after the CA may not continue to be relevant after a few weeks, and again, reinforces the importance of using the AUA to guide reassessment practices. Importantly, the AUA is intended as decision support and not a decision-making tool. Even though clients with high AUA were more likely to be assessed in high MAPLe, still one-third of clients in AUA 1 were in MAPLe 4 or 5. As a brief screener, the CA is not perfect and thus care coordinators should always apply their clinical judgment when interpreting the assessment results. While it is possible that there might be some inefficiencies in the assessment process, there will always be situations in which it is clinically justifiable to conduct a comprehensive assessment on a client with a low AUA level.

This study suggests that more widespread adoption of the AUA in home care policy and performance measurement may increase the efficiency of the public home care sector. In Ontario, assessment frequency guidelines could be based on the AUA. Clients in the higher AUA levels could be prioritised to receive comprehensive assessment within two weeks, for example, and this could be tracked by Health Quality Ontario as part of their quality indicators. Currently, Health Quality Ontario publicly reports on wait times as indicators of access to home care services [190]. The two indicators are the median number of days that new home care clients wait to receive PS/HM and nursing services, respectively. Although these measures are useful indicators of access among clients for whom services were ordered, exemplary performance on these indicators can still mask problems of access to the sector more broadly. For instance, a

client in a moderate or high AUA level who did not receive any home-based services would not appear in the denominator. Adoption of the proposed indicator would indicate if clients identified with potential needs received the appropriate comprehensive follow-up assessment and care.

3B.5.1 Strengths

The use of census-level assessment and administrative data means that these results are generalisable across Ontario's public home care population. Linking the assessment databases is a gold standard way of identifying clients receiving an HC assessment since the databases contain all completed assessments and assessment dates. Competing events were identified from the discharge destination that might have explained the non-observation of the event of interest. As well, the fact that clinical items are conceptualised in the same way across the interRAI suite made it possible to compare the agreement between assessments directly.

3B.5.2 Limitations

Although some competing events were accounted for in the analysis, this study did not identify clients who may have received other comprehensive assessments at follow-up, including the interRAI Palliative Care and interRAI Community Mental Health instruments. As well, the billed services dataset could have provided additional insight into the care trajectories of clients who did not receive comprehensive follow-up assessment. Future work, in collaboration with HSSOntario and the LHINs, is needed to corroborate these findings and discuss practice and policy implications.

SUB-CHAPTER 3C

3C.1 Objectives

The objective of this sub-chapter is to identify predisposing, enabling, and need characteristics that predict receipt of greater or lesser amounts of formal publicly funded PS/HM services between the CA and HC assessments in Ontario.

3C.2 Variables of Interest

This study employed the same predisposing, enabling, and need variables and formal publicly funded PS/HM service variables as described in Section 3A.2. The service variables represent the monthly average publicly funded PS/HM hours received up to 28 days after the CA and up to 84 days after the HC. When calculating the monthly utilisation, the observation period was adjusted if the first home visit was delayed, or if the client received a subsequent assessment or was discharged earlier than 28 and 84 days, respectively. The difference in hours was calculated by subtracting the monthly publicly funded PS/HM hours received after the HC from the monthly publicly funded PS/HM hours received after the CA for each client.

3C.3 Analysis Plan

Agreement between publicly funded PS/HM services received after the CA and HC was summarised in frequency tables and compared using Spearman's rank correlation and Cohen's kappa statistic. Change in monthly publicly funded PS/HM hours was examined in three logistic models: clients receiving no PS/HM services after the CA and receiving some after the HC (i.e., service initiation), clients receiving some PS/HM services after the CA and receiving more after the HC (i.e., service increase), and clients receiving some PS/HM services after the CA and

receiving less after the HC (i.e., service decrease). A conservative definition of change was adopted since the service data come from actual home care visits and client or service provider circumstances may have small effects on monthly utilisation. Thus, only clients whose monthly publicly funded PS/HM hours differed by at least four hours per month (i.e., one hour per week) were said to have experienced a change in service hours. Candidate variables were manually entered in stepwise fashion in bivariate and multivariable models in predisposing, enabling, and need blocks informed by the Andersen-Newman model. Variables that were significant at $p < .05$ at these stages were entered in the full model; however, only variables remaining significant at $p < .0001$ were included in the final models. All analyses were done using SAS 9.4.

3C.4 Results

In Ontario FY 2016/17, there were 70,023 unique clients who were newly admitted to the publicly funded home care program under SRCs 91, 92, 93, and 94 and assessed with both the CA and HC. About one-third of clients received any PS/HM services within 28 days after the CA and about half of clients received any PS/HM services within 84 days after the HC.

For the majority of clients, receipt or not of PS/HM services at one time point matched their receipt status at follow-up (Table 3-22). Nearly half (47.4%) did not receive PS/HM services after either time point and 30.7% received PS/HM services after both time points. Where there was a mismatch, it was more likely that the client did not receive any PS/HM services after the CA but received PS/HM services after the HC than vice versa. Overall, the percentage agreement was 78.1% and the kappa statistic was 0.56 (95% CI: 0.56–0.57).

Table 3-22 Receipt of Any Publicly Funded PS/HM Services after CA and HC Assessments, among Newly Admitted CA-Assessed LHIN Home Care Clients in CA+HC Group, Ontario FY 2016/17

% (n)	Any PS/HM after HC**		
	No	Yes	Total
Any PS/HM after CA*			
No	47.4 (33,205)	19.1 (13,409)	66.6 (46,614)
Yes	2.7 (1,916)	30.7 (21,493)	33.4 (23,409)
Total	50.2 (35,121)	49.8 (34,902)	70,023

*Received up to 4 weeks after CA; **Received up to 12 weeks after HC

Table 3-23 provides additional information about the amount of PS/HM by expanding the yes” category (i.e., receipt of any PS/HM) to four categories based on monthly utilisation cut-offs.

Whereas Table 3-22 showed that 30.7% of clients received PS/HM services after both assessments, 17.3% of clients received service hours that was in the same utilisation bracket at both time points. Across all clients, 27.2% (19,054) received more PS/HM services and 8.1% (5,664) received less PS/HM services between the CA and HC. Overall, the percentage agreement was 64.7% and Spearman’s rank correlation was 0.65 (p<.0001).

Table 3-23 Receipt of Hours of Publicly Funded PS/HM Services after CA and HC Assessments, among Newly Admitted CA-Assessed LHIN Home Care Clients in CA+HC Clients, Ontario FY 2016/17

% (n)	Monthly publicly funded PS/HM hours after HC				
	0 hours	>0 to 8 hours	>8 to 16 hours	>16 to 24 hours	>24 hours
Monthly publicly funded PS/HM hours after CA					
0 hours	47.4 (33,205)	10.8 (7,582)	4.0 (2,804)	1.9 (1,305)	2.5 (1,718)
>0 to 8 hours	1.8 (1,279)	7.5 (5,225)	2.9 (1,994)	0.8 (534)	0.8 (570)
>8 to 16 hours	0.5 (347)	2.1 (1,472)	3.3 (2,310)	1.1 (776)	1.0 (730)
>16 to 24 hours	0.2 (142)	0.5 (366)	0.9 (643)	1.2 (825)	1.5 (1,041)
>24 hours	0.2 (148)	0.4 (274)	0.6 (414)	0.8 (579)	5.3 (3,740)

*Received up to 4 weeks after CA; **Received up to 12 weeks after HC

The finding that receipt status and amount of PS/HM services may change over time raises the question of whether these changes were driven by predisposing, enabling, or need characteristics. Figure 3-12 and Figure 3-13 depict the magnitude of difference in monthly publicly funded PS/HM hours, among clients receiving no PS/HM services and those receiving some PS/HM services, respectively. Again, this analysis adopted a conservation definition of change, in which only differences in monthly utilisation of at least four hours per month were considered.

Figure 3-12 depicts the magnitude of difference in monthly publicly funded PS/HM hours among clients receiving no PS/HM services after the CA. There were 20.3% (9,452) of clients whose monthly PS/HM utilisation increased by at least four hours after the HC. In the no change group, 8.5% of clients received PS/HM hours but their monthly utilisation was less than four hours per month, and 71.2% of clients continued to receive no PS/HM services after the HC.

Figure 3-12 Difference in Monthly Publicly Funded PS/HM Hours Received After CA and HC, among CA+HC Clients Receiving No PS/HM Services After CA, Ontario FY 2016/17

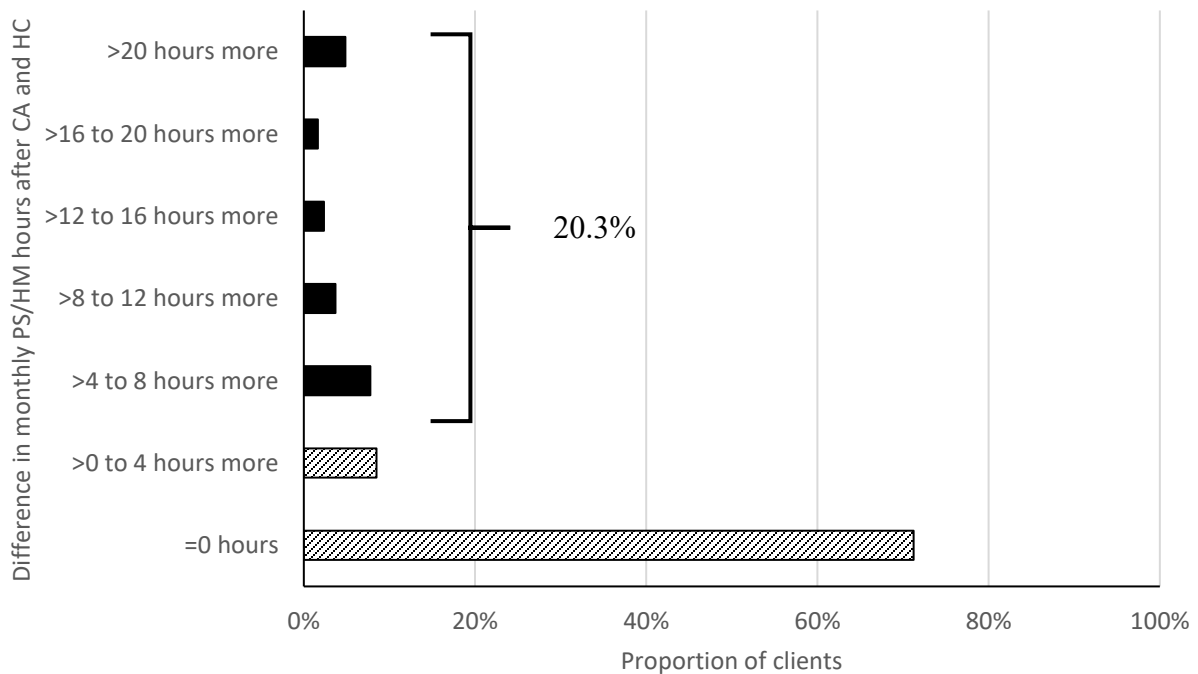
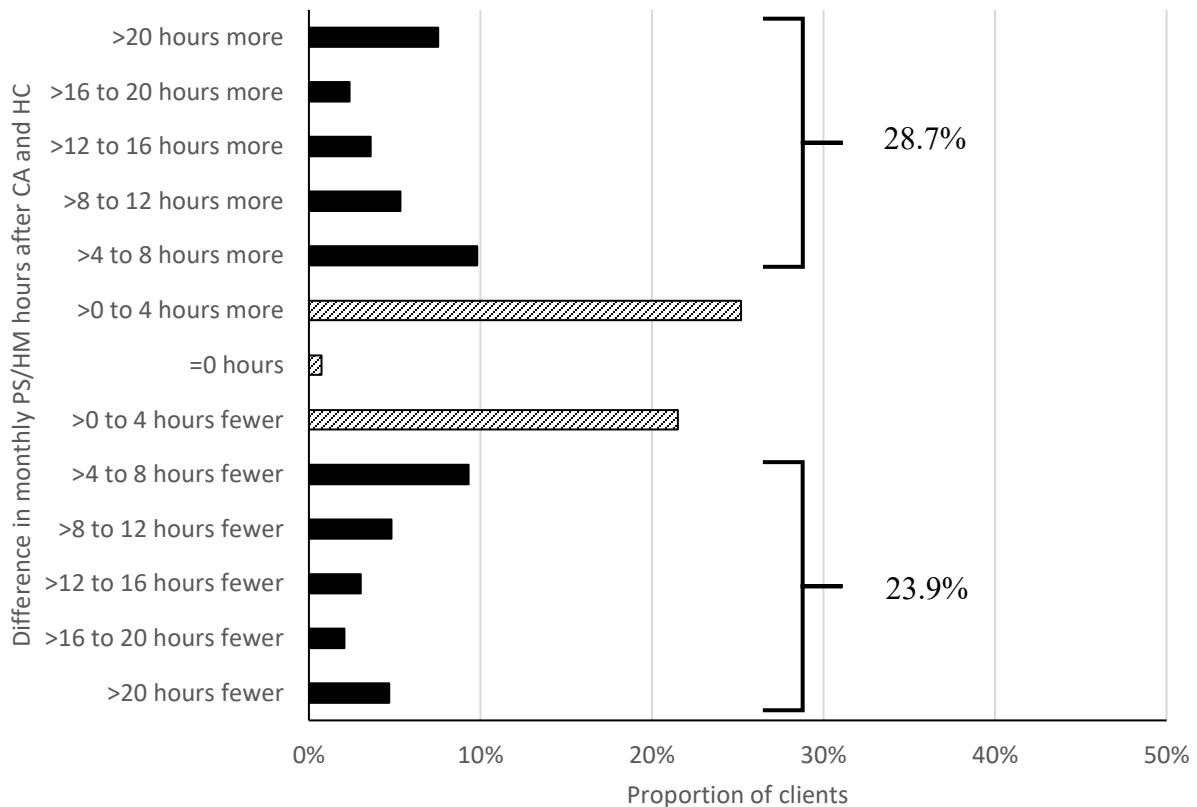


Figure 3-13 depicts the magnitude of difference in monthly publicly funded PS/HM hours among clients receiving some PS/HM services after the CA. There were 28.7% (6,709) of clients whose monthly PS/HM utilisation increased by at least four hours and another 23.9% (5,596) of clients whose monthly PS/HM utilisation decreased by at least four hours. Monthly PS/HM utilisation either differed by less than four hours or did not change for nearly half (47.4%) of clients.

Figure 3-13 Difference in Monthly Publicly Funded PS/HM Hours Received After CA and HC, among CA+HC Clients Receiving Some PS/HM Services after CA, Ontario FY 2016/17



Separate logistic models were fit to predict each of the change groups. Candidate variables were identified from bivariate analyses and tested in block adjusted models for inclusion in the fully adjusted model. The following tables summarise the model building process and final models.

Table 3-24 describes the service initiation model, in other words, clients receiving no PS/HM services after the CA and whose monthly utilisation increased by at least four hours after the HC (refer to the sub-sample labelled 20.3% in Figure 3-12). In the predisposing block, older age (ORs=1.16 to 1.69) and female (OR=1.18) significantly increased the odds of receiving more PS/HM hours after the HC. Being ever married or having a partner decreased the odds of service initiation in the block adjusted model, but was not significant in the fully adjusted model.

In the enabling block, being referred to home care services by the hospital significantly decreased the odds of receiving more PS/HM hours after the HC. Although the LHIN variable was significant in the fully adjusted model, the direction of association was inconsistent.

Compared to Hamilton Niagara Haldimand Brant LHIN, five LHINs had greater odds (Central, Erie St. Clair, North West, South East, Toronto Central; ORs=1.16 to 1.94) and five LHINs had lower odds (Central East, Champlain, Central West, Mississauga Halton, South West; ORs=0.46 to 0.88). Absence of a primary caregiver significantly increased the odds of service initiation in the block adjusted models, but was not significant in the fully adjusted model. Neither living alone nor rural geography was significant.

Need characteristics were associated with greater likelihood of service initiation, including caregiver distress (OR=1.30), count of ADL impairment (ORs=1.57 to 2.44), count of IADL impairment (ORs=1.19 to 1.77), and decline in cognitive status (OR=1.16). Cognitive skills, comprehension, decline in ADL status, unstable health patterns, poor self-rated health, falls, and AUA were significant earlier in the model building process, but did not reach the benchmark for inclusion in the fully adjusted model. The c statistic for need characteristics (c=0.63) was

stronger than predisposing ($c=0.56$) and enabling ($c=0.62$) characteristics. The c statistic for the full model was 0.68.

Table 3-24 Unadjusted and Adjusted Odds of Service Initiation (i.e., Clients Receiving No PS/HM after CA and Receiving Some PS/HM after HC), among Newly Admitted LHIN Home Care Clients in CA+HC Group, Ontario FY 2016/17

Odds ratio (95% CI)		Single variable (unadjusted)	Block of variables (adjusted)	Full model (adjusted)
				c=0.68
Predisposing characteristics		c=0.56		
Age group (REF=18 to 44 years)	45 to 64 years	1.11 (0.94–1.31)	1.17 (0.99–1.38)	1.16 (0.98–1.38)
	65 to 74 years	1.45 (1.24–1.71)	1.55 (1.31–1.83)	1.37 (1.15–1.62)
	75 to 84 years	1.88 (1.61–2.19)	2.00 (1.70–2.35)	1.59 (1.34–1.87)
	85+ years	2.16 (1.85–2.53)	2.29 (1.94–2.69)	1.69 (1.43–2.00)
Sex (REF=Not female)	Female	1.21 (1.16–1.27)	1.18 (1.13–1.24)	1.18 (1.12–1.24)
Relationship status (REF=Never married)	Ever married or had a partner/significant other	1.19 (1.09–1.29)	0.88 (0.81–0.97)	
Enabling characteristics		c=0.62		
Caregiver status (REF=Caregiver present)	Caregiver absent	1.28 (1.13–1.45)	1.53 (1.34–1.73)	
Living arrangement (REF=With other(s))	Lives alone	0.93 (0.88–0.97)		
Referral source (REF=Community)	Hospital	0.67 (0.64–0.70)	0.65 (0.62–0.69)	0.75 (0.72–0.79)
Geography (REF=Urban)	Rural			
LHIN (REF=Hamilton Niagara Haldimand Brant)	Central East	0.91 (0.82–1.00)	0.80 (0.73–0.89)	0.59 (0.53–0.66)
	Central	1.88 (1.72–2.04)	1.83 (1.68–2.00)	1.32 (1.21–1.45)
	Champlain	0.81 (0.72–0.91)	0.75 (0.67–0.85)	0.49 (0.43–0.55)
	Central West	0.69 (0.60–0.78)	0.65 (0.57–0.74)	0.46 (0.40–0.53)
	Erie St. Clair	1.25 (1.12–1.40)	1.17 (1.04–1.31)	1.16 (1.02–1.30)
	Mississauga Halton	0.66 (0.58–0.75)	0.65 (0.57–0.73)	0.50 (0.44–0.57)
	North East	1.28 (1.16–1.42)	1.18 (1.07–1.30)	1.09 (0.99–1.22)
	North Simcoe Muskoka	1.23 (1.09–1.39)	1.16 (1.02–1.31)	1.03 (0.90–1.17)
	North West	1.70 (1.47–1.96)	1.57 (1.36–1.82)	1.75 (1.50–2.05)
	South East	1.68 (1.52–1.86)	1.52 (1.37–1.68)	1.57 (1.42–1.75)
	South West	1.00 (0.89–1.11)	0.91 (0.82–1.02)	0.88 (0.78–0.98)
	Toronto Central	2.54 (2.29–2.82)	2.52 (2.27–2.80)	1.94 (1.73–2.16)
	Waterloo Wellington	1.15 (1.03–1.28)	0.65 (0.62–0.69)	0.94 (0.84–1.05)

<i>Odds ratio (95% CI)</i>		Single variable (unadjusted)	Block of variables (adjusted)	Full model (adjusted)
Need characteristics			c=0.63	
Caregiver distress (REF=No)	Yes	1.67 (1.59–1.75)	1.24 (1.18–1.31)	1.30 (1.23–1.37)
Count of ADL impairment (REF=None)	One	1.89 (1.77–2.02)	1.57 (1.47–1.69)	1.57 (1.46–1.69)
	Some	2.71 (2.55–2.87)	2.02 (1.89–2.16)	2.13 (1.99–2.29)
	All	3.12 (2.90–3.37)	2.15 (1.96–2.35)	2.44 (2.23–2.67)
Count of IADL impairment (REF=None)	One	1.47 (1.29–1.69)	1.28 (1.11–1.46)	1.19 (1.04–1.37)
	Some	2.54 (2.27–2.83)	1.63 (1.45–1.83)	1.61 (1.43–1.81)
	All	3.64 (3.25–4.07)	1.74 (1.54–1.97)	1.77 (1.56–2.01)
Cognitive skills for daily decision-making (REF=Independent)	Not independent	1.65 (1.57–1.73)	1.12 (1.05–1.19)	
Comprehension (REF=At least understand conversation with repetition)	At most understand simple and direct questions/directions only	1.64 (1.54–1.74)		
Decline in cognitive status (REF=No)	Yes	1.56 (1.48–1.64)	1.13 (1.06–1.21)	1.16 (1.10–1.23)
Decline in ADL status (REF=No)	Yes	1.51 (1.43–1.59)		
Unstable or fluctuating health patterns (REF=No)	Yes	1.49 (1.41–1.56)		
Poor self-rated health (REF=No)	Yes	1.12 (1.05–1.20)		
Falls (REF=No)	Yes	1.26 (1.20–1.32)	1.09 (1.04–1.14)	
AUA (REF=1)	2	1.31 (1.10–1.55)		
	3	1.32 (1.16–1.49)		
	4	2.50 (2.22–2.81)		
	5	3.45 (3.04–3.91)		
	6	3.50 (3.12–3.92)		

- Only significant variables are reported in each column. The significance level was set at $p < .05$ for a single variable and block of variables, and $p < .0001$ for inclusion in the full model.

Table 3-25 describes the service increase model, in other words, clients receiving some PS/HM services after the CA and whose monthly utilisation increased by at least four hours after the HC (refer to the sub-sample labelled 28.7% in Figure 3-13). In the predisposing block, only female sex was significant in the fully adjusted model (OR=0.88). Older age decreased the odds of service increase in the block adjusted model, but was not significant in the fully adjusted model.

In the enabling block, living alone (OR=0.88) and being referred to home care services by the hospital (OR=0.86) significantly decreased the odds of receiving more PS/HM hours after the HC. Compared to Hamilton Niagara Haldimand Brant LHIN, three LHINs had greater odds (Central West, North West, Toronto Central; ORs=1.18 to 1.41), four LHINs had lesser odds (Central East, Central, Mississauga Halton, North Simcoe Muskoka; ORs=0.58 to 0.82), and six LHINs had comparable odds of service increase. Neither absence of a primary caregiver nor living in a rural geography was significant, even at the bivariate level.

In the need block, caregiver distress (OR=1.26), cognitive skills (OR=1.25), comprehension (OR=1.30), and unstable health patterns (OR=1.18) were significantly associated with greater odds of service increase. The count of ADL impairment and decline in ADL status (OR=0.81) decreased the odds of service increase. Having fewer impaired ADLs was associated with a strong protective effect, where the odds ratio was 0.57 if the client was impaired in one ADL and 0.81 if the client was impaired in all four ADLs. Clients with no ADL impairment were the most likely to receive additional PS/HM hours after the HC. Like the first model, the c statistic for need characteristics (c=0.60) was stronger than predisposing (c=0.54) and enabling (c=0.58) characteristics. The c statistic for the full model was 0.62.

Table 3-25 Unadjusted and Adjusted Odds of Service Increase (i.e., Clients Receiving Some PS/HM Services after CA and Receiving More PS/HM Services after HC), among Newly Admitted LHIN Home Care Clients in CA+HC Group, Ontario FY 2016/17

Odds ratio (95% CI)		Single variable (unadjusted)	Block of variables (adjusted)	Full model (adjusted)
				c=0.62
Predisposing characteristics		c=0.54		
Age group (REF=18 to 44 years)	45 to 64 years	0.75 (0.59–0.96)	0.75 (0.59–0.96)	
	65 to 74 years	0.78 (0.62–0.99)	0.78 (0.61–0.99)	
	75 to 84 years	0.75 (0.60–0.95)	0.75 (0.60–0.95)	
	85+ years	0.88 (0.70–1.11)	0.89 (0.71–1.12)	
Sex (REF=Not female)	Female	0.80 (0.76–0.85)	0.80 (0.75–0.85)	0.88 (0.83–0.94)
Relationship status (REF=Never married)	Ever married or had a partner/significant other			
Enabling characteristics		c=0.58		
Caregiver status (REF=Caregiver present)	Caregiver absent			
Living arrangement (REF=With other(s))	Lives alone	0.77 (0.73–0.82)	0.76 (0.71–0.81)	0.88 (0.83–0.94)
Referral source (REF=Community)	Hospital	0.82 (0.77–0.88)	0.83 (0.77–0.88)	0.86 (0.80–0.92)
Geography (REF=Urban)	Rural			
LHIN (REF=Hamilton Niagara Haldimand Brant)	Central East	0.56 (0.50–0.64)	0.56 (0.49–0.64)	0.58 (0.51–0.66)
	Central	1.11 (0.98–1.25)	1.09 (0.97–1.23)	1.01 (0.89–1.15)
	Champlain	0.93 (0.82–1.07)	0.91 (0.79–1.04)	0.77 (0.66–0.89)
	Central West	1.70 (1.30–2.21)	1.63 (1.25–2.12)	1.38 (1.05–1.82)
	Erie St. Clair	1.00 (0.86–1.17)	0.96 (0.82–1.12)	0.99 (0.84–1.16)
	Mississauga Halton	0.87 (0.76–1.00)	0.86 (0.75–0.99)	0.82 (0.71–0.95)
	North East	0.91 (0.78–1.07)	0.91 (0.77–1.07)	0.95 (0.80–1.12)
	North Simcoe Muskoka	0.88 (0.74–1.06)	0.87 (0.72–1.04)	0.82 (0.68–0.99)
	North West	1.32 (1.03–1.70)	1.39 (1.09–1.79)	1.41 (1.09–1.82)
	South East	0.93 (0.80–1.08)	0.92 (0.79–1.07)	0.94 (0.80–1.10)
	South West	0.88 (0.76–1.01)	0.87 (0.76–1.00)	0.92 (0.79–1.07)
	Toronto Central	1.15 (1.00–1.32)	1.19 (1.04–1.37)	1.18 (1.02–1.36)
	Waterloo Wellington	1.00 (0.86–1.15)	0.95 (0.82–1.09)	0.93 (0.80–1.08)

<i>Odds ratio (95% CI)</i>		Single variable (unadjusted)	Block of variables (adjusted)	Full model (adjusted)
Need characteristics			c=0.60	
Caregiver distress (REF=No)	Yes	1.47 (1.39–1.56)	1.30 (1.22–1.38)	1.26 (1.18–1.34)
Count of ADL impairment (REF=None)	One	0.54 (0.46–0.62)	0.53 (0.45–0.62)	0.57 (0.49–0.67)
	Some	0.62 (0.54–0.70)	0.58 (0.50–0.67)	0.61 (0.53–0.70)
	All	0.96 (0.84–1.09)	0.78 (0.67–0.90)	0.81 (0.70–0.94)
Count of IADL impairment (REF=None)	One	0.68 (0.51–0.90)		
	Some	0.71 (0.56–0.90)		
	All	1.23 (0.97–1.55)		
Cognitive skills for daily decision-making (REF=Independent)	Not independent	1.63 (1.53–1.72)	1.26 (1.17–1.35)	1.25 (1.17–1.34)
Comprehension (REF=At least understand conversation with repetition)	At most understand simple and direct questions/directions only	1.80 (1.67–1.94)	1.33 (1.23–1.45)	1.30 (1.20–1.42)
Decline in cognitive status (REF=No)	Yes	1.58 (1.48–1.68)		
Decline in ADL status (REF=No)	Yes	0.82 (0.76–0.89)	0.77 (0.71–0.84)	0.81 (0.75–0.89)
Unstable or fluctuating health patterns (REF=No)	Yes	1.42 (1.33–1.52)	1.19 (1.10–1.28)	1.18 (1.10–1.27)
Poor self-rated health (REF=No)	Yes			
Falls (REF=No)	Yes			
AUA (REF=1)	2	1.15 (0.74–1.79)		
	3	1.15 (0.85–1.57)		
	4	0.58 (0.45–0.74)		
	5	0.77 (0.60–0.98)		
	6	0.94 (0.73–1.19)		

- Only significant variables are reported in each column. The significance level was set at $p < .05$ for a single variable and block of variables, and $p < .0001$ for inclusion in the full model.

Table 3-26 describes the service decrease model, in other words, clients receiving some PS/HM services after the CA and whose monthly utilisation decreased by at least four hours after the HC (refer to the sub-sample labelled 23.9% in Figure 3-13). In the predisposing block, only female sex was significant in the fully adjusted model (OR=0.87). Neither age group nor relationship status was significant, even at the bivariate level.

In the enabling block, living alone (OR=0.85) and being referred to home care services by the hospital (OR=0.84) significantly decreased the odds of receiving fewer PS/HM hours after the HC. Compared to Hamilton Niagara Haldimand Brant LHIN, three LHINs had greater odds (Central West, North West, Toronto Central; ORs=1.25 to 1.48), three LHINs had lesser odds (Central East, Champlain, Mississauga Halton; ORs=0.59 to 0.86), and seven LHINs had comparable odds of service decrease. Living in a rural geography significantly reduced the odds of receiving fewer PS/HM hours at the bivariate level only.

In the need block, decline in cognitive status (OR=1.42) and unstable health patterns (OR=1.26) were significantly associated with greater odds of service decrease. Decline in ADL status (OR=0.78) was associated with lesser odds of service decrease. A U-shaped relationship was observed between the count of ADL impairment and service decrease, where the odds ratio was 0.59 for impairment in one ADL, 0.64 for impairment in two or three ADLs, and not significant for impairment in all ADLs. In other words, clients at the highest levels of independence and dependence had higher odds of receiving fewer PS/HM hours. Cognitive skills, poor self-rated health, and falls were significant earlier in the model building process, but did not reach the benchmark for inclusion in the fully adjusted model. Caregiver distress was not significant, even at the bivariate level.

The c statistic for enabling characteristics ($c=0.62$) was stronger than predisposing ($c=0.51$) and need ($c=0.60$) characteristics. Predisposing and need characteristics contributed in a minor way to improving the discriminatory power of the full model beyond that of enabling characteristics alone. By adding in the predisposing and need blocks to the enabling block, the percentage of concordant pairs increased from 60.3% to 61.1% and the percentage of tied pairs decreased from 3.7% to 0.9% although the c statistic of the full model did not change ($c=0.62$).

Table 3-26 Unadjusted and Adjusted Odds of Service Decrease (i.e., Clients Receiving Some PS/HM Services after CA and Receiving Less PS/HM Services after HC), among Newly Admitted LHIN Home Care Clients in CA+HC Group, Ontario FY 2016/17

Odds ratio (95% CI)		Single variable (unadjusted)	Block of variables (adjusted)	Full model (adjusted)
				c=0.62
Predisposing characteristics		c=0.51		
Age group (REF=18 to 44 years)	45 to 64 years			
	65 to 74 years			
	75 to 84 years			
	85+ years			
Sex (REF=Not female)	Female	1.09 (1.02–1.16)	1.09 (1.02–1.16)	0.87 (0.81–0.92)
Relationship status (REF=Never married)	Ever married or had a partner/significant other			
Enabling characteristics		c=0.62		
Caregiver status (REF=Caregiver present)	Caregiver absent			
Living arrangement (REF=With other(s))	Lives alone	1.15 (1.08–1.23)	1.19 (1.12–1.27)	0.85 (0.79–0.90)
Referral source (REF=Community)	Hospital	1.95 (1.80–2.12)	2.00 (1.84–2.17)	0.84 (0.79–0.91)
Geography (REF=Urban)	Rural	0.91 (0.83–0.99)		
LHIN (REF=Hamilton Niagara Haldimand Brant)	Central East	0.36 (0.32–0.41)	0.37 (0.33–0.42)	0.59 (0.52–0.68)
	Central	0.41 (0.36–0.46)	0.42 (0.37–0.48)	1.07 (0.95–1.22)
	Champlain	0.47 (0.41–0.54)	0.51 (0.44–0.59)	0.85 (0.74–0.98)
	Central West	0.62 (0.47–0.83)	0.65 (0.48–0.87)	1.48 (1.13–1.94)
	Erie St. Clair	0.50 (0.43–0.59)	0.57 (0.48–0.67)	1.00 (0.85–1.17)
	Mississauga Halton	0.72 (0.62–0.82)	0.73 (0.63–0.84)	0.86 (0.74–0.99)
	North East	0.45 (0.38–0.53)	0.49 (0.41–0.58)	1.00 (0.85–1.18)
	North Simcoe Muskoka	0.84 (0.70–0.99)	0.88 (0.74–1.05)	0.87 (0.73–1.05)
	North West	0.55 (0.42–0.72)	0.55 (0.41–0.72)	1.45 (1.12–1.87)
	South East	0.67 (0.58–0.77)	0.71 (0.61–0.82)	0.96 (0.83–1.12)
	South West	0.56 (0.49–0.65)	0.61 (0.53–0.70)	0.94 (0.81–1.08)
	Toronto Central	0.40 (0.34–0.46)	0.40 (0.34–0.46)	1.25 (1.08–1.44)
	Waterloo Wellington	0.64 (0.56–0.74)	0.76 (0.65–0.87)	0.99 (0.85–1.15)

<i>Odds ratio (95% CI)</i>		Single variable (unadjusted)	Block of variables (adjusted)	Full model (adjusted)
Need characteristics			c=0.60	
Caregiver distress (REF=No)	Yes			
Count of ADL impairment (REF=None)	One	0.99 (0.81–1.21)	0.97 (0.79–1.19)	0.59 (0.50–0.69)
	Some	1.88 (1.58–2.24)	0.92 (0.86–0.99)	0.64 (0.56–0.74)
	All	2.58 (2.16–3.07)	2.56 (2.12–3.10)	0.91 (0.79–1.06)
Count of IADL impairment (REF=None)	One			
	Some			
	All			
Cognitive skills for daily decision-making (REF=Independent)	Not independent	1.10 (1.04–1.17)		
Comprehension (REF=At least understand conversation with repetition)	At most understand simple and direct questions/directions only			
Decline in cognitive status (REF=No)	Yes	1.03 (0.97–1.11)	0.92 (0.56–0.99)	1.42 (1.32–1.51)
Decline in ADL status (REF=No)	Yes	1.46 (1.33–1.60)	1.29 (1.17–1.43)	0.78 (0.71–0.85)
Unstable or fluctuating health patterns (REF=No)	Yes	0.86 (0.80–0.92)	0.77 (0.71–0.83)	1.26 (1.17–1.35)
Poor self-rated health (REF=No)	Yes	0.85 (0.78–0.94)	0.84 (0.76–0.93)	
Falls (REF=No)	Yes	1.25 (1.18–1.33)	1.17 (1.10–1.25)	
AUA (REF=1)	2	0.90 (0.50–1.62)		
	3	0.67 (0.44–1.02)		
	4	1.37 (1.00–1.87)		
	5	2.07 (1.51–2.82)		
	6	1.62 (1.19–2.20)		

- Only significant variables are reported in each column. The significance level was set at $p < .05$ for a single variable and block of variables, and $p < .0001$ for inclusion in the full model.

Among clients receiving fewer PS/HM hours after the HC, 1,096 (19.6%) received at least 20 fewer hours. The clinical significance of this group prompted further investigation into possible explanations for such a large service decrease. In the logistic model, the event of interest was a negative difference of at least 20 hours, and the non-event was a negative difference between four and 20 hours. The strongest model included just one variable: hours received after the CA ($c=0.89$). When this variable was entered in the model, no other predisposing, enabling, or need characteristic reached significance.

Table 3-27 compares the monthly PS/HM utilisation between the two groups. The observed mean difference between monthly PS/HM hours after the CA was 41.8 hours (95% CI: 38.2–45.4) and the t-test statistic for unequal variances was 22.9 ($p<.0001$). Although the monthly PS/HM hours after the HC remained significantly different between groups, the magnitude of the observed mean difference dropped to 11.0 hours (95% CI: 9.0–13.0) and the t-test statistic for unequal variances was 10.8 ($p<.0001$).

Table 3-27 Publicly Funded PS/HM Hours Received after CA and HC, among Newly Admitted LHIN Home Care Clients in CA+HC Group Receiving at Least 20 Fewer Hours after HC, Ontario FY 2016/17

Monthly publicly funded PS/HM hours	Clients whose monthly PS/HM utilisation decreased by more than 20 hours		Clients whose monthly PS/HM utilisation decreased between four to 20 hours	
	Mean \pm SD	Median	Mean \pm SD	Median
After CA	62.9 \pm 59.8	48.0	21.1 \pm 18.3	16.3
After HC	22.7 \pm 32.9	12.1	11.7 \pm 17.3	6.7
Mean difference after CA and after HC	-40.2 \pm 37.4	-28.4	-9.4 \pm 4.3	-8.2

Excluding the variable for hours received after the CA, the next strongest variable was LHIN ($c=0.66$). Of all clients receiving substantially less PS/HM service after the HC, the highest proportions of clients whose utilisation decreased by more than 20 hours per month were

observed in Central West (63.8%), Champlain (35.2%), and Hamilton Niagara Haldimand Brant (26.9%) LHINs. Service decreases of comparable magnitude were less common in other LHINs, such as Central East (3.6%), North East (6.2%), and North West (11.7%) LHINs.

3C.5 Discussion

For the most part, whether or not public home care clients received PS/HM services after the CA (i.e., at program intake) is consistent with whether they received PS/HM services after the HC if they are expected to require long-term home care services. Greater discrepancy is observed in the amount of PS/HM services between time points, where the monthly utilisation differed by at least four hours for one in six clients. As expected, need characteristics provide the highest explanatory power. However, enabling characteristics are also strongly associated with observed discrepancies, revealing the strong effect of LHIN-specific approaches to identifying and responding to need for PS/HM services early on in the home care episode.

Need characteristics contribute the highest *c* statistic in two of the three models, and the second highest *c* statistic in the service decrease model. While previous studies have consistently found a strong association between need characteristics and PS/HM service use [191–194], the present study adds to the literature from the perspective of adjusting service plans. For instance, it is widely established that greater ADL impairment predicts greater likelihood of receiving PS/HM services. In the present study, greater ADL impairment is associated with lower odds of either service increase or decrease. This finding suggests that the initial allocation of PS/HM services is rationally based on the presence of functional impairment and often requires little adjustment at follow-up. On the other hand, less impaired clients are more likely to experience service adjustments. Clients appearing as functionally independent on the CA may have a greater need

for PS/HM services than initially assessed because the CA—being a brief screener—may have missed detecting some more moderate forms of impairment. As well, it is possible that a person who was assessed as independent in the four ADLs in the CA may require assistance in at least one of the other six ADLs in the HC. In cases where PS/HM services were reduced, clients with complete independence and complete dependence were more likely to receive fewer hours after the HC. These cases may represent clients receiving a large amount of services to support short-term recovery. The HC may be better positioned to make distinctions between clients with high and very high ADL impairment that may lead to adjustments in service plans for the latter.

Decline in ADL status is protective or not significant in all models, suggesting that PS/HM service plans adequately address this aspect of need during the initial assessment. In contrast, other need characteristics such as cognitive skills, decline in cognitive status, and caregiver distress are often predictive of receiving more PS/HM hours after the HC. These characteristics may play a lesser role in resource allocation at the initial assessment. In the service decrease model, several need characteristics are predictive of receiving lesser services. However, it is notable that many of these variables changed direction between the block adjusted and fully adjusted model. In particular, female sex, living alone, referral from hospital, and decline in ADL status became associated with lesser odds and decline in cognitive status and unstable health patterns became associated with greater odds. Together, this cluster of variables describe the degree to which a client's health is undergoing recent changes that may be sudden and unexpected and the availability of social support that may help to respond to these changes. There may be many reasons why clients with unstable health patterns would receive fewer PS/HM hours after the HC. Perhaps the client recalled a period of better health that did not a

reflect a history of fluctuating health during the assessment, or the issue of unstable health was resolved by the HC assessment and the client no longer required the same level of services, or the client's family opted to increase involvement of informal care or privately-financed formal care. The fact that individuals with recent declines or unstable health patterns may have widely differing trajectories emphasises the importance of ensuring these clients receive a home visit and a comprehensive follow-up assessment so that the service plan matches their range of needs.

Enabling characteristics contribute the second highest c statistic in two of the three models and the highest c statistic in the service decrease model. The LHIN variable is by far the most influential enabling characteristic. As well, the directional effect in certain LHINs is remarkably consistent. Across the three models, higher odds are associated with Central East, Champlain, and Mississauga Halton LHINs, while lower odds are associated with North West and Toronto Central LHINs. The interpretation of these findings is difficult in the absence of information about their policies. Lack of change could mean that service plans in those LHINs are already very sensitive to need characteristics compared to those in other LHINs that require a lot of tinkering at every level of assessment. Contrastingly, lack of change could mean that service plans vary little with need characteristics compared to those in other LHINs that are frequently updated and responsive to changing client needs. Nevertheless, it is reasonable to conclude that enabling characteristics, especially the LHIN in which a client resides, substantially influences the degree of consistency of PS/HM services between the CA and HC.

Predisposing characteristics contribute the least to the three models. Female sex and older age are associated with greater odds of service initiation. Female sex is also associated with lower odds of service adjustments among clients receiving some PS/HM services after the CA.

Although more research may be warranted to verify if the PS/HM-specific needs of older women are more likely to go under-detected or unaddressed at home care intake, the influences of these predisposing characteristics are small in comparison to need and enabling characteristics.

The major implication of this study is that the approaches used to allocate publicly funded PS/HM services not only differ between LHINs, but may also differ between the CA and HC within LHINs. As raised in the Auditor General report, clients may be eligible to receive more PS/HM services in one LHIN than another. This study further demonstrates that clients in certain LHINs may expect to have their service plans adjusted up or down more often than in other LHINs. Although some level of discrepancy is expected given the brief nature of CA and the time between the CA and HC, the fair distribution of health services should aim to reduce discrepancies attributable to differential access to care. An equitable system should seek to minimise the relationship between enabling characteristics and health service use.

At present, the process of PS/HM service allocation is unstandardised and neither transparent nor accessible to clients and families. Unexpected service adjustments may adversely affect the informal caregiving network and may raise concerns about predictability. To date, Ontario's Ministry of Health and Long-Term Care has focused on standardising the criteria for allocating publicly funded PS/HM services from the HC assessment. While this effort is much needed, to actualise the important recommendations of the *Bringing Care Home* report, a common approach is needed to guide the allocation of PS/HM services from both the CA and HC so that services are clear, fairly distributed, and reliable.

3C.5.1 Strengths

The use of census-level assessment and administrative data means that these results are generalisable across Ontario's public home care population that is novel especially with the CA-assessed population. Whereas much of the existing literature relies on self-reported characteristics and PS/HM service use, this study linked CA and HC assessments that are completed by trained health professionals and billed services data whose integrity is maintained by the LHINs and service provider organisations. The denominator of the PS/HM use variable was adjusted if the client did not receive services for the full observation period, including if their first home visit was delayed or if the client was reassessed or discharged earlier, that was important in maintaining high accuracy of the service variable.

3C.5.2 Limitations

The billed services dataset represents the actual receipt of PS/HM service hours that may differ from the amount allocated in clients' service plans. In some cases, client availability (e.g., unexpected hospital stay) or service provider circumstances (e.g., insufficient supply of personal support workers to meet demand) would underestimate the PS/HM services they would have received. Steps were taken to minimise measurement error by calculating monthly utilisation and only defining change as monthly PS/HM utilisation that differed by at least four hours/month between the CA and HC. In this study, the LHIN variable acted as a sort of global variable of differences between LHINs. Future research could more closely examine the separate contributions of regional demographic and social factors, availability of other community and social services, and LHIN funding levels and specific policies and practices.

SUB-CHAPTER 3D

3D.1 Objectives

The objective of this sub-chapter is to compare the self-reported and billed formal care data and comment on the integrity of the self-reported care data in the HC assessments completed in Ontario. The CA+HC group affords a unique opportunity to examine the accuracy of self-reported formal utilisation data within normal assessment practice. All clients in the CA+HC group would have been assessed at intake for eligibility for publicly funded home care services. When completing the HC assessment, the care coordinator asks the client or caregiver to recall the amount of formal services received in the last seven days. Since the client has an active home care episode, every public home care visit would have been recorded in the billed services dataset, including services received in the seven days before the HC assessment. Since the integrity of the billed services data is upheld by countervailing LHIN and service provider motivations, comparing the self-reported and billed services data over the same lookback period will help to gauge the integrity of the self-reported services data.

3D.2 Variables of Interest

3D.2.1 Self-Reported Formal Care

Self-reported formal care hours were derived from the HC assessment. The HC item is the “hours and minutes (rounded to even 10 minutes) of formal care (care or care management) in the last seven days” and includes all publicly and privately funded care. The following service types were retained for this analysis: personal support/homemaking (sum of home health aides and homemaking services), nursing, occupational therapy, and physiotherapy.

3D.2.2 Billed Formal Care

Billed formal care hours were derived from the billed services dataset containing all publicly funded home care visits. For each client, all services that were received in the seven days leading up to the HC assessment date were retrieved. The quantity of home care services was summed for each service type. Quantity of personal support/homemaking and shift nursing were recorded in number of hours while other nursing services, occupational therapy, and physiotherapy were recorded in number of visits. Thus, the quantity of nursing is somewhat ambiguous because the sum consists of both hours and visits. The following service types were retained for this analysis: personal support/homemaking (sum of personal services, homemaking services, combined personal services and homemaking services, respite), nursing (sum of shift nursing, visiting nursing, and rapid response nursing), occupational therapy, and physiotherapy.

3D.2.3 Self-Reported Informal Care

Self-reported informal care hours were derived from the HC assessment. The HC item is the “hours of informal help (instrumental and personal activities of daily living) received over the last seven days”.

3D.3 Analysis Plan

For each service type, the billed hours (or visits) were divided by the self-reported hours to obtain “billed hours (or visits) as a percentage of self-reported hours”. All possible values ranging from 0% to >100% were classified into mutually exclusive categories. Cases in which the percentage was equal to 0% were classified separately based on whether the denominator had a positive (i.e., “0%”) or zero value (i.e., “both billed hours (or visits) and self-reported hours

equal 0”). Cases in which the numerator had a positive value and the denominator had a zero value were labelled as “some billed hours (or visits) but no self-reported hours”. Additionally, the relative share of each type of informal and formal PS/HM care was calculated based on the following definitions: “informal hours” is the amount of informal hours, “formal hours (public)” is the amount of billed PS/HM hours, and “formal hours (private)” is the difference after subtracting the amount of billed PS/HM hours from the amount of self-reported PS/HM hours. If the difference was negative, “formal hours (private)” was set to zero. All analyses were done using SAS 9.4.

3D.4 Results

In Ontario FY 2016/17, there were 70,023 unique clients who were newly admitted to the publicly funded home care program under SRCs 91, 92, 93, and 94 and assessed with both the CA and HC.

Table 3-28 shows the relationship between self-reported hours (or visits) and billed hours for each service type. Two logical checks were completed. The first logical check was to identify the proportion of cases in which the client reported that they did not receive any formal services despite the billed services record stating otherwise. For instance, in 3.6% of cases, the client (or caregiver) reported they did not receive any formal nursing services in the last seven days but they received at least one visiting nurse, shift nursing, or rapid response nursing visit according to the billed services record. The level of discrepancy ranged from 1.1% for PS/HM to 3.6% for nursing. The second logical check was to identify the proportion of cases in which the client reported that they received fewer hours of formal hours than the sum of the billed services record over the same period (i.e., >100%). The proportion of cases that failed the logical check ranged

from 2.6% for occupational therapy to 12.5% for nursing. For 4.5% of clients, the amount of billed PS/HM exceeded that reported by the client (or caregiver). In total, 16.1% of nursing, 5.6% of PS/HM, 5.6% of occupational therapy, and 5.5% of physiotherapy self-reported hours did not meet the logical checks.

For each service type, there were roughly 10 to 15% of cases in which there was an exact match between self-reported and billed services, suggesting that all formal services were received through the LHIN. Additionally, there were similar proportions of cases in which the billed services accounted for 0% of self-reported services, meaning that all formal services were received from outside the public system. For PS/HM services, 13.0% clients received publicly funded services only and 15.8% received privately funded services only. Nearly half (47.6%) did not receive any PS/HM services according to either source. The remaining 18.0% of clients can be interpreted to have received a combination of publicly and privately funded PS/HM services.

Table 3-28 Billed Hours as a Percentage of Self-Reported Hours in the Last Seven Days, among Newly Admitted LHIN Home Care Clients in CA+HC Group, Ontario FY 2016/17

Billed hours (or visits) as a percentage of self-reported hours, % (n)	PS/HM	Nursing	Occupational therapy	Physiotherapy
Some billed hours (or visits) but no self-reported hours	1.1 (774)	3.6 (2,538)	3.0 (2,091)	2.0 (1,377)
=0%	15.8 (11,052)	7.0 (4,903)	16.2 (11,374)	8.8 (6,141)
>0% to 25%	2.1 (1,496)	0.3 (173)	0.1 (66)	0.2 (109)
>25% to 50%	5.5 (3,816)	1.5 (1,046)	0.8 (579)	0.6 (438)
>50% to 75%	5.2 (3,637)	1.6 (1,125)	0.2 (136)	0.2 (134)
>75% to <100%	5.2 (3,655)	0.7 (482)	0.1 (100)	0.1 (101)
=100%	13.0 (9,093)	9.8 (6,884)	15.8 (11,047)	11.3 (7,900)
>100%	4.5 (3,162)	12.5 (8,748)	2.6 (1,787)	3.5 (2,449)
Both billed hours (or visits) and self-reported hours equal 0	47.6 (33,338)	63.0 (44,124)	61.2 (42,843)	73.4 (51,374)

As shown in Table 3-29, informal hours accounted for the majority of total home support hours. On average, home care clients received 74.6 hours of informal support, 9.0 hours of publicly funded PS/HM support, and 7.7 hours of privately funded PS/HM support per month. Relatively speaking, informal hours accounted for 81.6% of total home support hours on average, and at least 72.7% of total home support hours for three-quarters of the client population. Publicly and privately funded PS/HM hours accounted for 10.6% and 7.7% of total home support hours.

Table 3-29 Share of Monthly Informal and Formal (Publicly and Privately Funded) PS/HM Hours, among Newly Admitted LHIN Home Care Clients in CA+HC Group, Ontario FY 2016/17

Type of hours	Monthly hours, mean \pm SD	Monthly hours, interquartile range	Percent of total hours, mean \pm SD	Percent of total hours, interquartile range
Informal hours	74.6 \pm 79.4	28.0–100.0	81.6% \pm 25.4%	72.7–100.0%
Formal PS/HM hours (public)	9.0 \pm 21.6	0.0–9.8	10.6% \pm 18.2%	0.0–14.5%
Formal PS/HM hours (private)	7.7 \pm 36.5	0.0–3.4	7.7% \pm 17.6%	0.0–5.1%

There were 35,911 cases in which self-reported hours were greater than zero. To estimate the percentage of self-reported hours that could be reasonably assumed to represent privately funded PS/HM hours, the amount of billed hours was subtracted from the self-reported hours and divided by the self-reported hours. The mean was 30.2% and the median was 33.3%. In other words, approximately 30% of self-reported hours can be assumed to represent privately funded PS/HM hours when self-reported hours are greater than zero.

3D.5 Discussion

Since this thesis focuses on home care service utilisation, the results of this sub-chapter have important implications for subsequent chapters.

First, comparison of the self-reported and billed formal care data supports the use of self-reported PS/HM as a reasonable measure of publicly and privately funded PS/HM use. About 95–96% of self-reported PS/HM, occupational therapy, and physiotherapy services and 84% of self-reported nursing services passed both logical checks. This level of agreement is comparable to a recent study comparing the accuracy of caregiver reports with service records maintained by British Columbia’s Ministry of Health. Chappell & Kadlec [195] found that the percentage of correct matches ranged from 81.0% for home support to 96.6% for respite care. Notably, the study authors were interested in agreement on any service use rather than the more difficult test for agreement on amount of service that was examined in the present study.

Although there is no equivalent gold standard measure of privately funded home care services (like the billed services dataset for publicly funded home care services), the distributions of care hours do not differ from expectations. The distribution of billed PS/HM hours as a percentage of self-reported hours is more evenly spread compared to other service types. Whereas 18.0% of PS/HM hours are a mix of public and private sources (i.e., rows 3 through 6 in Table 3-28), this only applies to 4.1% of nursing, 1.2% of occupational therapy, and 1.0% of physiotherapy services. Since provincial regulations and local guidelines more tightly control the allocation of PS/HM services than nursing and therapy services, the finding that clients often purchase PS/HM services to supplement publicly funded PS/HM services and that they do so to varying degrees is expected. In contrast, formal nursing, occupational therapy, and physiotherapy services are likely to be provided through fully publicly or privately funded means.

Second, formal PS/HM hours account for a small fraction of help that clients receive. This study estimates clients receiving public home care services receive 74.6 hours/month (or roughly 19

hours/week) of informal support, accounting for 81.6% of total home support help. Other studies have offered similar estimates ranging from 70 to 90% [18, 20–22, 53, 196]. Recent caregiving reports in Ontario estimate that about one-third of caregivers spend at least 10 hours/week on caregiving activities [22, 23].

On the other hand, few estimates of privately funded PS/HM service use exist. Using data collected during the 2015/16 wave of the Canadian Community Health Survey, Gilmour [197] estimated that 39.7% of people received home support from public sources only, 47.9% received home support from private sources only, and 6.8% received home support at least in part by public and private sources [197]. The present study estimates that among public home care clients receiving any PS/HM services, 35.5% (13,029) received publicly funded services only, 30.1% (11,052) received privately funded services only, and 34.4% (12,604) received a combination of publicly and privately funded services. Since public home care clients form the population of interest, it would be expected that this study found relatively higher use of publicly funded PS/HM services than estimates for a general population. Using a more similar approach to the present study, Home Care Ontario estimated that 20 million out of 54.5 million hours or visits of home care were privately purchased, although their estimates were not specific to PS/HM services [47].

Although this thesis focuses on formal PS/HM service use, this sub-chapter highlights the importance of incorporating measures of both informal and formal care utilisation. Therefore, both publicly funded PS/HM service use and total home support use will be examined in Chapter 4 and the amount of informal care will be used in the multi-state transition model in Chapter 6.

3D.5.1 Strengths

To our knowledge, this is the first study to evaluate the integrity of the self-reported formal care data in the HC assessment. Since both LHINs and service providers are motivated to maintain the accuracy of the billed services dataset, it served as the gold standard against which the self-reported data were compared.

3D.5.2 Limitations

Although the two measures of formal care cover the same service types and time period, important differences between the self-reported and billed services data mean that they are not completely comparable. The billed services data represent publicly funded home care services only, whereas the self-reported data represent the sum of publicly and privately funded home care services that cannot be further distinguished. Only PS/HM services are recorded in the same units in both datasets. Larger discrepancies observed for nursing, occupational therapy, and physiotherapy may be partly explained by the fact that these service types were recorded using the number of visits in the self-reported data but recorded using the number of hours in the billed services data.

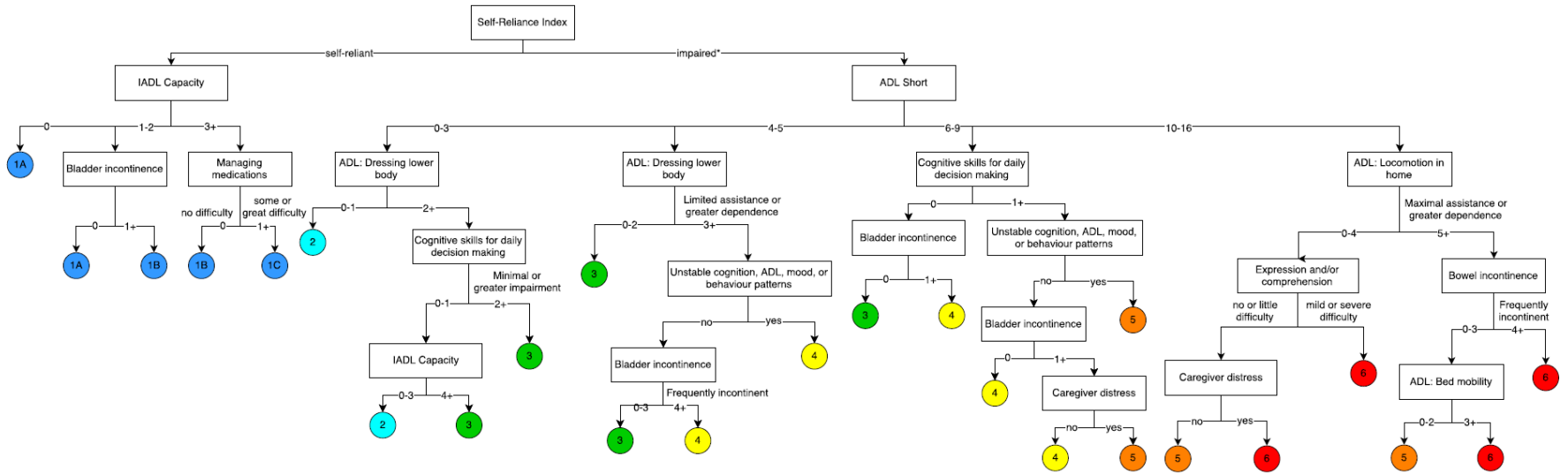
CHAPTER 4: What need characteristics are associated with receiving publicly funded PS/HM services among Ontario home care clients assessed with the RAI-Home Care (interRAI Home Care)?

4.1 Introduction

In April 2018, Ontario's LHINs adopted the Personal Support (PS) Algorithm as a common indicator of need for PS/HM services. The PS Algorithm ranges from 1 to 6, where higher PS Groups indicate greater need for PS/HM services [60]. Figure 4-1 illustrates the tree structure and Figure 4-2 lists the need characteristics within the PS Algorithm.

The PS Algorithm contains many of the relevant need characteristics that surfaced from the literature review in Section 2.3. The PS Algorithm was designed using the minimal number of variables to create a clinically meaningful classification system. Presence of any ADL or cognitive impairment and the degree of ADL impairment are assessed in 100% of root nodes. In other words, these variables are used to calculate the PS Group for all clients. Degree of IADL impairment, bladder incontinence, and unstable health patterns further classify clients with low to moderate functional impairment. Bowel incontinence, communication difficulties, and caregiver distress are used to differentiate among clients with higher levels of functional impairment. Having conditions or diseases that make cognition, ADL, mood, or behaviour patterns unstable was not directly examined in the literature although this item may represent some combination of general physical and mental health status and presence of chronic conditions.

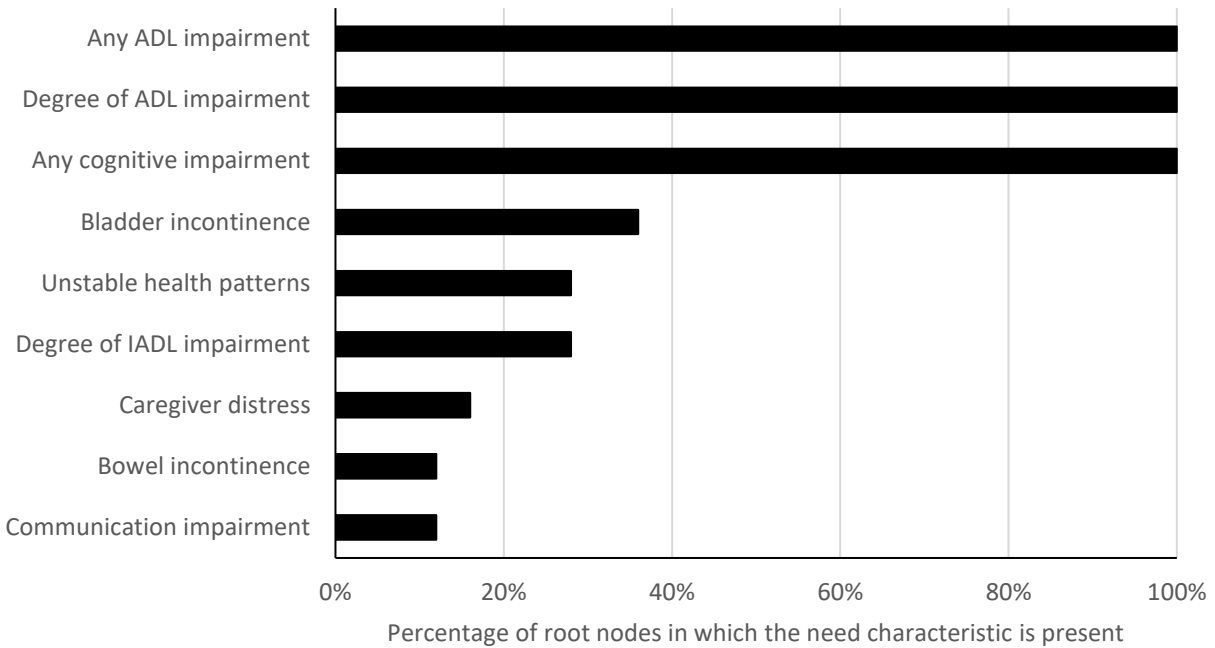
Figure 4-1 Schematic of the Personal Support Algorithm



*Person is impaired if ANY of:
 - Modified independent or any impairment in cognitive skills for daily decision making
 - Received supervision or any physical help in bathing, personal hygiene, dressing lower body, and/or locomotion

Adapted from Sinn et al. [60]

Figure 4-2 Representation of Need Characteristics in the PS Algorithm



The Levels of Care Framework proposed by the Levels of Care Expert Panel (refer to Section 1.4.1 for a general introduction) and the PS Algorithm share many similarities. Both sought to develop a needs-based tool to guide the allocation of home support services, sharing many of the same guiding principles such as equity, consistency, and flexibility. Although neither specify a theoretical framework, the emphasis on needs is consistent with the definition of equitable access in the Andersen-Newman model. Both propose that ADL and IADL impairment should primarily classify need for PS/HM services, which is operationalised using the interRAI IADL-ADL Functional Hierarchy Scale in the Levels of Care Framework and through other ADL and IADL scales and items in the PS Algorithm. Additionally, both acknowledge the relevance of other need (and possibly enabling) characteristics when considering need for PS/HM services. The Levels of Care Framework refers to these characteristics as “modifiers” that may modify the

level of functional need (although not to be confused with the epidemiologic term “effect modifier”) [35]. The PS Algorithm includes some of these modifiers within the algorithm itself.

Since the PS Algorithm and the Levels of Care Framework were developed mostly in isolation, it is important to study the relevance of modifiers that were raised by the Levels of Care Expert Panel. These additional variables include living arrangement, degree of cognitive impairment, health instability (based on its relationship with proximity to death), mental health needs, and caregiver distress. Cognitive impairment and caregiver distress appear in the PS Algorithm; however, it is worthwhile to explore whether the severity of cognitive impairment operates differently from the presence of any cognitive impairment and how caregiver distress is related to PS/HM service use at more moderate levels of functional impairment. The intention of this study is to discuss how care coordinators can consider these modifiers in conjunction with the PS Algorithm when developing service plans.

4.2 Objectives

1. Compare the performance of the PS Algorithm, IADL-ADL Functional Hierarchy Scale, and other relevant interRAI scales in explaining the allocation of publicly funded PS/HM services in Ontario.
2. Compare the median monthly hours of publicly funded PS/HM services and total home support by PS Algorithm and each of the following variables: living arrangement, degree of cognitive impairment, health instability, mental health needs, and caregiver distress.

4.3 Data Sources

This study uses client-level assessment and administrative data that were provided by HSSOntario, specifically home care referrals, RAI-HC assessments, and billed services.

4.4 Sample

First, all Ontario adult (age ≥ 18 years) home care referrals that had been admitted after 2010 to receive services were retrieved. Referrals without a valid client number or referral start date were deleted. If a client had overlapping referrals, the referral start date was reset to the earliest referral start date and the discharge date (if discharged) was reset to the latest discharge date. The home care episode refers to the length of time between the referral start date and the discharge date. Only referrals assigned one of the Acute, Rehabilitation, Maintenance, or Long-term Supportive Service Recipient Codes were kept. Second, all completed HC assessments (non-hospital versions) were retrieved. Using the client number, all assessments were matched with the referral that was active on the day that the assessment was completed. Within each episode, all assessments were sorted in ascending order and numbered from the first to n^{th} assessment. Next, only the HC assessments that were completed between April 1, 2016 and March 31, 2017 were retained. If a client had more than one assessment within the 12-month period, only the assessment closest to October 1, 2016 was retained.

This working dataset was joined with the billed services dataset. Other than case management and placement services, all other service types were retained. For each client, services that were received up to 84 days after the HC assessment date were retrieved. Clients receiving less than three weeks of home care services (e.g., PS/HM, nursing, physiotherapy, occupational therapy,

speech language pathology, nutrition/dietetic, social work, psychology) were removed from the dataset because they are not representative of the typical long-stay home care client.

Starting with 152,360 unique HC assessments, the final sample consisted of 126,001 unique assessments of individuals who received active home care services for at least three weeks. In Ontario, all long-stay home care clients must be routinely assessed with the HC assessment. Thus, this cross-sectional sample is a reflection of the long-stay home care client population in Ontario FY 2016/17.

4.5 Variables of Interest

4.5.1 Assessment Number

Each RAI-HC assessment was labelled with an assessment number during the dataset construction process, representing the client's n^{th} HC assessment received within their home care episode. Assessment numbers were grouped to facilitate the presentation of results: first HC, 2nd to 5th HC, 6th to 10th HC, and 11th+ HC. The first HC group was further divided into episodes in which the client did or did not receive a prior CA.

4.5.2 Enabling and Need Characteristics as Modifiers

Living arrangement at the time of referral is coded based on with whom the client lives and whether the primary informal caregiver lives with the client: “lives with primary caregiver” (client does not live alone and caregiver lives with client); “lives with other(s), not primary caregiver” (client does not live alone and caregiver does not live with client); and “lives alone” (client lives alone). *Degree of cognitive impairment* is operationalised using the Cognitive Performance Scale (CPS) [198]. The CPS is a hierarchical measure created from a count of

cognitive impairments and severe cognitive impairments, ranging from 0 (intact) to 6 (very severe impairment). *Health instability* is operationalised using the Changes in Health, End-stage disease, Signs, and Symptoms (CHESS) scale that measures medical complexity and health instability [178, 179]. CHESS is based on a count of decline in cognitive status, decline in ADL status, symptoms such as dehydration and weight loss, and clinician ratings of less than six months to live. *Mental health needs* is coded for the presence of any of the following: client is in a situation of or at substantial risk of neglect or abuse (i.e., Abusive Relationship Clinical Assessment Protocol (CAP) was triggered), client displays daily behavioural symptoms (i.e., Behaviour CAP was triggered), client displays depressive symptoms (i.e., Depression Rating Scale >0), or client experienced delusions or hallucinations in the last three days. *Caregiver distress* is coded for the presence of either “informal helper(s) is unable to continue in caring activities” or “primary informal helper expresses feelings of distress, anger, or depression”.

4.5.3 Formal and Informal Care

Monthly publicly funded PS/HM hours were derived from the billed services dataset. To represent PS/HM service visits, only visits classified as personal services, homemaking services, combined personal services and homemaking services, and respite were counted. To calculate monthly utilisation, the sum of PS/HM hours was divided by the number of service days (i.e., difference in days between the first and last visit) and multiplied by 28.

Review of the univariate distribution revealed 87 outliers accounting for 0.07% of episodes. Only two observations exceeded 672 hours/month (i.e., 24 hours/day) while 85 observations exceeded 336 hours/month (i.e., 12 hours/day). These episodes tended to represent short home care episodes for which the median PS/HM service length was 22 days and the median episode

length was 35 days. It is notable that 79% of outliers were referred from hospital (inpatient), 83% were eventually discharged to a long-term care home, and 75% occurred in either Hamilton Niagara Haldimand Brant or Waterloo Wellington LHINs that are known to operate transitional care programs. To minimise the effect of outliers, the maximum value of monthly public PS/HM hours was set at 336 for the purpose of calculating explained variance. The mean value decreased from 18.4 to 18.3 hours/month and the standard deviation decreased from 26.6 to 24.8 hours/month. Also of note is that the statutory maximum for publicly funded PS/HM services is 120 hours in any 30-day period that translates to 112 hours/month in this dataset [54]. Capping the maximum value did not affect 882 clients receiving more than the statutory maximum who may have been facing “extraordinary circumstances” according to the Ontario legislation.

Monthly total home support hours were derived from the HC assessment, representing the sum of formal (publicly and privately funded) and informal home support. Formal PS/HM hours were extrapolated from the “hours and minutes (rounded to even 10 minutes) of formal care (care or care management) in the last seven days” for home health aides and homemaking services. The minutes were divided by 60 and summed with the hours. Informal home support hours were extrapolated from the “hours of informal help (instrumental and personal activities of daily living) received over the last seven days”. Review of the univariate distributions revealed 1,743 cases of informal hours (1.4%) and 785 cases of formal hours (0.6%) exceeding 336 hours/month (i.e., 12 hours/day). Like the publicly funded PS/HM hours, each of the maximum values were set at 336 to minimise the effect of outliers when calculating explained variance. Summed together, the maximum value for monthly total home support hours was 672. The mean value

decreased from 108.4 to 104.1 hours/month and the standard deviation decreased from 115.2 to 92.2 hours/month.

4.6 Scales of Interest

4.6.1 Personal Support Algorithm

The PS Algorithm differentiates need for PS/HM services based on functional and cognitive impairment and other modifiers [60]. The PS Algorithm was developed using Ontario home and community care data, where higher groups were shown to be associated with greater use of publicly funded PS/HM services [60].

4.6.2 IADL-ADL Functional Hierarchy Scale

The IADL-ADL Functional Hierarchy Scale is a hierarchical measure of IADL and ADL performance that captures the full profile of functional loss from early loss IADLs to late loss ADLs [199]. The IADL-ADL Functional Hierarchy is a combination of the IADL Hierarchy Scale and ADL Hierarchy Scale, and ranges from 0 (independent) to 11 (ADL dependent). Each increase in the IADL-ADL Functional Hierarchy has been shown to be associated with a greater number of IADL and ADL areas requiring support as well as greater use of informal and formal support hours [199].

4.6.3 ADL Hierarchy Scale

The ADL Hierarchy Scale is a hierarchical measure of ADL performance that is based on the following self-performance items: personal hygiene (early loss ADL), toilet use and locomotion (middle loss ADLs), and eating (late loss ADLs) [200]. The ADL Hierarchy Scale ranges from 0 to 6, where higher scores indicate greater functional loss in ADL performance [200].

4.6.4 Assessment Urgency Algorithm

The Assessment Urgency Algorithm (AUA) ranges from 1 to 6, where higher scores indicate greater need and priority for a comprehensive follow-up assessment. Part of the AUA is the Self-Reliance Index that is based on four ADL self-performance items and cognitive skills for daily decision-making.

4.6.5 Resource Utilization Groups Version III for Home Care (RUG-III/HC)

The Resource Utilization Groups Version III for Home Care (RUG-III/HC) is a 23-group case mix system. Clients are first classified into seven hierarchical clinical categories (special rehabilitation, extensive services, special care, clinical complex, impaired cognition, behaviour problems, and reduced physical functions) and then further classified into 23 groups mostly based on ADL and IADL performance. At present, RUG-III/HC is used to calculate a part of LHIN home care budgets under the Health Based Allocation Model. In an Ontario validation study, RUG-III/HC explained 37.3% of the variance of the combined formal and informal cost of public home care services [174]

4.7 Analysis Plan

Client-level predisposing, enabling, and need characteristics were summarised in frequency tables and compared using chi-square tests. Performance and fit of various scales and algorithms in explaining service use were tested in linear regression models of publicly funded PS/HM hours and total home support hours. The IADL-ADL Functional Hierarchy Scale was collapsed into a seven-level framework in two ways: first, according to the recommended cut-offs in the Levels of Care Framework [35], and second, based on the best seven cluster definitions

generated by the varclus procedure. The expert-defined and data-informed clusters were identical except for the first level (Table 4-1). To test the relevance of additional modifiers, the median and distribution-free confidence intervals (95%) were calculated for monthly publicly funded PS/HM hours and total home support hours and compared across PS Groups and selected modifiers. Differences in the distribution of hours were tested using Wilcoxon Rank Sum tests. All analyses were done using SAS 9.4.

Table 4-1 Definition of Expert-Defined and Data-Informed IADL-ADL Functional Hierarchy Levels

Level of Care based on IADL-ADL Functional Hierarchy	1	2	3	4	5	6	7
Expert-defined groups	0	1, 2, 3, 4	5	6, 7	8	9	10, 11
Data-informed clusters	0, 1	2, 3, 4	5	6, 7	8	9	10, 11

4.8 Results

In Ontario FY 2016/17, there were 126,001 unique RAI-HC assessments completed for adult non-palliative long-stay clients receiving at least three weeks of active home care services. Of these, 45.9% (57,787) were the first HC assessments in the home care episode and 54.1% (68,214) were subsequent HC assessments. Most first HCs were preceded by a CA (81.9% (47,327)) although nearly one-fifth were not (18.1% (10,460)). The maximum assessment number was 33.

4.8.1 Sample Characteristics

Table 4-2 describes the predisposing and enabling characteristics. In general, many HC-assessed clients were older, female, and lived with their primary informal caregiver. At the first HC assessment, 60.1% of clients who had received a prior CA had been referred by the hospital

while 66.0% of clients who did not have a prior CA were referred from the community. Compared to other groups, those receiving a subsequent HC assessment were likely to be younger, female, and living with someone other than their primary caregiver. Receipt of publicly funded PS/HM services was common across all groups, but was particularly high among clients assessed with a subsequent HC (92.7%).

Table 4-3 describes the need characteristics. Comparing first and subsequent HC assessments, clients receiving their first HC were significantly more likely to have declined in ADL status, fallen in the last 90 days, have high health instability, and rate their health as poor. Subsequent HCs were more likely completed for clients with high functional impairment, severe cognitive impairment, bladder incontinence, unsteady gait, dyspnea, cardiovascular conditions, and psychiatric or mood conditions. Among the first HCs, those who did not receive a prior CA were significantly more likely to be more cognitively impaired (and have a diagnosis of dementia), have recently declined in cognitive status, and have unstable or fluctuating cognitive, ADL, mood, or behaviour patterns.

Table 4-2 Predisposing and Enabling Characteristics of HC-Assessed Clients, by First or Subsequent HC, Ontario FY 2016/17

% (n)	First HC (with prior CA) n=47,327	First HC (without prior CA) n=10,460	Subsequent HC n=68,214
Age			
18 to 64 years	17.7 (8,353)	13.5 (1,415)	19.5 (13,294)
65 to 84 years	49.0 (23,171)	46.9 (4,900)	50.1 (34,169)
85+ years	33.4 (15,803)	39.6 (4,145)	30.4 (20,751)
Sex			
Female	59.5 (28,179)	62.7 (6,556)	66.7 (45,478)
Not female	40.5 (19,148)	37.3 (3,904)	33.3 (22,736)
Living arrangement			
Lives with primary caregiver	52.4 (24,780)	49.5 (5,180)	49.0 (33,454)
Lives with other(s), not primary caregiver	15.7 (7,420)	17.9 (1,877)	19.4 (13,250)
Lives alone	32.0 (15,127)	32.5 (3,403)	31.5 (21,510)
Referral source			
Hospital	60.1 (28,456)	34.0 (3,553)	47.8 (32,600)
Community	39.9 (18,871)	66.0 (6,907)	52.2 (35,614)
Local Health Integration Network			
Central East	11.7 (5,523)	13.3 (1,388)	15.0 (10,209)
Central	12.2 (5,758)	15.8 (1,648)	15.9 (10,861)
Champlain	7.5 (3,548)	4.9 (514)	9.0 (6,107)
Central West	3.8 (1,800)	2.0 (210)	3.4 (2,310)
Erie St. Clair	5.8 (2,724)	3.6 (381)	5.6 (3,827)
Hamilton Niagara Haldimand Brant	12.8 (6,064)	20.8 (2,175)	8.8 (5,967)
Mississauga Halton	6.1 (2,903)	6.4 (669)	4.2 (2,874)
North East	6.3 (2,966)	2.6 (267)	5.8 (3,957)
North Simcoe Muskoka	4.0 (1,896)	5.2 (540)	3.5 (2,370)
North West	2.0 (932)	0.7 (73)	2.1 (1,419)
South East	6.5 (3,052)	2.0 (204)	5.1 (3,460)
South West	7.8 (3,703)	8.5 (885)	6.3 (4,327)
Toronto Central	7.0 (3,332)	11.4 (1,190)	10.3 (7,029)
Waterloo Wellington	6.6 (3,126)	3.0 (316)	5.1 (3,497)
Received any publicly funded PS/HM services	71.6 (33,884)	78.9 (8,255)	92.7 (63,223)

- Chi-square test: All results were significant at $p < .0001$ unless otherwise noted.

Table 4-3 Need Characteristics of HC-Assessed Clients, by First or Subsequent HC, Ontario FY 2016/17

% (n)	First HC (with prior CA) n=47,327	First HC (without prior CA) n=10,460	Subsequent HC n=68,214
Cognitive Performance Scale			
No impairment (0)	28.9 (13,676)	17.0 (1,782)	16.0 (10,890)
Mild impairment (1–2)	59.9 (28,364)	61.9 (6,471)	63.4 (43,272)
Moderate impairment (3–4)	8.0 (3,803)	14.6 (1,531)	12.6 (8,574)
Severe impairment (5–6)	3.1 (1,484)	6.5 (676)	8.0 (5,478)
Activities of Daily Living Hierarchy Scale			
Independent (0)	46.3 (21,902)	37.8 (3,949)	33.6 (22,914)
Mostly independent (1–2)	34.6 (16,373)	37.6 (3,930)	38.8 (26,463)
Extensive assistance (3–4)	15.1 (7,151)	19.4 (2,030)	20.7 (14,140)
Mostly dependent (5–6)	4.0 (1,901)	5.3 (551)	6.9 (4,697)
Cognitive decline in last 90 days	26.6 (12,607)	36.6 (3,827)	21.8 (14,834)
Functional decline in last 90 days	72.3 (34,193)	73.3 (7,663)	43.8 (29,877)
Bladder incontinence, at least twice weekly episodes	34.9 (16,503)	43.0 (4,496)	49.6 (33,810)
Fall in last 90 days	49.7 (23,526)	48.6 (5,083)	32.2 (21,951)
Unsteady gait	76.1 (36,018)	77.9 (8,149)	81.1 (55,289)
Dyspnea	35.2 (16,670)	31.0 (3,246)	36.7 (25,019)
Unstable or fluctuating cognitive/ADL/mood/behaviour patterns	59.3 (28,079)	65.7 (6,872)	64.7 (44,108)
Changes in Health, End-stage disease, Signs, and Symptoms Scale			
No health instability (0)	10.9 (5,155)	10.9 (1,138)	21.5 (14,670)
Minimal to moderate health instability (1–3)	81.5 (38,590)	81.1 (8,486)	74.2 (50,613)
High to very high health instability (4–5)	7.6 (3,582)	8.0 (836)	4.3 (2,931)
Poor self-rated health	31.6 (14,975)	30.0 (3,139)	28.5 (19,432)
Diagnosed conditions			
Cardiovascular conditions	39.3 (18,591)	37.4 (3,911)	44.6 (30,393)
Dementia	18.9 (8,934)	31.9 (3,336)	24.4 (16,619)
Psychiatric or mood conditions	19.2 (9,086)	21.0 (2,198)	22.8 (15,574)

- Chi-square test: All results were significant at $p < .0001$ unless otherwise noted.

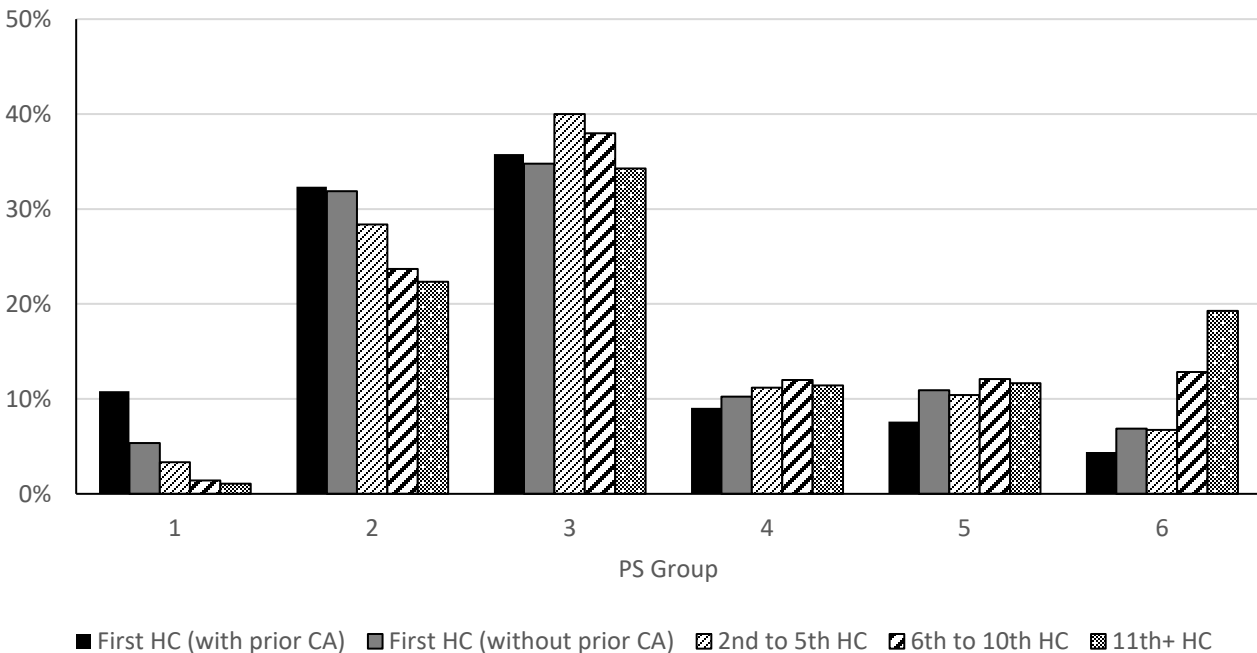
Table 4-4 shows the average number of days from the referral date to HC assessment date. In general, the first HCs were completed soon after the referral, although clients not receiving a prior assessment were usually assessed much sooner (i.e., within one to two weeks). Clients in the subsequent HC groups had been on home care service for two, five, and 10 years on average.

Table 4-4 Number of Days from Referral Date to HC Assessment Date among HC-Assessed Clients, Ontario FY 2016/17

HC assessment number	n	Number of days from referral date to HC assessment date			
		Mean ± SD		Median	
First HC (with prior CA)	47,327	49 ± 138		17	
First HC (without prior CA)	10,460	14 ± 48		8	
2nd to 5th HC	46,522	(1.8 ± 1.3 years)	669 ± 480	(1.5 years)	561
6th to 10th HC	14,687	(5.1 ± 2.6 years)	1,855 ± 945	(4.8 years)	1,741
11th+ HC	7,005	(10.0 ± 4.5 years)	3,651 ± 1,656	(9.6 years)	3,486

Figure 4-3 illustrates the distribution of clients by PS Group and HC assessment date. The distributions of first HCs were similar although clients who received a prior CA were significantly more likely to be in PS Groups 1 through 3 ($\chi^2=500.0$, $p<.0001$). More clients receiving subsequent HC assessments were in PS Groups 4 through 6 ($\chi^2=1745.0$, $p<.0001$).

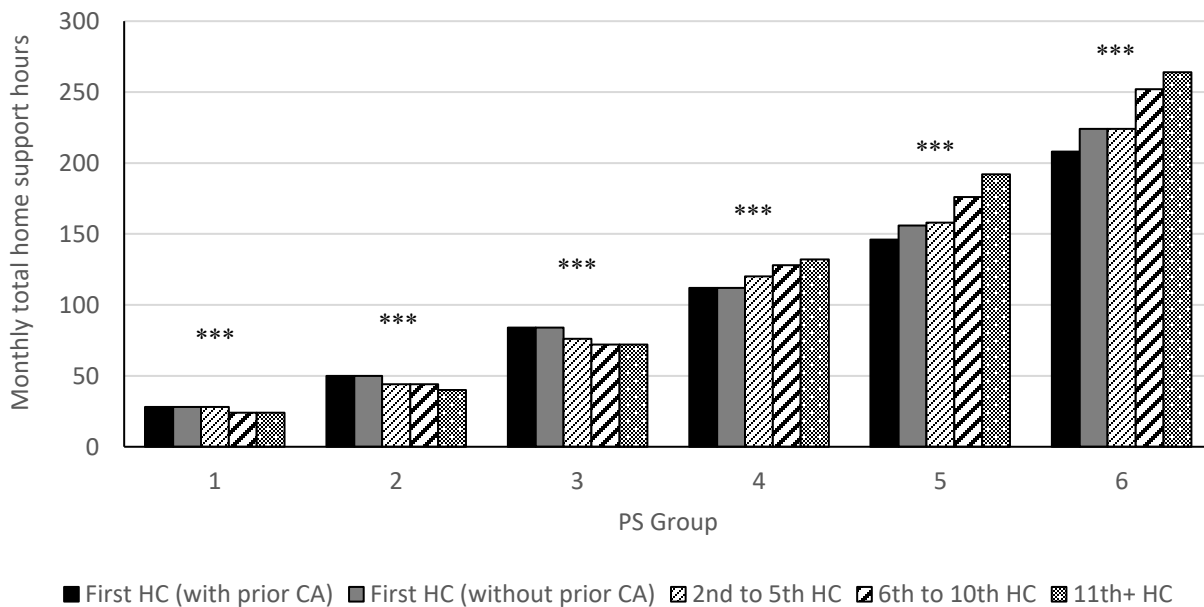
Figure 4-3 Distribution of HC-Assessed Clients by PS Group and HC Assessment Number, Ontario FY 2016/17



- Chi-square test: All results were significant at $p<.0001$ unless otherwise noted.
- For significance testing, the first HC (with prior CA) group was used as the reference group.

Figure 4-4 illustrates the median monthly total support hours by PS Group and HC assessment number. Clients in higher PS Groups received more total support hours. In PS Groups 1 through 3, clients assessed with subsequent HCs received fewer total support hours ($\chi^2=24.2$ to 76.0 , $p<.0001$). In contrast, clients assessed with subsequent HCs received more total support hours in PS Groups 4 through 6 ($\chi^2=54.1$ to 213.2 , $p<.0001$).

Figure 4-4 Median Monthly Total Home Support Hours among HC-Assessed Clients, by PS Group and HC Assessment Number, Ontario FY 2016/17



Kruskal-Wallis test: * $p<.05$, ** $p<.01$, *** $p<.0001$

In Table 4-5, the median monthly informal hours are presented as a proportion of total home support hours. On average, informal hours accounted for between 70% and 90% of total support hours. Informal hours accounted for nearly all support received by clients in PS Group 1 and clients receiving their first HC in PS Group 2.

Table 4-5 Median Monthly Informal Hours as a Proportion of Total Home Support Hours among HC-Assessed Clients, by PS Group and HC Assessment Number, Ontario FY 2016/17

Median (Q1–Q3)	Monthly informal hours as a proportion of total home support hours, %					
	PS Group	First HC (with prior CA)	First HC (without prior CA)	2nd to 5th HC	6th to 10th HC	11th+ HC
1	100.0 (100.0–100.0)	100.0 (100.0–100.0)	100.0 (100.0–100.0)	100.0 (100.0–100.0)	100.0 (100.0–100.0)	100.0 (93.3–100.0)
2	95.5 (75.9–100.0)	100.0 (80.0–100.0)	80.0 (60.0–91.3)	75.0 (50.0–87.5)	71.4 (50.0–85.7)	71.4 (50.0–85.7)
3	87.5 (65.0–100.0)	93.5 (68.6–100.0)	77.8 (55.6–90.6)	73.7 (50.0–87.5)	70.4 (45.5–85.1)	70.4 (45.5–85.1)
4	84.2 (58.0–100.0)	89.4 (60.0–100.0)	77.8 (54.4–90.3)	73.2 (50.0–85.7)	68.2 (40.0–82.4)	68.2 (40.0–82.4)
5	81.1 (52.2–97.7)	77.8 (46.2–100.0)	77.8 (57.1–89.6)	74.1 (53.8–85.4)	71.4 (47.3–84.8)	71.4 (47.3–84.8)
6	75.0 (46.2–93.3)	72.7 (44.4–93.5)	75.6 (55.3–87.5)	76.0 (60.0–84.9)	74.7 (58.8–83.3)	74.7 (58.8–83.3)

4.8.2 Comparison of Scales and Algorithms

Table 4-6 and Table 4-7 present the results of fitting linear regression models predicting publicly funded PS/HM and total home support hours. The results are ordered from the most to least predictive scales and algorithms.

All scales and algorithms were better at explaining total home support hours (vs. publicly funded hours alone), and among subsequent HC assessments. In all sub-samples, the PS Algorithm was the best performer with the highest explained variance and lowest coefficient of variation.

Overall, the PS Algorithm explained 25.5% of variance in publicly funded PS/HM hours and 33.4% of variance in total home support hours. Performance of the PS Algorithm among first HCs without a prior CA was weaker (17.5%) although clients in this group may represent local programs with unique goals and eligibility criteria. Performance of either the data-informed clusters or expert-defined groups of the IADL-ADL Functional Hierarchy were similar,

explaining 22.6% and 22.5% of the variance in publicly funded PS/HM hours and 30.5% and 29.3% of variance in total home support hours. The Assessment Urgency Algorithm was the least predictive option.

Table 4-6 Performance of interRAI Scales and Algorithms in Explaining Publicly Funded and Total Home Support Hours among Clients Receiving Their First HC Assessments, Ontario FY 2016/17

Scale or algorithm	First HC (with prior CA) n=47,327		First HC (without prior CA) n=10,460	
	Explained variance, %	Coefficient of variation	Explained variance, %	Coefficient of variation
PS Algorithm				
Formal (public) hours	21.1	151.3	17.5	168.3
Formal + informal hours	28.1	76.0	28.9	75.7
IADL-ADL Functional Hierarchy (data-informed clusters)				
Formal (public) hours	17.9	154.3	15.9	169.9
Formal + informal hours	25.0	77.6	26.0	77.3
IADL-ADL Functional Hierarchy (expert-defined groups)				
Formal (public) hours	17.8	154.4	15.9	169.9
Formal + informal hours	24.3	77.9	25.3	77.6
ADL Hierarchy Scale				
Formal (public) hours	17.4	154.7	15.7	170.1
Formal + informal hours	23.1	78.5	24.3	78.2
Assessment Urgency Algorithm				
Formal (public) hours	7.4	163.9	4.4	181.1
Formal + informal hours	12.0	84.0	10.5	85.0

Table 4-7 Performance of interRAI Scales and Algorithms in Explaining Publicly Funded and Total Home Support Hours among Clients Receiving Subsequent HC Assessments, Ontario FY 2016/17

	2nd to 5th HC n=46,522		6th to 10th HC n=14,687		11th+ HC n=7,005	
	Explained variance, %	Coefficient of variation	Explained variance, %	Coefficient of variation	Explained variance, %	Coefficient of variation
PS Algorithm						
Formal (public) hours	25.5	98.9	34.2	79.0	37.1	73.6
Formal + informal hours	30.7	71.6	40.6	66.4	48.5	60.8
IADL-ADL Functional Hierarchy (data-informed clusters)						
Formal (public) hours	23.1	100.5	31.6	80.5	33.5	75.7
Formal + informal hours	28.7	72.6	37.6	68.0	45.6	62.5
IADL-ADL Functional Hierarchy (expert-defined clusters)						
Formal (public) hours	23.0	100.6	31.4	80.7	33.2	75.9
Formal + informal hours	27.2	73.4	36.0	68.9	44.2	63.3
ADL Hierarchy Scale						
Formal (public) hours	22.6	100.9	31.2	80.8	33.3	75.8
Formal + informal hours	26.1	73.4	35.6	69.1	44.6	63.1
Assessment Urgency Algorithm						
Formal (public) hours	8.2	109.9	10.0	92.4	10.6	87.5
Formal + informal hours	10.4	81.4	10.4	81.5	12.0	79.5

Table 4-8 compares the performance of RUG-III/HC and the PS Algorithm. The two most common Resource Utilization Group (RUG) categories (“reduced physical functions” and “clinically complex”) represented over three-quarters of all clients. All other RUG categories accounted for less than 10% of the HC-assessed population. In every RUG category, the PS Algorithm outperformed RUG-III/HC in explaining the variance in monthly publicly funded PS/HM services. In the “reduced physical functions” clinical category, the PS Algorithm and RUG-III/HC explained 29.0% and 24.6% of the variance in monthly publicly funded PS/HM services, respectively. Aside from the “extensive services” category, the two algorithms were substantially correlated, with Spearman’s rank correlation coefficients ranging from 0.64 in the

“special care” category (i.e., clients requiring tracheostomy or ventilator/respirator care) to 0.80 in the “reduced physical functions” category.

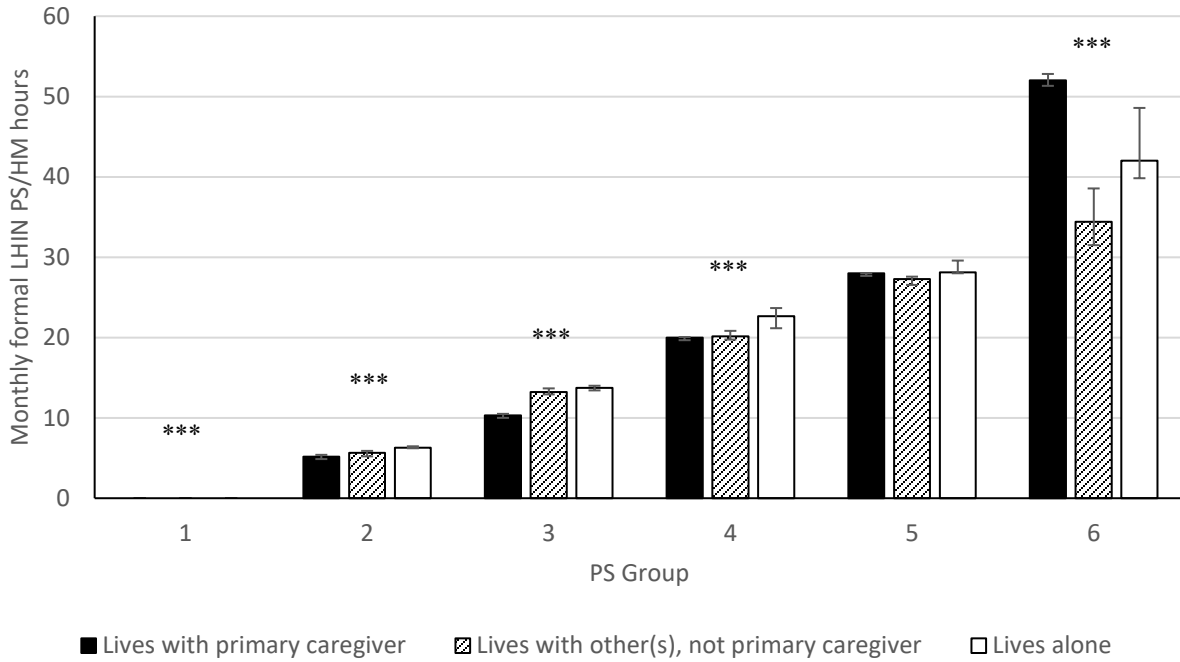
Table 4-8 Comparison of RUG-III/HC and PS Algorithm in Explaining Monthly Formal Publicly Funded PS/HM Hours, by RUG Clinical Category, Ontario FY 2016/17

RUG clinical category	Proportion of HC-assessed population, %	Explained variance, %		Spearman’s rank correlation (ρ) between RUG-III/HC and PS Algorithm
		RUG-III/HC	PS Algorithm	
Special rehabilitation	7.5	15.6	22.6	0.71
Extensive services	1.9	0.3	9.3	0.09
Special care	2.1	6.1	11.8	0.64
Clinically complex	24.5	20.9	28.7	0.74
Impaired cognition	9.1	3.8	6.1	0.71
Behaviour problems	1.3	8.0	14.1	0.65
Reduced physical functions	53.5	24.6	29.0	0.80

4.8.3 Additional Modifiers of Home Support Use

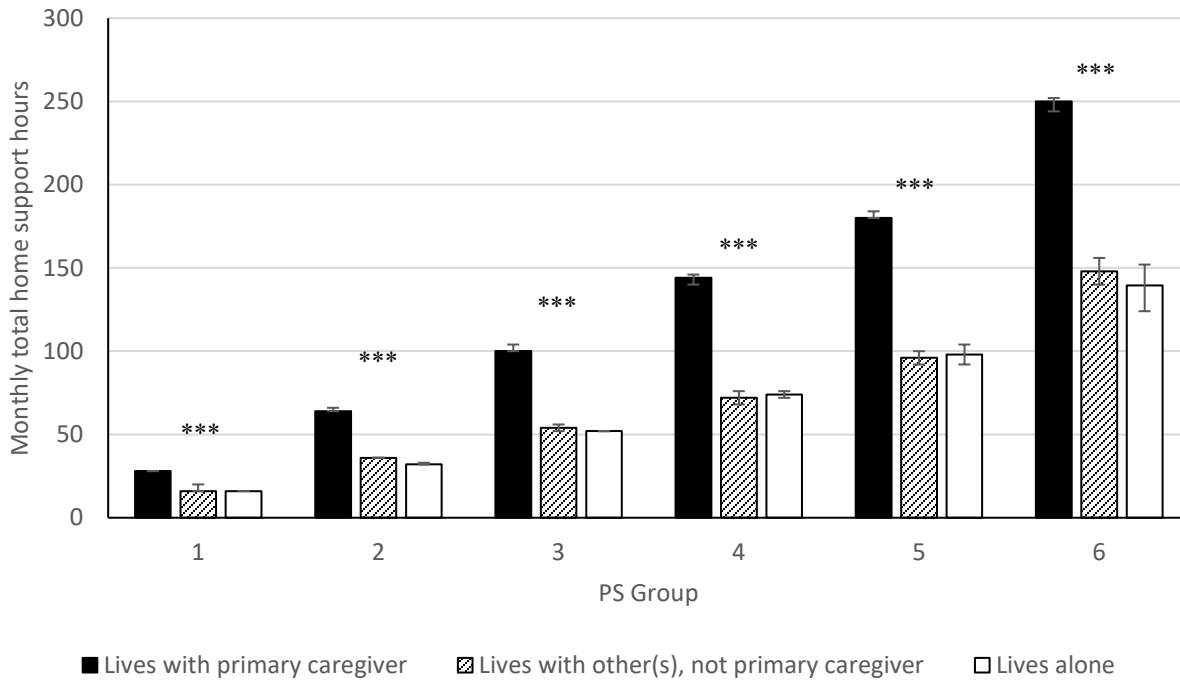
Monthly publicly funded PS/HM hours differed by living arrangement (Figure 4-5). In general, clients living alone received slightly but significantly more hours ($\chi^2=27.8$ to 739.4, $p<.0001$). The exception was PS Group 6 in which clients living with their primary informal caregiver received significantly more publicly funded PS/HM hours ($\chi^2=147.4$, $p<.0001$). In Figure 4-6, clients living with their primary informal caregiver received much more total home support hours than clients living with others or living alone ($\chi^2=865.0$ to 8916.7, $p<.0001$).

Figure 4-5 Median Monthly Publicly Funded PS/HM Hours by PS Group and Living Arrangement among HC-Assessed Clients, Ontario FY 2016/17



Kruskal-Wallis test: *p<.05, **p<.01, ***p<.0001

Figure 4-6 Median Monthly Total Home Support Hours by PS Group and Living Arrangement among HC-Assessed Clients, Ontario FY 2016/17



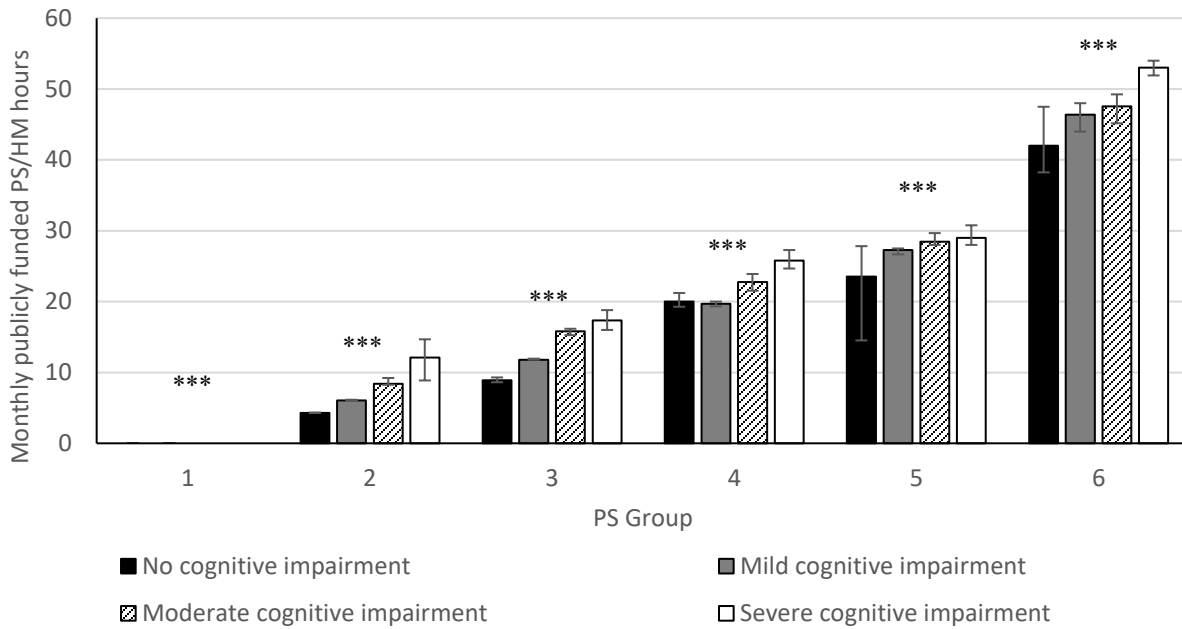
Kruskal-Wallis test: *p<.05, **p<.01, ***p<.0001

In Figure 4-7 and Figure 4-8, clients with greater cognitive impairment received significantly more monthly publicly funded PS/HM hours ($\chi^2=59.1$ to 939.9 , $p<.0001$) and total home support hours ($\chi^2=312.9$ to 1781.6 , $p<.0001$). In PS Group 1, monthly total home support hours did not vary with the degree of cognitive impairment ($p=0.75$). Visual inspection of the error bars suggests that most of the significant differences are attributable to comparisons between the most severely impaired clients compared to other clients. In Figure 4-8, clients with moderate cognitive impairment also received significantly more total home support hours than other clients. Generally, there was minimal difference in hours between clients with no and mild cognitive impairment.

Figure 4-9 and Figure 4-10 show that publicly funded PS/HM hours and total home support hours generally do not respond to health instability, except at very high levels (i.e., CHESS 5). Notably, neither monthly publicly funded PS/HM hours nor total home support hours were statistically different among clients in CHESS 5 across PS Groups 3, 4 ($p=0.06$), and 5 ($p=0.09$).

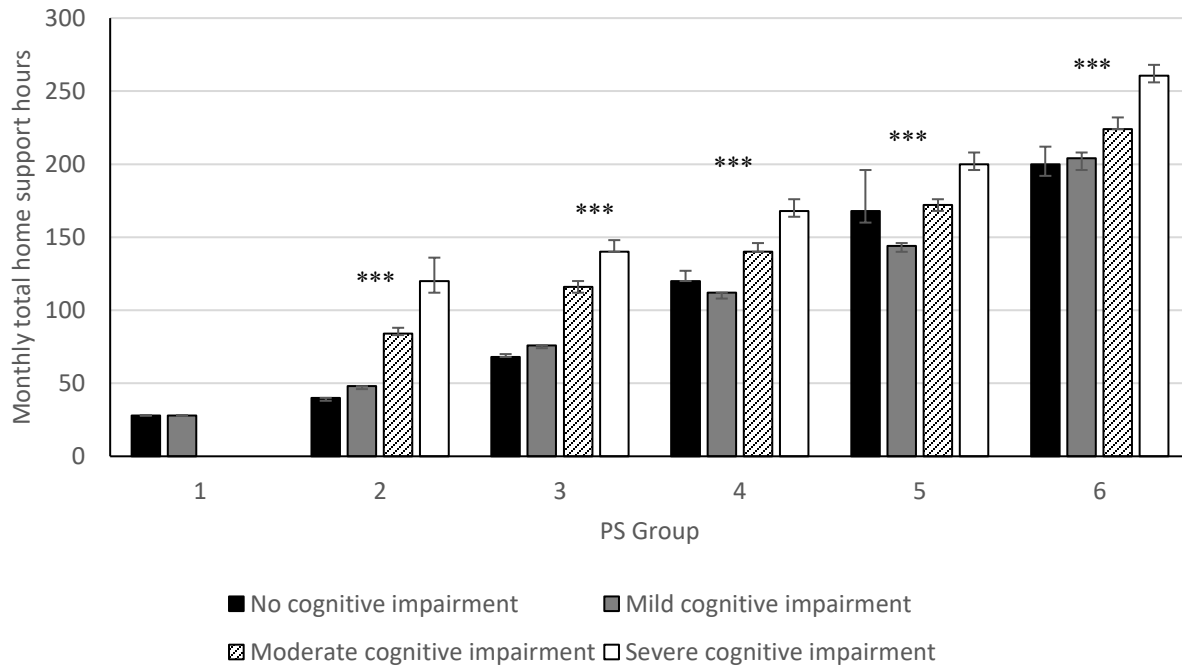
In Figure 4-11, clients with a mental health issue received significantly although only slightly more publicly funded PS/HM hours, except for clients in PS Group 4 ($p=0.06$). In Figure 4-12, clients with a mental health issue also received slightly more total home support hours, except for clients in PS Group 1 ($p=0.91$).

Figure 4-7 Median Monthly Publicly Funded PS/HM Hours by PS Group and Cognitive Impairment among HC-Assessed Clients, Ontario FY 2016/17



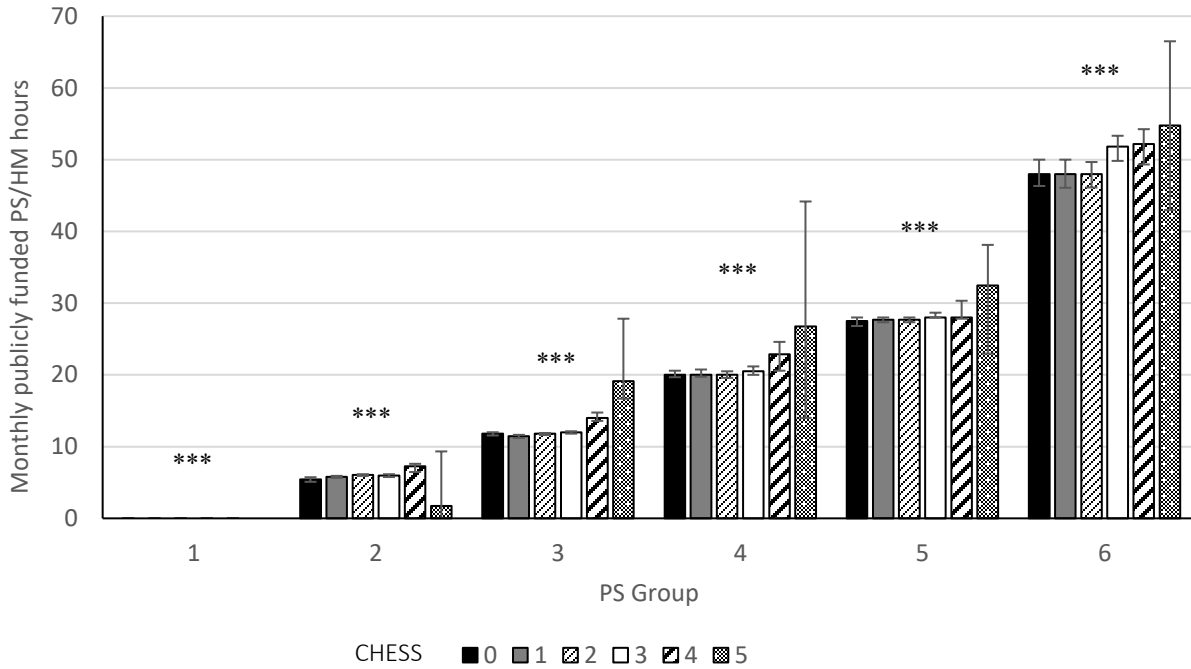
Kruskal-Wallis test: *p<.05, **p<.01, ***p<.0001

Figure 4-8 Median Monthly Total Home Support Hours by PS Group and Cognitive Impairment among HC-Assessed Clients, Ontario FY 2016/17



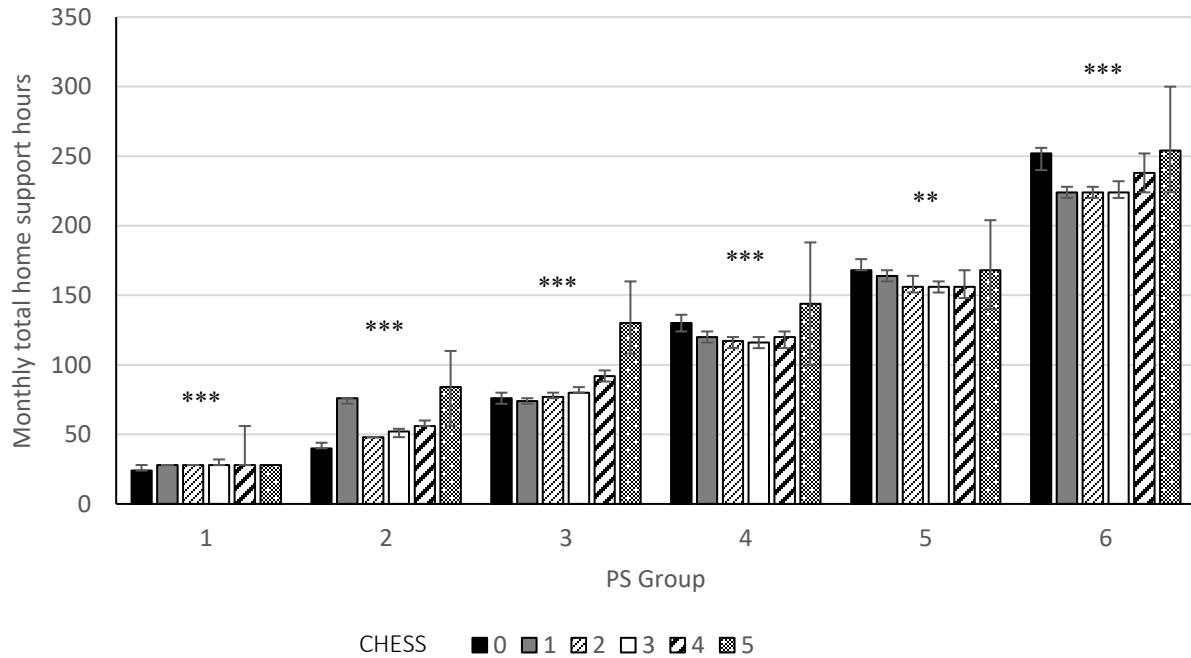
Kruskal-Wallis test: *p<.05, **p<.01, ***p<.0001

Figure 4-9 Median Monthly Publicly Funded PS/HM Hours by PS Group and Health Instability among HC-Assessed Clients, Ontario FY 2016/17



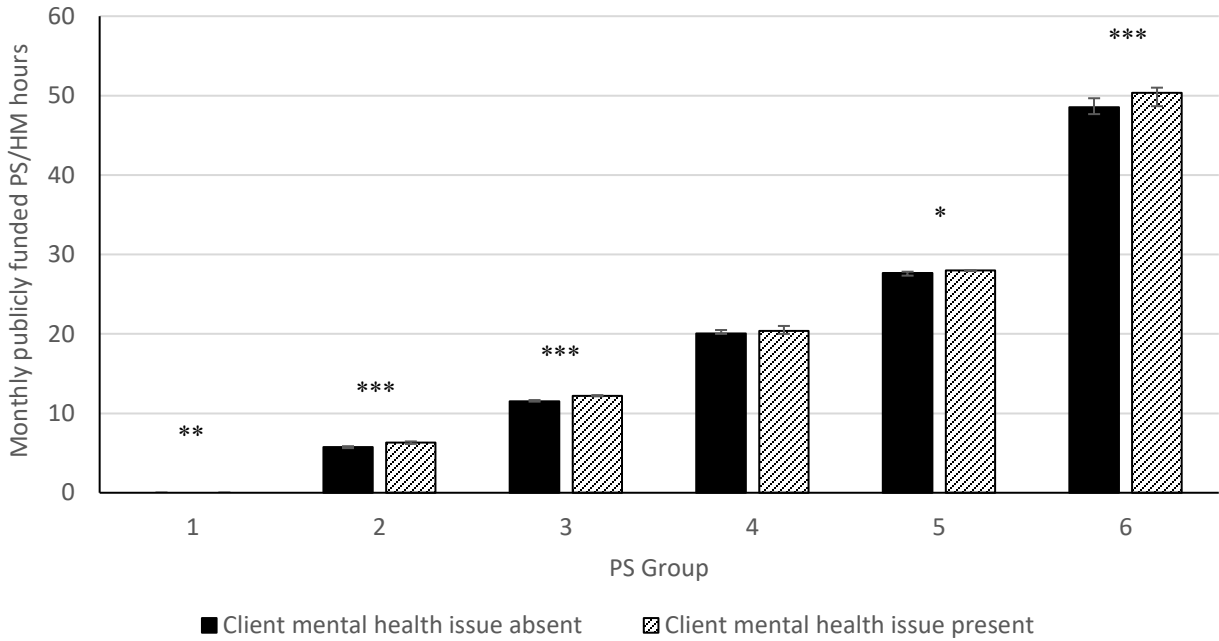
Kruskal-Wallis test: *p<.05, **p<.01, ***p<.0001

Figure 4-10 Median Monthly Total Home Support Hours by PS Group and Health Instability among HC-Assessed Clients, Ontario FY 2016/17



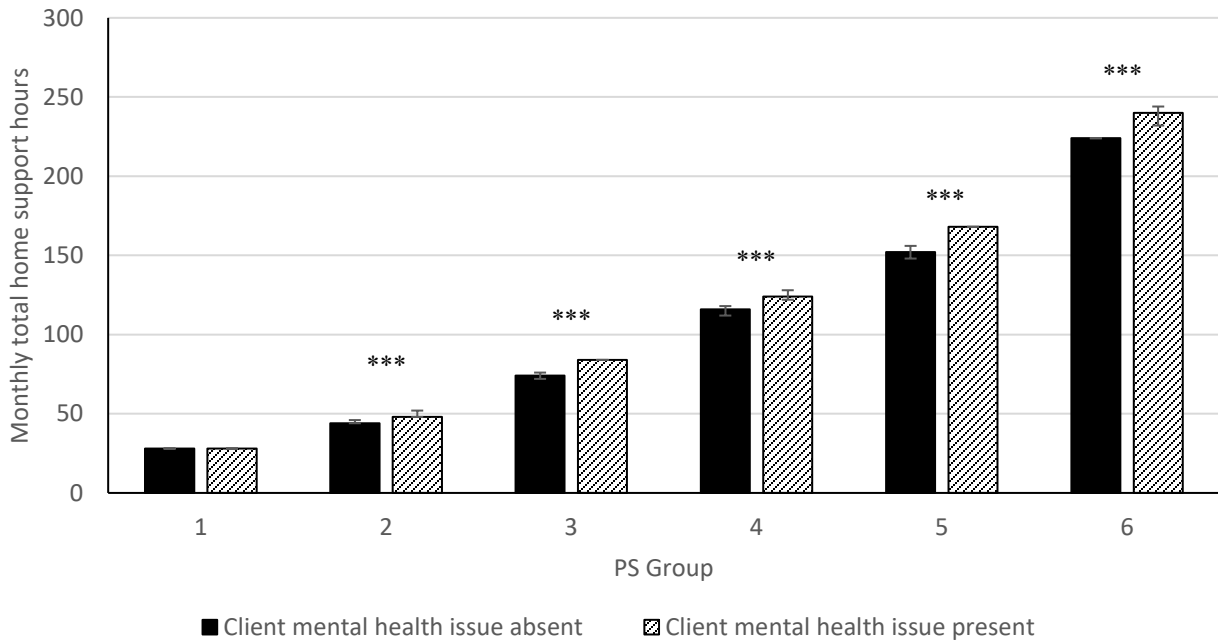
Kruskal-Wallis test: *p<.05, **p<.01, ***p<.0001

Figure 4-11 Median Monthly Publicly Funded PS/HM Hours by PS Group and Client Mental Health among HC-Assessed Clients, Ontario FY 2016/17



Kruskal-Wallis test: * $p < .05$, ** $p < .01$, *** $p < .0001$

Figure 4-12 Median Monthly Total Home Support Hours by PS Group and Client Mental Health among HC-Assessed Clients, Ontario FY 2016/17

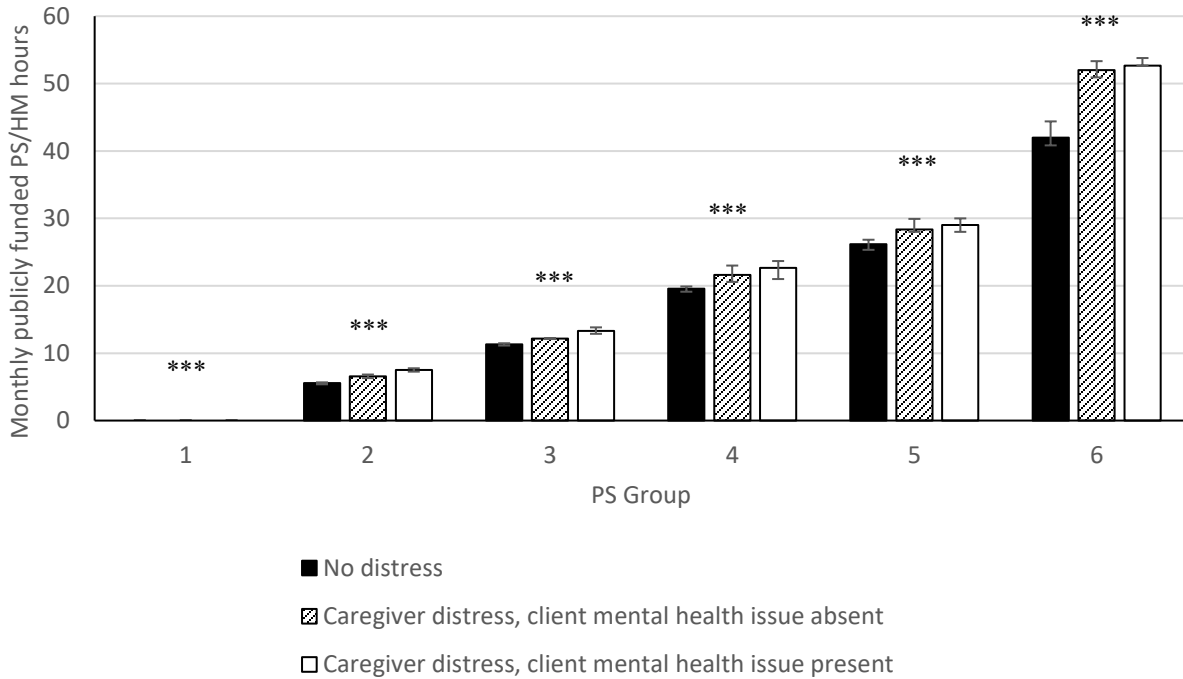


Kruskal-Wallis test: * $p < .05$, ** $p < .01$, *** $p < .0001$

In Figure 4-13, monthly publicly funded PS/HM hours increased with caregiver distress ($\chi^2=26.9$ to 374.1, $p<.0001$). Among distressed caregivers, clients with a mental health issue received significantly more publicly funded hours in PS Groups 2 ($\chi^2=41.0$, $p<.0001$) and 3 ($\chi^2=20.9$, $p<.0001$) only, suggesting that most of the difference in formal hours was explained by caregiver distress, regardless of the client's mental health status.

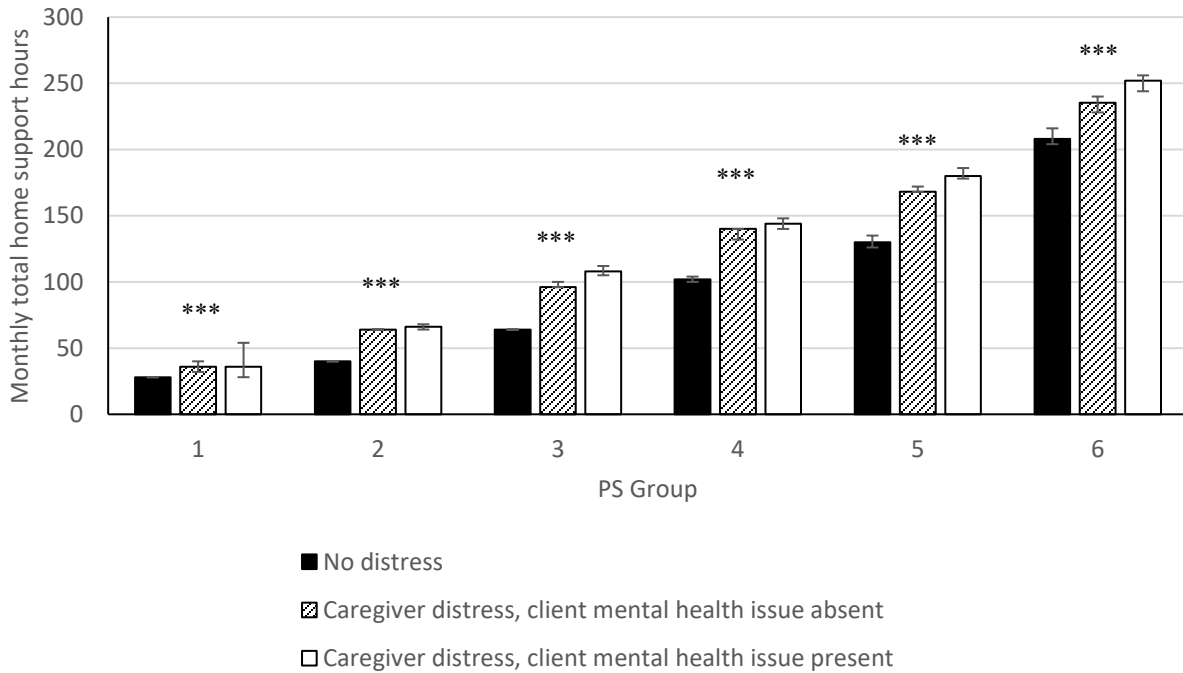
In Figure 4-14, monthly total home support hours increased with caregiver distress ($\chi^2=106.6$ to 3510.0, $p<.0001$). Among distressed caregivers, clients with a mental health issue received significantly more total home support hours in all PS Groups except PS Group 1 ($p=0.85$).

Figure 4-13 Median Monthly Publicly Funded PS/HM Hours by PS Group and Caregiver Distress among HC-Assessed Clients, Ontario FY 2016/17



Kruskal-Wallis test: *p<.05, **p<.01, ***p<.0001

Figure 4-14 Median Monthly Total Home Support Hours by PS Group and Caregiver Distress among HC-Assessed Clients, Ontario FY 2016/17

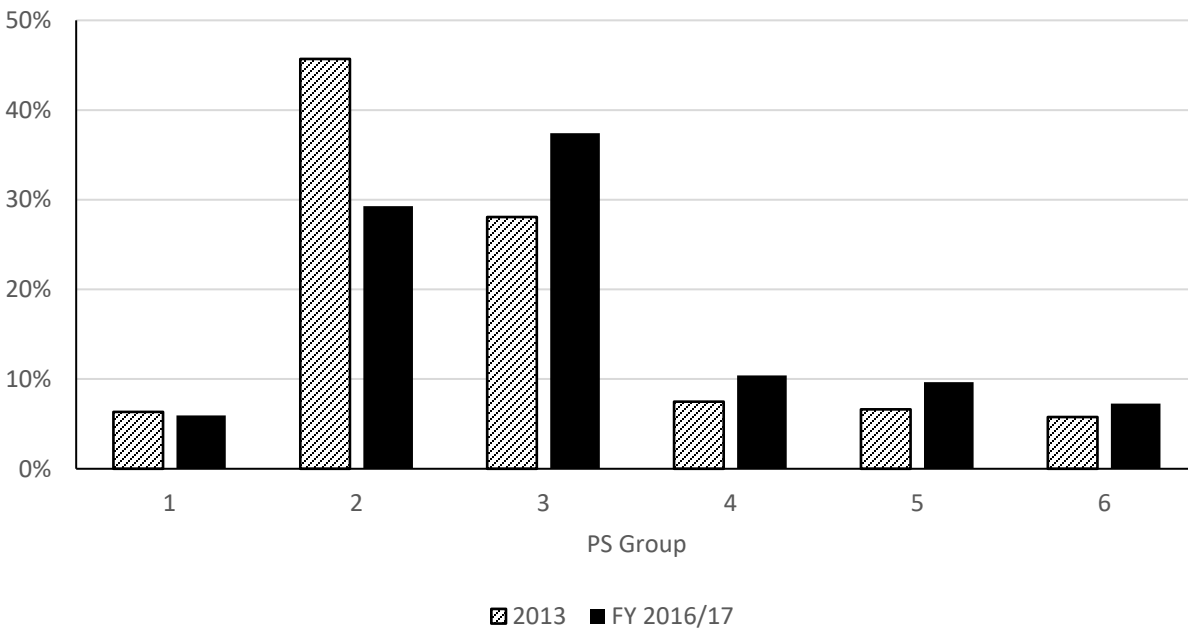


Kruskal-Wallis test: *p<.05, **p<.01, ***p<.0001

4.8.4 Updated Framework of Hours

The PS Algorithm was originally derived on data from January to December 2013. As shown in Figure 4-15, the proportion of clients in PS Groups 3 through 6 increased while the proportion of clients in lower PS Groups 1 and 2 decreased between calendar year 2013 and FY 2016/17 ($\chi^2=7847.0, p<.0001$). By percentage difference, the largest gains were observed in PS Group 5 (+45.9%) and PS Group 4 (+39.2%). The largest reduction was observed in PS Group 2 (-36.0%).

Figure 4-15 Comparison of the Distribution of HC-Assessed Clients by PS Group, Ontario 2013 and FY 2016/17



The PS Algorithm's Framework of Hours was originally derived on data from FY 2014/15 with the following exclusions: (1) clients residing in a retirement home, supportive housing, or assisted living; (2) clients who were on a waitlist or on hold and did not receive any publicly funded PS/HM services in the 12-week period; and (3) clients who were in Groups 3 to 6 but

received no publicly funded PS/HM services [60]. These exclusion criteria were intended to minimise the effect of non-need factors that were related to PS/HM utilisation, namely the presence of other sources of help and insufficient formal services to meet demand. In particular, clients meeting the third criterion likely received no PS/HM services for reasons other than absence of need (e.g., client or family declined offered services). The distribution of publicly funded PS/HM hours within each PS group were used to create the Framework of Hours, where care coordinators could expect to allocate PS/HM services most frequently within the 35th to 65th percentiles, occasionally between the 20th and 80th percentiles, and only in exceptional circumstances beyond the 20th and 80th percentiles. The original Framework of Hours is presented in Table 4-9.

Table 4-9 Original Framework of Hours for the PS Algorithm Based on Ontario FY 2014/15 Data

PS Group	Publicly funded PS/HM hours per month				
	20 th	35 th	50 th	65 th	80 th
1	0.0	0.0	0.0	0.0	0.0
2	0.0	3.6	6.1	8.2	12.3
3	7.7	11.1	16.0	23.1	32.1
4	11.5	19.1	26.7	36.4	53.5
5	15.7	25.2	34.8	48.2	56.8
6	28.0	42.2	54.3	56.7	75.9
		35 th to 65 th percentile band			
		20 th to 80 th percentile band			

To the extent that available data would allow, the same exclusion criteria were applied to FY 2016/17 data to replicate the Framework of Hours; however, waitlist information was not available to operationalise the second criterion. Many LHINs have partial or full waitlists for PS/HM services. A client’s utilisation would appear much lower if they were placed on a waitlist or on hold but received at least one PS/HM visit before and after the hold period. Thus, some

decrease in the percentile values, especially across the lower PS groups, would be expected since it is reasonable to assume that care coordinators would prioritise the allocation of limited resources to clients in the higher PS Groups. The updated Framework of Hours is presented in Table 4-10. Nearly all percentile values decreased except in PS Group 1 that had zero values in both the original and updated frameworks. The only increase was observed in the 35th percentile of PS Group 2, increasing from 3.6 hours/month to 4.0 hours/month.

Table 4-10 Updated Framework of Hours for the PS Algorithm Based on Ontario FY 2016/17 Data

PS Group	Publicly funded PS/HM hours per month				
	20 th	35 th	50 th	65 th	80 th
1	0.0	0.0	0.0	0.0	0.0
2	0.0	4.0	6.1	8.1	11.5
3	7.3	8.5	12.3	18.4	26.7
4	10.8	16.0	22.6	28.0	43.3
5	15.2	23.2	29.2	42.0	55.5
6	27.3	40.2	53.5	56.0	74.0
	35 th to 65 th percentile band				
	20 th to 80 th percentile band				

Based on percentage difference, the largest decreases occurred in the median and 35th to 65th percentile band in the higher PS Groups (Table 4-11). In PS Group 3, the median fell from 16.0 hours/month to 12.3 hours/month, a 23.2% percent decrease. Similarly, the median values fell by 15.3%, 16.1%, and 1.5% in PS Groups 4, 5, and 6. Notably, the width between pairs of percentiles also decreased substantially. The width of three 35th to 65th percentile bands and two 20th to 80th percentile bands decreased by at least 15%. Only the distance between the 35th and 65th percentiles in Group 6 increased.

Table 4-11 Percentage Change in Percentile Bands between Original and Updated Frameworks Based on Ontario FY 2014/15 and FY 2016/17 Data

PS Group	50 th	35 th to 65 th percentile band	20 th to 80 th percentile band
1	--	--	--
2	-0.5%	-8.6%	-6.5%
3	-23.2%	-17.1%	-20.2%
4	-15.3%	-30.7%	-22.4%
5	-16.1%	-18.2%	-1.8%
6	-1.5%	+9.2%	-2.6%

To examine allocation patterns between LHINs, the percentile values obtained from the Framework of Hours was applied to the full FY 2016/17 dataset after excluding the first HC (without prior CA) group. Table 4-12 compares the proportion of clients receiving publicly funded PS/HM services within the defined percentile bands. Since the percentile bands were developed from historical utilisation, one would expect that 30% of a given LHIN's allocation would fall within the 35th to 65th percentile band. Similarly, 60% of a LHIN's allocation would be expected to fall within the 20th to 80th percentile band. In five LHINs, smaller than expected proportions were observed although most discrepancies were small. The LHINs with the highest proportion of clients in either band were Central East (39.5% and 73.0%) and South East (35.8% and 70.6%) LHINs. Central West and North West LHINs were the only LHINs with smaller than expected percentages in both bands.

Table 4-13 shows the proportion of clients receiving PS/HM services above and below defined percentile bands. In 10 out of 14 LHINs, more than 15% of clients were allocated below the 10th percentile of PS/HM hours. North West LHIN was the only LHIN with larger than expected proportions of clients below the 10th percentile (16.6%) and above the 90th percentile (18.4%).

Table 4-12 Proportion of HC-Assessed Clients Receiving Publicly Funded PS/HM Services within Defined Percentile Bands, by LHIN, Ontario FY 2016/17

LHIN	% of clients within 35 th to 65 th percentiles ^a	% of clients within 20 th to 80 th percentiles ^b
Central East	39.5	73.0
Central	32.4	67.3
Champlain	*28.1	60.3
Central West	*29.0	*59.9
Erie St. Clair	36.8	66.7
Hamilton Niagara Haldimand Brant	30.9	62.9
Mississauga Halton	30.1	*59.1
North East	31.6	63.7
North Simcoe Muskoka	31.1	62.6
North West	*29.7	*56.4
South East	35.8	70.6
South West	30.2	61.9
Toronto Central	*29.7	61.3
Waterloo Wellington	33.6	62.5

*Smaller than expected percentages (<30%^a and <60%^b)

Table 4-13 Proportion of HC-Assessed Clients Receiving Publicly Funded PS/HM Services Beyond Defined Percentile Bands, by LHIN, Ontario FY 2016/17

LHIN	% of clients below 10 th percentile	% of clients above 90 th percentile
Central East	13.3	4.1
Central	*16.9	6.7
Champlain	*19.5	13.2
Central West	*30.7	8.7
Erie St. Clair	*17.9	9.3
Hamilton Niagara Haldimand Brant	*18.8	11.4
Mississauga Halton	*21.6	11.7
North East	*21.1	10.5
North Simcoe Muskoka	*17.7	10.7
North West	*16.6	*18.4
South East	14.6	9.4
South West	*20.4	14.1
Toronto Central	12.5	13.7
Waterloo Wellington	14.3	14.6

*Larger than expected percentages (>15%)

4.9 Discussion

Compared to existing interRAI scales and algorithms (including the IADL-ADL Functional Hierarchy Scale), the PS Algorithm is the best predictor of PS/HM service use. The PS Algorithm explains 25.5% of publicly funded PS/HM hours and 33.4% of total home support hours received by adult long-stay Ontario home care clients. Direct comparison of the PS Algorithm and IADL-ADL Functional Hierarchy confirms the importance of clinical needs other than physical functioning in the use of PS/HM services. The present study adds to the original derivation study by showing how PS/HM service use varies with other enabling and need factors within PS Groups. The discussion focuses on the clinical and policy implications of these factors.

Additional need characteristics emerged from the analysis. The PS Algorithm already considers the presence of cognitive impairment broadly as well as caregiver distress among clients with high functional impairment. However, the degree of cognitive impairment and presence of caregiver distress were found to further modify PS/HM service use across PS Groups. In general, clients with at least moderate levels of cognitive impairment received more support than clients with no or mild impairment. Individuals in PS Group 6 with the highest levels of cognitive impairment received the most publicly funded PS/HM and total home support hours. Of the five modifiers examined in this study, caregiver distress offers the largest gain in explained variance when entered with the PS Algorithm (+0.6%). These results emphasise the importance of considering clinical domains other than physical functioning when assessing need for PS/HM services.

Although ADL and IADL impairment rely on the person's ability to plan and carry out the sub-tasks of a given activity, cognition exists as an indicator of need separate from physical

impairment through its effect on the person's insight to complete the tasks safely and independently [111, 201]. Hence, care coordinators should refer to the Cognitive Performance Scale in conjunction with the PS Algorithm. Notably, the PS Algorithm measures the client's performance (i.e., not capacity) of ADL tasks, even if the client does so facing heightened risk. The Cognitive Performance Scale provides additional information about the client's capacity to complete ADL tasks. Thus, moderate or severe cognitive impairment may be reasonable grounds for allocating greater amounts of PS/HM services.

Given the emphasis on shifting from client-centred to family-centred care in Ontario and elsewhere [33, 202], client and caregiver needs alike should be measured and the allocation of publicly funded PS/HM services should be responsive to the needs of the family unit. Caregiver distress is part of the PS Algorithm and shown here as an important modifier within PS Groups. There are opportunities to improve on current methods of assessing and responding to caregiver needs. Although a good starting point, the HC assessment (and other interRAI assessments used in home and community care) focuses almost exclusively on the client's needs aside from two binary variables that capture caregiver distress. The addition of a standardised caregiver-specific assessment such as the Caregiver Well-being Index [203] or the interRAI Carer Needs Assessment [204] would offer a more comprehensive assessment of the caregiver's needs. As an extension of this study, it would be possible to link the client and caregiver assessments with service utilisation information to study caregiver-specific factors (e.g., caregiver's physical function) that have been proposed but not fully explored in the literature.

Health instability also emerged as an important need characteristic, although its influence was more variable and only appeared at the highest levels. A pan-Canadian study showed that

CHESS is strongly associated with short-term mortality, where approximately 40% of home care clients assessed with a CHESS score of 5 died within a month of assessment [179]. The present study shows that clients in CHESS 5 received more publicly funded PS/HM services although the trend with total home support hours was inconsistent. For clients in the highest CHESS level, publicly funded PS/HM service use did not significantly differ among PS Groups 3, 4, and 5. Overall, these findings suggest that health instability or proximity to death is relevant in allocating PS/HM services even within non-palliative home care programs. Declines in physical functioning and other global measures of health can be expected with proximity to death. Formal PS/HM services may be offered to help with assessment and monitoring (including vital signs) or provide relief for caregivers [42]. Despite the wide confidence intervals, this study's findings suggest that some clients with at least moderate levels of functional impairment and a CHESS score of 5 may require additional PS/HM supports. For some clients, high medical complexity may be a more important predictor of PS/HM service use than the PS Algorithm. Either the guidelines themselves should be sufficiently flexible to accommodate the service needs of clients with high health instability, or internal processes for requesting exceptions for these clients should be clear and streamlined.

Clients with mental health needs account for one-third of the adult long-stay home care population, defined as being at risk of neglect or abuse, displaying behavioural or depressive symptoms, or experiencing delusions or hallucinations. Previous literature has shown that persons receiving PS/HM services are at high risk for depression that may arise from the confluence of older age, comorbid conditions, functional decline, diminished quality of life, reduced social contacts, and reliance on others for help [205, 206]. However, mental health needs

are also the least likely to be met adequately or at all in this population [205, 207, 208].

Especially for clients with limited mobility or social networks, having regular contact with personal support workers provide opportunities for socialisation and companionship [42, 209, 210]. Others have noted that high workloads and tight schedules mean that personal support workers face limited time to attend to clients' physical needs, much less their emotional or psychosocial needs [211, 212]. This study's results shows that clients with mental health needs receive slightly more publicly funded PS/HM services and total home support compared to clients without any of above indicators. Although the client's mental health needs modify the intensity of PS/HM services, care plans that incorporate interdisciplinary interventions focused on promoting mental health and well-being (rather than relying on personal support workers alone for whom socialisation is more an inherent part of the role rather than a stated goal) is a more suitable approach for ensuring the mental health needs of home care clients are appropriately addressed or treated.

Although living arrangement is an enabling characteristic, it is an important contextual variable in the allocation of resources. Consistent with the literature, existing utilisation reveals that clients living alone receive more publicly funded PS/HM hours. However, this does little to close the gap in total home support hours between persons who do and do not co-reside with their primary caregiver. These findings lead to important policy discussions about how living arrangement fits with use of the PS Algorithm when distributing publicly funded PS/HM resources.

Strict application of Andersen's definition of equitable access would suggest that enabling resources such as living arrangement should not be part of an equitable allocation system [64].

Since the PS Algorithm is a needs-based measure, the addition of living arrangement directly into the algorithm seems antithetical to the underlying theoretical framework. But given that informal caregivers account for approximately 80% of total care provided in the home, it seems that PS/HM services are a little different from other types of health services. Whereas it is reasonable to argue that living arrangement should not be related to the use of primary care or acute care services, one should view living arrangement as simultaneously an enabling and need characteristic from the perspective of total home support. The nature of co-residence means that co-residing caregivers are physically present, so they are more likely to be able to provide help more often, for longer periods, and even if needs arise unexpectedly. In comparison, not being able to rely on a co-residing caregiver can be said to create a need for the formal system to replace missing total home support hours. That is to say, living arrangement and caregiver availability represent an enabling resource for clients who can rely on a co-residing caregiver but a need for those who cannot. Living arrangement creates a need through the lack of supports although it is not a need in itself.

Rather than fitting living arrangement into the PS Algorithm, a consistent, equitable, and transparent approach means that care coordinators should consider living arrangement as a contextual variable when explaining the reasons for providing more or fewer hours within the Framework of Hours. This perspective is consistent with the Expert Panel's position that a client's level of care is assigned independent of available supports, but care planning should be based on unmet functional needs [35]. Beyond living arrangement, it is important to assess the availability and capacity of informal and other home supports. Care coordinators also should consider the type of social supports provided by the informal caregiving network [68]. While

feeling supported through a loving relationship or through positive social interactions will undoubtedly benefit the client's well-being, the ability of the caregiving network to provide tangible hands-on assistance may be most relevant in assessing need for PS/HM services. Moreover, for co-residing caregivers, it should not be presumed that resources are limitless or necessarily abundant [213]. Again, the importance of implementing a caregiver assessment and using its outputs to inform service planning is made clear.

Comparison of the PS Group distributions reveals that Ontario's long-stay home care population is more complex than it was three years ago. In this study, only limited conclusions can be drawn from the updated Framework of Hours because waitlisted clients could not be excluded from the calculations. At least part of the absolute decreases observed in the percentile values can be attributed to this limitation. Nevertheless, a promising finding is the observation that the width of the percentile bands decreased substantially with some bands narrowing by more than 15%. This narrowing was observed even though one might have expected the presence of waitlisted clients to have asymmetrically pulled down the lower percentiles and thus widen the percentile bands. Conceptually, the Framework of Hours is designed to encourage the allocation of PS/HM services toward a central value within each PS group [60]. Although this study's updated framework represents a best guess and should be confirmed in collaboration with HSSOntario, preliminary findings suggest that allocations have started to cluster as LHINs move away from local allocation practices toward a common provincial standard.

Finally, the discussion would be remiss not to return to the challenges that LHINs face with differential per-client funding amounts [34, 56]. Although most of home care funding is still allocated under global budgets, 30% of the funding for long-stay home care clients is distributed

under the Health Based Allocation Model (HBAM). Under HBAM, this portion of LHIN funding is based on the expected service intensity across client groups. Each client's group is determined by the Resource Utilization Groups Version III for Home Care (RUG-III/HC) case mix system [174]. Within each RUG group, HBAM expected expenses are the product of the group's expected services per day, actual number of service days, and the LHIN's actual cost per service [214]. As expected, since the RUG-III/HC system was designed to predict total service costs (including professional services), the PS Algorithm is a better predictor of PS/HM services alone. However, the two algorithms are also moderately correlated. Thus, while the RUG-III/HC case mix system is primarily an administrative tool for allocating budgets, the PS Algorithm acts as a reasonable link between funding and service planning at the front-line level. Further expansion of HBAM would mean moving away from global budgets that currently allow regional inequities to persist and toward more consistent per-client funding that will more closely tie home care resources with client need.

4.9.1 Strengths

The use of census-level clinical assessment and administrative data means that these results are generalisable across Ontario's public long-stay home care population. Whereas much of the existing literature relies on self-reported characteristics and PS/HM service use, this study linked RAI-HC assessments that are completed by trained health professionals and billed services data whose integrity is maintained by the LHINs and service provider organisations. Additionally, the large sample size permitted the exploration of service use in rare groups, such as clients at the highest level of medical complexity and health instability.

4.9.2 Limitations

In contrast to publicly funded PS/HM services, measurement of total home support service use relied on self-reported receipt of formal and informal care. Variables describing caregiver need were limited to two binary variables about caregiver distress. In the short term, the pilot study data used to develop the Caregiver Well-being Index could be linked to billed services data to study the association between caregiver need characteristics and PS/HM service use. In the long term, implementation of a caregiver assessment is an important part of adopting a family-centred approach in home care. Caution should be applied in making generalisations about the updated Framework of Hours. Lack of access to the full home care administrative records means that it was not possible to replicate all of the exclusion criteria applied to the original Framework of Hours. Engaging with HSSOntario to update the Framework of Hours and discuss the implementation of provincial guidelines (including the choice of percentile values) is necessary.

CHAPTER 5: What need characteristics are associated with receiving publicly funded PS/HM Services among Ontario home care clients assessed with the interRAI Contact Assessment?

5.1 Introduction

While the PS Algorithm is helpful for guiding the allocation of PS/HM services for home care clients assessed with the RAI-HC (interRAI HC), there remains a problem of equitable and consistent allocation without a corresponding decision support tool for the CA. Description of the HC sample in the second study showed that at least four in every five long-stay home care clients are assessed with the CA prior to receiving the HC. For most clients in Ontario, their initial contact with the public home care system is through a hospital or intake care coordinator who determines that the client is eligible for home care services and orders services that are immediately needed. The same care coordinator may remain the point of contact for clients expected to require short-term services only or the client is assigned to a community care coordinator if they require long-term services.

Consistency of service planning before and after the caseload transfer is important for clients, families, and health professionals involved in referring, organising, and delivering services. Especially for clients referred from hospital, there is a concern that unsustainably high amounts of publicly funded PS/HM services are being offered that have to be cut back once the client returns home. More consistent service planning would mean that the client is not sent home without a sustainable plan for maximising their personal well-being and safety or that may cause undue burden on their informal caregiving network. Clients and families can be confident that service provision is based on needs and other relevant considerations and will not drastically

change without a concomitant change in needs or circumstances. Health professionals involved in sending home care referrals can provide a more realistic description to their patients of what they can expect from the public home care system. In the first study, the linked sample of new referrals showed that 40% of CA-assessed clients received the HC assessment within two weeks while 33% waited more than a month before receiving the follow-up assessment. Thus, for the majority of long-stay clients, the services they receive after the CA are needed to address short-term needs (that may be urgent or chronic in nature) before a comprehensive assessment and care plan can be completed. Finally, PS/HM allocation should not depend on the type of assessment that the client receives. Even if the client is expected to require PS/HM services for a short period, the same level of service should be allocated to short-stay and long-stay clients with equivalent assessed needs.

Very few published studies have examined PS/HM service utilisation either at home care program intake or post-hospital discharge. Among new home care clients, Liu et al. [127] found that older age, female sex, living alone, low income, count of impaired ADLs, and moderate or severe cognitive impairment were associated with higher daily costs of PS/HM services in the next six months. Marital status, ethnicity, and having either a diagnosis of cancer or stroke did not affect the daily cost. Fries et al. [215] examined the associations between RAI-HC assessment items and the level of care for new home care clients in one American state. Clients assigned to the “home care” level that included skilled nursing care and daily PS services were dependent in locomotion and relied on others for preparing meals. Clients assigned to the “intermittent personal care” level (i.e., less than daily PS services) had difficulty in at least five

of six ADLs and IADLs and were more likely to feel that they would be better off living elsewhere.

Three studies examined the receipt of PS/HM services after hospital discharge. Bull [114] recruited older patients recently admitted to hospital for an acute episode of a chronic condition and found that the number of PS/HM hours received within two weeks of discharge was associated with older age, ADL impairment, and more hours of caregiver employment. Hammar [66] examined the odds of receiving any PS/HM services within a sample of older long-stay home care clients who had an inpatient hospital stay in the last six months. Older clients and clients requiring help with ADLs, receiving professional home care services, not receiving meals-on-wheels services, not receiving informal help, or living alone had greater odds of receiving PS/HM services. The number of diagnoses, number of medications, self-perceived health, and need for help with IADLs or managing pain were not significantly associated. Among individuals who were discharged from hospital and had some level of cognitive or functional impairment, Dellasega & Fisher [116] found that the pattern of PS/HM use declined slightly at two weeks post-discharge but was otherwise consistent immediately after discharge and at four weeks post-discharge.

Although the evidence is limited, the characteristics associated with PS/HM use at home care intake and after hospital discharge appear consistent with the characteristics identified among the general home care population. This chapter will utilise census-level clinical assessment and administrative data to identify need characteristics associated with receipt of publicly funded PS/HM services in Ontario's CA-assessed population. Since Ontario's LHINs have already

implemented the PS Algorithm, the goal is to create a conceptually similar algorithm based on the CA assessment that differentiates need for PS/HM services.

5.2 Objectives

1. Identify client-level need characteristics that are associated with greater odds of receiving any publicly funded PS/HM services after the CA.
2. Identify client-level need characteristics that are associated with receipt of more weekly publicly funded PS/HM hours after the CA.
3. Using the need characteristics identified in Objectives 1 and 2, develop decision trees that predict the weekly publicly funded PS/HM hours received after the CA.
4. Compare the performance of the candidate decision trees in predicting the weekly publicly funded PS/HM hours received after the CA and the PS Group after the HC, and recommend a final version of the Personal Support Algorithm for the CA.

5.3 Data Sources

This study uses client-level clinical assessment and administrative data that were provided by HSSOntario, specifically home care referrals, interRAI CA and RAI-HC assessments, and billed services.

5.4 Samples

5.4.1 CA Derivation Sample

The derivation sample was used for Objectives 1 through 3. First, all Ontario adult (age ≥ 18 years) home care referrals that had been admitted after 2010 to receive services were retrieved. Referrals without a valid client number or referral start date were deleted. If a client had

overlapping referrals, the referral start date was reset to the earliest referral start date and the discharge date (if discharged) was reset to the latest discharge date. The home care episode refers to the length of time between the referral start date and the discharge date. Only referrals assigned one of the Acute, Rehabilitation, Maintenance, or Long-term Supportive Service Recipient Codes were kept. Second, all completed CA assessments were retrieved. Using the client number, all assessments were matched with the referral that was active on the day that the assessment was completed. Only the CA assessments that were completed between April 1, 2016 and March 31, 2017 were retained. If a client had more than one assessment within the 12-month period, only the assessment closest to October 1, 2016 was retained. Third, all completed HC assessments (non-hospital versions) were retrieved. Based on the client number and CA assessment date, the first HC that was completed within 182 days of the CA date was matched to the referral. This working dataset was joined with the billed services dataset. Only PS/HM-related service types were retained. For each CA, PS/HM services that were received up to 14 days after the CA assessment date (but not after the discharge date or HC assessment date (if applicable)) were retrieved.

Linking all assessments made it possible to differentiate between “existing” and “new” clients based on the receipt of previous assessments within a given home care episode. An existing client either received a prior CA or HC assessment dated before the CA of interest or had been on service for more than 30 days at the time of CA assessment. Therefore, new clients includes all clients receiving their first assessment (i.e., CA) of the episode within 30 days of referral. To develop the decision trees in Objective 3, the sample was randomly partitioned into 70% for derivation and 30% for internal validation.

5.4.2 CA Validation Sample

For Objective 4, an out-of-time validation sample was created by applying the same sample criteria on a non-overlapping time period. All CA assessments completed between April 1, 2017 and December 31, 2017 were matched to the same referral dataset as outlined above. If a client had more than one assessment within the nine-month period, only the assessment closest to August 15, 2017 was retained. The same procedures for identifying and linking billed services (i.e., within 14 days of the CA assessment date) and HC assessments (i.e., within 182 days of the CA assessment date) were followed.

5.4.3 HC Validation Sample

The HC sample constructed for the second study was used as an additional validation sample in this study. This sample consisted of unique RAI-HC assessments completed between April 1, 2016 and March 31, 2017 and was linked to billed services up to 84 days after the HC assessment date (for more detail, see section 4.4 on page 151).

5.5 Descriptive Variables

Predisposing and enabling characteristics are used to describe the sample, but they were not considered when developing the algorithm. Age, sex, living arrangement, and type of CA were drawn from the CA assessment. *Age at the time of assessment* was calculated by taking the difference between the birth date and assessment reference date and collapsed into three groups (18–64, 65–84, 85+). *Sex* is reported as a binary variable (female, not female). *Living arrangement* is defined using the expected living arrangement during service provision and classified into one of three groups (lives with primary caregiver; lives with other(s), not primary

caregiver; and lives alone). *Type of CA* is identified based on whether all CA variables were completed (full CA) or some CA variables were missing according to the expected skip pattern (early triage CA). Referral source and Local Health Integration Network (LHIN) were drawn from the referral dataset. *Referral source* was collapsed into a binary variable (hospital, community). *LHIN* was a variable provided by HSSOntario based on geographic boundaries established by the Ministry of Health and Long-Term Care and identified the LHIN region in which the client lives.

5.6 Independent Variables

Need characteristics reported in the CA describe the client's status in the last 24 hours. There are four ADL self-performance measures (bathing, personal hygiene, dressing lower body, and locomotion) and four IADL capacity measures (meal preparation, ordinary housework, managing medications, and stairs). *ADL/IADL impairment* is present if the client received or requires any supervision, cueing, or physical assistance during the activity. The number of impaired ADL and IADL areas were also summed. *Cognitive impairment* is present if the client had any difficulty making reasonable and safe decisions in new or routine situations. *Decline in cognitive status and decline in ADL status* reflect poorer functioning as compared to the client's cognitive or functional status three months ago from the perspective of the client, family, or assessor. *Difficulty with comprehension* is present if the client requires repetition or explanation to understand (or is unable to understand) conversation using the hearing appliance normally used. *Client sad or depressed* is based on the client's response to the question "have you felt sad, depressed, or hopeless in the last three days". *Caregiver depressed or overwhelmed* is present if the primary informal caregiver, family, or close friends expressed feelings of distress, anger,

depression, or being overwhelmed by the client's illness. *Dyspnea* indicates shortness of breath while performing day-to-day activities. *Poor self-rated health* is based on the client's response to the question "in general, how would you rate your health". *Unstable cognitive/ADL/mood/behaviour patterns* refer to unstable or fluctuating care needs attributable to the client's health condition. *Acute episode or flare-up* refers to clients who are either experiencing an acute episode of illness or disability or transient worsening of a recurrent or chronic problem such as COPD. *Fall(s)* indicates the occurrence of any falls in the last 90 days. *Dizziness, chest pain, peripheral edema, or pain* is present if the client exhibits the symptom in the last three days. *Decrease in food or fluid* refers to a noticeable decrease in the amount of food usually eaten or fluids usually consumed in the last three days. *Weight loss* refers to an unintended decrease in weight of at least 5% in the last 30 days or at least 10% in the last 180 days. Any pressure ulcer, major skin problem (e.g., lesions, severe burns), or traumatic injury (e.g., fracture) was also reported. The *Changes in Health, End-stage disease, Signs, and Symptoms Scale (CHESS)* is a measure of health instability and has been shown to predict mortality, health service use, and caregiver distress among home care clients [178–180]. The CA-adapted version of the CHESS was used in this study [216]. Finally, *any emergency department (ED) visit or overnight hospital stay* in the last 90 days was recorded.

5.7 Dependent Variables

5.7.1 Publicly Funded PS/HM Service Utilisation

Weekly publicly funded PS/HM hours were derived from the billed services dataset. To represent PS/HM service visits, only visits classified as personal services, homemaking services, combined personal services and homemaking services, and respite were counted. To calculate weekly

utilisation, the sum of PS/HM hours was divided by the number of service days (i.e., difference in days between the first and last visit) and multiplied by 7. Review of the univariate distribution revealed 101 outliers accounting for 0.04% of episodes. All outliers exceeded 84 hours/week (i.e., 12 hours/day) but did not exceed 168 hours/week (i.e., 24 hours/day). Most observations were referred from hospital (inpatient), and were eventually discharged to long-term care, died, or hospitalised for more than 14 days. Three LHINs (South West, Central, Waterloo Wellington) accounted for 84% of the episodes. Over half (58%) were existing home care clients while 42% were new to the public home care system. To minimise the effect of outliers, the maximum value of weekly publicly funded PS/HM hours was set to 84 for the purpose of calculating explained variance. As a result, among clients receiving any PS/HM, the mean value decreased from 8.1 to 8.0 hours/week and the standard deviation decreased from 10.4 to 9.0 hours/week. The median and interquartile range remained unchanged at 6.0 and 5.3 hours/week, respectively. Also of note is that the statutory maximum for publicly funded PS/HM services is 120 hours in any 30-day period that translates to 28 hours/week in this study [54]. Capping the maximum value did not affect 784 clients receiving more than the statutory maximum who may have been facing “extraordinary circumstances” according to the Ontario legislation.

5.7.2 PS Group

The PS Algorithm differentiates need for PS/HM services based on functional and cognitive impairment and other modifiers [60]. The PS Algorithm was developed using Ontario home and community care data, where higher groups were shown to be associated with greater use of publicly funded PS/HM services [60]. The PS Group was calculated for clients who received a subsequent HC assessment.

5.8 Analysis Plan

Predisposing, enabling, and need characteristics of new and existing clients were summarised in frequency tables and compared using chi-square tests. Other health services researchers have employed a hierarchical or two-stage approach when analysing data characterised by high skewness and many zeros (examples include Hawranik [98] and Stoller [217]). In this study, 84.6% (193,142) of episodes did not receive any PS/HM services after the CA. Accordingly, bivariate logistic models predicting the odds of receiving any publicly funded PS/HM services were fitted for the full derivation sample, and bivariate linear models predicting the amount of services were fitted for clients who received any publicly funded PS/HM services.

Next, several decision trees were developed in SAS Enterprise Miner 13.1 [SAS Institute Inc., Cary, NC]. Automatic trees were automatically generated by the software that selected the variables that maximised either variance reduction or information gain at every step [218]. Growth of interactive trees is determined by the researcher who may seek a more balanced approach toward both statistical significance and clinical meaningfulness [218]. In all cases, the splitting criterion was variance reduction for interval targets (i.e., amount of PS/HM services after the CA) and information gain for ordinal targets (i.e., PS Group at the time of HC assessment). The other key parameters were binary splitting at each node, a maximum number of six levels in the tree structure, a minimum number of 200 observations in any root node, and a significance level of 0.2 adjusted by the Bonferroni correction.

The first automatic tree included the full sample and the target variable was the amount of services received (including zero hours). The second automatic tree included clients who received both the CA and HC and the target variable was the PS Group at the time of HC

assessment. To replicate the PS Algorithm, a third tree structure was developed by cross-walking the PS Algorithm using the CA items. Finally, a fourth tree structure was developed through interactive training that was informed by variables and interactions known to be significant from the logistic, linear, and decision tree models. The validation samples were used to assess each model's explained variance of the amount of publicly funded PS/HM services received after the CA and weighted kappa of the PS Group at the time of HC assessment. Additionally, performance indicators were observed for new and existing clients, phone only CAs, and hospital (inpatient) CAs. Selection of the final algorithm ("PS Algorithm for the CA") was based on these performance indicators with preference given to an algorithm that was conceptually similar to the PS Algorithm.

5.9 Results

In Ontario FY 2016/17, there were 228,354 unique interRAI CA assessments completed for adult non-palliative home care clients. Of these, 88.1% (201,130) were new clients and 11.9% (27,224) were existing clients.

Table 5-1 describes the predisposing and enabling characteristics of new and existing clients. On average, new clients were younger than existing clients (mean \pm SD: 67.1 \pm 17.8 years vs. 74.5 \pm 14.4 years). Existing clients were significantly more likely to be female, live with their caregiver, and referred from the community. Nearly six times more new clients received an early triage CA compared to existing clients.

Overall, 15.4% (35,212) of CA-assessed clients received any PS/HM services after the CA, although the proportion was below 5.0% in three LHINs. Existing clients were more likely to

receive any publicly funded PS/HM services after the CA ($\chi^2=36999.4$, $p<.0001$) as well as an HC assessment after the CA ($\chi^2=7342.2$, $p<.0001$). Among those receiving an HC assessment, existing clients were still more likely to receive any publicly funded PS/HM services after the HC ($\chi^2=10443.0$, $p<.0001$). In contrast, new clients were more likely to receive any publicly funded nursing or therapy services after the CA ($\chi^2=2453.1$, $p<.0001$).

Table 5-2 describes the need characteristics of new and existing clients. Existing clients were significantly more likely to require supervision or any physical assistance with a greater number of ADLs and IADLs. The proportion of clients requiring any help with ADLs was 82.5% of existing clients and 43.1% of new clients. Existing clients had greater needs across nearly all clinical domains, including cognition, communication, mood, self-reported health, health symptoms, pain, health instability, and acute care use. New clients were significantly more likely to be experiencing an acute episode or a flare-up of a recurrent or chronic problem (77.2% vs. 64.3%) or have undergone surgery in the last 90 days (23.7% vs. 20.4%).

Table 5-1 Predisposing and Enabling Characteristics of CA-Assessed Clients, by Client Status, Ontario FY 2016/17

% (n)		New clients n=201,130	Existing clients n=27,224
Age	18 to 64 years	39.1 (78,610)	22.2 (6,032)
	65 to 84 years	43.7 (87,874)	50.0 (13,607)
	85+ years	17.2 (34,646)	27.9 (7,585)
Sex	Female	53.6 (107,822)	57.9 (15,763)
	Not female	46.4 (93,308)	42.1 (11,461)
Living arrangement	Lives with primary caregiver	43.0 (86,569)	54.5 (14,823)
	Lives with other(s), not primary caregiver	31.2 (62,726)	17.1 (4,652)
	Lives alone	25.8 (51,835)	28.5 (7,749)
Referral source	Hospital	67.1 (134,953)	56.8 (15,449)
	Community	32.9 (66,177)	43.3 (11,775)
Local Health Integration Network	Central East	11.0 (22,129)	18.2 (4,948)
	Central	9.4 (18,987)	12.4 (3,361)
	Champlain	9.6 (19,373)	4.2 (1,133)
	Central West	5.1 (10,178)	4.9 (1,329)
	Erie St. Clair	6.7 (13,462)	7.8 (2,135)
	Hamilton Niagara Haldimand Brant	13.0 (26,216)	15.6 (4,236)
	Mississauga Halton	7.6 (15,245)	5.6 (1,521)
	North East	6.0 (12,059)	5.5 (1,500)
	North Simcoe Muskoka	3.8 (7,661)	3.9 (1,059)
	North West	2.5 (5,049)	0.8 (208)
	South East	5.4 (10,804)	7.5 (2,039)
	South West	7.7 (15,417)	5.4 (1,462)
	Toronto Central	6.3 (12,749)	5.0 (1,372)
	Waterloo Wellington	5.9 (11,801)	3.4 (921)
Type of CA	Full CA	71.7 (144,258)	95.3 (25,950)
	Early triage CA	28.3 (56,872)	4.7 (1,274)
Received any publicly funded PS/HM after CA	Yes	10.0 (20,166)	55.3 (15,046)
	No	90.0 (180,964)	44.7 (12,178)
Received any publicly funded nursing or therapy services after CA	Yes	88.4 (177,786)	77.7 (21,147)
	No	11.6 (23,344)	22.3 (6,077)
Received HC assessment after CA	Yes, first HC	27.5 (55,264)	14.3 (3,889)
	Yes, subsequent HC	--	38.7 (10,528)
	No	72.5 (145,866)	47.0 (12,807)
Received any publicly funded PS/HM after HC (among those receiving HC assessment)	Yes	58.9 (32,562)	79.8 (11,497)
	No	41.1 (22,702)	20.2 (2,920)

- Chi-square test: All results were significant at $p < .0001$ unless otherwise noted.

Table 5-2 Need Characteristics of CA-Assessed Clients, by Client Status, Ontario FY 2016/17

% (n)	New clients n=201,130	Existing clients n=27,224
Count of ADL areas needing supervision or any physical assistance ^a		
0	56.9 (114,339)	17.5 (4,768)
1	12.9 (25,929)	13.3 (3,628)
2	10.9 (21,869)	15.3 (4,165)
3	7.2 (18,504)	19.2 (5,233)
4	10.2 (20,489)	34.6 (9,430)
Count of IADL areas needing supervision or any physical assistance ^{*b}		
0	11.9 (23,911)	4.5 (1,220)
1	7.6 (15,279)	5.0 (1,350)
2	14.2 (28,525)	11.6 (3,148)
3	20.9 (41,978)	25.6 (6,980)
4	16.7 (33,643)	48.2 (13,126)
Cognitive impairment	15.4 (30,967)	36.3 (9,893)
Cognitive decline in last 90 days*	10.2 (20,561)	19.5 (5,315)
ADL decline in last 90 days*	44.7 (89,887)	61.1 (16,640)
Difficulty with comprehension ^{*c}	6.4 (12,886)	16.0 (4,362)
Client sad or depressed*	10.7 (21,425)	14.7 (3,997)
Caregiver distressed or overwhelmed*	17.6 (35,359)	34.8 (9,474)
Dyspnea (performing day-to-day activities)	13.9 (27,975)	29.3 (7,981)
Poor self-reported health	26.2 (52,601)	45.7 (12,447)
Unstable or fluctuating cognitive/ADL/mood/ behaviour patterns	40.1 (80,742)	71.0 (19,321)
Acute episode or flare-up	77.2 (21,013)	64.3 (129,325)
Fall(s)*	24.1 (48,484)	40.3 (10,981)
Dizziness*	12.4 (24,889)	18.9 (5,151)
Chest pain*	2.5 (5,068)	4.7 (1,288)
Peripheral edema*	22.5 (45,260)	36.1 (9,823)
Pain*	50.0 (100,478)	62.6 (1,051)
Decrease in food or fluid*	11.5 (23,176)	21.1 (5,737)
Weight loss*	8.6 (17,357)	15.4 (4,200)
Special diet*	14.5 (29,246)	31.1 (8,471)
Pressure ulcer(s)*	3.9 (7,889)	11.4 (3,094)
Major skin problem(s)*	n.s. 18.7 (37,504)	18.8 (5,126)
Traumatic injury*	n.s. 5.6 (11,283)	6.0 (1,635)
Surgery*	23.7 (47,656)	20.4 (5,549)
Changes in Health, End-stage disease, Signs and Symptoms Scale		
High to very high health instability (4–5)	3.9 (7,906)	13.0 (3,548)
No to moderate health instability (0–3)	67.3 (135,430)	81.8 (22,276)
Any ED visit*	23.4 (47,095)	36.3 (9,873)
Any hospital stay*	41.2 (82,768)	77.6 (21,134)

*Not assessed for clients meeting early triage criteria

^a Bathing, personal hygiene, dressing lower body, locomotion

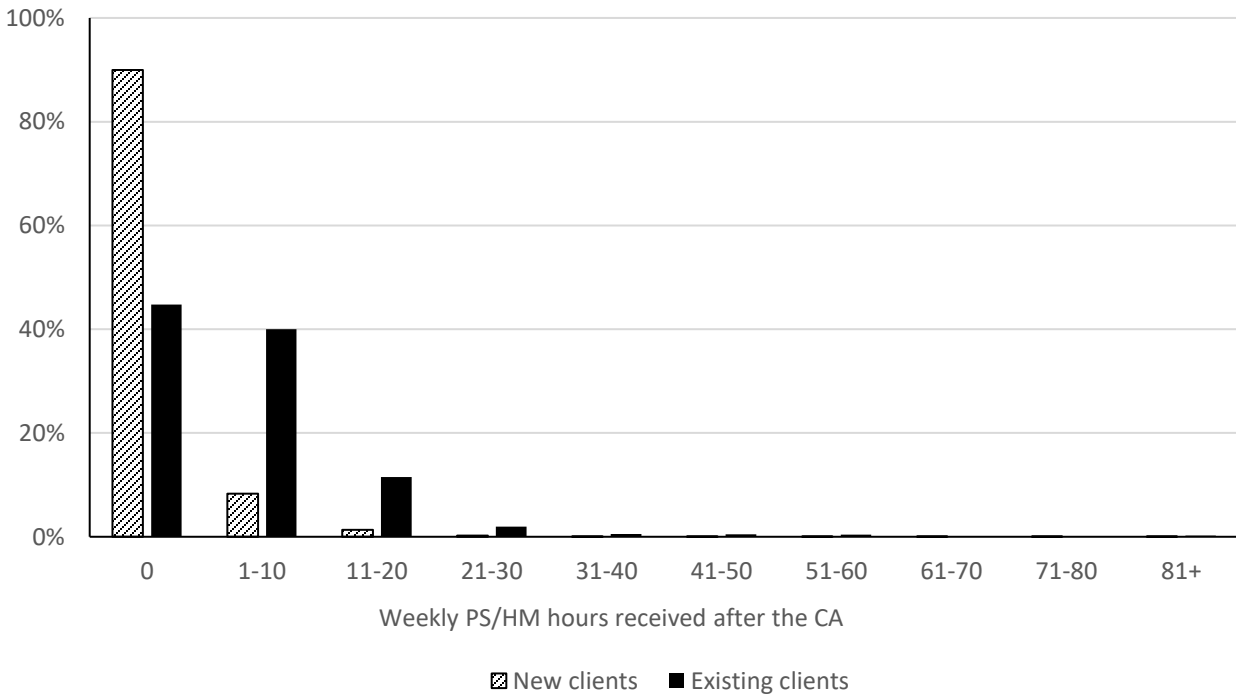
^b Meal preparation, ordinary housework, managing medications, managing stairs

^c Client does not comprehend most of the conversation without repetition or additional explanation

- Chi-square test: All results were significant at p<.0001 unless otherwise noted.

Figure 5-1 depicts the distribution of weekly publicly funded PS/HM hours received after the CA. Existing clients were twice as likely to receive publicly funded PS/HM hours after the CA, whereas 90% of new clients did not receive any PS/HM hours. Among existing clients receiving any publicly funded PS/HM hours, 72.4% received up to 10 hours/week and 93.1% received up to 20 hours/week. In comparison, 82.8% of new clients receiving any publicly funded PS/HM hours received up to 20 hours/week and 95.4% received up to 20 hours/week. Among both existing and new clients, the most common frequency of hours received was seven hours per week.

Figure 5-1 Distribution of Weekly Publicly Funded PS/HM Hours Received after the CA among CA-Assessed Clients, by Client Status, Ontario FY 2016/17



5.9.2 Exploratory Analyses and Development of Candidate Trees

Table 5-3 presents the unadjusted odds of receipt of any publicly funded PS/HM after the CA based on the bivariate logistic model for each need characteristic. The direction and relative strength of the associations were similar between new and existing clients. The strongest associations were consistently observed across measures of the client's ADL status. The count of impaired ADLs (i.e., degree of ADL impairment) outperformed any individual ADL. The presence of one impaired ADL was associated with 20.26 (new clients) and 16.45 (existing clients) greater odds of receiving any PS/HM after the CA. Each increase in the count of impaired ADLs roughly doubled the odds of receiving any publicly funded PS/HM services. The concordance statistics for the count of impaired ADLs were 0.85 among new clients and 0.74 among existing clients. The count of impaired IADLs behaved similarly.

Cognitive impairment was associated with 4.56 (new clients) and 2.72 (existing clients) greater odds of receiving any publicly funded PS/HM after the CA. Similar odds ratios were observed for difficulty with comprehension. Caregiver distress was associated with 5.75 (new clients) and 1.97 (existing clients) greater odds of receiving any publicly funded PS/HM after the CA.

Having unstable health patterns, recent hospital stay, recent fall(s), and high or very high health instability had odds ratios greater than 2.0 across all clients. Dyspnea, poor self-rated health, dizziness, peripheral edema, pain, special diet, pressure ulcer(s), and traumatic injury had odds ratios greater than 2.0 among new clients but less than 2.0 among existing clients. Weight loss doubled the odds of receiving publicly funded PS/HM after the CA among new clients, but was associated with lesser odds among existing clients. Having a major skin problem was associated with lesser odds among both new and existing clients.

Table 5-3 Unadjusted Odds of Receipt of Any Publicly Funded PS/HM Services after CA among CA-Assessed Clients, by Client Status, Ontario FY 2016/17

Need characteristics	New clients n=201,130		Existing clients n=27,224	
	Odds ratio (95% CI)	C statistic	Odds ratio (95% CI)	C statistic
Cognition status				
Cognitive impairment	4.56 (4.41–4.70)	0.64	2.72 (2.58–2.87)	0.61
Difficulty with comprehension	4.46 (4.33–4.60)	0.64	2.76 (2.62–2.91)	0.62
Cognitive decline	4.10 (4.00–4.25)	0.59	1.94 (1.82–2.07)	0.55
ADL status				
Bathing self-performance	43.78 (40.93–46.81)	0.82	32.45 (28.87–36.47)	0.70
Personal hygiene self-performance	7.87 (7.63–8.12)	0.70	4.07 (3.87–4.29)	0.67
Dressing lower body self-performance	12.15 (11.73–12.59)	0.78	6.15 (5.82–6.50)	0.70
Locomotion self-performance	5.57 (5.41–5.74)	0.68	2.87 (2.73–3.01)	0.63
Count of 4 ADLs	1 20.26 (18.54–22.13)	0.85	16.45 (14.21–19.06)	0.74
	2 44.70 (41.04–48.67)		32.67 (28.24–37.80)	
	3 81.13 (74.56–88.27)		46.72 (40.43–53.98)	
	4 91.91 (84.53–99.93)		51.59 (44.89–59.30)	
ADL decline	8.94 (8.58–9.31)	0.73	1.87 (1.78–1.96)	0.57
IADL status				
Meal preparation	6.36 (6.05–6.68)	0.65	3.69 (3.44–3.97)	0.59
Ordinary housework	10.83 (9.98–11.75)	0.61	7.29 (6.46–8.24)	0.56
Managing medications	3.60 (3.49–3.71)	0.65	2.57 (2.44–2.70)	0.61
Stairs	5.67 (5.43–5.91)	0.67	4.19 (3.92–4.47)	0.61
Count of 4 IADLs	1 3.75 (3.21–4.38)	0.75	3.00 (2.42–3.72)	0.66
	2 7.60 (6.62–8.72)		5.28 (4.35–6.40)	
	3 21.03 (18.42–24.00)		10.56 (8.78–12.71)	
	4 44.06 (38.61–50.27)		18.50 (15.41–22.20)	
Coping				
Client sad or depressed	2.02 (1.94–2.10)	0.51	n.s. 1.03 (0.96–1.10)	0.50
Caregiver distressed or overwhelmed	5.75 (5.58–5.93)	0.67	1.97 (1.87–2.08)	0.58
Any ED visit	2.02 (1.96–2.09)	0.57	1.41 (1.34–1.48)	0.54
Any hospital stay	5.32 (5.14–5.50)	0.69	2.16 (2.04–2.29)	0.60
Health conditions				
Dyspnea	2.55 (2.46–2.64)	0.57	1.62 (1.53–1.71)	0.55
Poor self-reported health	2.37 (2.30–2.44)	0.59	1.47 (1.40–1.55)	0.55
Unstable health patterns	5.63 (5.45–5.83)	0.70	2.48 (2.35–2.62)	0.59
Acute episode or flare-up	1.86 (1.80–1.92)	0.57	1.42 (1.34–1.50)	0.53
Fall(s)	5.21 (5.05–5.37)	0.68	2.05 (1.95–2.15)	0.58
Dizziness	2.26 (2.19–2.34)	0.57	1.39 (1.31–1.47)	0.53
Chest pain	1.80 (1.69–1.92)	0.51	1.48 (1.36–1.64)	0.51
Peripheral edema	2.20 (2.14–2.27)	0.58	1.27 (1.21–1.34)	0.53
Pain	2.23 (2.16–2.30)	0.60	1.15 (1.09–1.21)	0.52
Decrease in food or fluid	1.92 (1.85–1.99)	0.54	1.09 (1.03–1.16)	0.51
Weight loss	2.00 (1.92–2.09)	0.53	0.85 (0.79–0.90)	0.51
Special diet	2.47 (2.38–2.55)	0.57	1.34 (1.27–1.41)	0.53
Pressure ulcer(s)	2.48 (2.35–2.63)	0.52	1.26 (1.17–1.36)	0.51
Major skin problem(s)	0.86 (0.82–0.89)	0.51	0.63 (0.59–0.67)	0.54
Traumatic injury	3.49 (3.34–3.65)	0.55	1.47 (1.33–1.63)	0.51
Surgery	1.16 (1.12–1.20)	0.51	0.56 (0.53–0.59)	0.55
High or very high health instability	3.45 (3.28–3.64)	0.54	1.11 (1.03–1.19)	0.51

- Chi-square test: All results were significant at <.05 unless otherwise noted.

Table 5-4 presents the unadjusted estimates of the amount of publicly funded PS/HM received after the CA based on the bivariate linear model for each need characteristic. The direction and magnitude of the associations were similar between new and existing clients. Whereas need characteristics were more strongly associated with receipt of any publicly funded PS/HM among new clients, the same characteristics were more strongly associated with the amount of publicly funded PS/HM received among existing clients. Similar to the logistic model, the strongest associations were observed for the counts of ADL and IADL impairment. The count of impaired ADLs explained 7.0% and 8.4% of variance in publicly funded PS/HM hours although only clients impaired in all four areas received significantly more hours. The unadjusted estimates showed that new clients with one or two impaired ADLs and existing clients with one impaired ADL received fewer publicly funded PS/HM hours than clients with no ADL impairment. Likewise, only clients impaired in all four IADLs received more hours than clients with no IADL impairment. Recent hospital stay, caregiver distress, cognitive characteristics (impaired cognitive skills, difficulty with comprehension, and cognitive decline), pressure ulcer(s), poor self-rated health, and unstable health patterns were associated with receiving more publicly funded PS/HM hours. While most of the remaining characteristics were significantly associated with the amount of publicly funded PS/HM, their explained variance was less than 0.5%.

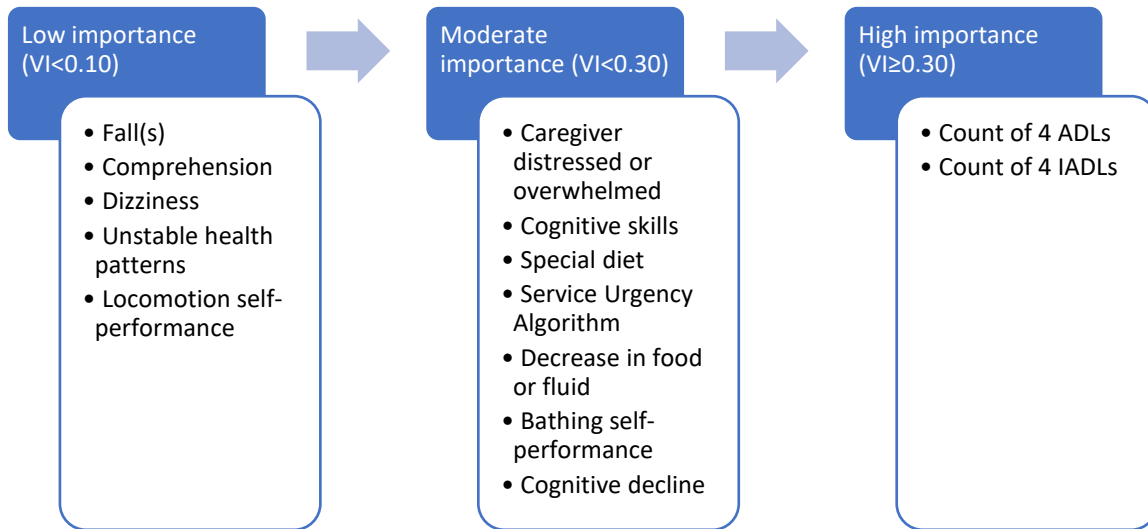
Table 5-4 Unadjusted Estimates of Weekly Publicly Funded PS/HM Hours Received after CA among CA-Assessed Clients, by Client Status, Ontario FY 2016/17

Need characteristics	New clients n=201,130		Existing clients n=27,224	
	Parameter estimate (95% CI)	Explained variance	Parameter estimate (95% CI)	Explained variance
Cognition status				
Cognitive impairment	3.41 (3.15–3.66)	3.3%	4.49 (4.12–4.86)	3.7%
Difficulty with comprehension	2.80 (2.54–3.05)	2.3%	3.92 (3.56–4.29)	2.8%
Cognitive decline	2.84 (2.56–3.12)	1.9%	4.71 (4.28–5.14)	3.0%
ADL status				
Bathing self-performance	1.53 (0.91–2.13)	0.1%	2.81 (1.51–4.10)	0.1%
Personal hygiene self-performance	3.59 (3.34–3.84)	3.8%	5.60 (5.22–5.97)	5.4%
Dressing lower body self-performance	3.20 (2.89–3.50)	2.1%	5.46 (4.98–5.95)	3.2%
Locomotion self-performance	3.71 (3.46–3.96)	4.1%	5.43 (5.06–5.80)	5.3%
Count of 4 ADLs				
1	-1.60 (-2.37–0.83)	7.0%	-2.14 (-3.66–0.61)	8.4%
2	-0.98 (-1.72–0.23)		n.s. -0.67 (-2.16–0.83)	
3	n.s. 0.45 (-0.28–1.18)		n.s. 1.37 (-0.11–2.84)	
4	4.48 (3.76–5.21)		6.42 (4.97–7.87)	
ADL decline	0.25 (-0.12–0.61)	0.1%	2.66 (2.26–3.05)	1.1%
IADL status				
Meal preparation	2.48 (2.03–2.92)	<0.1%	4.41 (3.74–5.08)	1.1%
Ordinary housework	1.77 (1.02–2.52)	0.1%	4.70 (3.43–5.98)	0.4%
Managing medications	3.34 (3.09–3.60)	3.2%	4.93 (4.54–5.32)	4.0%
Stairs	1.97 (1.60–2.35)	0.5%	3.54 (2.93–4.15)	0.9%
Count of 4 IADLs				
1	n.s. -1.30 (-2.70–0.10)	3.9%	n.s. -0.50 (-2.75–1.75)	4.5%
2	n.s. -1.01 (-2.24–0.23)		n.s. 0.35 (-1.68–2.37)	
3	n.s. -0.46 (-1.64–0.73)		n.s. 1.75 (-0.21–3.71)	
4	3.02 (1.84–4.20)		6.25 (4.31–8.19)	
Coping				
Client sad or depressed	n.s. -0.02 (-0.35–0.31)	<0.1%	n.s. 0.04 (-0.48–0.57)	<0.1%
Caregiver distressed or overwhelmed	1.96 (1.71–2.21)	1.1%	4.43 (4.05–4.80)	3.5%
Any ED visit	-0.79 (-1.05–0.53)	0.2%	-0.45 (-0.83–0.07)	<0.1%
Any hospital stay	2.64 (2.35–2.93)	1.5%	2.52 (2.07–3.02)	0.6%
Health conditions				
Dyspnea	-0.76 (-1.05–0.47)	0.1%	-0.42 (-0.81–0.02)	<0.1%
Poor self-reported health	1.60 (1.34–1.85)	0.7%	3.09 (2.72–3.46)	1.8%
Unstable health patterns	1.88 (1.58–2.17)	0.8%	3.18 (2.73–3.64)	1.2%
Acute episode or flare-up	0.43 (0.13–0.72)	<0.1%	0.48 (0.02–0.95)	<0.1%
Fall(s)	0.88 (0.63–1.14)	0.2%	1.37 (0.99–1.74)	0.3%
Dizziness	-0.98 (-1.28–0.67)	0.2%	-1.54 (-2.00–1.09)	0.3%
Chest pain	-0.83 (-1.46–0.19)	<0.1%	-1.01 (-1.83–0.19)	<0.1%
Peripheral edema	-0.41 (-0.68–0.15)	<0.1%	-0.46 (-0.85–0.08)	<0.1%
Pain	-0.68 (-0.95–0.41)	0.1%	n.s. -0.34 (0.72–0.05)	<0.1%
Decrease in food or fluid	0.51 (0.18–0.83)	0.1%	2.56 (2.12–3.01)	0.8%
Weight loss	1.18 (0.82–1.54)	0.2%	2.77 (2.25–3.30)	0.7%
Special diet	1.51 (1.23–1.80)	0.5%	1.85 (1.46–2.24)	0.6%
Pressure ulcer(s)	2.78 (2.32–3.25)	0.7%	3.09 (2.52–3.65)	0.8%
Major skin problem(s)	n.s. -0.30 (-0.63–0.05)	<0.1%	-1.17 (-1.69–0.66)	0.1%
Traumatic injury	n.s. 0.14 (-0.22–0.50)	<0.1%	0.83 (0.10–1.56)	<0.1%
Surgery	-0.43 (-0.72–0.14)	<0.1%	-1.00 (-1.50–0.49)	0.1%
High or very high health instability	2.46 (2.05–2.88)	<0.1%	5.45 (4.91–5.98)	<0.1%

- Chi-square test: All results were significant at <.05 unless otherwise noted.

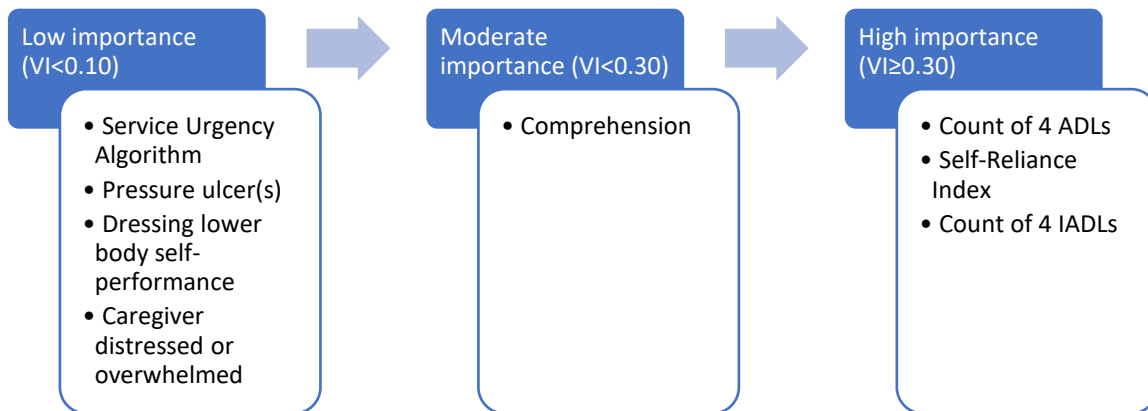
Figure 5-2 and Figure 5-3 present the variable importance statistics from the automated decision trees. Consistent with the logistic and linear models, the counts of impaired ADLs and IADLs emerged as the most important need characteristics. The Self-Reliance Index (a composite measure reflecting cognitive and ADL status) emerged as a highly important characteristic when predicting PS Group at the time of HC assessment. Cognitive impairment and cognitive decline were also identified as moderately important characteristics when predicting weekly publicly funded PS/HM hours after the CA. Difficulty with comprehension, caregiver distress, and the Service Urgency Algorithm appeared in both lists as either moderate or low importance characteristics. Some characteristics only appeared in one tree. For instance, decrease in food or fluid, special diet, falls, dizziness, and unstable patterns emerged from the tree predicting weekly publicly funded PS/HM hours, but pressure ulcer(s) emerged from the tree predicting the PS Group. In subsequent validation analyses, the “automatic” tree refers to the decision tree predicting weekly publicly funded PS/HM hours received after the CA. Other variables that were part of the automatic tree includes no primary informal caregiver, recent surgery, dressing lower body self-performance, self-rated health, dyspnea, recent ED visit, major skin problem(s), Assessment Urgency Algorithm, and self-reported mood. Its root nodes were categorised into six groups based on similar mean PS/HM hours received after the CA.

Figure 5-2 Summary of Variable Importance Statistics from Automated Decision Tree Predicting Weekly Publicly Funded PS/HM Hours Received after CA among CA-Assessed Clients, Ontario FY 2016/17



Note: The variable importance (VI) statistic is a summary statistic reflecting the number of nodes influenced by the variable and the purity of the resulting nodes. Only the order of variable importance values should be interpreted; neither the absolute nor relative values are meaningful.

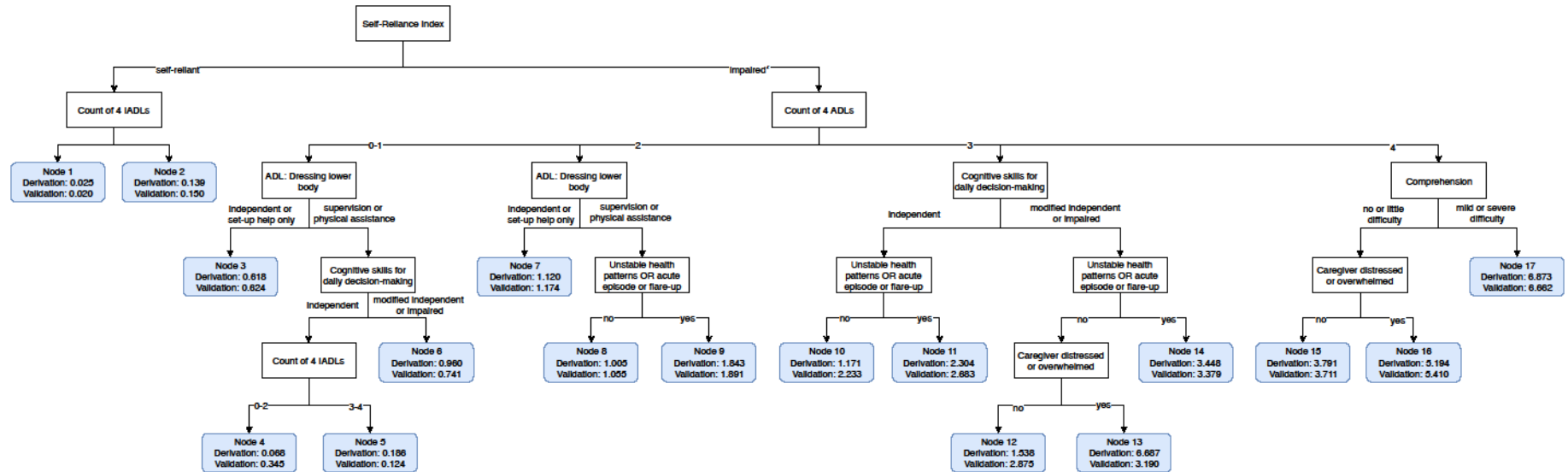
Figure 5-3 Summary of Variable Importance Statistics from Automated Decision Tree Predicting PS Group at Time of HC Assessment among CA- and HC-Assessed Clients, Ontario FY 2016/17



Note: The variable importance (VI) statistic is a summary statistic reflecting the number of nodes influenced by the variable and the purity of the resulting nodes. Only the order of variable importance values should be interpreted; neither the absolute nor relative values are meaningful.

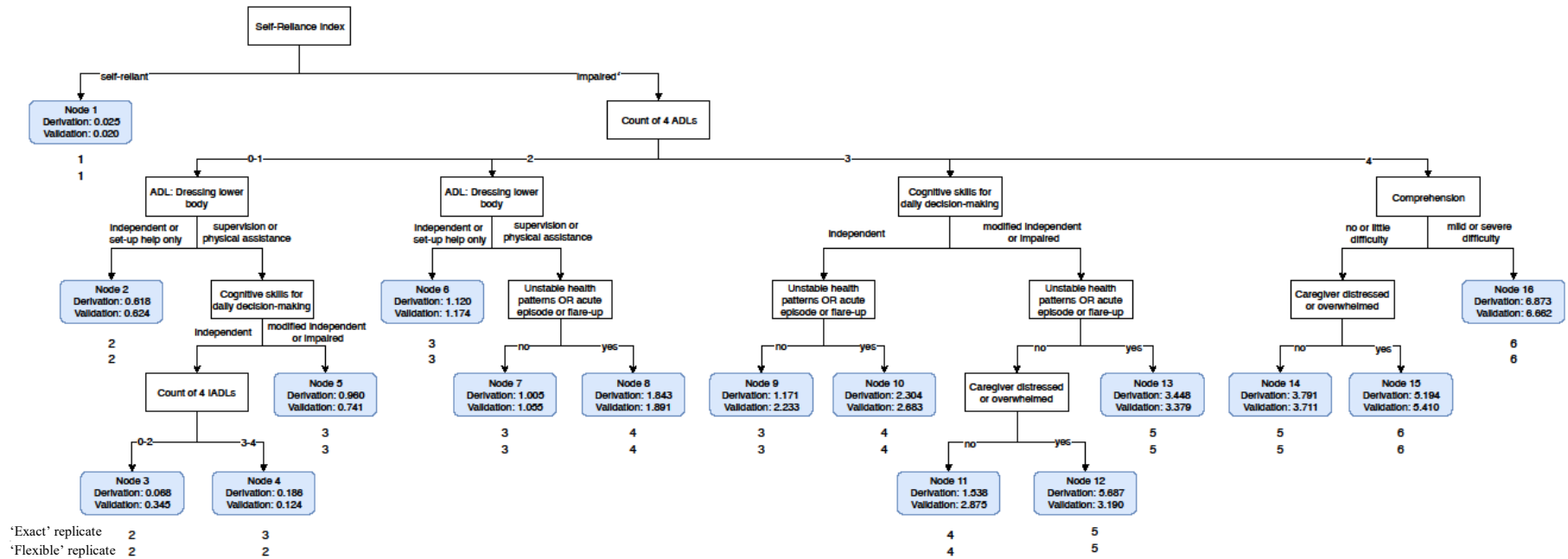
The PS Algorithm was cross-walked using the available CA items. The Self-Reliance Index, unstable health patterns, caregiver distress, and comprehension items were replicated exactly. The count of ADLs and IADLs substituted for the ADL Short Scale and the IADL Capacity Scale, respectively. The CA employs a more simplified response set for the individual ADLs and cognitive skills, but this simplification only affected two out of four nodes. Locomotion, bed mobility, and bowel incontinence are higher-order functional losses that are not measured in the CA and were removed from the highest branch. Bladder incontinence is also not measured in the CA. During the interactive model building process, unstable health patterns was found to discriminate between nodes 10 and 11 in a similar way as bladder incontinence. Reasonable substitutes for the other two nodes representing bladder incontinence in the PS Algorithm could not be found and these nodes were removed. In Figure 5-4, the values in the root nodes (shaded) are the mean weekly publicly funded PS/HM hours received after the CA in the derivation (70%) and validation datasets (30%), respectively.

Figure 5-4 Exploratory Tree Structure Replicating PS Algorithm, Using CA Items, Ontario FY 2016/17



Note: Root nodes are shaded in blue. The values in the root nodes are the mean weekly publicly funded PS/HM hours received within two weeks of the CA within the derivation and validation datasets, respectively.

Figure 5-5 Pruned Tree Structure Replicating PS Algorithm and Mapping of Root Nodes, Using CA Items, Ontario FY 2016/17



Note: Root nodes are shaded in blue. The values in the root nodes are the mean weekly publicly funded PS/HM hours received within two weeks of the CA within the derivation and validation datasets, respectively.

- 'Exact' replicate: root nodes were grouped according to the PS Algorithm mapping
- 'Flexible' replicate: root nodes were grouped according to similar mean weekly publicly funded PS/HM hours received within two weeks of the CA

Figure 5-5 shows the final tree structure replicating the PS Algorithm after pruning. Nodes 1 and 2 were collapsed due to similar mean publicly funded PS/HM hours. The final tree structure consists of 16 root nodes that were grouped in two ways. The “exact” method grouped root nodes according to the PS Algorithm mapping. The “flexible” method grouped root nodes according to similar mean publicly funded PS/HM hours received after the CA. Only node 4 was classified differently, being classified as Group 3 under the “exact” method and Group 2 under the “flexible” method.

A second interactive decision tree (not shown) was built using the weekly publicly funded PS/HM hours received after the CA as the target variable. As the best predictors in every single model, the Self-Reliance Index and count of ADLs comprise the first two levels. Other characteristics are the count of IADLs, cognitive skills, cognitive decline, personal hygiene self-performance, bathing self-performance, unstable health patterns, dyspnea, pressure ulcer(s), fall(s), and caregiver distress. Some of these variables describing health symptoms are less strongly associated with the dependent variables but are hypothesised to describe unique client needs that were not captured in the other candidate models. Its root nodes were categorised into six groups based on the similar mean publicly funded PS/HM hours received after the CA. This tree is referred to as the “interactive” tree in subsequent validation analyses.

5.9.3 CA Validation

Candidate trees were tested using an out-of-time validation sample (n=202,586). In this sample, 88.5% were new clients and 11.5% were existing clients. Overall, 19.8% of clients received any publicly funded PS/HM after the CA that included 14.5% of new clients and 60.5% of existing clients. Among clients receiving any publicly funded PS/HM services, the mean (\pm SD) publicly

funded PS/HM hours was 7.1 (\pm 7.5) hours/week, the median was 5.5 hours/week, and the interquartile range was 4.2 hours/week. Nearly two-thirds (65.2%) of CAs were conducted by phone only.

Table 5-5 presents the performance statistics for each model. The automatic tree had the highest explained variance (23.9%) followed by the interactive tree (22.1%), flexible replicate tree (20.4%), and exact replicate tree (20.4%). The interactive tree had the highest weighted kappa statistic (0.37) although most of the confidence intervals were overlapping between candidate trees. The performance statistics for the Assessment Urgency Algorithm (AUA), an existing CA algorithm that has been shown to partly explain the cost of publicly funded PS/HM services, were much lower.

Table 5-5 Performance Statistics across Candidate Trees for CA-Assessed Clients, Ontario April–December 2017

Model	Explained variance of publicly funded PS/HM hours received after CA, %	Weighted kappa (95% CI) of PS Group at time of HC assessment
Automatic	23.9	0.35 (0.35–0.36)
Interactive	22.1	0.37 (0.36–0.37)
Exact replicate	20.4	0.36 (0.35–0.36)
Flexible replicate	20.4	0.35 (0.35–0.36)
AUA	11.6	0.09 (0.08–0.09)

Table 5-6 presents the performance statistics stratified by new and existing clients. The explained variance of the automatic and interactive trees was similar between client types, whereas the explained variance of the replicate trees (either method) was somewhat higher among existing clients. Across candidate trees, the weighted kappa statistic was higher among existing clients although the differences between candidate trees were insignificant.

Table 5-6 Performance Statistics across Candidate Trees for CA-Assessed Clients, by Client Status, Ontario April–December 2017

Model	Explained variance of publicly funded PS/HM hours received after CA, %		Weighted kappa (95% CI) of PS Group at time of HC assessment	
	New clients	Existing clients	New clients	Existing clients
Automatic	19.9	20.0	0.33 (0.32–0.33)	0.38 (0.36–0.39)
Interactive	18.6	18.6	0.35 (0.34–0.35)	0.38 (0.36–0.39)
Exact replicate	16.4	18.7	0.34 (0.33–0.34)	0.37 (0.36–0.39)
Flexible replicate	16.5	18.5	0.33 (0.33–0.34)	0.36 (0.35–0.37)
AUA	9.7	11.3	0.08 (0.07–0.08)	0.11 (0.11–0.12)

Table 5-7 presents the performance statistics for CAs that were completed by phone only.

Overall, the explained variance and weighted kappa statistics were lower among CAs completed over the phone only; however, all candidate trees still demonstrated marked improvement over the AUA.

Table 5-7 Performance Statistics across Candidate Trees for CA-Assessed Clients, Phone Only CAs, Ontario April–December 2017

Model	Explained variance of publicly funded PS/HM hours received after CA, %	Weighted kappa (95% CI) of PS Group at time of HC assessment
Automatic	15.6	0.32 (0.31–0.33)
Interactive	14.4	0.33 (0.32–0.34)
Exact replicate	13.0	0.34 (0.34–0.35)
Flexible replicate	13.2	0.34 (0.33–0.35)
AUA	8.2	0.07 (0.07–0.07)

Table 5-8 presents the performance statistics for CAs that were completed in the hospital only.

Compared to all clients, model performance improved when restricting to clients assessed as a hospital inpatient.

Table 5-8 Performance Statistics across Candidate Trees for CA-Assessed Clients, Hospital (Inpatient) CAs, Ontario April–December 2017

Model	Explained variance of publicly funded PS/HM hours received after CA, %	Weighted kappa (95% CI) of PS Group at time of HC assessment
Automatic	25.9	0.35 (0.34–0.36)
Interactive	24.6	0.38 (0.37–0.38)
Exact replicate	23.9	0.35 (0.32–0.36)
Flexible replicate	24.0	0.34 (0.33–0.35)
AUA	15.3	0.10 (0.10–0.10)

5.9.4 HC Validation

All HC items were recoded to match the CA’s simplified response sets. The purpose of the HC validation is to test the performance of the candidate trees in the general adult long-stay home care population. In Table 5-9, the exact replicate tree had the highest explained variance (18.0%), weighted kappa statistic (0.51), and Spearman’s rank correlation coefficient (0.81).

Table 5-9 Performance Statistics across Candidate Trees for HC-Assessed Clients, Ontario FY 2016/17

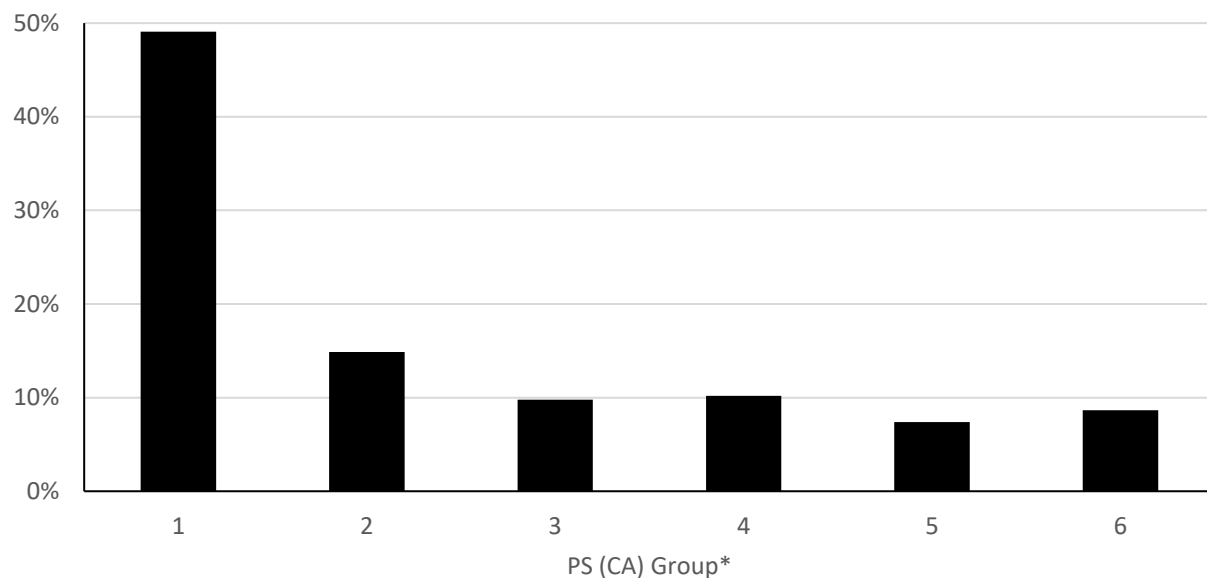
Model	Explained variance of publicly funded PS/HM hours received after HC, %	Weighted kappa (95% CI) of PS Group	Spearman’s rank correlation (ρ) with PS Group
Automatic	17.6	0.35 (0.35–0.36)	0.73
Interactive	13.8	0.49 (0.49–0.50)	0.72
Exact replicate	18.0	0.51 (0.51–0.52)	0.81
Flexible replicate	17.5	0.48 (0.47–0.48)	0.77
AUA	8.2	0.12 (0.11–0.12)	0.42

5.9.5 Model Selection

Overall, all candidate trees performed similarly in explaining variance of publicly funded PS/HM hours received after the CA and HC, and agreement with PS Group at the time of HC assessment. Given comparable statistical performance, the choice of the final model (i.e., PS Algorithm for the CA) was based on consistency with the PS Algorithm. Thus, the exact replicate tree was selected because it uses the same items (in collapsed form) and classification rules as the PS Algorithm.

The distribution of CA-assessed clients across the PS (CA) Algorithm is shown in Figure 5-6. About half (49.1%) of CA-assessed clients were in PS (CA) Group 1. There were 7.4% and 8.6% of clients in PS (CA) Groups 5 and 6, respectively.

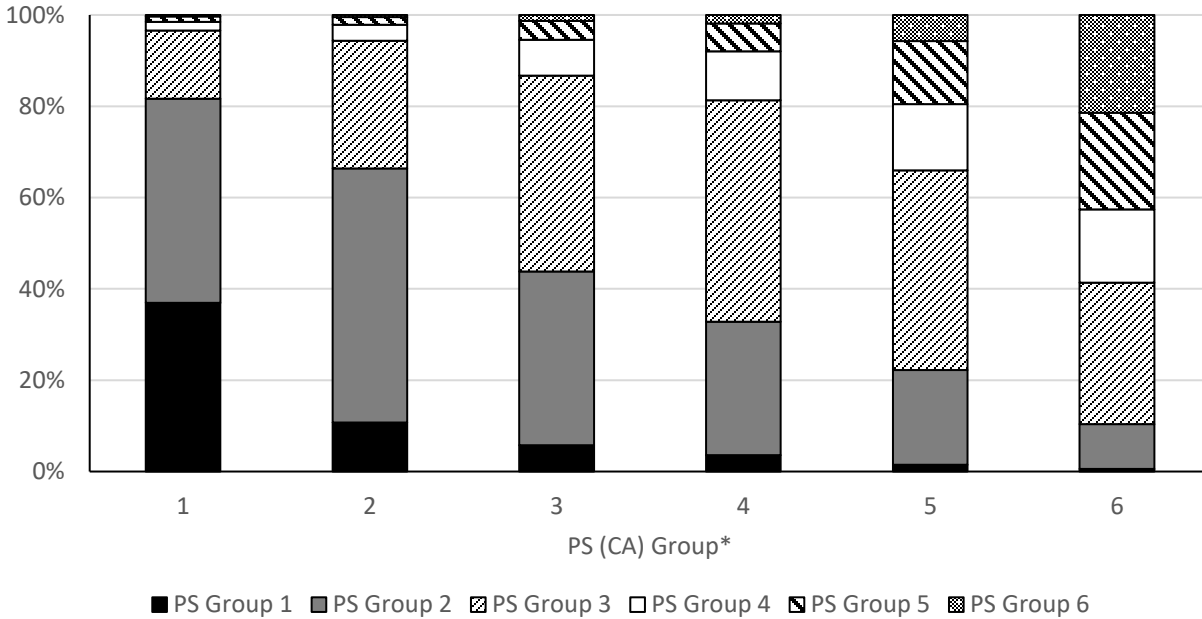
Figure 5-6 Distribution of CA-Assessed Clients by PS (CA) Group, Ontario April–December 2017



*Equivalent to flexible replicate tree

Figure 5-7 illustrates the distribution of PS Groups for each PS (CA) Group. With each increase in PS (CA) Group, there were proportionately fewer clients in the lowest PS Groups and more clients in the highest PS Groups.

Figure 5-7 Distribution of PS Group by PS (CA) Group among CA- and HC-Assessed Clients, Ontario FY 2016/17



*Equivalent to flexible replicate tree

Among clients in PS (CA) Group 1, 81.7% were later assessed to be in PS Group 1 or 2 and only 1.5% were later assessed to be in PS Group 5 or 6 (Table 5-10). In contrast, 42.6% of clients in PS (CA) Group 6 were in PS Groups 5 or 6. Only 10.4% of clients in PS (CA) Group 6 were in the lowest PS Groups in a subsequent HC assessment.

Table 5-10 Distribution of PS Group by PS (CA) Group among CA- and HC-Assessed Clients, Ontario FY 2016/17

Row % (n) PS (CA) Group*	PS Group at time of HC assessment			Odds ratio (95% CI) of PS Group 5 or 6
	Low or mild (PS Group 1 or 2)	Moderate (PS Group 3 or 4)	High or very high (PS Group 5 or 6)	
1	81.7 (5,247)	16.8 (1,082)	1.5 (96)	Reference
2	66.4 (6,286)	31.4 (2,973)	2.2 (206)	1.45 (1.15–1.87)
3	43.8 (2,649)	50.8 (3,071)	5.4 (328)	3.78 (3.00–4.76)
4	32.8 (2,881)	59.2 (5,200)	8.0 (698)	5.69 (4.59–7.07)
5	22.2 (1,311)	58.2 (3,436)	19.5 (1,153)	16.01 (12.96–19.79)
6	10.4 (848)	47.0 (3,831)	42.6 (3,468)	48.86 (39.76–60.06)

*Equivalent to flexible replicate tree

Table 5-11 presents the performance statistics of the PS (CA) Algorithm for each LHIN. The weighted kappa statistics were similar across LHINs, suggesting similar coding of CA and HC assessments for clinical characteristics capturing need for publicly funded PS/HM services. Greater variation was observed with explained variance that ranged from 10.7% in South West LHIN to 28.0% in North Simcoe Muskoka LHIN.

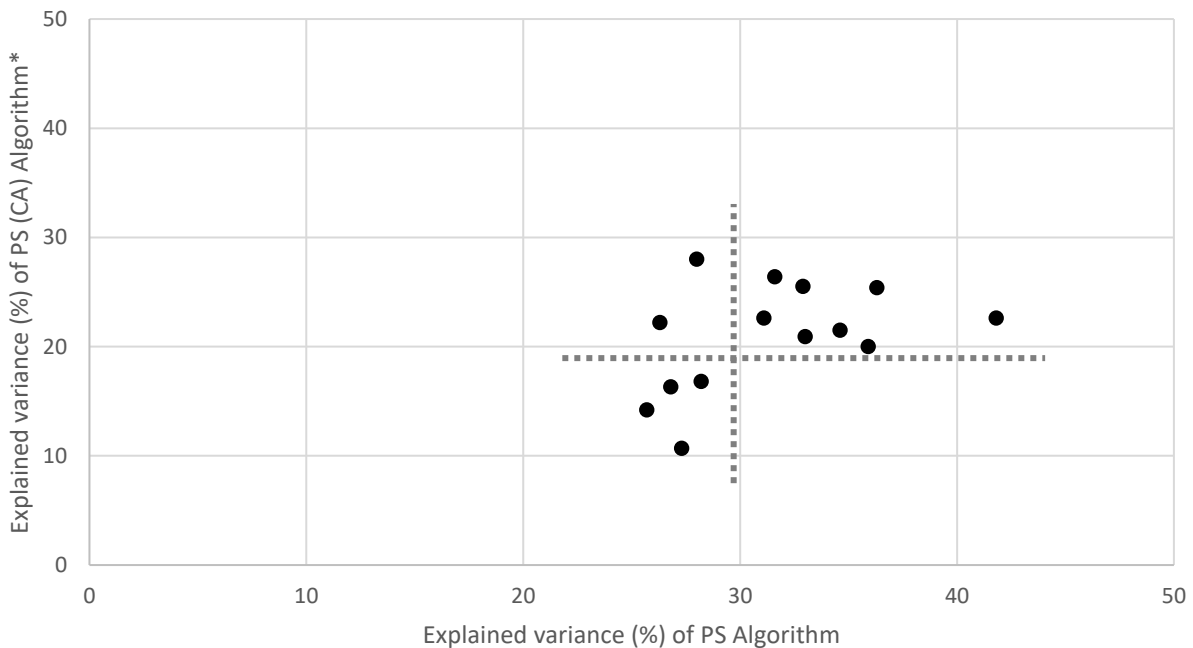
Table 5-11 Performance Statistics of PS (CA) Algorithm among CA-Assessed Clients, by LHIN, Ontario FY 2016/17

LHIN	Performance statistics of PS (CA) Algorithm*	
	Explained variance of publicly funded PS/HM hours received after CA, %	Weighted kappa (95% CI) of PS Group at time of HC assessment
Central East	20.0	0.27 (0.27–0.29)
Central	25.4	0.30 (0.28–0.31)
Champlain	25.5	0.29 (0.27–0.30)
Central West	21.5	0.41 (0.38–0.44)
Erie St. Clair	16.8	0.38 (0.35–0.40)
Hamilton Niagara Haldimand Brant	26.4	0.41 (0.40–0.43)
Mississauga Halton	22.6	0.40 (0.38–0.42)
North East	16.3	0.31 (0.29–0.34)
North Simcoe Muskoka	28.0	0.37 (0.34–0.40)
North West	14.2	0.35 (0.31–0.39)
South East	22.6	0.38 (0.36–0.40)
South West	10.7	0.33 (0.31–0.35)
Toronto Central	20.9	0.28 (0.26–0.31)
Waterloo Wellington	22.2	0.33 (0.31–0.36)

*Equivalent to flexible replicate tree

Figure 5-8 depicts the ordering of the LHINs in terms of the variance in publicly funded PS/HM services received after the CA that is explained by the PS (CA) Algorithm and the variance in publicly funded PS/HM services received after the HC that is explained by the PS Algorithm. The explained variance values for the PS Algorithm were extracted from the derivation of the PS Algorithm published by Sinn et al. [60]. LHINs generally ranked high or low on both the explained variances of the PS (CA) Algorithm and PS Algorithm. For eight LHINs (upper right quadrant), the explained variances of the PS (CA) Algorithm and PS Algorithm were consistently at or above 20.0% and 30.0%, respectively. For four LHINs (lower left quadrant), the explained variances were consistently below 20.0% and below 30.0%, respectively.

Figure 5-8 Scatterplot of Variance Explained by PS (CA) Algorithm of Publicly Funded PS/HM Services Received after CA (Ontario FY 2016/17) and Variance Explained by PS Algorithm of Publicly Funded PS/HM Services Received after HC (Ontario Jan–Dec 2013)



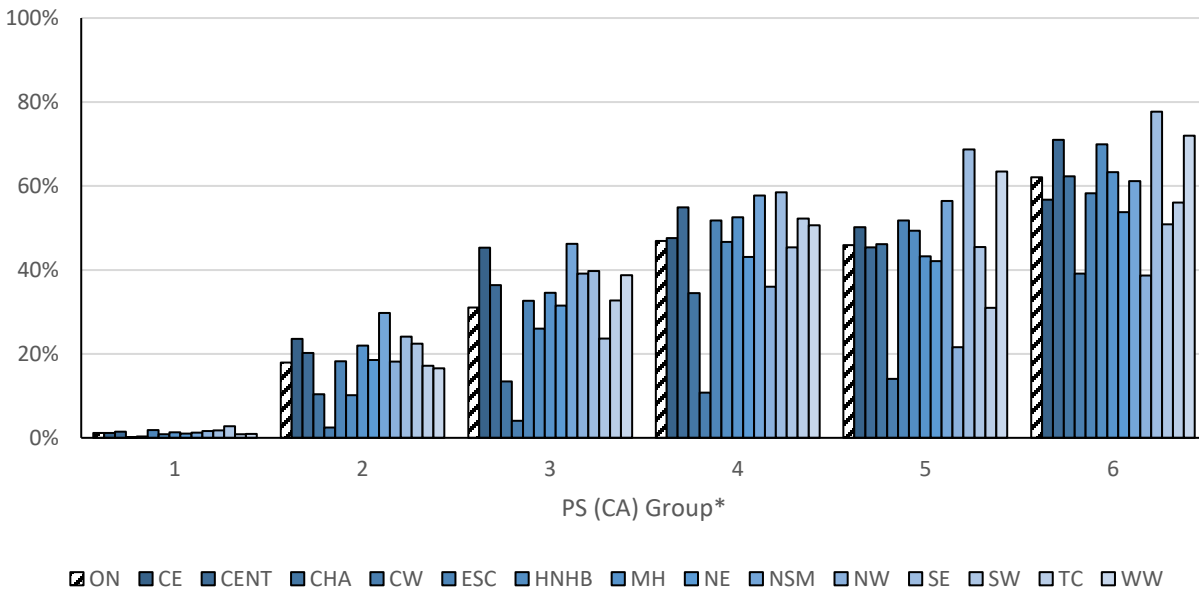
*Equivalent to flexible replicate tree

Note: Each dot represents one of the 14 LHINs. The grey axes were superimposed onto the figure to help with describing their pattern.

Provincially, the proportion of clients receiving any publicly funded PS/HM services after the CA ranged from 1.2% in PS (CA) Group 1 to 62.1% in PS (CA) Group 6 (Figure 5-9). The most consistent LHIN-level results were observed in PS (CA) Group 1. Other LHIN-level results were more mixed.

In every PS (CA) Group, clients in Central and South East LHIN were more likely to receive any publicly funded PS/HM services after the CA. Clients in Central West LHIN were less likely to receive any PS/HM services after the CA. Clients in Central East, Erie St. Clair, Mississauga Halton, North East, North Simcoe Muskoka, North West, Toronto Central, and South West LHINs were more likely to receive services after the CA in lower PS (CA) Groups but less likely in higher PS (CA) Groups. In contrast, clients in Champlain, Hamilton Niagara Haldimand Brant, and Waterloo Wellington LHINs were more likely to receive services after the CA in higher PS (CA) Groups but less likely in lower PS (CA) Groups.

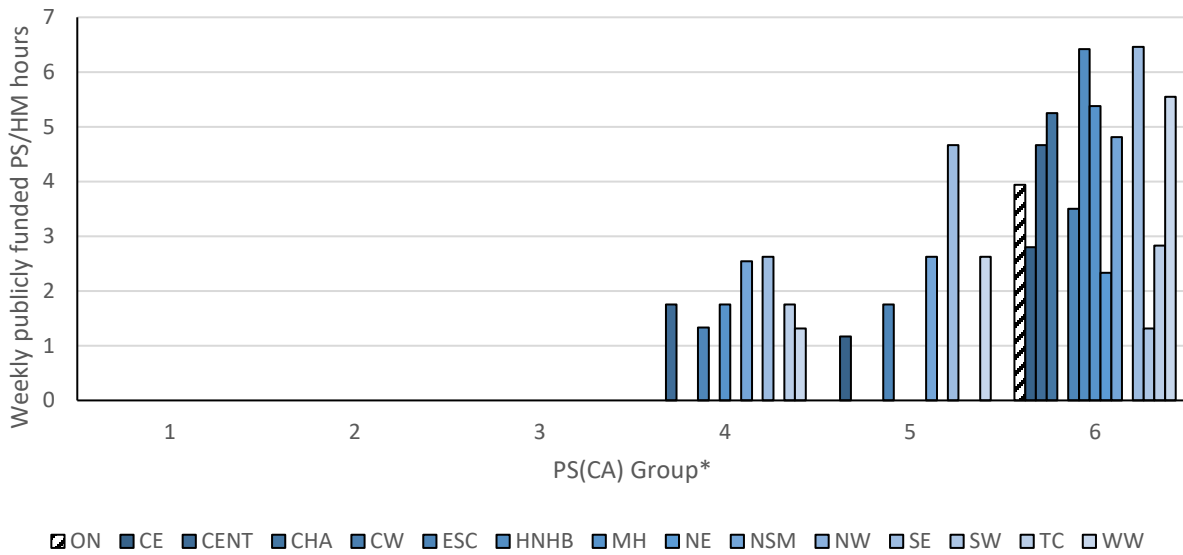
Figure 5-9 Proportion of CA-Assessed Clients Receiving Any Publicly Funded PS/HM Services after CA, by PS (CA) Group and LHIN, Ontario April–December 2017



*Equivalent to flexible replicate tree

The following two figures show the weekly publicly funded PS/HM hours received after the CA in each PS Group and LHIN. In Figure 5-10, there were non-zero median values for seven LHINs in PS (CA) Group 4, five LHINs in PS (CA) Group 5, and 12 LHINs in PS (CA) Group 6. Only Central West and North West LHINs had zero median values in the highest group.

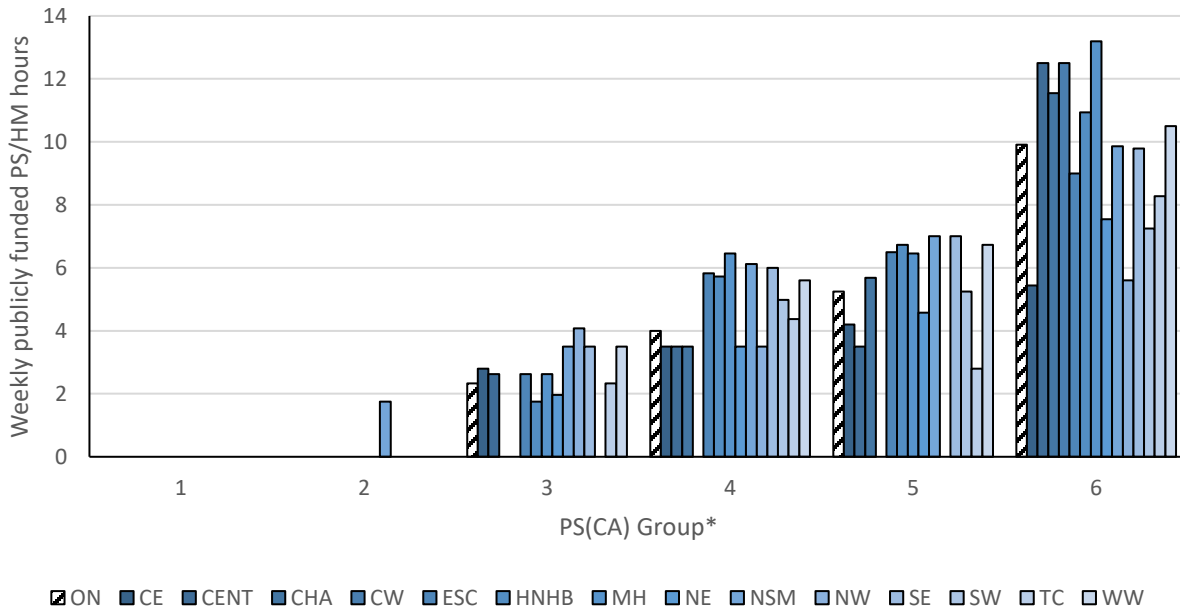
Figure 5-10 Median Weekly Publicly Funded PS/HM Hours by PS (CA) Group and LHIN, Ontario April–December 2017



*Equivalent to flexible replicate tree

In Figure 5-11, most LHINs had non-zero values at the 75th percentile for PS (CA) Groups 3 and above. Only Central West and North West LHINs had zero values at the 75th percentile in PS (CA) Group 5. At the provincial level and across most LHINs, clients in higher PS (CA) Groups received more publicly funded PS/HM services after the CA. In PS (CA) Group 6, the provincial average was 9.9 hours/week, ranging from 5.4 hours/week in Central East LHIN to 13.2 hours/week in Mississauga Halton LHIN.

Figure 5-11 75th Percentile of Weekly Publicly Funded PS/HM Hours by PS (CA) Group and LHIN, Ontario April–December 2017



*Equivalent to flexible replicate tree

5.10 Discussion

The PS (CA) Algorithm differentiates need for PS/HM services among CA-assessed clients. In jurisdictions where home care programs have adopted the CA and HC as a stepped approach to assessment, and especially in Ontario where the PS Algorithm is already used to guide public PS/HM service allocation for long-stay clients, the PS (CA) Algorithm can serve an important role. Existing CA algorithms guide assessors to consider comprehensive assessment (via the Assessment Urgency Algorithm) and prioritise nursing and therapy services (via the Service Urgency Algorithm and Rehabilitation Algorithm) but not PS/HM services. Use of the PS (CA) Algorithm would guide assessors to consider each client’s need for PS/HM services, regardless if the client was referred for a professional service or if the client was already receiving PS/HM services but required more than the usual amount of personal care after hospitalisation. For

future long-stay clients, the PS (CA) Group predicts future PS Group, meaning that clients and families can expect more consistent services when switching to a long-stay caseload. Thus, together with the PS Algorithm, these tools provide a unified evidence-informed approach for allocating publicly funded PS/HM services throughout the home care episode.

Consistent with the derivation of the PS Algorithm, measures of ADL/IADL impairment, cognitive impairment, and caregiver distress are strongly associated with the amount of publicly funded PS/HM hours received after the CA. Comprehension and unstable health patterns also appear in both algorithms. The fact that nearly all CA items are associated with publicly funded PS/HM service is evidence that the CA captures the essential information needed at the time of program intake to support decisions for short-term service provision and further assessment [161].

The PS (CA) Algorithm explains 20.4% of the variance in weekly publicly funded PS/HM hours received after the CA. Comparison to existing case mix tools in similar populations suggest good performance of the PS (CA) Algorithm. Smith et al. [219] explained 20% of the cost variance (12% in the cross-validation sample) among clients receiving home-based primary health care after being discharged from hospital or nursing home. Using CA data from New Zealand, Parsons et al. [168] developed a case mix system for non-complex clients that explained 16% of total home care service cost. The three “lead” categories were defined using measures of ADL and IADL impairment, while the presence of unstable health patterns and need for therapies further differentiated clients [168]. Compared to the present study, both algorithms share similar conceptual bases although the PS (CA) Algorithm also includes cognitive impairment. As well, the PS (CA) Algorithm may be more broadly applicable. In Parsons et al. [168], only 17.7% of

CA-assessed clients had any ADL impairment and 44.2% did not have any ADL or IADL impairment. As a result, clients with any ADL impairment were classified into two groups. However, these two groups would account for 43.1% of the total CA-assessed population in the present study. The PS (CA) Algorithm offers a more useful system for classifying clients along the spectrum of PS/HM need.

While the PS Algorithm explained 30.8% of the variance in weekly publicly funded PS/HM hours received after the HC [60], much of the difference in variance between the PS (CA) Algorithm and PS Algorithm can be explained by the CA's simplified response set, especially of the ADL items. As well, there was a wider spread in the magnitude of the LHIN-level explained variance. The PS (CA) Algorithm explains between 10.7% to 28.0% of the variance in weekly PS/HM hours received after the CA, while the PS Algorithm explains 25.7% to 41.8% of the variance in weekly PS/HM hours received after the HC [60]. In general, LHINs with high explained variance by the PS Algorithm tend also to have high explained variance by the PS (CA) Algorithm. Still, the proportion of clients receiving any publicly funded PS/HM services and the amount of services received varies substantially across LHINs. Larger variations in LHIN service guidelines and practice policies could partially explain the smaller variance explained by the PS (CA) Algorithm. Over time, one would expect that use of a common algorithm would reduce these discrepancies, resulting in larger variance explained by the PS (CA) Algorithm.

The validation analyses show that the PS (CA) Algorithm is somewhat better at predicting PS/HM services for existing clients than new clients. Further, CAs that were completed in the hospital represent the subset of CAs for which the PS (CA) Algorithm is most predictive of

PS/HM services ($R^2=24.0\%$). These findings suggest that better performance can be expected when more information is available to the assessor, either because the client is already known to the care coordinator or in-person assessment is possible (as is usually the case for CAs completed in the hospital). Importantly, these findings do not mean that the PS (CA) Algorithm is inappropriate for other client populations. Rather, more grey areas are present when the assessment is done over the phone, further underlying the importance of timely comprehensive follow-up assessment. The benefits of an in-person assessment include having more subjective cues about the client's needs and circumstances, more time to probe responses, and involvement of both the client and family.

The next obvious question is how to link the PS (CA) Algorithm to standard service guidelines. With the two algorithms being conceptually identical, one could utilise the PS Algorithm's Framework of Hours. An important caveat is that the PS (CA) Algorithm is based on a screening assessment and therefore has a wider margin of error than the PS Algorithm. One option would be to adopt the Framework of Hours exactly but collapse the groups to allow for increased flexibility. For instance, the same guideline based on the 35th percentile of PS Group 1 (i.e., 0 hours/week) and 65th percentile of PS Group 2 (i.e., 2 hours/week) could apply to both PS (CA) Groups 1 and 2. However, this method assumes that the nature of PS/HM need is the same after the CA and HC even though the CA-assessed population is quite heterogeneous. Another option could be to tailor the Framework of Hours to the type of client. For example, the upper end of the percentile bands might be more flexible for clients returning from the hospital, or the percentile bands might be more conservative for new clients as long as they are appropriately triaged for a comprehensive follow-up assessment.

Importantly, care coordinators will still have the flexibility to allocate PS/HM services based on other factors that may place the client at greater or lesser need but are not captured in the algorithm. Some of these factors raised by the Levels of Care Expert Panel include living arrangement and caregiver distress that were examined in the previous chapter [35]. In this chapter, the presence of pressure ulcers, falls, poor self-reported health, and high health instability (i.e., CHESS) were associated with greater need within the CA-assessed population. These factors may be particularly relevant after hospital discharge, at a time when clients may need additional help with mobility or other personal care activities immediately after returning home. As well, clients who may be seeking home care services for the first time may have more unmet needs, which may explain the stronger association between self-rated health and PS/HM hours among CA-assessed clients compared to HC-assessed clients. In short, these factors are also important modifiers for care coordinators to consider when allocating PS/HM services.

Use of the PS (CA) Algorithm and PS Algorithm can be expected to confer system-wide benefits. A more transparent and equitable process for identifying and responding to personal care needs will help health professionals outside of home care to better understand the public home care system. There may also be an opportunity to integrate the PS (CA) Algorithm into workflows of community support service agencies and primary care providers. Aside from the comprehension variable used to differentiate between PS (CA) Groups 5 and 6, the PS (CA) Algorithm is fully compatible with the interRAI Preliminary Screener for Primary Care and Community Care Settings. In Ontario, many community support service agencies that do not provide clinical supports use the Preliminary Screener as a screener for program eligibility. Just as the PS Algorithm that can be derived from the HC and CHA supports the home and

community care “one sector” model, the PS (CA) Algorithm can also be used to screen for personal care needs at a common intake point. As Ontario begins to pilot fully-integrated Ontario Health Teams that cover the spectrum of health care services, the PS (CA) Algorithm also presents an opportunity for improving referral efficiency and ongoing communication between primary care and home care about public PS/HM delivery. Since the structure, client population, and funding model will vary by each Ontario Health Team, ensuring that resources are equally accessible across the province is paramount. Data about the PS (CA) and PS Groups and the proportion of clients receiving services within the expected provincial ranges can serve as an important quality indicator and be monitored at the regional and provincial levels.

5.10.1 Strengths

The use of census-level clinical assessment and administrative data means that these results are generalisable across Ontario’s public home care population. Although these data regularly flow to researchers, the data are first and foremost collected by clinicians or trained staff and used for front-line assessment and service provision. The data are also used in funding models and quality indicators and thus can be expected to be highly accurate. Linking across multiple referrals, assessments, and services means that both receipt of PS/HM services and the PS Group at the time of HC assessment could be used to develop and validate the models. The PS (CA) Algorithm was validated on an external dataset and stratified results demonstrate that the algorithm is robust. Finally, the PS (CA) Algorithm is conceptually consistent with the PS Algorithm and can be readily implemented into HSSOntario’s Client Health and Related Information System (CHRIS) and deployed across Ontario’s LHINs.

5.10.2 Limitations

Although the number of days between the first and last service visit (denominator) was adjusted if the client was assessed or discharged within 14 days, data were not available on whether the client was placed on a partial waitlist, hospitalised, or received less PS/HM service for other reasons. As Ontario Health Teams form, it may be of interest to repeat these analyses at the hospital level. While there have been local-level discussions about using the PS Algorithm in some community support service agencies, progress has been limited to date. The PS (CA) Algorithm presents another tool to encourage greater integration of LHINs and community support services agencies. Additional testing of the PS (CA) Algorithm will be needed to translate for the interRAI Preliminary Screener, but achieving greater equity and transparency in PS/HM service allocation will require working across the sector to develop consistent referral and service policies.

CHAPTER 6: What is the relationship between publicly funded PS/HM services and outcomes among Ontario home care clients assessed with the RAI-Home Care (interRAI Home Care)?

6.1 Introduction

Derivation of the PS Algorithm and PS (CA) Algorithm was based on the premise that the average historical allocation of PS/HM services can be used to classify need. Under the care coordination model, publicly funded PS/HM service use is largely driven by the service plan that is developed by the care coordinator with input from the client and family. The care coordinator gathers information through observation and interviewing, and allocates PS/HM services based on the client's level of need and risk in relation to other clients' needs. Even though per-client funding amounts differ by LHIN, the assumption that care coordinators allocate publicly funded PS/HM services in proportion to the degree of need is valid, as long as they allocate resources in a consistent and logical manner. Moreover, the PS Algorithm's Framework of Hours was designed to attenuate the influence of local resources and guidelines by defining the Framework of Hours using the median and percentile bands from the median [60]. In the Framework of Hours, the median (i.e., average) PS/HM hours is assumed to represent the "right" response of the public home care system in the context of client need and available public resources.

These assumptions may present challenges for LHINs planning to implement the percentile bands described in the Framework of Hours. The question of what is the "right" amount of services arises and whether future allocation should be based on the status quo. Practically speaking, LHINs will need to justify to clients, families, providers, and funders that updating their PS/HM allocation policies to align with the Framework of Hours will lead to optimal

outcomes. Some LHINs that may have historically received less per-client funding and whose policies allowed for less PS/HM service may find it difficult to increase services without additional funding. To facilitate discussions about re-allocating or increasing the home care budget, funders will expect to see evidence that providing services above a certain minimum level will lead to positive outcomes or avoid poor outcomes. Other LHINs that may have historically received more per-client funding and provided more than the average allocation may have to reduce services to match the Framework of Hours. Stakeholders in these LHINs will be concerned that reducing services will lead to an increase in avoidable adverse events. It is clear that research is needed to be able to explain the relationship between PS/HM services and outcomes before the Framework of Hours can be fully implemented and properly resourced.

At present, there are no standardised outcome indicators used to measure publicly funded PS/HM services [50]. Indicators of public home care performance in Ontario related to the provision of PS/HM services focus on process measures. The “percentage of home care patients aged 19 and older with complex needs who received their personal support visit within five days of service authorization” is the only indicator that is publicly reported by Health Quality Ontario that specifically references PS/HM services [190]. Other publicly reported indicators that apply to the overall home care experience include home care service wait times, client satisfaction, client-provider communication, client involvement in their home care plan, caregiver distress, and acute care use [190].

Compared to other home care or health care services that have a clear medical function, the fact that many clients receive ongoing PS/HM services for the purpose of maintaining health status or avoiding decline adds to the complexity of identifying PS/HM-sensitive client outcomes. Since

one of the primary functions of public home care is to prevent, delay, or substitute for long-term care placement, this chapter focuses on the relationship between PS/HM services and client and caregiver measures related to remaining in the community. This chapter will directly test the percentile bands of the Framework of Hours while using the PS Algorithm to control for need for PS/HM services.

6.2 Objectives

This chapter tests the hypothesis that PS/HM services help clients to stay at home. More specifically, the objective of this chapter is to examine the relationship between the amount of publicly funded PS/HM services and client and caregiver outcomes related to remaining in the community. In contrast to most of the published literature on this topic that focuses on single adverse events, the outcome measures include caregiver distress, moving to a cluster care residence, moving to a long-term care home, and death. Although caregiver distress is neither a direct measure of the client's health state nor a discharge destination per se, caregiver distress is an important indicator of the capacity of the informal caregiving network and a strong predictor of future long-term care placement [175, 220–222]. We hypothesise that some level of service below a threshold would increase the risk of poor outcomes and some level of service above a threshold would decrease risk of poor outcomes.

6.3 Data Sources

Client-level assessment and administrative data were sent by Hamilton Niagara Haldimand Brant (HNHB) LHIN to the University of Waterloo through agreements between these two organisations. All data were anonymised by HNHB LHIN prior to transfer to the University of Waterloo although a real-world linking field (client number) was generated to allow merging of

the data tables. Use of these data was approved by the University of Waterloo's Office of Research Ethics (ORE# 20862).

The following data tables are used in this study:

- Home care referrals (up to February 2019): Each row contains a unique referral. All referrals made to the LHIN are captured in this table even if the person was not admitted. Selected data columns include age, sex, referral date, referral source, referral decision, admission date, Service Recipient Code at admission, caseload, discharge date, and discharge disposition.
- RAI-HC and interRAI HC assessments (up to February 2019): In 2018, the interRAI HC replaced the RAI-HC as the standard assessment used to assess long-stay home care clients in Ontario. For simplicity, HC refers to any RAI-HC or interRAI HC assessment. Each row contains a unique assessment. All HCs are captured in this table. The data columns include assessment date, and all HC items, outcome scales, and algorithms. In this study, hospital versions (i.e., HCs completed in hospital as part of a long-term care application) were excluded from analysis.
- Addresses (up to February 2019): Each row contains an address record. The dataset consists of all active and inactive addresses. Data columns include start date, end date, and residence type (e.g., private dwelling, retirement home, cluster care residence, long-term care home). Actual addresses were removed prior to data transfer and thus were not available to researchers.

- Billed services (up to February 2019): Each row contains a unique home care service visit. The dataset consists of all services that were paid by the LHIN to service provider agencies, the sum of which represents all publicly funded home care services. Selected data columns include visit date, care location type, service type, and units of service provided (in hours or visits). Only PS/HM services and shift nursing are reported in hours. All other service types are counted by the number of visits.
- National Ambulatory Care Reporting System (NACRS; up to September 2018): Each row contains a unique emergency department discharge. The dataset consists of all NACRS records for discharges in the HNHB LHIN region of HNHB LHIN home care clients. Selected data columns include registration date, discharge date, and discharge disposition.
- Discharge Abstract Database (DAD; up to September 2018): Each row contains a unique hospital discharge. The dataset consists of all DAD records for discharges in the HNHB LHIN region for HNHB LHIN home care clients. Selected data columns include admit date, discharge date, and discharge reason.

6.4 Sample

All adult (age ≥ 18 years) home care referrals that were initiated on or after January 1, 2010 and subsequently admitted for HNHB LHIN home care services were retrieved. Referrals without a valid client number or referral start date were deleted. If a client had overlapping referrals, the referral start date was reset to the earliest referral start date and the discharge date (if discharged) was reset to the latest discharge date. The home care episode refers to the length of time between the referral start date and the discharge date. Referrals associated with the LHIN's Transitional

Care Program were excluded because program clients often receive PS/HM services above the statutory maximum and this program is not available in every LHIN. Only referrals assigned to one of the Acute, Rehabilitation, Maintenance, or Long-term Supportive Service Recipient Codes were kept. Home care referrals that were initiated while the client had an active long-term care placement referral were also excluded. To better represent the long-stay home care client populations, home care episodes that were shorter than 30 days were excluded.

Referrals were linked to the address and assessment data tables using the client number. Only HC assessments (non-hospital versions) that were completed on or after January 1, 2013 were retained. The restriction by referral and assessment dates meant that the sample would be representative of both newly referred and existing clients up to seven years on service. To allow for the observation of some of the discharge outcomes, HC assessments were excluded if the client was in hospital or not living in a private dwelling at the time of assessment. HC assessments were also excluded if the client did not identify a primary informal caregiver.

This working dataset was joined with the billed services dataset. Other than case management and placement services, all other service types were retained. For each client, services that were received up to 28 days after the HC assessment were retrieved. Clients who did not receive any home care services at all were excluded. However, this sample retained clients receiving some home care services after at least one HC assessment even if they did not receive home care services after other HC assessments. Monthly publicly funded PS/HM hours were calculated by dividing the sum of PS/HM hours by the number of service days. The numerator was the sum of hours across visits classified as personal services, homemaking services, combined personal services and homemaking services, or respite. The denominator was the difference in days

between the first and last visit; thus, the denominator was adjusted for clients whose first service visit was delayed or for clients not receiving service for the full observation period. Additionally, the denominator was reduced by the number of overlapping days that the client was in hospital and therefore would have been unable to receive home visits.

6.5 State Transitions

Each HC assessment up to December 2017 was assigned an initial state based on two indicators of caregiver distress recorded in the assessment: “informal helper is unable to continue in caring activities (e.g., decline in health of helper makes it difficult to continue)” and “primary informal helper expresses feelings of distress, anger, or depression”. As part of the assessment process, assessors ask the informal caregiver and client separately about the caregiver’s ability to continue providing care. Assessors may also record the presence of distress even if the caregivers themselves do not indicate distress if the assessor observes other signs of frustration or depression that may be related to the caregiving role. Previous studies have also combined these items to characterise the well-being of the informal caregiving system (examples include Betini et al. [175], Mitchell et al. [223], and Chang et al. [87]). An international validation study of the RAI-HC showed that the items assessing informal caregiver status have a weighted kappa of 0.66, indicating good reliability [155]. In 2017, the federal, provincial, and territorial health ministers in collaboration with the Canadian Institute for Health Information committed to publicly report on a national indicator of caregiver distress based on these HC items [224, 225]. In the present study, HC assessments were assigned to one of three mutually exclusive initial states: 0 caregiver distress items present, 1 caregiver distress item present, and 2 caregiver

distress items present. The order of these initial states represents a hypothesised hierarchy of greater risk of long-term care placement.

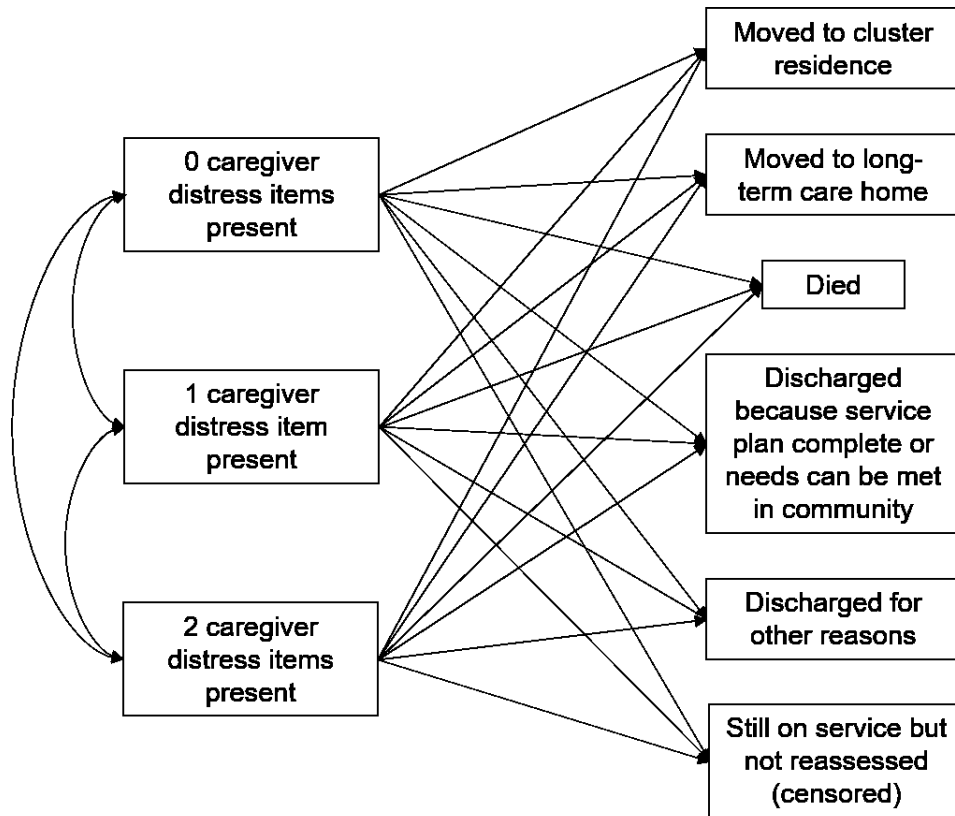
A period of up to 456 days (15 months) was allowed to observe a follow-up HC assessment or home care episode discharge. In Ontario, home care clients are generally reassessed every six to 12 months, with some care coordinator discretion related to the client's complexity and medical stability. The 15-month observation period was chosen to reflect the same definition of reassessment employed by the Canadian Institute for Health Information to calculate home care quality indicators [226]. Examination of this study's data showed that the censoring rate dropped from 15.2% to 8.9% when the observation period was extended from 12 to 15 months. Those still on service at the end of 15 months but not yet reassessed were classified as an additional state. All cases were assigned to one of nine follow-up states based on the first event that occurred following the initial state.

- 0 caregiver distress items present: The client was reassessed with the HC and no caregiver distress items were present.
- 1 caregiver distress item present: The client was reassessed with the HC and one caregiver distress item was present.
- 2 caregiver distress items present: The client was reassessed with the HC and two caregiver distress items were present.
- Moved to cluster residence: The client's home address residence type was changed from "private dwelling" to one of "retirement home", "cluster care residence", or "assisted living residence" OR the client was discharged in NACRS to "group/supportive living" OR the client was discharged in DAD to "group/supportive living".

- Moved to long-term care home: The client was discharged from home care service due “admitted to long-term care home” OR the client was discharged in NACRS to “residential care” OR the client was discharged in DAD to “residential care” or “continuing care”.
- Died: The client was discharged from home care service due to “death” or “died in hospital” OR the client was discharged in NACRS to “death on/after arrival” or “died in facility” OR the client was discharged in DAD to “death” or “died in facility”.
- Discharged because service plan complete or needs can be met in community: The client was discharged from home care service due to “service plan complete” or “transferred to community services”.
- Discharged for other reasons: The client was discharged from home care service for other reasons, including “transfer to other LHIN”, “hospitalised >14 days”, “client preference”, “vacation >30 days”, and “other”.
- Still on service but not reassessed (censored): The client was still on service at the end of 15 months but had not been reassessed with the HC.

Figure 6-1 shows the state-space diagram of the possible state transitions. The states on the right-hand side depict absorbing states that removed the client from receiving a follow-up HC assessment. In cases where a client did not transition to an absorbing state, the next follow-up HC defined the initial state of the next observation pair.

Figure 6-1 State-Space Diagram for Transitions within Home Care



6.6 Independent Variable

The independent variable of interest is the quintile of publicly funded PS/HM services. Shown in Table 6-1, monthly publicly funded PS/HM hours were sorted into quintiles based on the PS Algorithm's Framework of Hours published by Sinn et al. [60]. For example, a client in PS Group 6 would be sorted into the 1st quintile if they received between 0.0 and 28.0 PS/HM hours in the next month, the 2nd quintile if they received between 28.1 and 47.2 PS/HM hours in the next month, and so on. The 3rd quintile was inclusive of the median and thus was selected as the reference group. In PS Group 1, only the 90th percentile received any monthly hours; thus, all zeroes were set as the 3rd quintile (i.e., reference group) and any non-zeroes were sorted into the 5th quintile.

Table 6-1 Definition of PS/HM Quintiles Based on the Framework of Hours (FY 2014/15), in Monthly Publicly Funded PS/HM Hours

PS Group	1st quintile (0 to 20th)	2nd quintile (>20th to 40th)	3rd quintile (>40th to 60th)	4th quintile (>60th to 80th)	5th quintile (>80th to 100th)
1	N/A	N/A	0.0	N/A	>0.0
2	0.0	0.1–4.1	4.2–7.8	7.9–12.3	>12.3
3	<7.8	7.8–12.1	12.2–20.2	20.3–32.1	>32.1
4	<11.6	11.6–20.8	20.9–31.7	31.8–53.5	>53.5
5	<15.8	15.8–27.9	28.0–43.2	43.3–56.8	>56.8
6	<28.1	28.1–47.2	47.3–56.7	56.8–75.9	>75.9

6.7 Covariates

Based on existing literature [9, 179, 187], covariates were selected because of their known relationships with the study outcomes: sociodemographic characteristics, informal care, formal care, behavioural symptoms, cognitive status, dementia diagnosis, and health instability.

Age at the time of assessment was calculated by taking the difference between the birth date and assessment reference date and collapsed into three groups (18–64, 65–84, 85+). *Sex* is reported as a binary variable (female, not female). *Client lives with caregiver* is a binary variable describing whether the client and caregiver live in the same residence. *Client-caregiver relationship* describes the nature of relationship between the client and caregiver and was collapsed into four categories (spouse, child/child-in-law, relative, non-relative). *Referral source* is reported as a binary variable (hospital, community). *Average informal care per week* is equal to the sum of informal help received in the last week recorded in the RAI-HC, and extrapolated from the sum of informal help received in the last three days recorded in the interRAI HC. *Average publicly funded nursing and therapy per week* was calculated from the billed services dataset by dividing the sum of nursing hours and visits and therapy visits received within 28 days of assessment by the number of service days. *Days on home care service* was calculated by

taking the difference between the start of the home care episode and the HC assessment reference date. *Observation pair* refers to the n^{th} observation pair contributed by a given referral.

Cognitive impairment is operationalised using the Cognitive Performance Scale that is a hierarchical measure created from a count of cognitive impairments and severe cognitive impairments [198, 227]. This seven-point scale was collapsed into three groups: no impairment (0), mild to moderate impairment (1–3), and moderate to severe impairment (4–6). *Dementia diagnosis* is based on the presence of diagnosed Alzheimer’s disease or dementia other than Alzheimer’s disease. *Behavioural symptoms* indicates any wandering, verbal abuse, physical abuse, socially inappropriate or disruptive behaviour, or resisting care in the last three days. *Health instability* is operationalised using the Changes in Health, End-stage disease, Signs, and Symptoms (CHESS) scale that measures medical complexity and health instability [178, 179]. CHESS is based on a count of decline in cognitive status, decline in ADL status, symptoms such as dehydration and weight loss, and clinician ratings of less than six months to live. This six-point scale was collapsed into three groups: no health instability (0), minimal to moderate health instability (1–3), and high to very high health instability (4–5). The *Personal Support Algorithm* ranges from 0 to 6, where higher levels indicate higher need for PS/HM services based on ADL and IADL impairment and other modifiers [60]. The uncollapsed PS Groups were used as covariates in the full model and used to divide the sample in the stratified models.

6.8 Analysis Plan

A Markov chain multi-state transition model was fit by producing a series of generalised multinomial logit models, one for each initial state [228]. Each model was used to estimate the adjusted odds ratio for each follow-up state of each PS/HM quintile compared to the 3rd quintile.

All models were adjusted using the same list of covariates. The unit of analysis was the observation pair, so the variable Observation Pair was used to control for the number of observation pairs contributed to the sample by each referral. A transition matrix was used to summarise the odds ratios and 95% confidence intervals for each state transition across all PS Groups. Stratified results were also summarised in transition matrices for each PS Group. In earlier analyses, each quintile (1st, 2nd, 4th, and 5th) was treated as a separate treatment group. The findings were similar when the 1st and 2nd quintiles were combined to represent PS/HM services below the median (i.e., below the 40th percentile) and when the 4th and 5th quintiles were combined to represent PS/HM services above the median (i.e., above the 60th percentile). Thus, for ease of interpretation, only the models testing the effect of the combined quintiles are shown in the matrices. Equivalent binary logistic regressions for each pair of outcome states were run to assess pairwise c-statistics. Compared to conventional c-statistics that convey the model's ability to discriminate between dichotomous groups, the pairwise c-statistics describe the model's ability to discriminate across all outcome states [229]. All analyses were done using SAS 9.4.

6.9 Results

The sample consisted of 57,208 observation pairs representing 35,116 unique referrals and 30,625 unique clients. Table 6-2 and Table 6-3 describe the predisposing, enabling, and need characteristics of the sample that were entered as covariates in the regression models. Having no caregiver distress items was the most common initial state (65.8%) followed by having one caregiver distress item (24.4%) and having two caregiver distress items (9.9%). Clients whose caregivers were not distressed were more likely to be younger than 65 years and less likely to be older than 85 years, more likely to be female, and less likely to co-reside with their caregiver.

Nearly half of non-distressed caregivers were caring for parents or parents-in-law. In contrast, distressed caregivers were more likely to live with the client who was often their spouse. Clients whose caregivers were distressed were often referred to home care services from the community setting.

Caregiver distress was associated with greater informal care use. While 42.6% of non-distressed caregivers provided up to 10 hours of informal care per week, only 15.5% and 10.2% of distressed caregivers provided up to 10 hours per week. Caregivers with one caregiver distress item present were the most likely to provide 11–35 hours of informal care per week. Where 36 hours per week is roughly equivalent to a full-time job, 25.6% of caregivers with one caregiver distress item and 36.5% of caregivers with two caregiver distress items provided more than 36 hours of informal care per week. Although providing 71+ hours of informal care per week was relatively rare in the overall sample, this was done by 8.7% of caregivers with two caregiver distress items.

The pattern of publicly funded home care service use shows that fewer clients with non-distressed caregivers use PS/HM services (54.9%) than nursing or therapy services (73.1%). Among clients whose caregivers had one caregiver distress item present, 74.6% received any publicly funded PS/HM services and 64.2% received any publicly funded nursing or therapy services. Among clients whose caregivers had two caregiver distress items present, 84.2% received any publicly funded PS/HM services (59.5% received 5+ hours/week) and 59.6% received any publicly funded nursing or therapy services.

Clients with non-distressed caregivers were more likely to have been on home care service for a shorter time, where 63.8% had been on service for up to six months at the time of assessment.

Compared to other clients, clients whose caregivers had two caregiver distress items present were the most likely to have been on service for longer than two years. Similarly, this group of clients was more likely to contribute multiple observation pairs.

Overall, caregiver distress was associated with an increasingly complex client population. Clients whose caregivers had two caregiver distress items had the highest proportions with moderate to severe cognitive impairment (18.4%), dementia diagnosis (47.1%), and behavioural symptoms (29.9%) that are associated with increased risk for long-term care placement. Clients whose caregivers had two caregiver distress items also had the highest proportion with high to very high health instability (9.5%) that is associated with increased risk for death. Distribution of the PS Algorithm was shifted toward lower PS Groups among clients with non-distressed caregivers and higher PS Groups among clients with distressed caregivers. Although the proportion of clients in PS Group 6 was only 5.0% in the overall sample, 12.9% of clients whose caregivers had two caregiver distress items were in PS Group 6.

Table 6-2 Predisposing and Enabling Characteristics of HC-Assessed Clients, by Initial State, HNHB LHIN January 2013–December 2017

% (n)	0 caregiver distress items present n=37,622	1 caregiver distress item present n=13,943	2 caregiver distress items present n=5,643
Age			
18 to 64 years	17.8 (6,699)	12.5 (1,744)	9.8 (553)
65 to 84 years	47.6 (17,921)	48.9 (6,823)	48.5 (2,735)
85+ years	30.6 (11,499)	34.4 (4,793)	36.9 (2,081)
Sex			
Female	63.3 (23,800)	55.0 (7,662)	49.9 (2,816)
Not female	36.7 (13,822)	45.1 (6,281)	50.1 (2,827)
Client lives with caregiver			
Yes	54.0 (20,327)	72.4 (10,088)	78.5 (4,428)
No	46.0 (17,295)	27.7 (3,855)	21.5 (1,215)
Client-caregiver relationship			
Spouse	33.1 (12,462)	48.7 (6,785)	53.8 (3,037)
Child/child-in-law	46.0 (17,287)	40.1 (5,591)	35.9 (2,027)
Relative	12.8 (4,823)	8.2 (1,148)	8.1 (457)
Non-relative	8.1 (3,050)	3.0 (419)	2.2 (122)
Referral source			
Hospital	41.8 (15,731)	32.6 (4,548)	28.2 (1,591)
Community	58.2 (21,891)	67.4 (9,395)	71.8 (4,052)
Average informal care per week			
0–10 hours	42.6 (16,026)	15.5 (2,157)	10.2 (574)
11–35 hours	48.2 (18,128)	58.9 (8,217)	53.4 (3,011)
36–70 hours	7.5 (2,823)	20.1 (2,799)	27.8 (1,569)
71+ hours	1.7 (645)	5.5 (770)	8.7 (489)
Average publicly funded PS/HM per week			
0 hours	45.1 (16,984)	25.4 (3,540)	15.8 (891)
1–4 hours	28.6 (10,747)	29.3 (4,080)	24.7 (1,396)
5+ hours	26.3 (9,891)	45.4 (6,323)	59.5 (3,356)
Average publicly funded nursing and therapy per week			
0 hours or visits	26.9 (10,137)	35.8 (4,997)	40.4 (2,278)
1–4 hours or visits	55.9 (21,019)	52.3 (7,298)	49.1 (2,768)
5+ hours or visits	17.2 (6,466)	11.8 (1,648)	10.6 (597)
Days on home care service at time of assessment			
Up to 6 months	63.8 (23,996)	58.8 (8,193)	52.5 (2,962)
Up to 1 year	9.1 (3,415)	12.6 (1,759)	15.8 (892)
Up to 2 years	12.6 (4,744)	14.6 (2,041)	15.6 (878)
More than 2 years	14.5 (5,467)	14.0 (1,950)	16.1 (911)
Observation pair			
1 st pair	66.9 (25,162)	54.2 (7,561)	42.4 (2,390)
2 nd pair	19.3 (7,244)	23.6 (3,292)	26.0 (1,467)
3 rd pair	8.2 (3,068)	11.6 (1,610)	15.2 (860)
4 th + pair	5.7 (2,148)	10.6 (1,480)	16.4 (926)

- Chi-square test: All results were significant at $p < .0001$ unless otherwise noted.

Table 6-3 Need Characteristics of HC-Assessed Clients, by Initial State, HNHB LHIN January 2013–December 2017

% (n)	0 caregiver distress items present n=37,622	1 caregiver distress item present n=13,943	2 caregiver distress items present n=5,643
Cognitive impairment ^a			
None	46.9 (17,634)	20.5 (2,864)	11.6 (654)
Mild to moderate	50.0 (18,805)	69.3 (9,661)	70.1 (3,953)
Moderate to severe	3.1 (1,183)	10.2 (1,418)	18.4 (1,036)
Dementia diagnosis			
Yes	13.9 (5,214)	36.2 (5,050)	47.1 (2,655)
No	86.1 (32,408)	63.8 (8,893)	53.0 (2,988)
Behavioural symptoms			
Yes	4.6 (1,720)	18.2 (2,542)	29.9 (1,688)
No	95.4 (35,902)	81.8 (11,401)	70.1 (3,955)
Health instability ^b			
None	22.1 (8,306)	13.6 (1,889)	10.0 (563)
Minimal to moderate	75.8 (28,524)	80.6 (11,238)	80.6 (4,546)
High to very high	2.1 (792)	5.9 (816)	9.5 (534)
Personal Support Algorithm			
PS Group 1	15.1 (5,661)	2.9 (410)	0.9 (53)
PS Group 2	39.1 (14,714)	24.1 (3,355)	14.3 (808)
PS Group 3	29.9 (11,259)	36.0 (5,014)	30.7 (1,732)
PS Group 4	8.7 (3,255)	14.6 (2,037)	16.8 (950)
PS Group 5	4.4 (1,671)	14.6 (2,036)	24.3 (1,370)
PS Group 6	2.8 (1,062)	7.8 (1,091)	12.9 (730)

^a Cognitive Performance Scale

^b Changes in Health, End-stage disease, and Signs and Symptoms Scale

- Chi-square test: All results were significant at p<.0001 unless otherwise noted.

Figure 6-2 shows the proportion of clients receiving publicly funded PS/HM hours consistent with the predefined quintiles. The reference groups (3rd quintile) accounted for 27.6%, 18.9%, and 18.1% of clients in each initial state. Clients whose caregivers had one caregiver distress item were the most likely to receive PS/HM hours in the 1st and 2nd quintile (47.9%). Clients whose caregivers had two caregiver distress items were the most likely to receive PS/HM hours in the 4th and 5th quintile (39.6%).

Figure 6-2 Proportion of HC-Assessed Clients in PS/HM Quintiles, by Initial State, HNHB LHIN January 2013–December 2017

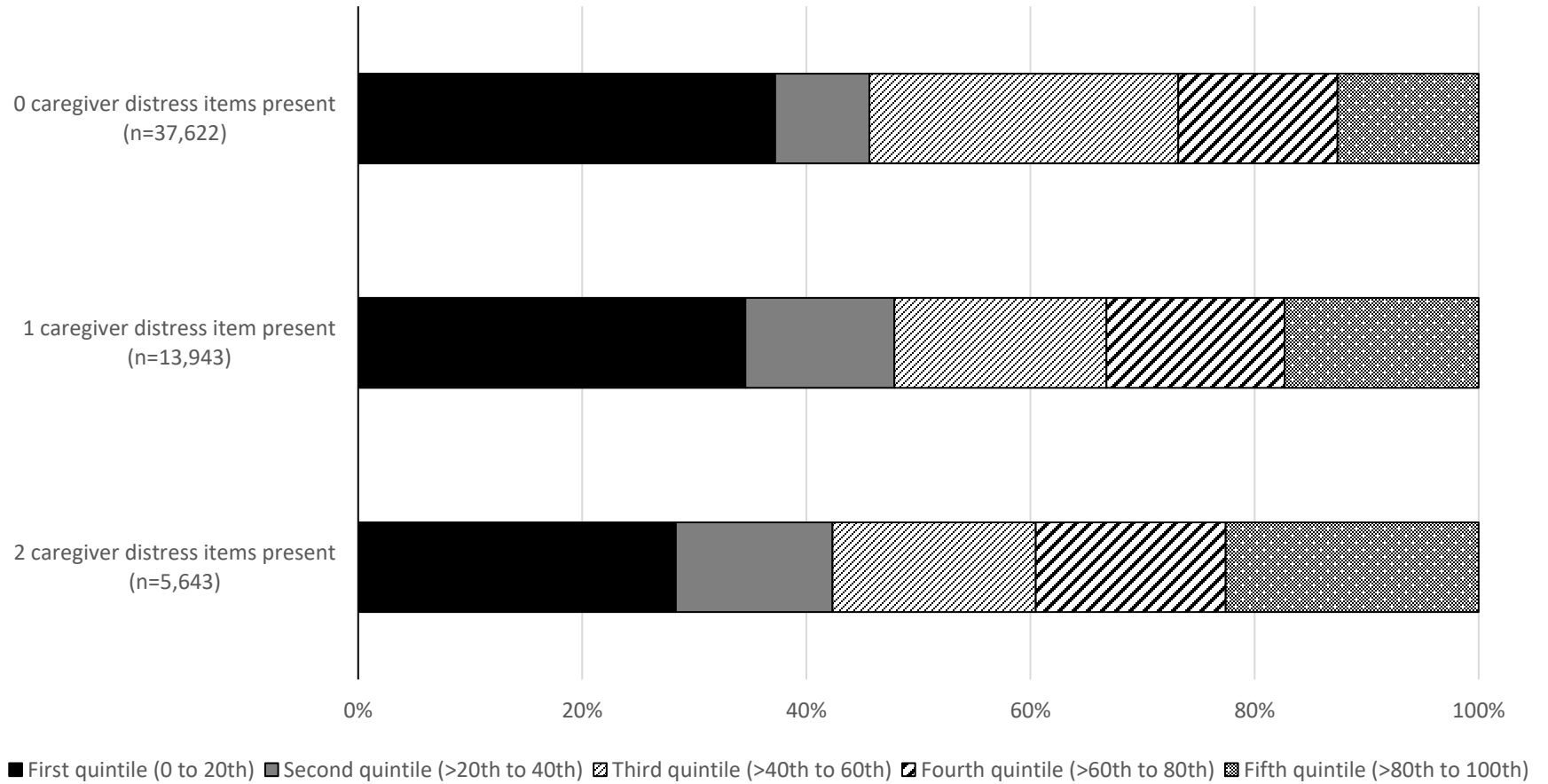


Figure 6-3 shows the transition proportions from each initial state to each follow-up state. Clients with distressed caregivers (47.8% and 46.4%) were significantly more likely to receive a follow-up HC assessment than clients with non-distressed caregivers (37.0%; $\chi^2=573.7$, $p<.0001$). For most clients receiving a follow-up assessment, their follow-up state was the same as their initial state. Clients whose caregivers had neither or both caregiver distress items present were significantly more likely to remain in the same initial state (80.0% and 81.9%) than clients whose caregivers had one caregiver distress item (69.0%; $\chi^2=333.9$, $p<.0001$).

Nearly one-third of clients with non-distressed clients were discharged from home care services because their service plan was complete or their needs could be met in the community. More clients with two caregiver distress items present moved to cluster residence or to long-term care. Across initial states, similar proportions of clients died or were discharged from home care services for other reasons. Clients with non-distressed caregivers were more likely to be censored than clients with distressed caregivers.

Figure 6-3 Transition Proportions from Initial State to Follow-up State, HC-Assessed Clients, HNHB LHIN January 2013–December 2017

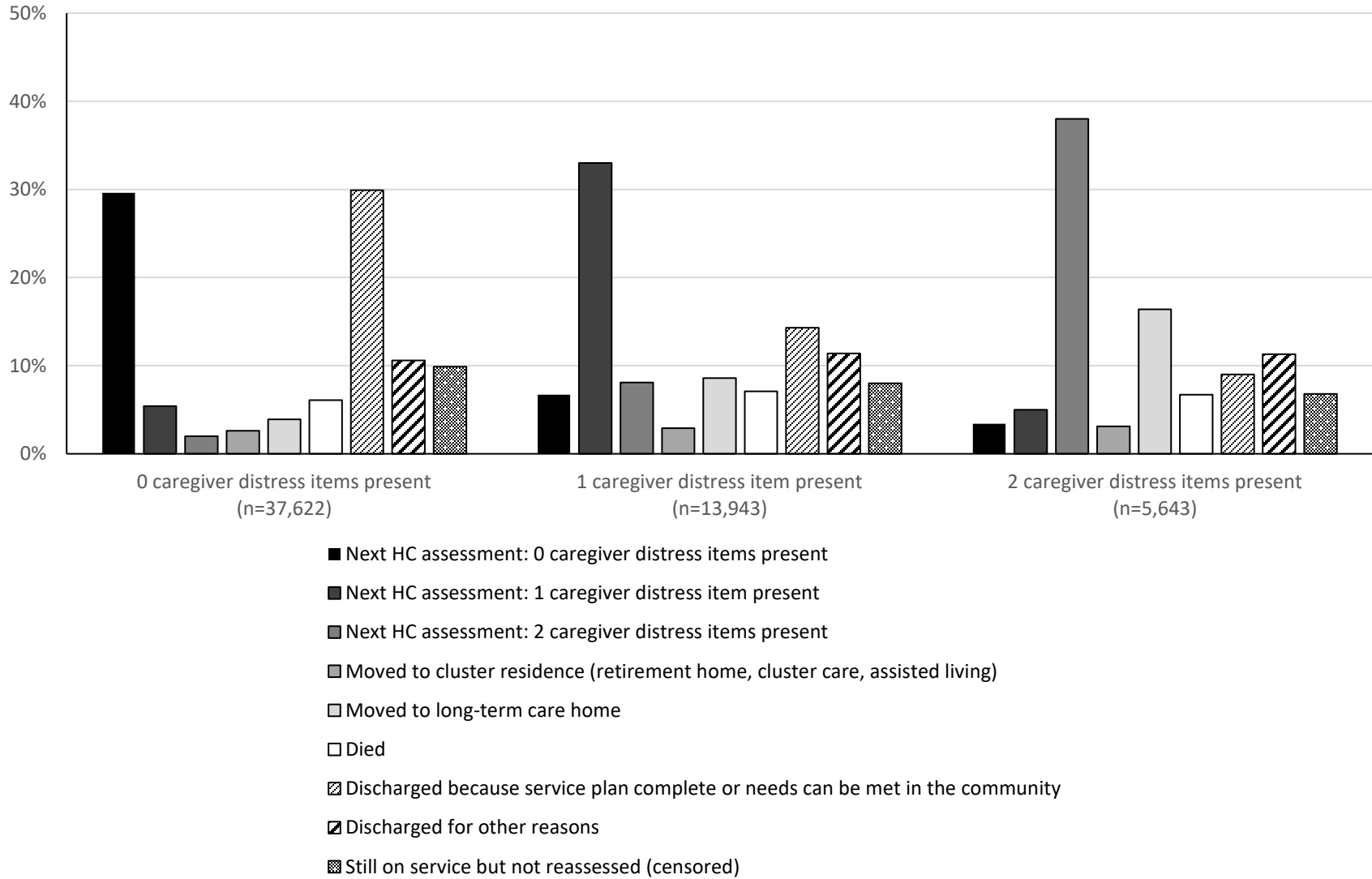


Table 6-4 presents the chi-square statistics for all variables included in the multi-state transition model. All covariates were statistically significant except for sex and co-residing status in the model for clients whose caregivers had two caregiver distress items present.

Table 6-4 Chi-Square Statistics for Variables in Multi-state Transition Model

Variable	Degrees of freedom	Initial state		
		0 caregiver distress items present	1 caregiver distress item present	2 caregiver distress items present
PS/HM hours (quintile)	16	1710.1 ***	399.3 ***	148.4 ***
Age	8	329.8 ***	193.3 ***	81.4 ***
Sex	8	131.8 ***	63.0 ***	11.5 n.s.
Client lives with caregiver	8	161.8 ***	89.4 ***	15.2 n.s.
Client-caregiver relationship	24	77.3 ***	69.3 ***	39.2 *
Referral source	8	178.4 ***	93.3 ***	61.2 ***
Informal care hours	8	63.4 ***	32.3 ***	15.7 *
Nursing and therapy hours	8	317.7 ***	215.6 ***	87.1 ***
Days on home care service	8	971.0 ***	223.4 ***	48.9 ***
Observation pair	24	356.9 ***	146.7 ***	121.4 ***
Cognitive impairment	16	285.5 ***	78.0 ***	42.6 **
Dementia diagnosis	8	229.6 ***	190.8 ***	42.4 ***
Behavioural symptoms	8	46.5 ***	59.7 ***	34.3 ***
Health instability	16	379.1 ***	107.8 ***	89.3 ***
Personal Support Algorithm	40	1815.0 ***	590.2 ***	175.5 ***

Chi-square test: *p<.05, **p<.001, ***p<.0001

Table 6-5 presents the adjusted odds of state transitions for all clients (i.e., all PS Groups). The odds ratios estimate the effect of receiving more or less PS/HM hours (compared to the 3rd quintile representing the median allocation) on the adjusted likelihood of transitioning from the initial state to the follow-up state. Across all initial states, pairwise c-statistics ranged from 0.61 to 0.92.

Among clients with non-distressed caregivers, receiving less than the median PS/HM hours was significantly associated with higher odds of new caregiver distress, moving to long-term care,

death, and discharge from home care service. Receiving more than the median PS/HM hours was significantly associated with lower odds of moving to cluster residence and completing the home care service plan or being transferred to community services.

Among clients whose caregivers had one caregiver distress item present, receiving less than the median PS/HM hours was significantly associated with lower odds of resolving caregiver distress and moving to long-term care and higher odds of completing the home care service plan or being transferred to community services. Clients receiving more than the median PS/HM hours were significantly more likely to move to long-term care.

Among clients whose caregivers had two caregiver distress items present, receiving less than the median PS/HM hours was significantly associated with higher odds of completing the home care service plan or being transferred to community services. Receiving more than the median PS/HM hours was significantly associated with higher odds of moving to long-term care. The amount of PS/HM service was not significantly associated with the odds of transitioning to any of the caregiver distress states.

For the most part, testing the effect of each quintile separately did not change the direction or significance of the results. Generally, the adjusted odds ratios in the original analysis were somewhat larger in magnitude for the extreme quintiles than the combined quintiles (i.e., odds ratios for the 1st quintile were greater than the odds ratios for the 1st and 2nd quintile, and odds ratios for the 5th quintile were greater than the odds ratios for the 4th and 5th quintile).

Table 6-5 Adjusted Odds of State Transitions by Initial State and PS/HM Quintile, All PS Groups, HC-Assessed Clients, HNHB LHIN January 2013–December 2017, n=57,208

Initial state	PS/HM quintile (REF=3 rd quintile)	Follow-up state (REF=no state change)								
		Next HC assessment: 0 caregiver distress items present	Next HC assessment: 1 caregiver distress item present	Next HC assessment: 2 caregiver distress items present	Moved to cluster residence	Moved to long-term care home	Died	Discharged because service plan complete or needs can be met in community	Discharged for other reasons	Still on service but not reassessed (censored)
0 caregiver distress items present	1 st or 2 nd quintile	–	1.29 (1.11–1.48)	1.31 (1.05–1.64)	1.01 (0.83–1.22)	1.19 (1.01–1.41)	1.35 (1.17–1.56)	3.81 (3.43–4.23)	1.20 (1.07–1.35)	0.95 (0.85–1.06)
	4 th or 5 th quintile	–	0.97 (0.84–1.12)	0.90 (0.71–1.13)	0.73 (0.60–0.88)	1.15 (0.98–1.36)	1.03 (0.89–1.19)	0.74 (0.66–0.83)	0.96 (0.86–1.07)	0.94 (0.85–1.05)
1 caregiver distress item present	1 st or 2 nd quintile	0.76 (0.62–0.92)	–	0.97 (0.81–1.17)	1.04 (0.76–1.40)	0.80 (0.67–0.97)	0.95 (0.77–1.17)	2.89 (2.35–3.54)	1.01 (0.85–1.20)	0.84 (0.70–1.01)
	4 th or 5 th quintile	0.85 (0.69–1.03)	–	0.88 (0.73–1.06)	0.93 (0.76–1.11)	1.32 (1.10–1.59)	1.09 (0.88–1.35)	0.86 (0.69–1.09)	1.05 (0.88–1.25)	0.92 (0.76–1.11)
2 caregiver distress items present	1 st or 2 nd quintile	1.27 (0.82–1.97)	0.95 (0.68–1.33)	–	0.97 (0.63–1.49)	0.99 (0.78–1.26)	1.02 (0.74–1.42)	3.08 (2.14–4.45)	1.02 (0.79–1.32)	0.87 (0.63–1.20)
	4 th or 5 th quintile	1.41 (0.91–2.18)	0.81 (0.57–1.16)	–	0.82 (0.53–1.28)	1.56 (1.24–1.96)	1.21 (0.87–1.68)	1.05 (0.70–1.58)	1.20 (0.92–1.55)	1.25 (0.92–1.71)

- Controlled for age (continuous); sex; client lives with caregiver; client-caregiver relationship; referral source (hospital or community); informal care hours (continuous); nursing and therapy hours (continuous); days on home care service (continuous); observation pair; Cognitive Performance Scale; dementia diagnosis; behavioural symptoms; Changes in Health, End-stage disease, Signs and Symptoms Scale; PS Group.
- Significant results are highlighted red for greater likelihood (OR, 95% CI >1.00) or green for lesser likelihood (OR, 95% CI <1.00). Some cells with 1.00 may still meet criteria for significance due to rounding.

Table 6-6 through Table 6-10 present the adjusted odds of state transitions for clients in each PS Group. Results for PS Group 1 are not shown because the variable of interest (i.e., PS/HM quintile) caused quasi-complete separation of data points. Quasi-complete separation of data points was detected in two other models; however, the models converged after excluding the Cognitive Performance Scale as a covariate.

Overall, the stratified results by PS Group 2 reproduced the significant findings in the full sample. Fewer significant associations were reproduced in other PS Groups although this could be mostly attributable to small cell sizes. Cell sizes were smaller than 1000 for all combinations of initial states and PS/HM quintiles across PS Groups 5 and 6, and all but two combinations across PS Group 4. Among clients with non-distressed caregivers, receiving less than the median PS/HM hours was significantly associated with higher odds of death in PS Groups 2 and 3 and receiving more than the median PS/HM hours was significantly associated with lesser odds of moving to cluster care in PS Groups 3 and 4. Among clients whose caregivers had one caregiver distress item present, receiving less than the median PS/HM hours was significantly associated with lesser odds of resolving caregiver distress and dying in PS Group 4 and significantly associated with lesser odds of moving to long-term care in PS Group 5. Among clients whose caregivers had two caregiver distress items present, receiving less than the median PS/HM hours was significantly associated with higher odds of moving to long-term care in PS Groups 5 and 6. As well, receiving less than the median PS/HM hours was significantly associated with lesser odds of changing from two to one caregiver distress indicators in PS Group 2, a finding that had not emerged in the full sample.

Table 6-6 Adjusted Odds of State Transitions by Initial State and PS/HM Quintile, PS Group 2, HC-Assessed Clients, HNHB LHIN January 2013–December 2017, n=18,877

Initial state	PS/HM quintile (REF=3 rd quintile)	Follow-up state (REF=no state change)								
		Next HC assessment: 0 caregiver distress items present	Next HC assessment: 1 caregiver distress item present	Next HC assessment: 2 caregiver distress items present	Moved to cluster residence	Moved to long-term care home	Died	Discharged because service plan complete or needs can be met in community	Discharged for other reasons	Still on service but not reassessed (censored)
0 caregiver distress items present	1 st or 2 nd quintile	–	1.50 (1.16–1.94)	1.65 (1.06–2.56)	1.08 (0.81–1.44)	1.46 (1.08–1.97)	1.44 (1.12–1.86)	5.17 (4.45–6.00)	1.36 (1.13–1.63)	0.69 (0.58–0.83)
	4 th or 5 th quintile	–	1.06 (0.82–1.36)	0.93 (0.59–1.45)	0.92 (0.70–1.21)	1.28 (0.96–1.71)	1.07 (0.82–1.38)	1.06 (0.90–1.24)	1.00 (0.83–1.20)	1.04 (0.89–1.21)
1 caregiver distress item present	1 st or 2 nd quintile	0.62 (0.40–0.96)	–	1.04 (0.64–1.69)	0.62 (0.36–1.07)	0.81 (0.47–1.42)	0.84 (0.48–1.48)	4.98 (3.32–7.47)	1.15 (0.79–1.69)	0.40 (0.26–0.63)
	4 th or 5 th quintile	0.79 (0.52–1.20)	–	1.02 (0.64–1.63)	0.80 (0.47–1.36)	1.52 (0.91–2.53)	0.90 (0.50–1.60)	1.09 (0.70–1.69)	0.98 (0.67–1.45)	0.82 (0.55–1.22)
2 caregiver distress items present	1 st or 2 nd quintile	1.10 (0.21–5.92)	0.32 (0.11–0.96)	–	0.84 (0.31–2.22)	1.92 (0.63–5.82)	0.52 (0.13–2.02)	7.14 (2.35–21.7)	1.42 (0.48–4.19)	0.38 (0.10–1.42)
	4 th or 5 th quintile	3.48 (0.70–17.2)	0.58 (0.21–1.59)	–	0.47 (0.16–1.37)	1.24 (0.42–3.71)	1.74 (0.47–6.50)	2.83 (0.96–8.34)	2.10 (0.65–6.79)	1.62 (0.54–4.94)

- Controlled for age (continuous); sex; client lives with caregiver; client-caregiver relationship; referral source (hospital or community); informal care hours (continuous); nursing and therapy hours (continuous); days on home care service (continuous); observation pair; Cognitive Performance Scale; dementia diagnosis; behavioural symptoms; Changes in Health, End-stage disease, Signs and Symptoms Scale; PS Group.
- Significant results are highlighted red for greater likelihood (OR, 95% CI >1.00) or green for lesser likelihood (OR, 95% CI <1.00). Some cells with 1.00 may still meet criteria for significance due to rounding.

Table 6-7 Adjusted Odds of State Transitions by Initial State and PS/HM Quintile, PS Group 3, HC-Assessed Clients, HNHB LHIN January 2013–December 2017, n=18,005

Initial state	PS/HM quintile (REF=3 rd quintile)	Follow-up state (REF=no state change)								
		Next HC assessment: 0 caregiver distress items present	Next HC assessment: 1 caregiver distress item present	Next HC assessment: 2 caregiver distress items present	Moved to cluster residence	Moved to long-term care home	Died	Discharged because service plan complete or needs can be met in community	Discharged for other reasons	Still on service but not reassessed (censored)
0 caregiver distress items present	1 st or 2 nd quintile	–	1.22 (0.95–1.56)	1.14 (0.79–1.63)	0.76 (0.55–1.06)	1.12 (0.84–1.50)	1.34 (1.02–1.76)	3.01 (2.46–3.70)	1.04 (0.85–1.27)	1.15 (0.94–1.40)
	4 th or 5 th quintile	–	0.94 (0.73–1.21)	0.80 (0.55–1.16)	0.55 (0.40–0.75)	1.08 (0.81–1.43)	0.94 (0.71–1.25)	0.66 (0.53–0.83)	0.98 (0.80–1.19)	0.90 (0.74–1.10)
1 caregiver distress item present	1 st or 2 nd quintile	0.94 (0.68–1.32)	–	1.13 (0.83–1.55)	1.25 (0.74–2.11)	0.87 (0.63–1.20)	1.25 (0.84–1.85)	3.04 (2.16–4.27)	1.26 (0.93–1.71)	1.15 (0.85–1.56)
	4 th or 5 th quintile	0.94 (0.67–1.31)	–	1.00 (0.72–1.37)	1.10 (0.65–1.86)	1.33 (0.98–1.82)	1.48 (0.99–2.21)	1.13 (0.78–1.65)	1.48 (1.09–2.01)	1.01 (0.74–1.38)
2 caregiver distress items present	1 st or 2 nd quintile	0.71 (0.35–1.46)	0.93 (0.52–1.66)	–	1.69 (0.69–4.14)	0.69 (0.43–1.10)	0.95 (0.50–1.81)	2.85 (1.54–5.28)	1.17 (0.71–1.94)	1.05 (0.59–1.88)
	4 th or 5 th quintile	1.13 (0.58–2.20)	0.81 (0.45–1.45)	–	1.60 (0.66–3.85)	1.25 (0.81–1.91)	1.14 (0.60–2.18)	0.67 (0.32–1.37)	1.46 (0.89–2.41)	1.29 (0.73–2.26)

- Controlled for age (continuous); sex; client lives with caregiver; client-caregiver relationship; referral source (hospital or community); informal care hours (continuous); nursing and therapy hours (continuous); days on home care service (continuous); observation pair; Cognitive Performance Scale; dementia diagnosis; behavioural symptoms; Changes in Health, End-stage disease, Signs and Symptoms Scale; PS Group.
- Significant results are highlighted red for greater likelihood (OR, 95% CI >1.00) or green for lesser likelihood (OR, 95% CI <1.00). Some cells with 1.00 may still meet criteria for significance due to rounding.

Table 6-8 Adjusted Odds of State Transitions by Initial State and PS/HM Quintile, PS Group 4, HC-Assessed Clients, HNHB LHIN January 2013–December 2017, n=6,242

Initial state	PS/HM quintile (REF=3 rd quintile)	Follow-up state (REF=no state change)								
		Next HC assessment: 0 caregiver distress items present	Next HC assessment: 1 caregiver distress item present	Next HC assessment: 2 caregiver distress items present	Moved to cluster residence	Moved to long-term care home	Died	Discharged because service plan complete or needs can be met in community	Discharged for other reasons	Still on service but not reassessed (censored)
0 caregiver distress items present	1 st or 2 nd quintile	–	1.16 (0.82–1.64)	1.32 (0.78–2.25)	0.77 (0.45–1.32)	0.77 (0.50–1.18)	1.16 (0.78–1.74)	3.78 (2.43–5.88)	1.16 (0.85–1.58)	1.15 (0.83–1.58)
	4 th or 5 th quintile	–	0.85 (0.60–1.22)	0.93 (0.54–1.62)	0.26 (0.14–0.49)	0.95 (0.63–1.43)	1.17 (0.78–1.75)	0.52 (0.30–0.91)	0.87 (0.63–1.19)	0.71 (0.51–0.99)
1 caregiver distress item present	1 st or 2 nd quintile	0.61 (0.38–0.97)	–	0.75 (0.48–1.16)	1.68 (0.72–3.91)	0.82 (0.53–1.27)	0.57 (0.35–0.91)	1.46 (0.87–2.43)	0.62 (0.41–0.91)	0.82 (0.52–1.29)
	4 th or 5 th quintile	0.79 (0.50–1.26)	–	0.79 (0.49–1.26)	1.01 (0.40–2.55)	1.33 (0.85–2.09)	0.76 (0.46–1.24)	0.57 (0.31–1.05)	0.81 (0.54–1.21)	1.06 (0.67–1.67)
2 caregiver distress items present*	1 st or 2 nd quintile	1.08 (0.41–2.82)	1.07 (0.48–2.37)	–	0.65 (0.22–1.92)	1.22 (0.70–2.14)	1.56 (0.69–3.51)	1.81 (0.83–3.94)	1.398 (0.76–2.51)	0.79 (0.39–1.59)
	4 th or 5 th quintile	0.58 (0.21–1.61)	0.66 (0.27–1.59)	–	0.80 (0.29–2.45)	1.36 (0.79–2.34)	1.38 (0.61–3.12)	0.84 (0.35–2.03)	1.11 (0.60–2.06)	0.68 (0.33–1.38)

*Model converged after excluding Cognitive Performance Scale as a covariate

- Controlled for age (continuous); sex; client lives with caregiver; client-caregiver relationship; referral source (hospital or community); informal care hours (continuous); nursing and therapy hours (continuous); days on home care service (continuous); observation pair; Cognitive Performance Scale; dementia diagnosis; behavioural symptoms; Changes in Health, End-stage disease, Signs and Symptoms Scale; PS Group.
- Significant results are highlighted red for greater likelihood (OR, 95% CI >1.00) or green for lesser likelihood (OR, 95% CI <1.00). Some cells with 1.00 may still meet criteria for significance due to rounding.

Table 6-9 Adjusted Odds of State Transitions by Initial State and PS/HM Quintile, PS Group 5, HC-Assessed Clients, HNHB LHIN January 2013–December 2017, n=5,077

Initial state	PS/HM quintile (REF=3 rd quintile)	Follow-up state (REF=no state change)								
		Next HC assessment: 0 caregiver distress items present	Next HC assessment: 1 caregiver distress item present	Next HC assessment: 2 caregiver distress items present	Moved to cluster residence	Moved to long-term care home	Died	Discharged because service plan complete or needs can be met in community	Discharged for other reasons	Still on service but not reassessed (censored)
0 caregiver distress items present	1 st or 2 nd quintile	–	1.16 (0.72–1.87)	0.91 (0.48–1.70)	1.20 (0.40–3.55)	1.43 (0.76–2.71)	1.17 (0.69–1.97)	6.13 (2.17–17.4)	0.89 (0.57–1.39)	2.70 (1.43–5.12)
	4 th or 5 th quintile	–	0.83 (0.50–1.38)	0.64 (0.32–1.30)	1.04 (0.32–3.33)	2.30 (1.22–4.33)	0.95 (0.55–1.63)	1.24 (0.38–4.04)	0.76 (0.47–1.21)	1.97 (1.02–3.82)
1 caregiver distress item present*	1 st or 2 nd quintile	0.68 (0.41–1.12)	–	0.87 (0.59–1.28)	0.98 (0.43–2.24)	0.54 (0.37–0.79)	0.88 (0.54–1.42)	1.58 (0.81–3.05)	0.89 (0.60–1.33)	0.78 (0.47–1.30)
	4 th or 5 th quintile	0.71 (0.41–1.24)	–	0.65 (0.42–1.02)	0.94 (0.38–2.35)	1.07 (0.72–1.57)	0.88 (0.52–1.49)	0.68 (0.30–1.58)	0.85 (0.55–1.31)	0.87 (0.51–1.50)
2 caregiver distress items present	1 st or 2 nd quintile	2.13 (0.75–8.35)	1.39 (0.65–2.97)	–	0.74 (0.31–1.77)	0.77 (0.51–1.17)	0.87 (0.46–1.65)	1.63 (0.68–3.92)	0.61 (0.38–0.97)	0.84 (0.43–1.61)
	4 th or 5 th quintile	2.45 (0.78–7.67)	1.31 (0.59–2.91)	–	0.55 (0.21–1.46)	1.94 (1.29–2.91)	0.92 (0.47–1.81)	1.27 (0.49–3.27)	1.02 (0.64–1.64)	1.11 (0.58–2.10)

*Model converged after excluding Cognitive Performance Scale as a covariate

- Controlled for age (continuous); sex; client lives with caregiver; client-caregiver relationship; referral source (hospital or community); informal care hours (continuous); nursing and therapy hours (continuous); days on home care service (continuous); observation pair; Cognitive Performance Scale; dementia diagnosis; behavioural symptoms; Changes in Health, End-stage disease, Signs and Symptoms Scale; PS Group.
- Significant results are highlighted red for greater likelihood (OR, 95% CI >1.00) or green for lesser likelihood (OR, 95% CI <1.00). Some cells with 1.00 may still meet criteria for significance due to rounding.

Table 6-10 Adjusted Odds of State Transitions by Initial State and PS/HM Quintile, PS Group 6, HC-Assessed Clients, HNHB LHIN January 2013–December 2017, n=2,883

Initial state	PS/HM quintile (REF=3 rd quintile)	Follow-up state (REF=no state change)								
		Next HC assessment: 0 caregiver distress items present	Next HC assessment: 1 caregiver distress item present	Next HC assessment: 2 caregiver distress items present	Moved to cluster residence	Moved to long-term care home	Died	Discharged because service plan complete or needs can be met in community	Discharged for other reasons	Still on service but not reassessed (censored)
0 caregiver distress items present	1 st or 2 nd quintile	Model did not converge								
	4 th or 5 th quintile									
1 caregiver distress item present	1 st or 2 nd quintile	Model did not converge								
	4 th or 5 th quintile									
2 caregiver distress items present	1 st or 2 nd quintile	2.48 (0.47–13.0)	0.69 (0.25–1.94)	–	0.65 (0.10–4.49)	1.58 (0.84–2.95)	0.92 (0.44–1.92)	*3.84 (1.07–13.9)	1.10 (0.53–2.32)	1.57 (0.60–4.09)
	4 th or 5 th quintile	2.44 (0.45–13.2)	0.67 (0.23–2.01)	–	0.99 (0.14–7.18)	*2.51 (1.34–4.69)	1.67 (0.83–3.38)	1.83 (0.46–7.33)	1.17 (0.55–2.49)	*2.52 (1.00–6.33)

- Controlled for age (continuous); sex; client lives with caregiver; client-caregiver relationship; referral source (hospital or community); informal care hours (continuous); nursing and therapy hours (continuous); days on home care service (continuous); observation pair; Cognitive Performance Scale; dementia diagnosis; behavioural symptoms; Changes in Health, End-stage disease, Signs and Symptoms Scale; PS Group.
- Significant results are highlighted red for greater likelihood (OR, 95% CI >1.00) or green for lesser likelihood (OR, 95% CI <1.00). Some cells with 1.00 may still meet criteria for significance due to rounding.

6.10 Discussion

This study's findings suggest that the PS Algorithm's Framework of Hours identified minimum thresholds below which publicly funded PS/HM allocation may lead to poorer client and caregiver outcomes. Providing less than the median PS/HM services significantly increases the adjusted odds of new caregiver distress, moving to long-term care, and death within 15 months. Among clients with distressed caregivers, providing less than the median PS/HM services significantly decreases the adjusted odds of resolving caregiver distress. Providing more than the median PS/HM services decreases the odds of moving to cluster residence among clients with non-distressed caregivers only. In short, these results suggest that the PS Algorithm's Framework of Hours should be adequate for most clients. Using the Framework of Hours will not only promote greater transparency and consistency across PS/HM service plans, but should also maximise the value of positive client and family outcomes for money.

According to Andersen-Newman model [64], effective access occurs when health service use improves health status and efficient access occurs when there is a significant dose-response relationship between the two. This study suggests that publicly funded PS/HM services are effective because their use is associated with reducing caregiver distress and avoiding negative discharge outcomes. This study also suggests some efficiency in the allocation of publicly funded PS/HM services. Receiving the median amount of PS/HM services is associated with lower odds of experiencing negative outcomes compared to receiving PS/HM services below the median utilisation. In contrast, there is minimal evidence of additional benefit at very high levels of publicly funded PS/HM service use, suggesting that the dose-response relationship between PS/HM services and outcomes weakens once services exceed an upper threshold.

This study's multi-state transition model enabled the concurrent examination of multiple outcomes. In comparison, the existing literature on PS/HM use has largely focused on single adverse events. Even among studies examining multiple adverse events, separate models were fit for each outcome. As a result, the type of conclusions that could be drawn from these studies were limited to associations (or lack thereof) between PS/HM use and a given adverse event. However, this approach did not answer questions such as "if the client did not move to long-term care, did the client avoid adverse events altogether?"

Some studies that examined the association between PS/HM use and total health service cost form the exception. Markle-Reid et al. [146] found that clients receiving more than one hour of PS/HM services per week had lower direct and indirect health and social services costs compared to clients receiving less than one hour per week. Although the differences were not statistically significant, the cost savings likely stemmed from lower costs for emergency department and hospital use, physiotherapy, and nursing. Similarly, Hollander & Tessaro [137] found that low-needs clients whose services were not severely cut incurred lower direct costs of public health services. Descriptive tables suggested that at least some of the cost savings could be due to avoidance of institutionalisation and death. In the current study, providing less than the median PS/HM services across all PS Groups (including lower PS Groups) was shown to be associated with negative outcomes. This finding has important implications when considering past examples of how home care budget increases or decreases have tended to favour clients with higher needs.

The 1994 policy in British Columbia was an example of a targeted cost reduction strategy that cut PS/HM services for low-needs clients [137]. In Ontario, between FY 2008/09 and 2014/15,

public home care spending increased from \$1.76 billion to \$2.50 billion and the number of home care clients increased from 586,400 to 713,500 clients [34, 230]. Although public home care spending increased by 42.0%, the share of home and community care spending plateaued around four to five percent of Ontario's overall health budget [18, 34]. A more modest increase was observed in the average funding amount per client, increasing by 17.6% from \$3,003 in FY 2008/09 to \$3,532 in FY 2014/15 [34, 230]. With an increasingly complex and acute client population and limited resources in the public home care system, there has been a trend to prioritise services for clients with acute medical needs [231, 232]. In turn, the provision of publicly funded PS/HM services has been tightly controlled. For example, the Auditor General report found that clients with comparable needs would receive publicly funded PS/HM services in one LHIN but not in another LHIN [34]. In effect, the latter LHIN's approach is equivalent to reducing services for low-needs clients in order to operate within budgetary constraints. At the same time, recent increases in home care funding have been mostly directed to those with higher needs. In FY 2017/18, the Ontario government committed an additional 950,000 million PS/HM hours for personal care and respite support for "home care clients with high needs and their caregivers" [185].

In light of this study's findings, there is strong evidence that PS/HM services provide clinically and statistically significant benefits for low-needs clients and that policy makers should consider the implications of funding decisions that exclude this client group. From a population health perspective, past policies are consistent with a "high risk" approach that focuses on clients with the highest PS/HM needs. However, this approach may yield smaller benefits than a more general approach that addresses the broader population. When the PS/HM quintiles were not

combined in the sensitivity analyses, the adjusted odds ratios were somewhat larger in magnitude for the 5th quintile than the combined 4th and 5th quintile, suggesting some additional benefit at the highest levels of service. There is stronger evidence that providing less than the median PS/HM services increases the odds of a variety of negative outcomes. From a population perspective, it is probably more important to ensure that every client across the spectrum of PS/HM needs has access to sufficient resources before singling out a particular group to receive relatively more services.

There is an important caveat. Odds ratios are, by definition, a ratio of the likelihood of an event occurring and not occurring (i.e., a relative measure). It is also important to consider the absolute differences in event rates (Appendix B). For instance, 3.0% and 4.6% of clients with non-distressed caregivers in PS Group 2 moved to long-term care or died in the next 15 months. In contrast, the corresponding event rates were 4.9% and 17.6% for these clients in PS Group 6. Even though clients in the lower PS Groups receiving less than the median PS/HM services may face relatively larger risks, the level of risk measured in absolute terms may still be less than those in higher PS Groups. Actual policies may wish to blend elements of a “high risk” and population approach to minimise both relative and absolute risks. Regardless of the policy stance, the PS Algorithm provides a clear roadmap for funders to implement an evidence-informed approach to distributing funding for PS/HM services.

Nevertheless, these findings do not preclude the idea of providing additional PS/HM services to a specific client group. In particular, there has been growing interest in restorative or re-ablement models of home care. The philosophy of restorative care stands in contrast to more conventional models because the goal of service provision is not merely to meet the client’s need, but to

reduce the need for long-term supports [233, 234]. Restorative care seeks to equip the client with the necessary skills and level of confidence to maintain and restore physical function and increase independence. For example, King et al. [233] evaluated a restorative home care service that incorporated exercises designed to optimise functional ability and provided enhanced training for informal caregivers. Given that Ontario's home care budget has increased only modestly in the last decade and that additional investments in home care are fairly recent, it would have been unlikely that LHINs were able to support a restorative model for most of their clients. Implementing a restorative care approach would require greater home care investment, not just in PS/HM services, but also nursing and therapy services and a system that enables these providers to work together with each other and their clients. Perhaps one way to defray the costs would be to reinvest some of the funding intended for very high levels of PS/HM services that do not provide significant additional benefits in other service types such as physiotherapy and occupational therapy. Some small-scale studies of restorative care approaches have suggested benefits such as improving quality of life or delaying institutionalisation (examples include King et al. [233], Parsons et al. [235], Markle-Reid et al. [236], and Tinetti et al. [237]). In this study, receiving more than the median PS/HM services decreased the adjusted likelihood of moving to a cluster residence among clients with non-distressed caregivers. More research is needed to examine the benefits of providing more than the minimum PS/HM services as well as deemphasising task-based care in favour of restorative approaches to care.

There were two unexpected findings that appeared to contradict the hypothesised relationship between PS/HM service use and outcomes. First, receiving less than the median PS/HM services was significantly associated with greater odds of completing the home care service plan or being

transferred to a community support services organisation. Although the PS Algorithm indirectly adjusted for functional impairment and relate modifiers broadly, the nature of need can still vary substantially within a PS Group. For instance, PS Group 3 includes clients ranging from being independent in all ADLs to requiring assistance with mid-loss ADLs. Thus, it is possible that clients receiving the least amount of PS/HM services have relatively lower PS/HM needs than other clients within a PS Group, and these clients are the most likely to be discharged from home care services. The second finding was that receiving more than the median PS/HM services was significantly associated with greater odds of moving to long-term care among clients with distressed caregivers. Again, it is likely that care coordinators allocated the most PS/HM services to clients at the highest risk for placement. Although the transition model adjusted for some of the strongest predictors of placement such as ADL impairment (through PS Group), cognitive impairment, living arrangement, and behavioural symptoms including wandering that appear in Canadian Institute for Health Information's *Seniors in Transition* report [9] and in the Method for Assigning Priority Levels algorithm [187], differences in baseline risk for long-term care placement may have persisted. Thus, these unexpected findings may have arisen because the amount of PS/HM allocation may have acted as a proxy of risk rather than a measure of resource use in these cases.

6.10.1 Strengths

Having access to high-quality client-level clinical assessment and administrative data with reliable measurement of independent and dependent variables was one of the key strengths of this study. Whereas much of the existing literature relies on self-reported characteristics and PS/HM service use, this study linked RAI-HC assessments that are completed by trained health

professionals and billed services data whose integrity is jointly maintained by HNHB LHIN and service provider organisations. The dependent variables were drawn from multiple administrative databases, namely CHRIS, NACRS, and DAD, that could be expected to represent the vast majority of events that actually occurred. In particular, outcomes related to home care discharges and long-term care placement should be highly reliable since the LHIN has sole responsibility for coordinating publicly funded home care services and long-term care placement. The multi-state transition model allowed for the observation of multiple possible outcomes at once that represented a more global assessment of client and caregiver outcomes than existing studies. Additionally, the model adjusted for major differences in baseline characteristics and known predictors of the outcomes of interest. From a practice and policy standpoint, the conceptualisation of the study methods based on the PS Algorithm and Framework of Hours makes the findings readily usable in Ontario. Accordingly, concrete suggestions on how to implement the Framework of Hours were discussed.

6.10.2 Limitations

The data used in this study come from one of Ontario's 14 LHINs. Due to wide variability in specific policies and programs available in each LHIN, the conclusions may not be generalisable across Ontario or in other jurisdictions. Although this is the largest study to date examining outcomes related to PS/HM use, small cell sizes led to insignificant findings in the stratified models. Future analyses could replicate this study at the provincial level by employing assessment and administrative data from HSSOntario and acute service use data from the Canadian Institute for Health Information (and possibly other health service data from Institute for Clinical Evaluative Sciences) using generalised estimating equations for correlated

multinomial responses. The large provincial datasets could address the problem of small sample sizes and increase the likelihood of detecting significant differences.

Although the LHIN's administrative records can be expected to have captured all address changes (up-to-date address records are necessary for delivering services), home care discharges, and long-term care admissions, there may have been some under-counting of deaths although this limitation was minimised by counting any death reported in CHRIS, NACRS, and DAD. The model strived to consider client and caregiver health jointly by defining the outcome states using the client's discharge status to represent the client's health and indicators of caregiver distress to represent the caregiver's health. A future model could use a more direct measure of client health such as functional status. Doing so would also broaden the results to clients who do not identify a primary informal caregiver that was an exclusion criterion in this study.

Another important limitation is that there were no data on receipt of private home care services. Any given client may have received more total formal (i.e., publicly and privately funded) PS/HM services than just publicly funded PS/HM services. All other things equal, the likely scenario is that clients receiving less publicly funded PS/HM services are more likely to receive privately funded PS/HM services. The result is that the PS/HM quintiles may have been more similar in receipt of formal PS/HM services, making it more difficult to detect significant differences. Finally, future research should also explore the influence of different home care models (e.g., restorative versus maintenance focus), service delivery models (e.g., single provider versus multiple providers), and agency characteristics (e.g., single service versus multiple services) on the outcomes of PS/HM use.

CHAPTER 7: Overall Implications

7.1 Summary of Findings

This thesis sought to provide actionable evidence on the predictors and outcomes of publicly funded PS/HM service allocation in Ontario. It is the first comprehensive study of the interRAI Contact Assessment since its province-wide adoption in 2010. The Contact Assessment is part of an efficient assessment process that identifies clients who should be at the highest priority to receive the more comprehensive interRAI Home Care assessment. As well, information from the Contact Assessment can be used in a structured way to guide the allocation of PS/HM services for short-stay clients as well as within short-term service plans for long-stay clients. Together, the PS (CA) Algorithm and PS Algorithm provide a unified evidence-informed approach for allocating publicly funded PS/HM services throughout the home care episode. To date, Ontario's LHINs have adopted the PS Algorithm without the corresponding Framework of Hours. The final part of this thesis demonstrates that the Framework of Hours identifies minimum thresholds below which publicly funded PS/HM allocation may lead to poorer client and caregiver outcomes. The findings provide compelling evidence for policy-makers to set standard service guidelines and monitor PS/HM-sensitive outcomes. Doing so will ensure that clients and families know what supports to expect from the public home and community care system, that public resources are distributed fairly, that investments in home care can be demonstrated, and that the valuable contributions of personal support workers can be properly recognised.

The Andersen-Newman model provided a strong theoretical basis for understanding how individual characteristics should be related to PS/HM service use that in turn should influence health outcomes within an equitable and effective health care system. In this thesis, client

information captured in interRAI assessments and administrative systems identified important predisposing, enabling, and need characteristics of public home care clients. While some have raised concerns that conducting assessments takes time and resources away from providing client care, analyses with the CA data demonstrated that nearly every assessment item is associated with service use. As expected, assessment items capturing the client and family's needs predict publicly funded PS/HM service use and need characteristics should continue to guide allocation of these services. The implication is that, over time, more variance in PS/HM service hours should be explained by need characteristics. When planning a health care system, effectiveness is also an important consideration. At the core of any claim of need is a problem that can be solved, in this case, by accessing health care services [79]. This thesis adds to the existing literature by providing evidence of a relationship between PS/HM service use and client and caregiver outcomes.

The main strength of this thesis comes from the use of high quality data and its transformation into evidence and tools that can be readily integrated into clinical practice and health system policy. Whereas most research on this topic relies on small samples and self-reported health status and service use, the data used in this thesis are fully representative of Ontario's public home care clients and the publicly funded PS/HM services they receive. The outputs of this thesis provide tangible guidance to clinicians and administrators on how to improve the public home care system. At the same time, it is important to note substantial data gaps about the services that are received through community support services agencies and other privately financed services.

7.2 Implications for Clinical Practice and Policy in Ontario

In Ontario, the PS (CA) Algorithm is ready to be implemented alongside the PS Algorithm to guide the allocation of publicly funded PS/HM services. Since they share the same conceptual basis, use of the two algorithms should make the process of allocating PS/HM services more transparent and consistent throughout the home care episode, regardless of the length of time these services are expected (i.e., short- or long-term) or when the client started receiving these services (i.e., new or existing clients).

Consistent with the *Thriving at Home* report, the algorithms primarily classify need for PS/HM services according to the degree of functional needs. Beyond functional need, other clinical characteristics that are consistently associated with PS/HM use are also used to classify need for PS/HM services, including cognitive impairment, incontinence, and caregiver distress. Other modifiers (mostly socioeconomic in nature) were not built into the algorithms since they require a more nuanced approach than a standard algorithm will allow. An example is living arrangement. The relationship between need for formal PS/HM services and living arrangement is less direct than that with functional impairment. While clients who live alone are likely to receive more publicly funded PS/HM services, the fact that a client lives with others should not automatically lead to eligibility for fewer hours. Instead, the care coordinator should consider living arrangement in the context of the individual's specific situation (e.g., individual preferences, safety of the living environment, and capacity of the informal caregiving network) and adjust the allocation of PS/HM services accordingly.

In developing the algorithms, an important consideration was how future arrangements in home and community care would be shaped by their implementation. Although living arrangement

may create a need for PS/HM services, this type of need is related to the client's (lack of) access to support and resources, and not simply their state of health and well-being. Classification of need arising from current social structures risks entrenching current ways of organising and delivering PS/HM services. Including these social factors in the algorithms may actually hinder the use of innovative models that would increase access to support and resources. Using a present-day example, the Hamilton Niagara Haldimand Brant LHIN is exploring opportunities to cluster the delivery of PS/HM services within retirement homes and congregate settings. Doing so is expected to reduce travelling time for personal support workers and decrease the volume of missed visits that poses substantial client safety concerns. If living arrangement were made part of the PS Algorithm such that clients living alone would be classified into higher PS Groups, it would create a disincentive for the LHIN to pursue this service delivery model even though clients would ultimately benefit from safer, more consistent, and higher quality care.

The PS Algorithm and PS (CA) Algorithm are decision support, not decision-making, tools. Concerns that using decision support tools will lead to mechanistic decision-making are unfounded. The algorithms account for the clinical characteristics that consistently predict need for PS/HM services. Importantly, the care coordinator considers the degree of unmet needs and not merely the presence of total needs when creating an appropriate service plan. Thus, the care coordinator must also consider other clinical needs, individual circumstances, sources of informal and other formal supports, as well as the client and family's values and preferences. The PS Algorithm and PS (CA) Algorithm measure needs whether they are met or unmet, and they provide a mechanism for care coordinators to judge the extent that needs are unmet when total needs exceed available resources. As well, the Framework of Hours is expressed as a range

of hours that are likely to meet the needs of a typical client within a PS Group. While traditional guidelines tend to constrain and automate decisions, the percentile bands standardise the magnitude of the care coordinator's allocation decisions while respecting their clinical autonomy to make decisions on a case-by-case basis. Rather than seeing the use of algorithms at odds with clinical judgment, these decision support tools provide additional information on which the clinician can base their decisions.

Part of the misconception that use of algorithms leads to mechanistic behaviour likely stems from how care coordinators are trained to use decision support tools. Traditional guidelines are often presented such that each score from a scale or algorithm is linked to an exact amount or maximum amount of services that a client can receive. Organisations such as HSSOntario and clinical educators within LHINs should ensure that clinical judgment is emphasised when educating care coordinators on the interRAI scales and algorithms. As well, the use of clinical decision support systems in general should feature in standard curricula, so that new clinicians will already be familiar with their use upon entering the workforce.

Public home and community care services are a limited resource. At present, it is likely that most clients in need receive some public PS/HM services but few clients receive all the services they require. Work to derive the PS (CA) Algorithm and PS Algorithm shows that, at minimum, provincial practices to allocate resources are rational. On the whole, clients with greater needs receive more publicly funded PS/HM services. As well, the allocation practices in one LHIN appear to align with clients' capacity to benefit.

An important finding was that allocating PS/HM services at the highest quintiles of PS/HM service use did not appear to confer significant additional benefits above the middle quintile.

First, it should be stated that the results come from a single LHIN and do not necessarily apply to all LHINs. Also, the study excluded clients without a primary informal caregiver and those already living in a congregate setting. Despite these caveats, the findings raise the question of whether need with personal care is always best met by providing PS/HM services. This question returns to the fundamental definition of need, where the object of need is needed because it achieves a valuable end state. One can hypothesise that, for some clients, therapy services or coaching about self-management skills may be a more effective intervention than PS/HM services alone that helps the client to reach their preferred goals. A future study could test this hypothesis directly through a randomised controlled trial. Such a study could compare the outcomes of three groups: a) clients receiving the median amount of PS/HM services, b) clients receiving more than the median amount of PS/HM services, c) clients receiving the median amount of PS/HM services plus additional supports such as therapy services.

Although this thesis is unable to provide a straightforward answer on how to allocate public PS/HM services equitably, it does provide a starting point for policy discussions. Compared to other options, the easiest strategy would be to implement the original Framework of Hours across all LHINs (see Sinn et al. [60]). Use of a common service guideline would reduce the degree of regional variation that was a major concern raised by the Auditor General. From an economic perspective, there would be no net difference in provincial spending on PS/HM services by guiding care coordinators to allocate toward the median. However, this strategy would still require considerable leadership and commitment from the Ministry of Health and Long-Term Care to address long-standing issues, particularly between-LHIN differences in per-client funding amounts and the need for a long-term health human resource strategy.

The framework also makes it possible to explore strategies other than allocating toward the median in concrete terms. Within a cost-neutral approach, existing resources could be redistributed to provide PS/HM services above the median for clients in certain PS Groups at the expense of other PS Groups. However, this study shows that cutting services too much would be problematic. Alternatively, additional investments could be used to shift the whole distribution of PS/HM hours such that the new median is at the former 55th percentile, for example. Again, these investments could be targeted toward some or all PS Groups. Once the spectrum of possible strategies has been identified and their respective approaches to equity clearly stated, it will be important for policy makers to consult with the public to gauge the acceptability of these values. Although it is unlikely that any strategy will be fully supported by every stakeholder group, the selected strategy should be one that is generally acceptable on reasonable grounds by all.

From a health system perspective, one of the key strengths of the PS (CA) Algorithm and PS Algorithm is that they can be readily derived from standard clinical assessments used in public home and community care. The PS Algorithm can be derived from both the interRAI Home Care and interRAI Community Health Assessment. Likewise, the PS (CA) Algorithm that was developed for the interRAI Contact Assessment can be adapted for the interRAI Preliminary Screener. In Ontario, many community support services agencies that do not provide clinical supports use the Preliminary Screener to screen for program eligibility. The Preliminary Screener is identical to the Contact Assessment's Preliminary Screener section with the addition of three questions. Aside from the comprehension variable used to differentiate between PS (CA) Groups 5 and 6, the full PS (CA) Algorithm can be calculated from the Preliminary Screener. If the goal is to provide a common intake experience for all home and community care clients regardless of

the intake point, all prospective clients should be screened for personal care needs. More independent clients represented in the lower PS Groups who do not require other clinical services could be primarily served by community support services agencies. Functionality to share assessments and algorithm outputs is essential to a streamlined process. Clinically, it is redundant for community support services agencies to repeat the same comprehensive assessment for clients referred from the LHIN (or vice versa), and clients and families should not feel that they are asked to repeat their story again and again.

Finally, there are opportunities to engage more closely with clients and families by sharing the assessment outputs with them. Clients and families will gain a better understanding of the assessment results and how the results are used to tailor the service plan to meet the client and family's needs. In simple terms, the care coordinator can explain the results of the PS Algorithm, in the same way they talk about clinical scales such as the Cognitive Performance Scale. The care coordinator can help the client and family to understand the degree of their needs relative to those of other clients, explore available formal and informal supports, and justify the amount of PS/HM services that can be covered by the public system. Based on the premise that transparency encourages accountability, clients and families can be confident that their needs are considered fully and their circumstances treated fairly.

7.2.1 Use in Specialised Home and Community Care Populations

While the PS (CA) Algorithm and PS Algorithm were developed for use with the general home and community care population, there may be interest in adapting these algorithms for specialised populations, such as clients near the end of life, adults with disabilities, and those directing their own services. In general, while the same characteristics associated with need for

PS/HM are likely applicable, it is important to consider the extent to that these characteristics are present and relevant for each population. As well, each population may have a unique subset of characteristics associated with need for PS/HM services.

For clients nearing the end of life, PS/HM services may be offered to help with managing symptoms (e.g., pain, dyspnea, fatigue) and provide some rest and relief for the informal caregiving network. Therefore, factors such as individual health symptoms, the Changes in Health, End-stage disease, Signs and Symptoms (CHESS) Scale that is a composite measure of functional decline and health symptoms, and proximity to death may play a larger role in the allocation decisions for this population.

Of particular policy relevance is that clients at the end of life (meeting the criterion of a time-limited exceptional circumstance) are exempted from *Ontario Regulation 386/99* [54]. In other words, clients at the end of life can receive more than 120 hours of public funded PS/HM services within a 30-day period. While the needs of clients at the end of life generally will be greater than those of the average home care client, it will not necessarily be true that all clients on palliative caseloads will have higher needs for PS/HM services than non-palliative clients. This is particularly relevant since many LHINs have developed and implemented strategies for the early identification of palliative care approaches. In 2018, six LHINs chose to focus on early identification as part of their Health Quality Ontario's Palliative Care Cohort projects (for more information, refer to Ontario Palliative Care Network [238] and Central LHIN [239]). Thus, a decision support tool to classify need for PS/HM services within the end-of-life population is essential to ensuring equity across all home care clients, so that service allocation remains tied to needs, independent of the caseload. The PS Algorithm provides a good starting point against

which to test the effect of proximity to death and the abovementioned factors captured in the interRAI Palliative Care assessment. If significant, these factors could be used to update the PS Algorithm (for a common tool between palliative and non-palliative clients) or to create an adapted version of the PS Algorithm for the interRAI Palliative Care instrument. Implementing the Framework of Hours will require thoughtful consideration. As with general home care clients, the ranges provide the amount of PS/HM hours that are likely to meet the needs of a typical client. The question will be if meeting certain criteria (e.g., proximity to death) constitutes an exceptional circumstance and therefore the upper limit (i.e., 120 hours or more) should be part of the normal range for all PS Groups or higher PS Groups only, or whether exceptional circumstances should still be considered the exception.

Adults with physical disabilities often receive PS/HM services through attendant outreach programs. Like public home care programs, attendant outreach programs provide scheduled in-home PS/HM service visits to help clients live independently in the community [240]. Unlike public home care programs, attendant services also help clients to engage in cultural and social activities, promote a participatory lifestyle, and pursue adult education programs or maintain paid employment [240]. Coming from a social rather than a medical perspective, the independent living philosophy underlying attendant services emphasises support in all aspects of clients' lives and not merely the ability to complete the basic ADLs.

On paper, it is likely that the PS/HM use is higher in attendant care than home care, even among clients with similar impairments. This scenario raises some important ethical questions about equitable distribution between these populations, especially since these programs are also funded by the Ministry of Health and Long-Term Care through the LHINs. Cognitively impaired clients

are not eligible for attendant care services since the ability to direct one's own care is a requirement of the program [240]. As well, older adults with disabilities are more likely to be served by home care unless they were already receiving attendant services as a younger adult. Whereas the traditional biomedical approach mostly focuses on health, the independent living philosophy emphasises health promotion. According to the World Health Organization, health promotion is "the process of enabling people to take control over and to improve their health" [241]. Notably, the Canadian Home Care Association's definition of home and community care explicitly includes elements such as "health promotion" and "social adaptation and integration" [1]. There is no simple answer for how to address this dilemma, but it should stir crucial conversations about how the provincial health and social and community care ministries should share responsibility for promoting health in all populations. In their discussion about health promotion for adults with intellectual and development disabilities, Marks and Heller [242] note that professionals may at times equate disability with ill health and fail to view the person as capable of benefiting from health promotion and self-care activities. Likewise, it should be recognised that home care clients with home support needs receiving PS/HM services can still benefit from health promotion and self-care activities.

The PS Algorithm could also play a part in determining the amount of funding for clients opting into Ontario's Direct Funding Program. The Direct Funding Program provides clients with a monthly amount to hire their own attendants, taking the place of a care coordinator organising and scheduling home visits. Care coordinators still complete standardised assessments to determine the monthly funding amount. Currently, only adults with physical disabilities are eligible for the Direct Funding Program although the *Bringing Care Home* report recommended

expanding the program so that public home care clients can choose to receive home care services under either the care coordination model or self-directed model [33].

7.2.2 Other Potential Uses and Misuses

According to the *Home Care and Community Services Act* [31], if a service outlined in the client's service plan is not immediately available, the client will be placed on a waitlist for that service. The Ministry also requires that "LHINs and [community support services] agencies providing PS/HM services must establish regional processes to manage waitlists and waitlist data in accordance with provincially agreed upon standards based on the client's condition, the client's support system, the availability of other community resources, and regionally adopted prioritisation criteria" [32]. In 2015, 11 of the 14 LHINs maintained at least one service waitlist although the service types were not specified [34]. The PS (CA) Algorithm and PS Algorithm may be a useful indicator of the client's condition as part of determining priority for the PS/HM service waitlist. LHINs may also run partial waitlists, meaning the client receives some services but not the full amount that is outlined in their service plan. One of the primary considerations should be whether the client is likely to experience adverse outcomes if they do not receive timely services.

If the PS (CA) Algorithm were to guide the allocation of PS/HM services at intake, it may be tempting to expand its use to guide the allocation of other service types. The PS (CA) Algorithm incorporates many clinical domains that are relevant to other service types. However, it is unlikely that all characteristics within the algorithm are associated with nursing or therapy services in the same direction or to the same degree. Nor is the PS (CA) Algorithm likely to account for all of the factors that would point to a need for nursing or rehabilitation

interventions. Establishing policies around an algorithm that is known to provide less-than-optimal decision support and at times may contradict clinical common sense may be as unjust as having no algorithm at all, especially for something as important as service allocation. The best practice is to select the most appropriate tool for the purpose, rather than fitting the purpose to the tool. Over time, policies can be updated as more appropriate tools become available.

Consider the Assessment Urgency Algorithm as an example. The Assessment Urgency Algorithm was designed to identify and prioritise clients to receive comprehensive assessment. During its development, the Assessment Urgency Algorithm was shown to explain substantial amounts of variance in PS/HM service cost [174]. Accordingly, the Assessment Urgency Algorithm features in some LHINs' allocation guidelines. However, this thesis demonstrates that the Assessment Urgency Algorithm is vastly outperformed by the PS (CA) Algorithm in predicting PS/HM service use. Thus, updating the PS/HM service guidelines in favour of the PS (CA) Algorithm would improve the value of the decision support in care coordinators' decision-making. This is not to say that the original purpose served by the Assessment Urgency Algorithm is not legitimate, but rather that the extension of the Assessment Urgency Algorithm to serve additional purposes may not be as useful as originally expected.

Many interRAI scales and algorithms are used to calculate quality indicators because they represent important functions and intended outcomes of the home and community care system. Health Quality Ontario reports on four types of quality indicators: access to home care services, home care experiences, getting care elsewhere, and care at the end of life [190]. At present, access to home care is represented by two wait time indicators. Although wait time indicators are useful measures of access among clients for whom services were ordered, exemplary

performance on these indicators can still mask problems of access to the sector more broadly.

Two additional quality indicators are recommended: 1) the proportion of clients in a high Assessment Urgency Algorithm level receiving comprehensive assessment within a specified time frame, and 2) the proportion of clients receiving PS/HM services within a given range of the Framework of Hours. The idea of equal access to assessment is important because needs can be met only if they are properly identified. The second indicator refers to the idea of equitable distribution. Although it would be unrealistic and even unwise to aim for 100% on the second indicator (because the hours within the percentile band would be too high or too low for some clients), the goal should be to increase the percentage over time until a plateau is reached. This would mean that, on average, similar clients with similar needs receive comparable amounts of PS/HM services across LHINs.

Finally, it is important to note that the PS (CA) Algorithm and PS Algorithm explain a substantial amount but not the majority of the variance in PS/HM service use. The algorithms utilise information on some of the most predictive and common indicators of need for PS/HM services observed at the population level [60]. The majority of variance cannot be explained in predictable and generalisable ways. As trained professionals, care coordinators have the clinical background and expertise to probe and assess for other contextual factors that make each client and family's circumstances unique. As such, the Framework of Hours should not direct the care coordinator to allocate a specific amount of service for each client. Instead, appropriate use of the Framework of Hours means to view it as a starting point.

7.3 Implications for Clinical Practice and Policy in Other Jurisdictions

Across Canada, one can reasonably expect that the same kinds of characteristics would differentiate need for PS/HM services in other provinces and territories. While there is no nation-wide basket of standard home and community care services, all publicly funded home care programs include personal support services and most offer at least partial coverage of homemaking services that are intended to support clients living in their homes [1]. As well, all Canadians access public home and community care services through a single entry point within a care coordination model and PS/HM services are provided on need-based criteria [1].

Even in jurisdictions outside of Canada, one can expect that the underlying rank order of need will be preserved. However, the response to the levels of the PS Algorithm will likely differ due to differences in the structure of the home and community care system, the roles of professional and non-professionals, and culturally defined values and expectations. As a result, the actual use of formal services will differ between countries. Thus, while the PS Algorithm can likely serve as an international measure of need for home support, the Framework of Hours (and even which services and programs count toward the “hours”) will be locally defined.

7.4 Implications for the Andersen-Newman Model

The definition of equity based on the Andersen-Newman model was a major organising principle used in this thesis. As such, the PS Algorithm and PS (CA) Algorithm focus exclusively on need characteristics. It would be expected that their implementation into public home care practice would translate into more variance in publicly funded PS/HM service hours explained by need characteristics in place of social structures, attitudes and beliefs, and enabling characteristics. However, it is unlikely that their use will fully meet the criteria for “equitable access” that

Andersen defines as demographic and need characteristics accounting for the *majority* of the variance in service use. This is because informal care provided by family members, friends, and neighbours account for the majority of support services received in the home, and thus, is directly related to PS/HM service use. Andersen himself acknowledged that the relative contributions of predisposing, enabling, and need characteristics would vary to some degree depending on the service of interest [62, 64]. To illustrate this, Andersen compared hospital services that are accessed in times of urgent medical needs with dental services that are considered more discretionary. While demographic and need characteristics should primarily explain use of hospital services, it is likely that social structures and enabling characteristics play a larger role in explaining use of dental services.

In the case of home care services, since nursing and therapy services are essentially hospital services provided in the outpatient setting, it would be expected that demographic and need characteristics should primarily explain use of home-based nursing and therapy services. However, it is sensible that the availability and capacity of the informal caregiving network relates to the need for publicly funded PS/HM services. Is there any way to reconcile the definition of equitable access when enabling resources also explain a substantial amount of variance in service use? Perhaps the difficulties faced when classifying the caregiving variables as either enabling or need characteristics exposes some imprecision in the element of need in the model. Based on this thesis work, it may be preferable to distinguish unmet needs from total needs. Total needs represent the client's true nature and degree of need that is evaluated by the care coordinator. Total needs remain essential to understanding the client's current and future health status to measure outcomes and quantify effectiveness and efficiency. Meanwhile, unmet

needs are those that persist after accounting for needs that can be met by the informal caregiving network. Unmet needs become the main indicator of equitable access—at least in the case of home support services. This modified approach is consistent with the view that public home and community care services supplement the care provided by family and friends. This approach would also recognise the valuable contributions of caregivers in establishing the level of unmet need and firmly place the client and caregiving network at the centre of home and community care.

7.5 Future Research

This thesis provides the first comprehensive review of the interRAI Contact Assessment and, combined with previous work developing the PS Algorithm, makes substantial contributions in addressing knowledge gaps and developing decision support tools to support a more transparent and equitable public home and community care system. The launch of the Canadian Institute for Health Information's Integrated interRAI Reporting System offers an exciting opportunity to link home care assessments with interRAI assessments from other parts of the health care system (e.g., long-term care, post-acute care). Building on this momentum, the Canadian Institute for Health Information should explore ways to support a national reporting system for the interRAI Community Health Assessment.

Future research should investigate PS/HM service use in the following populations: 1) home care clients assessed with the interRAI Palliative Care instrument, 2) clients assessed with the interRAI Preliminary Screener that is used by community support services agencies and some primary care providers, and 3) specialised populations such as adults with disabilities. Future research should also seek to replicate the chapter on PS/HM-sensitive outcomes in other

LHINs—preferably using provincial data so that there will be sufficient power to detect significant associations within each PS Group.

There are many opportunities to collaborate with HSSOntario and the Ministry of Health and Long-Term Care to discuss and evaluate strategies to standardise publicly funded PS/HM service allocation. The Ministry could fund intervention studies to examine the effect of a restorative care approach to providing PS/HM services. As well, while the PS (CA) Algorithm and PS Algorithm offer a standard measure of need for PS/HM services, this thesis did not investigate how the algorithm results should be shared with the client and family. Lastly, there may also be opportunities to share this work with other jurisdictions that have implemented or are planning to implement the interRAI Contact Assessment and explore topics such as assessment efficiency and longitudinal outcomes.

REFERENCES

1. Canadian Home Care Association. Portraits of Home Care in Canada. Mississauga, ON: Canadian Home Care Association; 2013.
2. Statistics Canada. Receiving care at home. Ottawa: Statistics Canada; 2014. <http://www.statcan.gc.ca/pub/89-652-x/89-652-x2014002-eng.htm#a11>.
3. Rodriguez L. Proceedings of the Special Senate Committee on Aging, Issue 2 – Evidence. 2007. <https://sencanada.ca/en/Content/Sen/committee/392/agei/02evb-e>.
4. Cutchin MP. The process of mediated aging in place: a theoretically and empirically based model. *Soc Sci Med.* 2003;57:1077–90.
5. Ballard SM, Jenkins C, Savut NY, McKinnon WH, Carroll KE, Escott-Stump S. Innovative and complementary approaches to aging in place. *J Fam Consum Sci.* 2011;103:24–34.
6. Iecovich E. Aging in place: From theory to practice. *Anthropol Noteb.* 2014;20:21–33.
7. Health Quality Ontario. Measuring Up 2018. Toronto, Ontario: Health Quality Ontario; 2018. <https://www.hqontario.ca/Portals/0/Documents/pr/measuring-up-2018-en.pdf>.
8. Gibbard R. Sizing Up the Challenge: Meeting the Demand for Long-Term Care in Canada. Ottawa: The Conference Board of Canada; 2017. <https://www.conferenceboard.ca/e-library/abstract.aspx?did=9228>.
9. Canadian Institute for Health Information. Seniors in Transition: Exploring Pathways Across the Care Continuum. Ottawa, Ontario: Canadian Institute for Health Information; 2017. <https://www.cihi.ca/sites/default/files/document/seniors-in-transition-report-2017-en.pdf>.
10. Leff B, Burton L, Mader SL, Naughton B, Burl J, Inouye SK, et al. Hospital at home: feasibility and outcomes of a program to provide hospital-level care at home for acutely ill older patients. *Ann Intern Med.* 2005;143:798–808.
11. North East Local Health Integration Network. HOME FIRST Shifts Care of Seniors to HOME. 2011.
12. Government of Canada. Home and Community Health Care. 2016. <https://www.canada.ca/en/health-canada/services/home-continuing-care/home-community-care.html>.
13. Sibbald B. Impasse over federal health transfers. *CMAJ.* 2017;189:E127–8.
14. Government of Canada. Canada Health Act. 1985. <http://laws-lois.justice.gc.ca/eng/acts/c-6/page-1.html>.

15. Canadian Healthcare Association. Home Care in Canada: From the Margins to the Mainstream. Ottawa: Canadian Healthcare Association; 2009. http://www.healthcarecan.ca/wp-content/uploads/2012/11/Home_Care_in_Canada_From_the_Margins_to_the_Mainstream_web.pdf.
16. Commission on the Future of Health Care in Canada. Building on Values: The Future of Health Care in Canada – Final Report. 2002. <http://publications.gc.ca/collections/Collection/CP32-85-2002E.pdf>.
17. Health Council of Canada. Fixing the Foundation: An Update of Primary Health Care and Home Care Renewal in Canada. 2008. https://healthcouncilcanada.ca/files/2.26-HCC_PHC_Main_web_E.pdf.
18. Hermus G, Stonebridge C, Thériault L, Bounajm F. Home and Community Care in Canada: An Economic Footprint. Ottawa: The Conference Board of Canada; 2012.
19. Canadian Institute for Health Information. National Health Expenditure Trends, 1975 to 2018. 2018. <https://www.cihi.ca/sites/default/files/document/nhex-trends-narrative-report-2018-en-web.pdf>.
20. Health Council of Canada. Seniors in Need, Caregivers in Distress. Toronto: Health Council of Canada; 2012. http://www.alzheimer.ca/pec/~media/Files/on/Media%20Releases/2012/April%202012/HCC_HomeCare_2d.pdf.
21. Stone R, Cafferata GL, Sangl J. Caregivers of the frail elderly: a national profile. *Gerontologist*. 1987;27:616–26.
22. The Change Foundation. Spotlight on Ontario’s Caregivers. Toronto, Ontario: The Change Foundation; 2018.
23. The Change Foundation. A Profile of Family Caregivers in Ontario. Toronto, Ontario: The Change Foundation; 2016.
24. Hollander MJ, Liu G, Chappell NL. Who cares and how much? The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly. *Healthc Q*. 2009;12:42–9.
25. Poss JW. Formal and informal resource utilization in long-stay home care clients: an evaluation of the RUG-III/HC case mix classification. University of Waterloo; 2006.
26. Fassbender K. Cost Implications of Informal Supports. Victoria, British Columbia; 2001.
27. Penning MJ. Hydra revisited: substituting formal for self- and informal in-home care among older adults with disabilities. *The Gerontologist*. 2002;42:4–16.

28. Penning MJ, Keating NC. Self-, informal and formal care: partnerships in community-based and residential long-term care settings. *Can J Aging*. 2000;19:75–100.
29. Government of Ontario. Local Health System Integration Act. 2006. <https://www.ontario.ca/laws/statute/06104>.
30. Legislative Assembly of Ontario. Patients First Act. 2016. <https://www.ola.org/en/legislative-business/bills/parliament-41/session-2/bill-41>.
31. Government of Ontario. Home Care and Community Services Act. 1994. <https://www.ontario.ca/laws/statute/94126>.
32. Ministry of Health and Long-Term Care. Policy Guideline Relating to the Delivery of Personal Support Services by Community Care Access Centres and Community Support Service Agencies, 2014. 2014.
33. Expert Group on Home and Community Care. Bringing Care Home: Report of the Expert Group on Home and Community Care. Toronto, Ontario; 2015. http://health.gov.on.ca/en/public/programs/lhin/docs/hcc_report.pdf.
34. Office of the Auditor General of Ontario. 2015 Annual Report. 2015. http://www.auditor.on.ca/en/content/annualreports/arreports/en15/2015AR_en_final.pdf.
35. Levels of Care Expert Panel. Thriving at Home: A Levels of Care Framework to Improve the Quality and Consistency of Home and Community Care for Ontarians. 2017. http://health.gov.on.ca/en/public/programs/lhin/docs/loc_report_2017.pdf.
36. Premier’s Council on Improving Healthcare and Ending Hallway Medicine. A Healthy Ontario: Building a Sustainable Health Care System. 2019. <https://www.ontario.ca/document/healthy-ontario-building-sustainable-health-care-system>.
37. Afzal A, Stolee P, Heckman GA, Boscart VM, Sanyal C. The role of unregulated care providers in Canada: a scoping review. *Int J Older People Nurs*. 2018;13:e12190.
38. Saari M, Xiao S, Rowe A, Patterson E, Killackey T, Raffaghello J, et al. The role of unregulated care providers in home care: a scoping review. *J Nurs Manag*. 2018.
39. Hewko SJ, Cooper SL, Huynh H, Spiwek TL, Carleton HL, Reid S, et al. Invisible no more: a scoping review of the health care aide workforce literature. *BMC Nurs*. 2015;14:38.
40. Lilly MB. Medical versus social work-places: constructing and compensating the personal support worker across health care settings in Ontario, Canada. *Gend Place Cult*. 2008;15:285–99.
41. Health Professions Regulatory Advisory Council. Regulation of Health Professions in Ontario: New Directions. 2006. https://hprac.org/en/reports/resources/New_Directions_April_2006_EN.pdf.

42. Saari M, Patterson E, Kelly S, Tourangeau AE. The evolving role of the personal support worker in home care in Ontario, Canada. *Health Soc Care Community*. 2018;26:240–9.
43. Estabrooks CA, Squires JE, Carleton HL, Cummings GG, Norton PG. Who is looking after mom and dad? Unregulated workers in Canadian long-term care homes. *Can J Aging*. 2015;34:47–59.
44. Canadian Research Network for Care in the Community. Ontario Personal Support Workers in home and community care: CRNCC/PSNO survey results. Toronto: CRNCC; 2010. <http://www.ryerson.ca/content/dam/crncc/knowledge/infocus/factsheets/InFocus-Ontario%20PSWs%20in%20Home%20and%20Community%20Care.pdf>.
45. Kelly C, Bourgeault IL. The Personal Support Worker Program Standard in Ontario: an alternative to self-regulation? *Healthc Policy*. 2015;11:20–6.
46. Waterloo Wellington LHIN. Addressing the PSW Shortage in Waterloo Wellington. 2018.
47. North Simcoe Muskoka LHIN. Personal Support Services: Examining the Factors Affecting the Gap between Supply and Demand in North Simcoe Muskoka. 2017.
48. Panagiotoglou D, Fancey P, Keefe J, Martin-Matthews A. Job satisfaction: insights from home support care workers in three Canadian jurisdictions. *Can J Aging*. 2017;36:1–14.
49. Home Care Ontario. More Home Care for Me and You: Preparing Ontario’s Home Care System for the Challenges of Tomorrow. 2018. <https://www.homecareontario.ca/docs/default-source/position-papers/home-care-ontario-more-home-care-for-me-and-you-february-28-2018.pdf?sfvrsn=16>.
50. Payne LH, Klopp J, Kirkpatrick T, Moore K, Roberts N. Evidence Based Brief Evaluating Personal Support Services to Individual Clients: Demonstrating a Need for Personal Support-Sensitive Client Outcome Indicators. Toronto: Personal Support Network of Ontario; 2010. http://www.p sno.ca/uploads/1/0/1/9/10197937/psw_cop_ebb_final02.08.10.pdf.
51. Berta W, Laporte A. Insights into the Work Lives of Health Support Workers in Ontario. 2015. https://www.uea.ac.uk/documents/5273605/10183310/Berta+Slides+UEA_2015_OCT16pdf+version.pdf/e525197e-0ed9-427c-9d9e-e2a89f7f943f.
52. Health Quality Ontario. The Reality of Caring: Distress among the Caregivers of Home Care Patients. Toronto: Health Quality Ontario; 2016. <http://www.hqontario.ca/Portals/0/documents/system-performance/reality-caring-report-en.pdf>.
53. Sinha M, Bleakney A. Receiving care at home. 2015. <https://www150.statcan.gc.ca/n1/pub/89-652-x/89-652-x2014002-eng.htm>.
54. Government of Ontario. O. Reg. 386/99: Provision of Community Services. 2014. <https://www.ontario.ca/laws/regulation/990386>.

55. Office of the Auditor General of Ontario. 2017 Annual Report Volume 2. 2017. http://www.auditor.on.ca/en/content/annualreports/arreports/en17/2017AR_v2_en_web.pdf.
56. Office of the Auditor General of Ontario. 2010 Annual Report. 2010. http://www.auditor.on.ca/en/content/annualreports/arreports/en10/2010ar_en.pdf.
57. Office of the Auditor General of Ontario. 1998 Annual Report. 1998. <http://www.auditor.on.ca/en/content/annualreports/arreports/en98/305en98.pdf>.
58. Office of the Auditor General of Ontario. 2004 Annual Report. 2004. <http://www.auditor.on.ca/en/content/annualreports/arreports/en04/307en04.pdf>.
59. Government of Ontario. Patients First: A Roadmap to Strengthen Home and Community Care. 2015. <http://www.health.gov.on.ca/en/public/programs/lhin/roadmap.pdf>.
60. Sinn CJ, Jones A, McMullan JL, Ackerman N, Curtin-Telegdi N, Eckel L, et al. Derivation and validation of the Personal Support Algorithm: an evidence-based framework to inform allocation of personal support services in home and community care. *BMC Health Serv Res.* 2017;17:775.
61. Andersen RM. National health surveys and the behavioral model of health services use. *Med Care.* 2008;46:647–53.
62. Andersen RM. Revisiting the behavioral model and access to medical care: does it matter? *J Health Soc Behav.* 1995;36:1–10.
63. Andersen R, Newman JF. Societal and individual determinants of medical care utilization in the United States. *Milbank Q.* 2005;83. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2690261/>.
64. Andersen R. *Behavioural Model of Families' Use of Health Services.* Chicago, IL: Centre for Health Administrative Studies, University of Chicago; 1968.
65. Murphy CM, Whelan BJ, Normand C. Formal home-care utilisation by older adults in Ireland: evidence from the Irish Longitudinal Study on Ageing (TILDA). *Health Soc Care Community.* 2015;23:408–18.
66. Hammar T, Rissanen P, Perälä M-L. Home-care clients' need for help, and use and costs of services. *Eur J Ageing.* 2008;5:147.
67. Sun Z, Laporte A, Guerriere DN, Coyte PC. Utilisation of home-based physician, nurse and personal support worker services within a palliative care programme in Ontario, Canada: trends over 2005–2015. *Health Soc Care Community.* 2017;25:1127–38.
68. Lee Y, Penning M. The determinants of informal, formal, and mixed in-home care in the Canadian context. *J Aging Health.* 2018;1:1–23.

69. Skarupski KA, McCann JJ, Bienias JL, Wolinsky FD, Aggarwal NT, Evans DA. Use of home-based formal services by adult day care clients with Alzheimer's disease. *Home Health Care Serv Q.* 2008;27:217–39.
70. Martindale-Adams J, Nichols LO, Zuber J, Burns R, Graney MJ. Dementia caregivers' use of services for themselves. *The Gerontologist.* 2016;56:1053–61.
71. Diduk-Smith RM. Unmet needs and service utilization by informal caregivers. Old Dominion University; 2017.
https://digitalcommons.odu.edu/cgi/viewcontent.cgi?article=1009&context=healthservices_etds.
72. Bass DM, Looman WJ, Ehrlich P. Predicting the volume of health and social services: integrating cognitive impairment into the modified Andersen framework. *The Gerontologist.* 1992;32:33–43.
73. Larsson K, Thorslund M, Kåreholt I. Are public care and services for older people targeted according to need? Applying the Behavioural Model on longitudinal data of a Swedish urban older population. *Eur J Ageing.* 2006;3:22–33.
74. Black BS, Johnston D, Rabins PV, Morrison A, Lyketos C, Samus QM. Unmet needs of community-residing persons with dementia and their informal caregivers: findings from the maximizing independence at home study. *J Am Geriatr Soc.* 2013;61:2087–95.
75. Andrew Joseph Potter. Informal caregivers and the health of older adult care recipients. University of Iowa; 2016. <https://search.proquest.com/docview/1878226885?pq-origsite=gscholar>.
76. Potter AJ. Factors associated with caregivers' use of support services and caregivers' nonuse of services sought. *J Aging Soc Policy.* 2018;30:155–72.
77. Willet M, Dorstyn D, Due C, Li W. Applying Andersen's model to explain service use and quality of life among Australian caregivers of children with autism spectrum disorder. *J Dev Phys Disabil.* 2018;30:339–54.
78. Bass DM, Noelker LS. The influence of family caregivers on elder's use of in-home services: an expanded conceptual framework. *J Health Soc Behav.* 1987;28:184–96.
79. McKillip JA. Needs Analysis: Tools for the Human Services and Education. California, USA: SAGE Publications; 1987.
80. Liss PE. Health Care Need: Meaning and Measurement. Aldershot, England: Avebury; 1993.
81. Donabedian A. Aspects of Medical Care Administration. Cambridge: Harvard University Press; 1974.
82. Hasman A, Hope T, Østerdal LP. Health care need: three interpretations. *J Appl Philos.* 2006;23:145–56.

83. Acheson RM. The definition and identification of need for health care. *J Epidemiol Community Health*. 1978;32:10–5.
84. Culyer A. Need: is a consensus possible? *J Med Ethics*. 1998;24:77–80.
85. Daniels N. *Just Health Care*. Cambridge: Cambridge University Press; 1985.
86. Gallagher E, Alcock D, Diem E, Angus D, Medves J. Ethical dilemmas in home care case management. *J Healthc Manag*. 2002;47:85–97.
87. Chang BW, Hirdes JP. A cross-sectional study to compare caregiver distress among Korean Canadian, Chinese Canadian, and other Canadian home care clients. *SAGE Open*. 2015;5:1–14.
88. Culyer AJ. Equity: some theory and its policy implications. *J Med Ethics*. 2001;27:275–83.
89. Beeber AS, Thorpe JM, Clipp EC. Community-based service use by elders with dementia and their caregivers: a latent class analysis. *Nurs Res*. 2008;57:312–21.
90. Blomgren J, Martikainen P, Martelin T, Koskinen S. Determinants of home-based formal help in community-dwelling older people in Finland. *Eur J Ageing*. 2008;5:335–47.
91. Boniface DR, Denham MJ. Factors influencing the use of community health and social services by those aged 65 and over. *Health Soc Care Community*. 1997;5:48–54.
92. Eichler T, Hoffmann W, Hertel J, Richter S, Wucherer D, Michalowsky B, et al. Living alone with dementia: prevalence, correlates and the utilization of health and nursing care services. *J Alzheimers Dis*. 2016;52:619–29.
93. Ely M, Brayne C, Huppert FA, O'Connor DW, Pollitt PA. Cognitive impairment: a challenge for community care. A comparison of the domiciliary service receipt of cognitively impaired and equally dependent physically impaired elderly women. *Age Ageing*. 1997;26:301–8.
94. Forbes DA, Stewart N, Morgan D, Anderson M, Parent K, Janzen BL. Individual determinants of home-care nursing and housework assistance. *Can J Nurs Res*. 2003;35:23.
95. Forbes DA, Jansen SL, Markle-Reid M, Hawranik P, Morgan D, Henderson S, et al. Gender differences in use and availability of home and community-based services for people with dementia. *Can J Nurs Res*. 2008;40:39–59.
96. Frederiks C, te Wierik M, van Rossum H. Factors associated with differential utilization of professional care among elderly people: residents of old people's homes compared to elderly people living at home. *Acta Hosp*. 1991;31:33–45.
97. Hasche LK, Lee MJ, Proctor EK, Morrow-Howell N. Does identification of depression affect community long-term care services ordered for older adults? *Soc Work Res*. 2013;37:255–62.

98. Hawranik P. The role of cognitive status in the use of inhome services: implications for nursing assessment. *Can J Nurs Res.* 1998;30:45–65.
99. Hawranik PG, Strain LA. Cognitive impairment, disruptive behaviors, and home care utilization. *West J Nurs Res.* 2001;23:148–62.
100. Hays BJ, Willborn EH. Characteristics of clients who receive home health aide service. *Public Health Nurs.* 1996;13:58–64.
101. Hoeck S, François G, Geerts J, Van der Heyden J, Vandewoude M, Van Hal G. Health-care and home-care utilization among frail elderly persons in Belgium. *Eur J Public Health.* 2012;22:671–7.
102. Kitchen P, Williams A, Pong RW, Wilson D. Socio-spatial patterns of home care use in Ontario, Canada: a case study. *Health Place.* 2011;17:195–206.
103. Lévesque L, Cossette S, Potvin L, Benigeri M. Community services and caregivers of a demented relative: users and those perceiving a barrier to use. *Can J Aging.* 2000;19:186–209.
104. Mery G, Wodchis WP, Laporte A. The determinants of the propensity to receive publicly funded home care services for the elderly in Canada: a panel two-stage residual inclusion approach. *Health Econ Rev.* 2016;6:8.
105. Pedlar DJ, Biegel DE. The impact of family caregiver attitudes on the use of community services for dementia care. *J Appl Gerontol.* 1999;18:201–21.
106. Penning MJ. Cognitive impairment, caregiver burden, and the utilization of home health services. *J Aging Health.* 1995;7:233–53.
107. Ranhoff A, Laake K. Health and functioning among elderly recipients of home help in Norway. *Health Soc Care Community.* 2007;3:115–23.
108. Remler DK, Teresi JA, Weinstock RS, Ramirez M, Eimicke JP, Silver S, et al. Health care utilization and self-care behaviors of Medicare beneficiaries with diabetes: comparison of national and ethnically diverse underserved populations. *Popul Health Manag.* 2011;14:11–20.
109. Roelands M, Oyen HV, Depoorter A, Baro F, Oost PV. Are cognitive impairment and depressive mood associated with increased service utilisation in community-dwelling elderly people? *Health Soc Care Community.* 2003;11:1–9.
110. Scharlach AE, Gustavson K, Dal Santo TS. Assistance received by employed caregivers and their care recipients: who helps care recipients when caregivers work full time? *The Gerontologist.* 2007;47:752–62.
111. Sun F, Kosberg J, Kaufman A, Leeper J, Burgin L. Formal services utilization by family caregivers of persons with dementia living in rural southeastern USA. *Rural Soc Work Community Pract.* 2007;12:22–30.

112. Wang JJ, Mitchell P, Smith W, Leeder SR. Factors associated with use of community support services in an older Australian population. *Aust N Z J Public Health*. 1999;23:147–53.
113. Zhu CW, Torgan R, Scarmeas N, Albert M, Brandt J, Blacker D, et al. Home health and informal care utilization and costs over time in Alzheimer’s disease. *Home Health Care Serv Q*. 2008;27:1–20.
114. Bull MJ. Use of formal community services by elders and their family caregivers 2 weeks following hospital discharge. *J Adv Nurs*. 1994;19:503–8.
115. Carpenter I, Gambassi G, Topinkova E, Schroll M, Finne-Soveri H, Henrard JC, et al. Community care in Europe. The Aged in Home Care project (AdHOC). *Aging Clin Exp Res*. 2004;16:259–69.
116. Dellasega CA, Fisher KM. Posthospital home care for frail older adults in rural locations. *J Community Health Nurs*. 2001;18:247–60.
117. Emler CA, Farkas KJ. Correlates of service utilization among midlife and older adults with HIV/AIDS: the role of age in the equation. *J Aging Health*. 2002;14:315–35.
118. Gure T, Kabeto K, Blaum C, Langa K. Degree of disability and patterns of caregiving among older Americans with congestive heart failure. *J Gen Intern Med*. 2008;23:70–6.
119. Hoell A, Weyerer S, Maier W, Wagner M, Scherer M, Stark A, et al. The impact of depressive symptoms on utilization of home care by the elderly: longitudinal results from the AgeMooDe study. *J Affect Disord*. 2016;204:247–54.
120. Seow H, Barbera L, Howell D, Dy SM. Did Ontario’s end-of-life care strategy reduce acute care service use? *Healthc Q*. 2010;13:93–100.
121. von Granitz H, Reine I, Sonnander K, Winblad U. Do personal assistance activities promote participation for persons with disabilities in Sweden? *Disabil Rehabil*. 2017;39:2512–21.
122. Freedman VA, Aykan H, Wolf DA, Marcotte JE. Disability and home care dynamics among older unmarried Americans. *J Gerontol Ser B*. 2004;59:S25–33.
123. Diwan S, Berger C, Manns EK. Composition of the home care service package: predictors of type, volume, and mix of services provided to poor and frail older people. *The Gerontologist*. 1997;37:169–81.
124. Edwardson SR, Nardone P. The dependency at discharge instrument as a measure of resource use in home care. *Public Health Nurs*. 1990;7:138–44.
125. Baker DI, Bice TW. The influence of urinary incontinence on publicly financed home care services to low-income elderly people. *The Gerontologist*. 1995;35:360–9.

126. Fogarty E, Walsh C, McGuigan C, Tubridy N, Barry M. Direct and indirect economic consequences of multiple sclerosis in Ireland. *Appl Health Econ Health Policy*. 2014;12:635–45.
127. Liu K, McBride TD, Coughlin TA. Costs of community care for disabled elderly persons: the policy implications. *Inquiry*. 1990;27:61–72.
128. Svensson M, Fajutrao L. Costs of formal and informal home care and quality of life for patients with multiple sclerosis in Sweden. *Mult Scler Int*. 2014;2014.
129. Otero A, de Yébenes MJG, Rodríguez-Laso A, Zunzunegui MV. Unmet home care needs among community-dwelling elderly people in Spain. *Aging Clin Exp Res*. 2003;15:234–42.
130. Corazzini-Gomez K. The relative effects of home care client characteristics on the resource allocation process: do personality and demeanor matter? *The Gerontologist*. 2002;42:740–50.
131. Seow H, Barbera L, Howell D, Dy SM. How end-of-life home care services are used from admission to death: a population-based cohort study. *J Palliat Care*. 2010;26:270–8.
132. Bogasky S, Sheingold S, Stearns SC. Medicare’s hospice benefit: analysis of utilization and resource use. *Medicare Medicaid Res Rev*. 2014;4:mmrr2014-004-02-b03.
133. Guerriere D, Husain A, Marshall D, Zagorski B, Seow H, Brazil K, et al. Predictors of place of death for those in receipt of home-based palliative care services in Ontario, Canada. *J Palliat Care*. 2015;31:76–88.
134. Health Services Utilization and Research Commission. *The Impact of Preventive Home Care and Seniors Housing on Health Outcomes*. Saskatoon, SK; 2000. <http://skdocs.legassembly.sk.ca/mono/87510.pdf>.
135. Albert SM, Simone B, Brassard A, Stern Y, Mayeux R. Medicaid home care services and survival in New York City. *The Gerontologist*. 2005;45:609–16.
136. Gené Badia J, Borràs Santos A, Contel Segura JC, Terén CA, González LC, Ramírez EL, et al. Predictors of mortality among elderly dependent home care patients. *BMC Health Serv Res*. 2013;13:316.
137. Hollander M, Tessaro A. *Evaluation of the Maintenance and Preventive Model of Home Care*. Ottawa: Health Canada; 2001. <http://www.teamgrant.ca/M-THAC%20Greatest%20Hits/Bonus%20Tracks/preventivehomecarereport.pdf>.
138. Chambers LW, Tugwell P, Goldsmith CH, Caulfield P, Haight M, Pickard L, et al. The impact of home care on recently discharged elderly hospital patients in an Ontario community. *Can J Aging*. 1990;9:327–47.
139. Hughes SL, Cordray DS, Spiker VA. Evaluation of a long-term home care program. *Med Care*. 1984;22:460–75.

140. Brazil K, Bedard M, Willison K. Factors associated with home death for individuals who receive home support services: a retrospective cohort study. *BMC Palliat Care*. 2002;1:2.
141. Riordan JM, Bennett AV. An evaluation of an augmented domiciliary service to older people with dementia and their carers. *Aging Ment Health*. 1998;2:137–43.
142. Sands LP, Xu H, Thomas J, Paul S, Craig BA, Rosenman M, et al. Volume of home- and community-based services and time to nursing-home placement. *Medicare Medicaid Res Rev*. 2012;2.
143. Thomas KS. The relationship between older Americans act in-home services and low-care residents in nursing homes. *J Aging Health*. 2014;26:250–60.
144. Xu H, Weiner M, Paul S, Thomas J, Craig B, Rosenman M, et al. Volume of home- and community-based Medicaid waiver services and risk of hospital admissions. *J Am Geriatr Soc*. 2010;58:109–15.
145. Contandriopoulos AP, Tessier G, Larouche D. The effects of Quebec home aid services on the utilization profile of sociosanitary resources: a substitution study. *Soc Sci Med*. 1986;22:731–6.
146. Markle-Reid M, Browne G, Weir R, Gafni A, Roberts J, Henderson S. Seniors at risk: the association between the six-month use of publicly funded home support services and quality of life and use of health services for older people. *Can J Aging*. 2008;27:207–24.
147. Kim JN, Shiwaku K. The effect of utilization of in-home services and the changes in levels of care needs of frail persons (2002-2004): results of a two-year follow-up study. *J Rural Med*. 2012;7:6–14.
148. Hansen EB, Christensen VT, Heinesen E. The effect of home care on the ability to perform the activities of daily living and the well-being of older people. *Eur J Ageing*. 2009;6:17–26.
149. Kato G, Tamiya G, Kashiwagi M, Sato S, Takahashi H. Relationship between home care service use and changes in the care needs level of Japanese elderly. *BMC Geriatr*. 2009;9.
150. Barnay T, Juin S. Does home care for dependent elderly people improve their mental health? *J Health Econ*. 2016;45:149–60.
151. Sussman T, Regehr C. The influence of community-based services on the burden of spouses caring for their partners with dementia. *Health Soc Work*. 2009;34:29–39.
152. Hooyman N, Gonyea J, Montgomery R. The impact of in-home services termination on family caregivers. *The Gerontologist*. 1985;25:141–5.
153. Statistics Canada. Age and sex, and type of dwelling data: Key results from the 2016 Census. 2017. <https://www150.statcan.gc.ca/n1/daily-quotidien/170503/dq170503a-eng.htm>.

154. Ontario Ministry of Finance. Ontario Population Projections Update, 2017–2041. 2018. <https://www.fin.gov.on.ca/en/economy/demographics/projections/#s2>.
155. Morris JN, Fries BE, Steel K, Ikegami N, Bernabei R, Carpenter GI, et al. Comprehensive clinical assessment in community setting: applicability of the MDS-HC. *J Am Geriatr Soc*. 1997;45:1017–24.
156. Carpenter I, Hirdes J. Using interRAI assessment systems to measure and maintain quality of long-term care. In: *A Good Life in Old Age? Monitoring and Improving Quality in Long-term Care*. OECD/European Commission; 2013. p. 93–139.
157. Heckman G, Gray LC, Hirdes JP. Addressing health care needs for frail seniors in Canada: the role of interRAI instruments. *Can Geriatr J*. 2013;3.
158. Hirdes JP, Fries BE, Morris JN, Steel K, Mor V, Frijters D, et al. Integrated health information systems based on the RAI/MDS series of instruments. *Healthc Manage Forum*. 1999;12:30–40.
159. Morris JN, Fries BE, Bernabei R, Steel K, Ikegami N, Carpenter GI, et al. *interRAI Home Care (HC) Assessment Form and User’s Manual*. Version 9.1, Canadian Edition. Washington, DC: interRAI; 2012.
160. Morris JN, Berg K, Bjorkgren M, Declercq A, Finne-Soveri H, Fries BE, et al. *interRAI Community Health Assessment (CHA) Assessment Form and User’s Manual*. Version 9.1, Canadian Edition. Washington, DC: interRAI; 2010.
161. Hirdes JP, Curtin-Telegdi N, Poss JW, Gray L, Berg K, Stolee P, et al. *interRAI Contact Assessment (CA) Form and User’s Manual*. interRAI; 2010.
162. Rolfson DB, Heckman GA, Bagshaw SM, Robertson D, Hirdes JP, Canadian Frailty Network. Implementing frailty measures in the Canadian healthcare system. *J Frailty Aging*. 2018;7:208–16.
163. Hogeveen SE, Chen J, Hirdes JP. Evaluation of data quality of interRAI assessments in home and community care. *BMC Med Inform Decis Mak*. 2017;17.
164. Morris JN, Howard EP, Fries BE, Berkowitz R, Goldman B, David D. Using the community health assessment to screen for continued driving. *Accid Anal Prev*. 2014;63:104–10.
165. Guthrie DM, Pitman R, Stolee P, Strong G, Poss J, Tjam EY, et al. Reliability of standardized assessment for adults who are deafblind. *J Rehabil Res Dev*. 2011;48:545–54.
166. Fletcher PC, Guthrie DM, Berg K, Hirdes JP. Risk factors for restriction in activity associated with fear of falling among seniors within the community. *J Patient Saf*. 2010;6:187–91.

167. Fletcher PC, Berg K, Dalby DM, Hirdes JP. Risk factors for falling among community-based seniors. *J Patient Saf.* 2009;5:61–6.
168. Parsons M, Rouse P, Sajtos L, Harrison J, Parsons J, Gestro L. Developing and utilising a new funding model for home-care services in New Zealand. *Health Soc Care Community.* 2018;26:345–55.
169. Cheng L, Zhu M, Poss JW, Hirdes JP, Glenny C, Stolee P. Opinion versus practice regarding the use of rehabilitation services in home care: an investigation using machine learning algorithms. *BMC Med Inform Decis Mak.* 2015;15:80.
170. Chiatti C, Furneri G, Rimland JM, Demma F, Bonfranceschi F, Cassetta L, et al. The economic impact of moderate stage Alzheimer’s disease in Italy: evidence from the UP-TECH randomized trial. *Int Psychogeriatr.* 2015;27:1563–72.
171. Hirdes JP. Addressing the health needs of frail elderly people: Ontario’s experience with an integrated health information system. *Age Ageing.* 2006;35:329–31.
172. Bucek J. Older Stroke Survivors in Home Care: Factors Associated with the use of CCAC Rehabilitation Services. University of Waterloo; 2015. <https://uwspace.uwaterloo.ca/handle/10012/9237>.
173. Dwyer C. Preliminary validation of a single self-report question as a screening tool for depression in older adult populations: Analyses using the Minimum Data Set Depression Rating Scale. University of Waterloo; 2008. <https://uwspace.uwaterloo.ca/handle/10012/4021>.
174. Poss JW, Hirdes JP, Fries BE, McKillop I, Chase M. Validation of Resource Utilization Groups Version III for Home Care (RUG-III/HC): evidence from a Canadian home care jurisdiction. *Med Care.* 2008;46:380–7.
175. Betini RSD, Hirdes JP, Lero DS, Cadell S, Poss J, Heckman G. A longitudinal study looking at and beyond care recipient health as a predictor of long term care home admission. *BMC Health Serv Res.* 2017;17:709.
176. Salam-White L, Hirdes JP, Poss JW, Blums J. Predictors of emergency room visits or acute hospital admissions prior to death among hospice palliative care clients in Ontario: a retrospective cohort study. *BMC Palliat Care.* 2014;13:35.
177. Ministry of Health and Long-Term Care. Chapter Five Schedule E: CCAC In-Home Service Recipient Categories. 2012.
178. Hirdes JP, Frijters DH, Teare GF. The MDS-CHESS scale: a new measure to predict mortality in institutionalized older people. *J Am Geriatr Soc.* 2003;51:96–100.
179. Hirdes JP, Poss JW, Mitchell L, Korngut L, Heckman G. Use of the interRAI CHESS scale to predict mortality among persons with neurological conditions in three care settings. *PLoS ONE.* 2014;9:e99066.

180. Armstrong JJ, Stolee P, Hirdes JP, Poss JW. Examining three frailty conceptualizations in their ability to predict negative outcomes for home-care clients. *Age Ageing*. 2010;39:755–8.
181. Doran D, Hirdes JP, Blais R, Baker GR, Poss JW, Li X. Adverse events associated with hospitalization or detected through the RAI-HC assessment among Canadian home care clients. *Healthc Policy*. 2013;9:76–88.
182. Poss JW, Sinn CJ, Grinchenko G, Blums J, Peirce T, Hirdes J. Location, location, location: characteristics and services of long-stay home care recipients in retirement homes compared to others in private homes and long-term care homes. *Healthc Policy*. 2017;12:80–93.
183. Vu M, Hogan DB, Patten SB, Jetté N, Bronskill SE, Heckman G, et al. A comprehensive profile of the sociodemographic, psychosocial and health characteristics of Ontario home care clients with dementia. *Chronic Dis Inj Can*. 2014;34:132–44.
184. Mondor L, Maxwell CJ, Hogan DB, Bronskill SE, Gruneir A, Lane NE, et al. Multimorbidity and healthcare utilization among home care clients with dementia in Ontario, Canada: A retrospective analysis of a population-based cohort. *PLOS Med*. 2017;14:e1002249.
185. Government of Ontario. Ontario Investing An Additional \$100 Million This Year in Home and Community Care. 2016. <https://news.ontario.ca/mohltc/en/2016/07/ontario-investing-an-additional-100-million-this-year-in-home-and-community-care.html>.
186. Hamilton Niagara Haldimand Brant Local Health Integration Network. Donna’s Blog. 2017. <http://www.hnhblhin.on.ca/newsandevents/donnasblog/march2017.aspx>.
187. Hirdes JP, Poss JW, Curtin-Telegdi N. The Method for Assigning Priority Levels (MAPLe): a new decision-support system for allocating home care resources. *BMC Med*. 2008;6:9.
188. Sinn CJ, Betini RSD, Wright J, Eckler L, Chang BW, Hogeveen S, et al. Adverse events in home care: identifying and responding with interRAI scales and Clinical Assessment Protocols. *Can J Aging*. 2018;37:60–9.
189. Landis JR, Koch GG. The measurement of observer agreement for categorical data. *Biometrics*. 1977;33:159–74.
190. Health Quality Ontario. Health Quality Ontario Indicator Library. 2019. <http://indicatorlibrary.hqontario.ca/Indicator/Search/EN>.
191. Chappell NL, Blandford AA. Health service utilization by elderly persons. *Can J Sociol Cah Can Sociol*. 1987;12:195–215.
192. Hall R, Coyte P. Determinants of home care utilization: who uses home care in Ontario? *Can J Aging Rev Can Vieil*. 2001;20:175–92.

193. Meinow B, Kåreholt I, Lagergren M. According to need? Predicting the amount of municipal home help allocated to elderly recipients in an urban area of Sweden. *Health Soc Care Community*. 2005;13:366–77.
194. Kemper P. The use of formal and informal home care by the disabled elderly. *Health Serv Res*. 1992;27:421–51.
195. Chappell NL, Kadlec H. Accuracy of caregiver proxy reports of home care service use. *J Appl Gerontol*. 2016;38:434–42.
196. Canadian Institute for Health Information. Supporting Informal Caregivers—The Heart of Home Care. Ottawa: Canadian Institute for Health Information; 2010. https://secure.cihi.ca/free_products/Caregiver_Distress_AIB_2010_EN.pdf.
197. Gilmour H. Formal home care use in Canada. Ottawa, Ontario: Statistics Canada; 2018. <https://www150.statcan.gc.ca/n1/pub/82-003-x/2018009/article/00001-eng.htm>.
198. Morris JN, Fries BE, Mehr DR, Hawes C, Phillips C, Mor V, et al. MDS Cognitive Performance Scale. *J Gerontol*. 1994;49:M174-182.
199. Morris JN, Berg K, Fries BE, Steel K, Howard EP. Scaling functional status within the interRAI suite of assessment instruments. *BMC Geriatr*. 2013;13:128.
200. Morris JN, Fries BE, Morris SA. Scaling ADLs within the MDS. *J Gerontol A Biol Sci Med Sci*. 1999;54:M546-553.
201. Mlinac ME, Feng MC. Assessment of activities of daily living, self-care, and independence. *Arch Clin Neuropsychol*. 2016;31:506–16.
202. Kelly K, Wolff N, Gibson MJ, Feinberg L. Listening to family caregivers: the need to include family caregiver assessment in Medicaid home- and community-based service waiver programs. 2013. https://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/the-need-to-include-family-caregiver-assessment-medicaid-hcbs-waiver-programs-report-AARP-ppi-ltc.pdf.
203. Betini RSD, Hirdes JP, Curtin-Telegdi N, Gammage L, Vansickle J, Poss J, et al. Development and validation of a screener based on interRAI assessments to measure informal caregiver wellbeing in the community. *BMC Geriatr*. 2018;18. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6293658/>.
204. O’Sullivan L, Scales LM, Duffy C, Vereker N, Dhondt K. Carer Needs Assessment development - A Republic of Ireland led international joint working project to support delivery of integrated health and social care. *Int J Integr Care*. 2017;17:A288.
205. Charney DS, Reynolds CF, Lewis L, Lebowitz BD, Sunderland T, Alexopoulos GS, et al. Depression and Bipolar Support Alliance consensus statement on the unmet needs in diagnosis and treatment of mood disorders in late life. *Arch Gen Psychiatry*. 2003;60:664–72.

206. Markle-Reid MF, McAiney C, Forbes D, Thabane L, Gibson M, Hoch JS, et al. Reducing depression in older home care clients: design of a prospective study of a nurse-led interprofessional mental health promotion intervention. *BMC Geriatr.* 2011;11:50.
207. Bruce ML, McAvay GJ, Raue PJ, Brown EL, Meyers BS, Keohane DJ, et al. Major depression in elderly home health care patients. *Am J Psychiatry.* 2002;159:1367–74.
208. Banerjee S, Macdonald A. Mental disorder in an elderly home care population: associations with health and social service use. *Br J Psychiatry.* 1996;168:750–6.
209. Eustis NN, Fischer LR. Relationships between home care clients and their workers: implications for quality of care. *The Gerontologist.* 1991;31:447–56.
210. Munson M, Proctor E, Morrow-Howell N, Fedoravicius N, Ware N. Case managers speak out: responding to depression in community long-term care. *Psychiatr Serv Wash DC.* 2007;58:1124–7.
211. Mellor D, Davison T, McCabe M, George K. Professional carers' knowledge and response to depression among their aged-care clients: the care recipients' perspective. *Aging Ment Health.* 2008;12:389–99.
212. Mallidou AA, Cummings GG, Schalm C, Estabrooks CA. Health care aides use of time in a residential long-term care unit: a time and motion study. *Int J Nurs Stud.* 2013;50:1229–39.
213. Ward-Griffin C, Hall J, DeForge R, St-Amant O, McWilliam C, Oudshoorn A, et al. Dementia home care resources: how are we managing? *Journal of Aging Research.* 2012.
214. Preya Solutions Group. Meeting Home Care Needs in the Champlain LHIN: Estimating and Managing CCAC Service Demand. 2017.
215. Fries BE, Shugarman LR, Morris JN, Simon SE, James M. A screening system for Michigan's home- and community-based long-term care programs. *The Gerontologist.* 2002;42:462–74.
216. Sinn CJ. Introducing the CHES-CA scale for the interRAI Contact Assessment. Oral session presented at Canadian interRAI Conference 2018; Calgary.
217. Stoller EP. Patterns of physician utilization by the elderly: a multivariate analysis. *Med Care.* 1982;20:1080–9.
218. de Ville B, Neville P. *Decision Trees for Analytics Using SAS Enterprise Miner.* Cary, NC: SAS Institute; 2013.
219. Smith ME, Baker CR, Branch LG, Walls RC, Grimes RM, Karklins JM, et al. Case-mix groups for VA hospital-based home care. *Med Care.* 1992;30:1–16.

220. Gaugler JE, Yu F, Krichbaum K, Wyman JF. Predictors of nursing home admission for persons with dementia. *Med Care*. 2009;47:191–8.
221. Cepoiu-Martin M, Tam-Tham H, Patten S, Maxwell CJ, Hogan DB. Predictors of long-term care placement in persons with dementia: a systematic review and meta-analysis. *Int J Geriatr Psychiatry*. 2016;31:1151–71.
222. Spillman BC, Long SK. Does high caregiver stress predict nursing home entry? *Inquiry*. 2009;46:140–61.
223. Mitchell LA, Hirdes J, Poss JW, Slegers-Boyd C, Caldarelli H, Martin L. Informal caregivers of clients with neurological conditions: profiles, patterns and risk factors for distress from a home care prevalence study. *BMC Health Serv Res*. 2015;15:350.
224. Canadian Institute for Health Information. A Canadian first: CIHI to measure access to mental health and addictions services and to home and community care | CIHI. 2018. <https://www.cihi.ca/en/a-canadian-first-cihi-to-measure-access-to-mental-health-and-addictions-services-and-to-home-and>.
225. Government of Canada. A Common Statement of Principles on Shared Health Priorities. 2017. https://www.canada.ca/content/dam/hc-sc/documents/corporate/transparency_229055456/health-agreements/principles-shared-health-priorities.pdf.
226. Canadian Institute for Health Information. Home Care Reporting System Data Users Guide, 2017–2018. 2019. https://secure.cihi.ca/free_products/HCRS-external-data-users-guide-2017-2018-en-web.pdf.
227. Landi F, Tua E, Onder G, Carrara B, Sgadari A, Rinaldi C, et al. Minimum data set for home care: a valid instrument to assess frail older people living in the community. *Med Care*. 2000;38:1184–90.
228. Cook RJ, Lawless JF. *Multistate Models for the Analysis of Life History Data*. Boca Raton, Florida: CRC Press; 2018.
229. Bertens LCM, Moons KGM, Rutten FH, van Mourik Y, Hoes AW, Reitsma JB. A nomogram was developed to enhance the use of multinomial logistic regression modeling in diagnostic research. *J Clin Epidemiol*. 2016;71:51–7.
230. Ontario Health Coalition. *The Care We Need*. 2015. <http://www.ontariohealthcoalition.ca/wp-content/uploads/home-care-the-care-we-need-report-final.pdf>.
231. Aronson J. Silenced complaints, suppressed expectations: the cumulative effects of home care rationing. *Int J Health Serv*. 2006;36:535–56.

232. Penning MJ, Brackley ME, Allan DE. Home care and health reform: changes in home care utilization in one Canadian province, 1990–2000. *The Gerontologist*. 2006;46:744–58.
233. King A., Parsons M., Robinson E., Jorgensen D. Assessing the impact of a restorative home care service in New Zealand: a cluster randomised controlled trial. *Health Soc Care Community*. 2012;20:365–74.
234. Glendinning C, Newbronner E. The effectiveness of home care reablement: developing the evidence base. *J Integr Care*. 2008;16:32–9.
235. Parsons M, Senior H, Kerse N, Chen MH, Jacobs S, Anderson C. Randomised trial of restorative home care for frail older people in New Zealand. *Nurs Older People*. 2017;29:27–33.
236. Markle-Reid M, Weir R, Browne G, Roberts J, Gafni A, Henderson S. Health promotion for frail older home care clients. *J Adv Nurs*. 2006;54:381–95.
237. Tinetti ME, Baker D, Gallo WT, Nanda A, Charpentier P, O’Leary J. Evaluation of restorative care vs usual care for older adults receiving an acute episode of home care. *JAMA*. 2002;287:2098–105.
238. Ontario Palliative Care Network. Tools to Support Earlier Identification for Palliative Care. 2019.
<https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/OPCNTToolsToSupportEarlierIdentificationForPC.pdf>.
239. Central LHIN. Early Identification & Prognostic Indicator Guide: Guidance for clinicians to support earlier identification of patients nearing the end of life and who could benefit from a hospice palliative care approach. 2016.
<http://healthcareathome.ca/central/en/partner/Documents/Early%20ID%20PIG%20Guide%20Central%20version%20Jan%202016.pdf>.
240. Ministry of Health and Long-Term Care. Attendant Outreach Services: Policy Guidelines and Operational Standards. 1996.
241. World Health Organization. Active Ageing: A Policy Framework. Madrid, Spain: World Health Organization; 2002. <https://extranet.who.int/agefriendlyworld/wp-content/uploads/2014/06/WHO-Active-Ageing-Framework.pdf>.
242. Marks BA, Heller T. Bridging the equity gap: health promotion for adults with intellectual and developmental disabilities. *Nurs Clin North Am*. 2003;38:205–28.
243. Albertsson M, Albin B, Siwertsson C, Hjelm K. Consuming care and social services: comparisons between Swedish-born older people and older people born outside Sweden. *Practice*. 2004;16:99–110.
244. Peckham A, Williams AP, Neysmith S. Balancing formal and informal care for older persons: how case managers respond. *Can J Aging*. 2014;33:123–36.

245. Aoun S., O'Connor M., Skett K., Deas K., Smith J. Do models of care designed for terminally ill "home alone" people improve their end-of-life experience? A patient perspective. *Health Soc Care Community*. 2012;20:599–606.
246. Fortinsky RH, Madigan EA. Home care resource consumption and patient outcomes: what are the relationships? *Home Health Care Serv Q*. 1997;16:55–73.
247. Townsend J, Dyer S, Cooper J, Meade T, Piper M, Frank A. Emergency hospital admissions and readmissions of patients aged over 75 years and the effects of a community-based discharge scheme. *Health Trends*. 1992;24:136–9.
248. Washio M, Arai Y, Mori M. Factors related to the depression among family caregivers of older people with disabilities who used home health care services in the metropolitan city of Hokkaido, Northern Japan. *Int Med J*. 2014;21:263–7.
249. Weissert WG, Wan TTH, Livieratos BB, Pellegrino J. Cost-effectiveness of homemaker services for the chronically ill. *Inquiry*. 1980;17:230–43.
250. Wilson S, Eccleston M, Marks R, Isouard G. Evaluation of domiciliary services and hospital discharge for older people with chronic and complex conditions. *Geriatrics*. 2003;21:5–9.

APPENDIX A: LITERATURE REVIEW

A.1 Ovid Search Strategy

Selected resources: Ovid MEDLINE®, 1946 to Present; Embase, 1974 to Present
 Search date: November 16, 2017

Adapted from Hewko et al. [39]

Search terms	Results
1. home health aides/ OR homemaker services/ 2. ((unregistered OR unregulated OR unlicensed) ADJ (professional* OR worker* OR assistant* OR nurs*)).mp. 3. (care aide* OR care attendant* OR paid caregiver* OR professional caregiver* OR certified nursing assistant* OR client care attendant* OR direct care worker* OR geriatric health aide* OR health care assistant*).tw. 4. (personal care attendant* OR personal care nurse* OR personal care assistant* OR personal care aide* OR personal support worker* OR residential aide*).tw. 5. (health care assistant* OR health care aide* OR home support worker* OR home care worker* OR home health aide* OR resident care attendant* OR resident care worker* OR patient support assistant*).tw. 6. ((personal support OR personal care OR personal assistance OR home support) AND services).tw. 7. OR/1-6 8. limit 7 to (english language and yr="1980 -Current")	169,991
9. (home care OR community care OR community support or community services OR home health services OR home support services OR home services).tw. 10. (private home* OR retirement home* OR assisted living OR retirement communit* OR congregate care OR retirement village* OR senior apartment* OR personal care home* OR group home* OR independent living OR supported living OR supportive housing).tw. 11. OR/9-10	68,550
12. resource allocation/ OR health care rationing/ 13. *case management/ 14. Decision Support Systems, Clinical/ 15. (allocat* OR authoris* OR authoriz* OR utilis* OR utiliz* OR care plan* OR service plan*).tw. 16. OR/12-15	1,613,173

17. (outcome* OR adverse event* OR admission* OR admit* OR placement* OR dying OR died OR death OR mortality OR improv* OR benefit* OR chang* OR delay* OR reduc* OR increas* OR decreas*).tw.	24,860,381
18. 8 AND 11 AND (16 OR 17)	9,034
19. 18 use pmoz (MEDLINE)	561
20. 19 use oemez (Embase)	8,473
21. remove duplicates from 19	527
22. 20 OR 21	9,000

A.2 EBSCO Search Strategy

Selected resources: CINAHL, 1981 to Present

Search date: November 22, 2017

Search terms	Results
1. MH "Home Health Aides" OR MH "Homemaker Services" 2. (unregistered or unregulated or unlicensed) N1 (professional* or worker* or assistant* or nurs*) 3. care aide* OR care attendant* OR paid caregiver* OR professional caregiver* OR certified nursing assistant* OR client care attendant* OR direct care worker* OR geriatric health aide* OR health care assistant* 4. personal care attendant* OR personal care nurse* OR personal care assistant* OR personal care aide* OR personal support worker* OR residential aide* 5. (health care assistant* OR health care aide* OR home support worker* OR home care worker* OR home health aide* OR resident care attendant* OR resident care worker* OR patient support assistant* 6. (personal support OR personal care OR personal assistance OR home support) AND services 7. S1 OR S2 OR S3 OR S4 OR S5 OR S6 8. Limiters - English Language	6,903
9. home care OR community care OR community support or community services OR home health services OR home support services OR home services 10. private home* OR retirement home* OR assisted living OR retirement communit* OR congregate care OR retirement village* OR senior apartment* OR personal care home* OR group home* OR independent living OR supported living OR supportive housing 11. S9 OR S10	85,397
12. MH "Resource Allocation" OR MM "Health Resource Utilization" 13. MM "Case Management" 14. MM "Decision Support Systems, Clinical" 15. allocat* OR authoris* OR authoriz* OR utilis* OR utiliz* OR care plan* OR service plan* 16. S12 OR S13 OR S14 OR S15	219,369
17. outcome* OR adverse event* OR admission* OR admit* OR placement* OR dying OR died OR death OR mortality OR improv* OR benefit* OR chang* OR delay* OR reduc* OR increas* OR decreas*	1,319,648
18. S8 AND S11 AND (S16 OR S17)	1,960
19. Limiters - Exclude MEDLINE records	775

A.3 Studies Included in Review of Literature on the Determinants of PS/HM Service Allocation or Utilisation

Study details	Sample	Measurement of PS/HM use	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Albertsson et al., 2004 [243] Sweden	Age 55+ receiving public care and services and/or living in special housing for older people. Compare those born outside of Sweden vs. Swedish-born control group matched on age and sex, n=177	Person's case manager completing questionnaire about the person's service types 42.8% receiving personal care services, 60.8% receiving domestic services	% receiving PS/HM services <ul style="list-style-type: none"> Swedish-born 	Small sample size; age distribution of the persons born outside of Sweden differed from national census data; no information about amount of services
Baker & Bice, 1995 [125] Connecticut, USA	Age 65+ who are low-income and enrolled in Promotion of Independent Living program, n=1,778	Sum of Medicare, Medicaid, and PIL claims files over 18 months multiplied by averaged service costs 76.4% receiving PS/HM services	Cost of PS/HM services <ul style="list-style-type: none"> ✓ ADL impairment measuring using Katz Scale, β=\$2394.9** ✓ Bladder incontinence, β=\$655.0* ✓ Bowel incontinence, β=\$786.2* × Hospital stay in last year, β=\$-790.9** ● Age, marital status, living alone, IADL impairment 	Not generalisable beyond low-income older adults in one state; focused on new admissions
Beeber et al., 2008 [89] USA	Non-institutionalised age 65+ male American veterans with dementia and their primary family caregivers completing the first wave of the National Longitudinal Caregiver Study, n=1,813	Caregiver indicated the number of hours of in-home aide received on an average week 10.3% belonging in class 3 (74% probability of using PS/HM)	Likelihood of belonging in class 3, expressed as multinomial odds ratios <ul style="list-style-type: none"> ✓ Client age, OR=0.99** ✓ Caregiver education (years), OR =1.12** ✓ Number of SNFs in county, OR=1.13* ✓ ADL impairment, OR=1.35** ✓ Caregiver comorbidity, OR=1.09** ● Caregiver age, spousal relationship, ethnicity, financial adequacy, social network size, rurality ● Client insurance status, behavioural symptoms, comorbidity 	Not generalisable beyond older male veterans with dementia; women were excluded from the study; not every member of class 3 received PS/HM services; utilisation data based on caregiver self-report

Study details	Sample	Measurement of PS/HM use	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Blomgren et al., 2008 [90] Finland	Community-dwelling adults completing the Health 2000 health examination survey (home interview and health examination) in 2000–2001. Analysis restricted to age 70+, participated in home interview, and living in private homes, n=1,166	Respondent indicated if they received recurrent help in normal tasks because of limitations in functional capacity and source of help 11.6% receiving formal ADL help	Likelihood of receiving PS services <ul style="list-style-type: none"> ✓ Age 80–84, $\beta=4.18^*$; 85+, OR=3.05* ✓ Severe mobility limitations, OR=2.44* ✓ Moderate IADL limitations, OR=4.34*; High IADL limitations, OR=9.55* ✓ Receive less than weekly help, OR=3.03*; receive weekly help, OR=3.71*; receive daily help, OR=4.78* × Live with spouse, OR=0.35*; live with others not spouse, OR=0.11* ● Sex, ADL limitations, cognitive status, education, household income, rurality 	Small sample size; difficult to compare their measure of ADL and IADL limitations; skewed toward more cognitively intact individuals; no information about amount of help
Boniface & Denham, 1997 [91] North West Thames, UK	Randomly sampled community-dwelling age 65+ living in private homes recruited by mailed invitations and interviewed, 68% response rate, n=1,841	Respondent indicated if they used home help services at least once a week during the past month by the person 8.2% receiving home help services	% receiving PS/HM services <ul style="list-style-type: none"> ✓ Older age: 82% of age 85+ vs. 11% of age 75–84 vs. 3% of age 65–74 ✓ Poor health status: 17% of chronic disabled vs. 4% of chronic not disabled vs. 1% of no chronic condition Likelihood of receiving PS/HM services, adjusted for age and health status <ul style="list-style-type: none"> ✓ Poor mental state, OR=1.60* ✓ Living alone, OR=5.51*** ✓ Female, OR=2.04*** ✓ Income below £275, OR=10.38*** ✓ Visual impairment, OR=2.04** ✓ Musculoskeletal condition, OR=2.47** ● Income below £75, hearing impairment, respiratory condition, cardiovascular condition 	Not generalisable beyond geographic region; health status variable is broadly defined and does not account for degree of functional impairment; all data based on self-report; no information about amount of help; bivariate associations only

Study details	Sample	Measurement of PS/HM use	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Bull, 1994 [114] Midwest, USA	Age 55+ discharged from hospital for an acute episode of COPD, diabetes, or COPD, dependent in at least one ADL or IADL, cognitive competent, living at home prior to admission, and with a primary caregiver recruited from five community hospitals, 60% participation rate, n=185	Respondent indicated the number of hours of home health aide and housekeeping services received during the two weeks after hospital discharge Approximately 25% receiving home health aide/housekeeping services	Number of PS/HM hours <ul style="list-style-type: none"> ✓ Client age, F=15.5*** ✓ ADL impairment measured 1–2 days before hospital discharge, F=27.6*** ✓ Hours caregiver employed, F=20.2*** 	Small sample size; small number of independent variables investigated; utilisation data based on self-report for use at least two weeks prior Final model explains 20.3%
Carpenter et al., 2004 [115] Denmark, Finland, Iceland, Norway, Sweden, Czech Republic, France, Germany, Italy, Netherlands, UK	Randomly sampled from among persons age 65+ receiving formal home care services in each country, n=3,785	Agency personnel or research assistants completed a form about the days per week of service provision for each patient	Median PS/HM hours across 11 countries <ul style="list-style-type: none"> ✓ Degree of ADL impairment measured using ADL Hierarchy scale ranging 0 to 6 <ul style="list-style-type: none"> ○ No impairment, 1.9 ○ Some impairment, 2.8 ○ Moderate impairment, 3.8 ○ Severe impairment, 4.1 	Some countries systematically provided much less or much more PS/HM so median value may represent a subset of countries

Study details	Sample	Measurement of PS/HM use	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Corazzini-Gomez, 2002 [130] Massachusetts, US	Case managers employed by the Massachusetts Home Care Program completing a mail survey, 70% response rate, n=355	Case managers reviewed client vignettes and determined care plan eligibility relative to the average care home care plan, ranging from 0 (not at all eligible for services) to 4 (eligible for much more than the average care plan)	<p>Care plan eligibility level (treated as interval measure) → final model explained 18% variance</p> <ul style="list-style-type: none"> ✓ Married and spouse in poor health, $\beta=0.17^{***}$; Never married, $\beta=0.15^*$ ✓ Mobility ADL, $\beta=0.05^*$ ✓ Personal hygiene ADL, $\beta=0.12^{***}$ ✓ Cognitive impairment, $\beta=0.13^{**}$ ✓ Terminally ill, $\beta=0.20^{***}$ ✓ History of manic depression, $\beta=0.25^{**}$ ✓ Case manager is a social worker, $\beta=0.36^{**}$ × Concurrently receiving professional home care services, $\beta=-0.11^*$ × Client denies needing help, $\beta=-0.16^*$ ● Client age, sex, ethnicity, immigration status, attitude, neighbourhood income level, insurance status, any informal care ● Case manager age, sex, higher education, caseload size, job satisfaction 	Case managers have access to much richer and more complete information in reality than presented in vignettes; manipulation of client characteristics in the vignettes can be easily identified by case managers and can introduce social desirability bias

Study details	Sample	Measurement of PS/HM use	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Dellasega & Fisher, 2001 [116] Pennsylvania, USA	Age 65+, having either a cognitive (MMSE <24) or functional impairment (need help with at least 4 of 12 ADLs/IADLs, and was treated for an acute medical or surgical problem recruited from four community hospitals, 60% participation rate, n=70	Client indicated if received non-professional services and type of caregiver by telephone call within 24–48 hours and at two and four weeks after discharge Approximately 6% within 24–48 hours, 8% after two weeks, 4% after four weeks	Mean hours of PS/HM service <ul style="list-style-type: none"> • Highest during the immediate post-discharge period (4.0), declined slightly by two weeks (3.9), and increased slightly by four weeks (4.0)* 	Small sample size; utilisation data based on self-report
Diwan et al., 1997 [123] Georgia, USA	Age 55+ and Medicaid waiver eligible persons enrolled in Community Care Service Program, n=270	Prescription of monthly home health aide and personal care aide visits in care plan 62% receiving home health aide visits	Number of PS visits → final model explained 36% variance <ul style="list-style-type: none"> ✓ ADL limitations ranging from 5 to 15, $\beta=0.35^{**}$ ✓ Number of disease conditions ranging from 0 to 10, $\beta=0.23^*$ • Age, sex, ethnicity, household members, income, informal help, IADL limitations, county, number of HM visits, number of nursing visits 	Small sample size; not generalisable beyond Medicaid waiver clients; difficult to compare their measure of ADL and comorbidity; no information on length of visit
Edwardson & Nardone, 1990 [124] Oregon, USA	Consecutive home care admissions by three home health care agencies, n=150	Number of home health aide visits in agency records	Number of PS/HM visits <ul style="list-style-type: none"> ✓ Bathing/hygiene, $r=0.37^*$ ✓ Activity/mobility, $r=0.19^*$ × Number and complexity of medical/nursing procedures, $r=-0.12^*$ • Signs and symptoms 	Small sample size; dependent and independent variables not well described and cannot be compared to other studies; correlations only

Study details	Sample	Measurement of PS/HM use	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Eichler et al., 2016 [92] Germany	Age 70+, living at home, and screened positive for dementia by their GP across 93 GP practices, 54% participation rate, 81% follow-up rate, n=511	Client/caregiver indicated if used professional housekeeping assistance in the past 12 months 11.6% received professional housekeeping assistance	Likelihood of formal HM help, after adjustment for age, sex, cognitive and functional impairment, presence of informal caregiver <ul style="list-style-type: none"> • Living alone vs. living with others 	Small sample size; insignificant power to detect differences within living alone group; data often missing for persons with severe cognitive impairment
Ely et al., 1997 [93] Cambridge, UK	Age 75+ community-dwelling adults selected from GP register lists and completing the Hughes Hall Project for Later Life population survey, 93% response rate. Analysis restricted to women, n=1,585	Client indicated if received any visit by either home help or meals-on-wheels in the previous week 25% received domiciliary services	Likelihood of receiving PS/HM services, adjusted for age, co-residence, dependency <ul style="list-style-type: none"> ✓ Physical impairment (restricted mobility or severe visual disability), OR=1.8* × Cognitive impairment (MMSE<18), OR=0.7* 	Not generalisable beyond women living in geographic region; men were excluded from the study; independent variables do not consider degree of impairment
Emlet & Farkas, 2002 [117] California, USA	Persons with AIDS or symptomatic HIV enrolled in California's AIDS Case Management Program in 1995–1996 (Karnofsky Performance Score must be ≤70). Included all age 50+ and randomly sampled for individuals age 30–49, n=571	Mean number of hours of attendant care and homemaker services received per month in the client's program records	Mean monthly PS/HM hours → final model explains 33.7% variance <ul style="list-style-type: none"> × Living in metropolitan area (i.e., urban centre), $\beta=-25.3^{***}$ • Age, sex, ethnicity, living alone, heterosexual, men who have sex with men, injection drug user, poverty level, receiving Medicaid, AIDS diagnosis, Karnofsky Performance Score (functional status), died during the year under study 	Not generalisable beyond existing service users, non-symptomatic persons, or those with higher functioning

Study details	Sample	Measurement of PS/HM use	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Fogarty et al., 2014 [126] Dublin, Ireland	Age 18+ with a confirmed diagnosis of multiple sclerosis attending a specialist MS outpatient clinic in 2011–2012, unknown participation rate, n=214	Client indicated number of hours of home help received in the past week multiplied by median point on relevant salary scale plus overheads 22% received professional help at home	Mean annual cost of home help <ul style="list-style-type: none"> ✓ Disability measured by the Expanded Disability Status Scale ranging from 0 (normal neurological examination) to 10 (death from MS) <ul style="list-style-type: none"> ○ Mild (0–3.5), €147 ○ Moderate (4–6.5), €2,476 ○ Severe (7–9.5), €26,231 	Small sample size; not generalisable beyond geographic region; focused on those early in the disease course
Forbes et al., 2003 [94] Canada	Household residents age 18+ completing the 1998/99 wave of the National Population Health Survey representative of Canadian provinces (multi-stage sampling design stratified by age and province), 98.5% response rate. Analysis restricted to those receiving housework assistance, n=252 (out of 14,148 individuals)	Client indicated if received any housework services at home with the cost being entirely or partially covered by government in the past 12 months 41.7% receiving housework assistance	Likelihood of using PS/HM services <ul style="list-style-type: none"> ✓ Living alone, OR=2.08*** ✓ Restricted activities because of a long-term condition, OR=3.62** ✓ Need for help with normal everyday housework, OR=6.36*** ✓ Does not need help with personal care, OR=2.66* ✓ Recent hospitalisation, OR=2.56** ● Age, sex, education, income, chronic conditions, perceived health 	Small number of people receiving housework assistance despite large number of respondents to NHPS; could not stratify analyses by provinces despite substantial differences in home care programs; individuals receiving more than one type of home care service were excluded
Forbes et al., 2008 [95] Canada	Community-dwelling age 12+ completing the 2003 Canadian Community Health Survey representative of Canadian provinces and territories, 80.6% response rate. Analysis restricted to those reporting a diagnosis of dementia by a health professional, n=467	Client indicated if received publicly funded personal care and housework services in the past 12 months	% receiving publicly funded personal care <ul style="list-style-type: none"> ✓ Sex: female (54.9%) vs. male (38.3%)* % receiving publicly funded housework <ul style="list-style-type: none"> ✓ Sex: female (44.6%) vs. male (25.9%)* 	Small sample size; no information about the amount of services; missing information about social support and other health information

Study details	Sample	Measurement of PS/HM use	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Frederiks et al., 1991 [96] Maastricht, Netherlands	Randomly sampled community-dwelling age 55+ in Maastricht completing a postal questionnaire (73% response rate) and subsequent interview (71% response rate). Analysis restricted to age 75+, n=423	Client indicated if received non-professional home care services (unknown time period)	Receipt of professional vs. non-professional services <ul style="list-style-type: none"> ✓ IADL performance, F=25.7*** ● Age, depressive complaints 	Small sample size; dependent and independent variables not well described and cannot be compared to other studies; small number of independent variables investigated
Freedman et al., 2004 [122] USA	Non-institutionalised persons born in 1923 or earlier identified from a 1992 household survey and Medicare enrolment files (i.e., AHEAD cohort) and completing three waves of interviews, 80.4% response rate for wave 1, 36.4% lost to follow-up by wave 3. Analysis restricted to unmarried in all waves, reported at least one ADL/IADL impairment in wave 2, and not living in an institution in waves 2 or 3, n=746	Client indicated number of days per week of help with ADL, IADL, and money management activities, average hours per day per caregiver, and whether the caregiver was paid	Change in hours of paid PS/HM help between 1995 (wave 2) and 1998 (wave 3) <ul style="list-style-type: none"> ✓ More than high school education, $\beta=96.8^*$ ✓ High income, $\beta=229.5^*$ ✓ Number of ADL limitations at baseline, $\beta=46.6^{**}$ ✓ Number of IADL limitations at baseline, $\beta=70.2$ ✓ More ADL limitations in wave 3 <ul style="list-style-type: none"> ○ +1 limitations, $\beta=141.6^*$ ○ +2 limitations, $\beta=195.5^{**}$ ✓ More IADL limitations in wave 3 <ul style="list-style-type: none"> ○ +2 limitations, $\beta=190.1^{**}$ ● Age, sex, ethnicity, high wealth, family structure, fewer ADL/IADL limitations 	Independent variables do not consider degree or type of impairment; unclear whether respondents were supposed to report limitations with or without help or equipment; one-third of original sample was lost to follow-up
Gure et al., 2008 [118] USA	Non-institutionalised persons born in 1947 or earlier identified from a 1992 household survey and Medicare enrolment files and their spouses/partners (i.e., HRS cohort) and completing the 2000 wave, 82% response rate. Analysis restricted to age 65+ and not living in a nursing home, n=11,093	Respondent indicated if received in-home care provided by a paid non-relative or someone with an organisational affiliation in the past two years and the average weekly hours	Hours of formal PS/HM services <ul style="list-style-type: none"> ✓ Heart disease category after adjustment for age, sex, ethnicity, education, living arrangement, net worth, incontinence, blood pressure, 9 diagnoses/conditions, and nursing home and hospital admission <ul style="list-style-type: none"> ○ CHF, $\beta=1.3$ ○ CHD and no CHF, $\beta=0.9$ ○ No CHD, $\beta=0.7$ 	Lower than expected CHF prevalence suggests self-report method under-reported CHF; limited information about health status beyond diagnoses

Study details	Sample	Measurement of PS/HM use	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Hammar et al., 2008 [66] Finland	Home care clients age 65+, living at home, regularly receiving home care services, and had an inpatient hospital stay in the last six months who were randomly selected for interviews, 86% response rate, n=721	Client indicated the number and length (hours) of home help visits during the previous week 67.1% receiving home help services	Likelihood of receiving PS/HM services <ul style="list-style-type: none"> ✓ Older age (years), OR=1.04** ✓ Did not receive informal care in the previous week, OR=2.56** ✓ Received home nursing in the previous week, OR=2.37*** × Living with others, OR=0.43** × Received meals-on-wheels in the previous week, OR=0.35*** × Moderate/good coping ability in daily life (combination of ADL and IADL scales), OR=0.55** × Did not need help with ADL, OR=0.52* × Did not need help with psychosocial well-being, OR=0.52** ● Sex, education, number of diagnoses, number of drugs, self-perceived health, need for help with IADL, need with help with caring for illnesses, need for help with relieving pain, need for help with getting rest, need for help with social/environment 	Not generalisable beyond geographic region and patient population; persons with cognitive impairment, dementia, acute psychiatric or cancer diagnoses were excluded; insufficient detail about collection of PS/HM measure

Study details	Sample	Measurement of PS/HM use	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Hasche et al., 2013 [97] USA	New clients age 60+, English-speaking, and their own legal guardians receiving community long-term care services between 2000 and 2003, 65% response rate and 84% consented. Interviewed all clients meeting depression criteria and random sample of non-depressed clients, 87% participation rate, n=533	Type of service and amount of hours per month that were ordered were abstracted from each client's log of services 73.0% ordered PS services, 73.4% ordered HM services	Likelihood of ordering PS services <ul style="list-style-type: none"> ✓ Number of physical health problems, OR=1.22* × Cognitive impairment, OR=0.93* × Caucasian ethnicity, OR=0.40* ● Age, sex, rurality, living alone, instrumental support, level of care, number of medications, depressed Likelihood of ordering HM services <ul style="list-style-type: none"> ✓ Older age (years), OR=1.10** × Urban, OR=0.31** × Number of medications, OR=1.08* ● Sex, ethnicity, living alone, instrumental support, physical health, level of care, cognitive impairment, depressed 	Small sample size; not generalisable beyond geographic region; limited number of need variables investigated and mostly recorded as a count or presence/absence

Study details	Sample	Measurement of PS/HM use	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Hawranik, 1998 [98] Manitoba, Canada	Randomly sampled age 65+ from those registered with Manitoba Health (provincial health insurance program for all permanent members of the province, with oversampling in the older age groups, and their caregiver (i.e., Manitoba Study on Health and Aging-1 cohort). Included all those who completed the screening interview, clinical assessment, and caregiver survey, n=380	Caregiver indicated whether the client or themselves used personal care services or homemaking/cleaning services in the past year 16.9% using PS services, 36.3% using HM services	Likelihood of using PS services <ul style="list-style-type: none"> ✓ Dementia, $\beta=1.44^*$ ✓ Client-perceived ADL limitations, $\beta=4.03^{**}$ ✓ Caregiver burden, $\beta=0.10^{**}$ ✓ Caregiver internal locus of control, $\beta=0.17^*$ × Co-reside with caregiver, $\beta=-2.54^{**}$ × Self-rated health, $\beta=-2.26^*$ × Caregiver is employed, $\beta=-1.10^*$ ● Age, sex, marital status, education, client locus of control, depression, client-perceived IADL limitations, caregiver-perceived ADL/IADL limitations, number of caregiver health problems, caregiver depression, household income Likelihood of using HM services <ul style="list-style-type: none"> ✓ Client age, $\beta=0.06^{**}$ ✓ Client-perceived ADL limitations, $\beta=1.23^{**}$ ✓ Client-perceived IADL limitations, $\beta=0.86^*$ ✓ Number of caregiver health problems, $\beta=0.20^{**}$ ✓ Co-reside with caregiver, $\beta=-0.85^*$ ● Caregiver age, sex, marital status, education, locus of control, cognitive status, depression, caregiver-perceived ADL/IADL limitations, caregiver burden, caregiver depression, household income, caregiver is employed 	Small sample size; independent variables do not consider degree of impairment

Study details	Sample	Measurement of PS/HM use	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
<p>Hawranik & Strain, 2001 [99]</p> <p>Manitoba, Canada</p>	<p>Randomly sampled age 65+ from those registered with Manitoba Health (provincial health insurance program for all permanent members of the province, with oversampling in the older age groups, and their caregiver (i.e., Manitoba Study on Health and Aging-1 cohort). Included all those who completed the screening interview, clinical assessment, and caregiver survey. Analysis restricted to client-caregiver dyads where the client was living in the community, client was diagnosed with dementia or cognitive impairment during the clinical assessment, and the caregiver answered questions on disruptive behaviors, n=124</p>	<p>Caregiver indicated whether the client or themselves used personal care services or homemaking/cleaning services in the past year</p> <p>27% using PS services, 50% using HM services</p>	<p>Likelihood of using PS services</p> <ul style="list-style-type: none"> ✓ ADL/IADL limitations, OR=1.32** ✓ Bladder incontinence, OR=9.52* ✓ Sleeps excessively during the day, OR=3.76* × Co-reside with caregiver, OR=0.11* ● Age, caregiver sex, dementia diagnosis, lack of interest in daily activities, dresses inappropriately, refuses to be helped with personal care tasks <p>Likelihood of using HM services</p> <ul style="list-style-type: none"> ✓ Age (years), OR=1.10* ✓ ADL/IADL limitations, OR=1.17* × Co-reside with caregiver, OR=0.12** ● Caregiver sex, dementia diagnosis, loses/misplaces/hides things, asks the same question over and over again 	<p>Small sample size; dementia and cognitive impairment may be under-detected in the general population; independent variables do not consider degree of impairment</p>
<p>Hays & Willborn, 1996 [100]</p> <p>Nebraska, USA</p>	<p>Randomly selected clients who were discharged during a six-month period and received at least two nursing visits through a single home health agency, n=237</p>	<p>Client's use of home health aide care was determined from the agency's files</p> <p>27.6% in nursing and HHA group</p>	<p>Mean differences, clients receiving both nursing and HHA care vs. nursing only</p> <ul style="list-style-type: none"> ✓ Client age: 75.8 vs. 66.0* ✓ Nursing care intensity: 26.1 vs. 24.8* ✓ Hours of direct nursing care: 10.8 vs. 7.5* ✓ Length of stay: 92.5 vs. 51.8* ● Number of nursing diagnoses 	<p>Small sample size; not generalisable beyond single agency; focuses on clients who require nursing services</p>

Study details	Sample	Measurement of PS/HM use	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Hoeck et al., 2012 [101] Belgium	Pooled data from the 2001 and 2004 Belgium Health Interview Survey that is a nationally representative sample of the Belgian population (multi-stage sampling design stratified by age, household size, province). Analysis restricted to age 65+, living at home, and completed the survey without a proxy respondent, n=4,777	Client indicated if made at least one appeal to home help during the past 12 months 16.4% using PS/HM services	Likelihood of using PS/HM services <ul style="list-style-type: none"> ✓ Frailty status (ref=robust) after adjusting for age, sex, comorbidity, living situation, region, SES <ul style="list-style-type: none"> ○ Frail, OR=3.97*** ○ Pre-frail, OR=2.51*** 	Independent and dependent variables were too simple to capture amount of services or degree of impairment beyond frailty
Hoell et al., 2016 [119] Germany	Baseline and follow-up data of a multi-centre prospective cohort study: age 75+, regular patients of participating GPs, visited their GP at least once in past six months, not end-of-life, not moderately or severely cognitively impaired, and capable to consent. Included all participants who screened positive for depression and a randomly selected participant without depression (i.e., AgeMooDe cohort). Unknown response rate, 97% follow-up rate, n=955	Client indicated the number of days of visits per or per month and the average amount of time (in minutes or hours) of paid domestic help received in the last six months 18.0% using paid domestic help	Hours of paid domestic help <ul style="list-style-type: none"> ✓ Age at baseline (years), $\beta=2.0^{**}$ ✓ IADL impairment, $\beta=8.4^{**}$ ✓ Depression (GDS ≥ 6), $\beta=8.2^*$ × Low education, $\beta=-7.3^*$ ● Sex, marital status, living alone, cognitive impairment, 4+ comorbid conditions, follow-up time 	Low participation rate of persons with depression, suggesting that results may not be generalisable to all persons with depression; may be difficult to recall health service utilisation up to six months prior

Study details	Sample	Measurement of PS/HM use	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Kitchen et al., 2011 [102] Ontario, Canada	Pooled data from the Canadian Community Health Survey Cycle 3.1 (2005) and 4.1 (2007) for which participants were selected using a multi-stage sampling design stratified by age and province. Analysis restricted to age 20+ and living in Ontario, n=46,862	Respondent indicated if received any personal care services at home with the cost being entirely or partially covered by government in the past 12 months 15.0% using government-funded PS services	% receiving government-funded PS services ✓ Proximity to urban area (Metropolitan Influence Zone (MIZ)) ○ CMA/CA (most urban), 12.0% ○ Strong MIZ, 20.8% ○ Moderate MIZ, 20.2% ○ Weak or no MIZ (most rural), 12.0%	No information about the amount of services
Lévesque et al., 2001 [103] Quebec, Canada	Convenience sample of French-speaking primary caregivers from urban centres in Quebec cohabiting with a relative with dementia and recruited from local organisations, 89% participation rate, n=265	Caregiver indicated whether the home help services (i.e., PS/HM) or attendant care services (i.e., respite) were currently used 46% using PS/HM services, 46% using respite services	Likelihood of using PS/HM services ✓ Caregiver age 70+, OR=4.20* ✓ Frequency of dysfunctional behaviours, (upper tercile), OR=3.54* ✓ High distress × low ADL impairment, OR=2.50* Likelihood of using respite services ✓ Frequency of dysfunctional behaviours (upper tercile), OR=2.90* ✓ Caregiver disturbance from ADL impairments (upper tercile), OR=2.40* ✓ High distress × low ADL impairment, OR=2.10* Likelihood of perceiving barrier to using respite services ✓ Low informal support × high ADL impairment, OR=12.00*	Small sample size; not generalisable beyond geographic area (urban); no information about the amount of service

Study details	Sample	Measurement of PS/HM use	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Liu et al., 1990 [127] USA	Data from the National Long-Term Care Channeling Demonstration Project for which enrollment was referred from a formal provider organisation or self-referred, and the individual must have at least moderate ADL impairment or severe IADL impairment, n=3,274	Client indicated hours of PS/HM services received at fixed interview intervals (e.g., six months)	Daily cost of PS/HM services → final model explained 24.5% variance <ul style="list-style-type: none"> ✓ Age 85+, $\beta=2.35^*$ ✓ Living alone, $\beta=1.23^*$ ✓ Income \leq\$1000, $\beta=1.22^*$ ✓ ADL impairment <ul style="list-style-type: none"> ○ 1 ADL, $\beta=1.94^*$ ○ 2 ADLs, $\beta=3.41^*$ ○ 3-4 ADLs, $\beta=3.96^*$ ○ 5-6 ADLs, $\beta=6.38^*$ ✓ Moderate or severe cognitive impairment based on SPMSQ test, $\beta=1.26^*$ ✓ Number of nursing home beds at site relative to national rate, $\beta=3.06^*$ × Male, $\beta=-2.08^*$ × Paralysis, $\beta=-2.48^*$ ● Marital status, ethnicity, Medicaid recipient, cancer, stroke 	May be difficult to recall health service utilisation up to six months prior; persons with more mild ADL impairment were excluded

Study details	Sample	Measurement of PS/HM use	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Mery et al., 2016 [104] Canada	Community-dwelling age 65+ residing in a Canadian province for at least one year during the study time frame that were part of National Population Health Survey from 1994/95 to 2010/11, including those with incomplete follow-up information or who died. Respondents were observed in three waves on average, n=7,255	Respondent indicated if received publicly funded PS/HM services (unknown time period) 7.9% receiving PS/HM services	Likelihood of receiving PS/HM services <ul style="list-style-type: none"> ✓ Age (years), OR=1.11*** ✓ Male, OR=1.87* ✓ Receiving home health care, OR=13.71*** ✓ ADL dependence: high (OR=36.39)***, middle (OR=13.39)***, low (OR=3.87)*** ✓ Any chronic disability, OR=1.55*** × High income, OR=0.54** × Living with other adult, OR=0.40* × Immigrant, OR=0.55* × Province (ref=ON): NF (OR=0.21)*, QC (OR=0.43)** ● Education, living with partner, ethnic minority, urban, 3+ chronic conditions, diabetes, heart disease, stroke, arthritis, emphysema, incontinence, dementia 	No information about the amount of services; independent variables do not cover caregiver items

Study details	Sample	Measurement of PS/HM use	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Murphy et al., 2015 [65] Ireland	Age 50+ living at a residential address in Ireland who were randomly sampled (stratified by SES and geography) from the Irish Geodirectory and completed a personal interview as part of the first wave of the Irish Longitudinal Study on Ageing (i.e., TILDA cohort). Analysis restricted to age 65+, n=3,507	Respondent indicated if had received publicly financed formal home help (i.e., domestic help) or personal care services in the last 12 months, excluding any services for which they had paid anything, other than a nominal amount 1.2% receiving PS services, 7.5% receiving HM services	Likelihood of receiving PS/HM services, among clients with a disability → final model explained 17.6% variance <ul style="list-style-type: none"> ✓ Age ≥75, OR=1.7* ✓ Female, OR=1.7* ✓ Living alone (ref=lives with spouse/partner), OR=3.5** ✓ Number of IADL difficulties, OR=1.5** ● Domestic help, self-reported health, hospital stay, depressive symptoms, pain, polypharmacy Likelihood of receiving PS/HM services, among clients without a disability → final model explained 24.2% variance <ul style="list-style-type: none"> ✓ Age ≥75, OR=7.2** ✓ Living alone (ref=lives with spouse/partner), OR=2.4** ✓ Domestic help, OR=3.0** ✓ Fair/poor self-rated health, OR=2.1* ✓ Admitted to hospital in last year, OR=1.8* ✓ Severe depressive symptoms, OR=2.3* ✓ Pain limits activity, OR=2.3** ✓ Polypharmacy, OR=1.8* ● Sex, number of ADL difficulties, number of IADL difficulties 	No information about the amount of services; independent variables do not cover caregiver items or degree of difficulty

Study details	Sample	Measurement of PS/HM use	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Otero et al., 2003 [129] Madrid, Spain	Community-dwelling age 65+ persons completing the 1993 baseline sample of the Aging in Leganés longitudinal study who were selected by the town register (sampling stratified by age and sex) and is representative of municipal older adult population. 73.4% participation rate in the two in-home interviews at baseline, n=189 with unmet daily needs and n=507 with unmet weekly needs	Presence of unmet daily needs was defined as the respondent indicating they either “did not have anybody to help them” or “receives insufficient help” with daily activities (ADLs), weekly activities (bathing and IADLs), and monthly (heavy housework, transport, managing budget) activities 32% with unmet daily needs, 22% with unmet weekly needs	Likelihood of reporting unmet daily needs <ul style="list-style-type: none"> ✓ Low income, OR=3.95* ✓ Living arrangement (ref=live with spouse): live alone, OR=5.53* × Depression (ref=no): yes, OR=0.21*; not assessed, OR=0.20* ● Age, education, self-rated health, sources of help Likelihood of reporting unmet weekly needs <ul style="list-style-type: none"> ✓ Age ≥75, OR=1.69* ✓ Low income, OR=1.92* × Less than primary education, OR=0.25* × Depression (ref=no): not assessed, OR=0.47* ● Age, depression, self-rated health, living arrangement 	Small sample size, low formal care (9%) use and high unmet daily needs (40%) suggest limited generalisability beyond geographic region; self-reported measures may have excluded persons with higher degree of cognitive impairment

Study details	Sample	Measurement of PS/HM use	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Peckham et al., 2014 [244] Ontario, Canada	Individuals on a long-term care waitlist were grouped into 36 sub-groups based on cognition, ADL status, IADL status, and presence of an informal caregiver in the home. Based on RAI-HC data, researchers wrote detailed vignettes for a typical individual in each sub-group. “Expert panel” of 16 case managers constructed a home and community care service package for each case.	Expert panel’s recommended frequency and duration of PS/HM services for each case	<p>Comparing two cases who were both described to be cognitively intact and require little ADL/IADL support, but differed on having co-residing informal caregiver</p> <ul style="list-style-type: none"> ✓ Without live-in caregiver: 2 hours 3 times a week of PS/HM, 2 times a month of home maintenance × With live-in caregiver: 2 hours 2 times a week of PS/HM <p>Comparing two cases who were both described to be cognitively impaired and require completely dependent in ADLs/IADLs, but differed on having co-residing informal caregiver</p> <ul style="list-style-type: none"> ✓ Without live-in caregiver: 24 hour supervision by PSW, 2 times a month of home maintenance, 2 times a month of home maintenance × With live-in caregiver: 3 hours per week of PS, 4 weeks per year of short-stay respite 	Case managers have access to much richer and more complete information in reality than presented in vignettes; manipulation of client characteristics in the vignettes can be easily identified by case managers and can introduce social desirability bias; group decisions may not reflect individual decisions in the real world; economical feasibility was not in scope

Study details	Sample	Measurement of PS/HM use	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
<p>Pedlar & Biegel, 1999 [105]</p> <p>Ontario, Canada</p>	<p>Community-dwelling wives who are primary caregivers for and living with their husband care recipients who had been diagnosed with dementia in a large urban area. Recruited based on client records with Veterans Affairs Canada, a community memory clinic, and an Alzheimer's support group, 86% participation rate, n=82</p>	<p>Caregiver indicated if had received PS, HM, or respite services provided by a community agency or paid helper in the past four weeks</p> <p>39% using PS services, 50% using HM services</p>	<p>Likelihood of using PS services → final model explained 44% variance</p> <ul style="list-style-type: none"> ✓ Physical function, OR=1.44** ✓ Caregiver burden, OR=1.22* × Cognitive impairment, OR=0.74* ● Age, behavioural disturbance, caregiver physical function, caregiver preferring to provide care, service trust, service confidence <p>Likelihood of using HM services → final model explained 36% variance</p> <ul style="list-style-type: none"> ✓ Physical function, OR=1.14* ✓ Caregiver physical function, OR=1.41** ✓ Caregiver preference to provide care, OR=0.66* ✓ Service trust, OR=1.71* × Behavioural disturbance, OR=0.73* × Service confidence, OR=0.52* ● Age, cognitive impairment, caregiver burden 	<p>Small sample size; not generalisable beyond geographic region; clients without dementia and different client-caregiver relations were excluded</p>

Study details	Sample	Measurement of PS/HM use	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Penning, 1995 [106] Canada	Community-dwelling sample of the Canadian Study of Health and Aging that represents Canadians age 65+ living in the Canadian provinces. Potential respondents were drawn from public insurance plans or enumeration records in 36 cities/areas, stratified by age. Analysis restricted to dementia diagnosis and their caregivers, n=327	Caregiver indicated whether a homemaking/cleaning/personal care service had been used in the care recipient's household during the past year 20% using PS services, 38% using HM services	Likelihood of using PS services <ul style="list-style-type: none"> ✓ Caregiver is spouse, $\beta=1.56^*$ ✓ Caregiver is child, $\beta=1.15^*$ ✓ Non-urban, $\beta=1.52^*$ ✓ Living alone, $\beta=1.51^*$ ✓ Number of ADL limitations, $\beta=0.46^*$ ● Age, sex, education, caregiver work status, number of caregivers, IADL limitations, cognitive impairment, number of chronic conditions, client perceived health, caregiver perceived health, caregiver burden (based on Zarit Burden Scale) Likelihood of using HM services <ul style="list-style-type: none"> ✓ Years of education, $\beta=0.09^*$ ✓ Living alone, $\beta=1.87^{**}$ ✓ Caregiver perceived health, $\beta=0.79^{**}$ × Cognitive impairment (≤ 77 on Modified MMSE), $\beta=-0.03^*$ ● Age, sex, caregiver work status, client-caregiver relationship, urban, number of caregivers, ADL/IADL limitations, number of chronic conditions, client perceived health, caregiver burden 	Small sample size; focused on older adults with dementia living in relatively urban areas; study does not consider amount of service utilisation or degree of impairment; difficult to generalise findings due to differences in how provinces fund and provide community services

Study details	Sample	Measurement of PS/HM use	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Ranhoff & Laake, 1995 [107] Norway	Representative sample of the community-dwelling general Norwegian population completing the Norwegian National Health Survey in 1985, 78.8% response rate. Analysis restricted to age 65+, n=2,111	Respondent indicated if had received home help services (does not include homemaker services) (unknown time period) 8.8% receiving home help	Likelihood of receiving home help <ul style="list-style-type: none"> ✓ Age (10-year unit), OR=2.1 ✓ Living alone, OR=3.5 ✓ Chronic health problem(s), OR=3.7 ✓ Poor perceived health, OR=1.4 ✓ Difficulties in doing housework, OR=7.3 ✓ Difficulties in using public transportation, OR=2.5 × Difficulties with hearing normal speech, OR=0.5 ● Sex, depressive symptoms, anxiety 	May have had insufficient power to detect associations with less common health status variables; self-reported measures may under-represent persons with cognitive impairment
Remler et al., 2011 [108] New York, USA	Age 55+ living in a federally designated medically under-served area or health professional shortage area within New York state (i.e., too few primary care providers, high infant mortality, high poverty, and/or large older adult population), have Medicare coverage, have diabetes, and have no severe cognitive or physical impairment who completed the IDEATel baseline survey, n=1,514	Respondent indicated average hours of care received by each type of care and by type of provider in the last three months 7.8% receiving personal care aide services, 5.7% receiving home health aide services	% use of any personal care aide <ul style="list-style-type: none"> ✓ Urban (15.5%) vs. non-urban (1.2%)* % use of any home health aide <ul style="list-style-type: none"> ✓ Urban (7.8%) vs. non-urban (3.9%)** Weekly hours of help with personal care <ul style="list-style-type: none"> ✓ Urban (0.7) vs. non-urban (0.4)* Weekly hours of help with housework <ul style="list-style-type: none"> × Urban (4.4) vs. non-urban (7.1)** Weekly hours of help with meal prep <ul style="list-style-type: none"> × Urban (4.0) vs. non-urban (5.2)** 	Not generalisable to the general medically under-served population; utilisation data based on self-report for use at least three months prior

Study details	Sample	Measurement of PS/HM use	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Roelands et al., 2003 [109] Belgium	Pooled samples: 1) Follow-up wave of the Epidemiologic Research on Dementia (age 65+ and living in select municipalities in Flanders, stratified sampling by sex and age (males and older individuals were oversampled)) who were alive after three years, 28% loss to follow-up, 78% response rate. 2) Additional sample following the same sampling design in same municipalities, 80% response rate. Analysis restricted to community-dwelling individuals, n=1,134	Respondent/proxy indicated the frequency they had received any home help services during the past month ("not at all" = no, all other categories = yes) 6.0% using home help services	Likelihood of using home help services, adjusting for age, sex, and education <ul style="list-style-type: none"> ✓ Depressive mood based on CGS-D ≥ 15, OR=1.29* ✓ Living with others (ref=living alone), OR=1.71* ● Cognitive impairment based on MMSE ≤ 24 	Individuals participating in the second wave may generally more robust than the baseline cohort; small number of independent variables investigated; data about the frequency of service use was collected but not used
Scharlach et al., 2007 [110] California, USA	Caregivers age 50+ residing in California who were selected by random digit dialing, 19% response rate. Analysis excluded caregivers who were employed part-time, n=1,183	Caregiver indicated whether the care recipient received any assistance with each of 5 ADLs and whether this assistance came from the caregiver, family or friends, or paid providers 33.5% receiving ADL help from paid carers	Likelihood of paid carers providing ADL help <ul style="list-style-type: none"> ✓ Age, OR=1.77** ✓ Caregiver is employed, OR=2.34* × Non-white, OR=0.44** × Primary caregiver, OR=0.32** × Caregiver is spouse/partner, OR=0.41* × Co-residing with caregiver, OR=0.60* × Medical needs, OR=0.41* ● Caregiver sex, caregiver education, caregiver health status, caregiver has children, client sex, personal care needs 	Caregivers working part-time were excluded; all data based on self-report; data about frequency of help was collected but not used

Study details	Sample	Measurement of PS/HM use	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Seow et al., 2010 [120] Ontario, Canada	Patients who were admitted for end-of-life home care in 2005/06 and died on or before March 2007 in 41 CCAC regions in Ontario. Excluded patients who were admitted to home care more than six months prior to death, or died before home care admission, n=9,368	Service records including types and amounts of services, and service and admission dates were used to calculate the average PS/HM hours per week for the last 12 weeks of life or from admission date, whichever was shortest	Weekly PS/HM hours <ul style="list-style-type: none"> ✓ Weeks from death: “steady from 12 to four week before death and increased usage in the last month of life” ✓ Period of home care admission <ul style="list-style-type: none"> ○ Apr–Sep 2005 (pre-implementation), 3.5 ○ Oct 2005–Mar 2006, 3.9* ○ Apr–Sep 2006, 3.8 	Utilisation does not include privately purchased services
Sun et al., 2007 [111] Alabama, USA	Family caregivers of care recipients with dementia living in 45 rural counties in Alabama selected by random digit dialing, n=141	Caregiver indicated if used any home health aide services or homemaker services in the last month 32.6% receiving help from home health aide, 24.8% receiving help from homemaker	Likelihood of receiving PS services <ul style="list-style-type: none"> ✓ Functional ability based on combined ADL/IADL scale, OR=1.31* ✓ Cognitive impairment based on DSRS, OR=1.05* ● Age, education, income adequacy, employment, physical/emotional health, behavioural problems, caregiver providing care to second person Likelihood of receiving HM services <ul style="list-style-type: none"> ✓ Caregiver providing care to second person, OR=1.21* ● Age, education, income adequacy, employment, ADL/IADL difficulty, cognitive impairment, physical/emotional health, behavioural problems 	Small sample size that limited number of independent variables; not generalisable beyond geographic location

Study details	Sample	Measurement of PS/HM use	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Svensson & Fajutrao, 2014 [128] Sweden	Persons who were members of the Swedish Organization for Patients with Neurological Diseases and had multiple sclerosis and completed a mailed survey within one month, 56% response rate, n=1,500	Respondents indicated the number of hours of publicly funded home help services and/or personal assistance services for MS-related care in the last month and multiplied by 2010 unit cost 27% received municipal home help and/or personal assistance services	Cost of formal PS/HM services → final model explained 43.4% variance <ul style="list-style-type: none"> ✓ Severe MS symptoms (ref=mild), $\beta=5.39^*$ ✓ Years since MS diagnosis, $\beta=0.09^*$ × Living with others (ref=living alone), $\beta=-1.57^*$ ● Age and sex 	Unable to compare this sample to determine the representativeness of the Swedish population with MS; utilisation data based on self-report for use in the last month
von Granitz et al., 2017 [121] Sweden	Swedish persons entitled to personal assistance allowance in 2010 (no minimum age; have intellectual disability, physical disability, and/or special needs) and completed a questionnaire, 67% response rate (equivalent to 67% of all eligible persons), n=10,201	Personal assistance defined as help with activities that the user would have done her/himself, if it were not for physical, mental, or intellectual limitations, that cover a range of ADL, IADL, and social functioning needs Measurement not explained	Mean PS/HM hours in Health and Care category (ADL component) <ul style="list-style-type: none"> ✓ Age ≤ 19 (13.2) vs. age >19 (12.7)* ✓ Type of eligibility <ul style="list-style-type: none"> ○ Special needs, 12.5 ○ Intellectual disability, 13.3* ○ Physical disability, 13.3* ● Gender 	Collection of dependent variable not explained; limited number of need variables investigated; bivariate associations only

Study details	Sample	Measurement of PS/HM use	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Wang et al., 1999 [112] New South Wales, Australia	Residents of a defined area west of Sydney who underwent an eye exam and interview as part of the Blue Mountains Eye Study, 87.9% response rate. Analysis restricted to age 50+ and used any home help/home nursing/meals on wheels services, n=186	Respondent indicated if regularly use home help services (excluding hired help from house cleaning or shopping) 79.0% regularly use home help services	Likelihood of using PS services <ul style="list-style-type: none"> ✓ Female, OR=1.6 ✓ Not married, OR=2.0 ✓ Own home, OR=2.2 ✓ Living alone, OR=2.2 ✓ Low perceived health, OR=3.1 ✓ 2+ hospital admissions, OR=2.5 ✓ Any falls in last year, OR=2.4 ✓ Walking disability, OR=5.6 ✓ Visual impairment, OR=2.6 ✓ Angina history, OR=2.0 ✓ Stroke history, OR=2.5 ✓ Arthritis history, OR=2.1 ✓ Cancer history, OR=2.1 ● Education, job prestige, obesity, hearing problem, other diagnoses 	Small sample size; not generalisable beyond geographic region; bivariate associations only
Zhu et al., 2008 [113] USA	Patients meeting criteria for dementia or probable dementia and having a modified MMSE score ≥ 30 at three academic AD centres were recruited and completed semi-annual visits (i.e., Predictors 2 cohort). Analysis restricted to observations when the patient was not in an institutional setting, n=170	Patient/informant indicated the number of days received of home health care, average hours per day, and out-of-pocket hourly cost in the last three months, and this was used to calculate total out-of-pocket cost of home health services 18.6% receiving home health services	Likelihood of receiving PS/HM services <ul style="list-style-type: none"> ✓ Female, $\beta=0.52^*$ ✓ Functional status based Blessed Dementia Rating Scale, $\beta=0.25^*$ ✓ Depressive symptoms, $\beta=0.47^*$ × Living with spouse (ref=living with others), $\beta=-0.66^*$ ● Age, cognitive impairment, number of comorbidities, behavioural problems, extrapyramidal signs, psychotic symptoms 	Small sample size; sample was predominantly white, highly educated, and most likely at early stages of dementia; utilisation data based on self-report for use three months prior

A.4 Studies Included in Review of Literature on the Outcomes of PS/HM Service Allocation or Utilisation

Study details	Sample	DV/IV Measurement	Analysis	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Albert et al., 2005 [135] New York, USA	Community-dwelling Medicaid-eligible participants age 65+ in the Washington Heights–Inwood Columbia Aging Project that began in 1992 and were reassessed between 1994–1996, n=617	IV: receipt of Medicaid Home Care Services Program (i.e., PS and/or HM services); weekly hours DV: mortality determined from follow-up interviews every 1.5 years and National Death Index records	Proportional hazards model, adjusted for sociodemographic, medical, and functional status	<ul style="list-style-type: none"> ✓ Mortality (clients with ADL disability only) and receipt of any PS/HM, HR=0.59 (0.40–0.89)* ✓ Mortality (clients with ADL disability only) and median hours per week (0, 1–19, 20+), HR=0.75 (95% CI: 0.59–0.95)* ● Mortality (clients with ADL disability only) and median hours per week (continuous) ● Mortality (all clients) 	Small sample size; some contamination of treatment effect because attendant care is integrated with regular registered nurse visits; majority of control variables were based on presence/absence or count
Aoun et al., 2012 [245] Western Australia	Palliative care patients receiving home-based care, living at home alone with no caregiver, and not cognitively impaired recruited from a single hospital. Interviewed care-aide group who received extra 10 hours/month, n=26	Participants were asked about the effect of having a care aide on physical, social, and/or emotional support needs	Line-by-line reading, constant comparison	<ul style="list-style-type: none"> ✓ Ease the burden of everyday living ✓ Support well-being and enhance self-worth and confidence ✓ Enhance quality of life and preserve dignity ✓ Reduce loneliness and isolation 	Care aide supports were not provided based on need (patients were randomly assigned to model of care as part of RCT)

Study details	Sample	DV/IV Measurement	Analysis	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Barnay & Juin, 2016 [150] France	Non-institutionalised persons completing French Disability and Health Survey in 2008. Analysis restricted to individuals age 65+ with difficulty in performing at least one ADL or IADL, n=4,067 for estimating depression and n=2,117 for estimating general mental health	IV: formal PS/HM hours received per week DV: <ul style="list-style-type: none"> • MHI-5 ranging 0 to 100 reflecting the past month • Self-reported depression in the last 12 months 	Linear probability and linear regression, adjusted for age, gender, SES, family availability, activity/functional limitations, age, informal care (instrumental variable)	<ul style="list-style-type: none"> ✓ General mental health, $\beta=1.82^*$ for each hour increase in PS/HM hours • Depression in last 12 months 	All variables based on self-report; sub-sample of participants who completed the paper questionnaire had fewer limitations and received less care
Brazil et al., 2002 [140] Ontario, Canada	Family caregivers of patients age 50+ who had died approximately 9 months prior to the study telephone interview and had received palliative care nursing services through one of two community nursing agencies. Excluded caregivers who were caring for someone with dementia, n=151	IV: self-reported receipt of HM services in the previous year DV: caregiver was asked if the care recipient had expressed a preferred place to die and if so, where	Multiple logistic regression	<ul style="list-style-type: none"> • Home death 	Small sample size; utilisation data based on self-report in past year

Study details	Sample	DV/IV Measurement	Analysis	Summary of findings ✓= positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Chambers et al., 1990 [138] Ontario, Canada	Hospital patients age 65+ needing at least one professional home care service who completed the Health Status Questionnaire at baseline, 3 months, and 12 months after hospital discharge. Participants were identified using hospital records and screened for eligibility using the Health Status Questionnaire from six acute care hospitals in the Regional Municipality of Hamilton-Wentworth, 92% participation rate, n=356	IV: sum of home care social services (homemaking, social work, meals on wheels, volunteer visiting) → 37.4% received HM services DV: Lawton Morale Scale ranging 0 to 17 after 12 months	Stepwise logistic and linear regression	<ul style="list-style-type: none"> • Morale, additional R²=0.02* (after Social Function Score and Morale Scale at baseline) • Physical function, social function, mental status, days in a nursing home, days in a hospital, admission to hospital/ nursing home, mortality 	Small sample size; sample not representative of patients with cognitive impairment; IV included services other than HM; unclear if utilisation data from out-of-region providers were included
Contandriopoulos et al., 1986 [145] Quebec, Canada	Modified non-equivalent control group design that compared two cross-sectional groups of home care clients age 65+: those on service before introduction of a home aide program, and those on service eight months after the program introduction, n=874	IV: presence of the program (“global” impact); use of home aide services (“specific” impact) DV: hospital length of stay	Multiple linear regression	<ul style="list-style-type: none"> • Hospital length of stay 	Small sample size; did not compare pre- and post-implementation in same cohort of clients; data on amount of PS/HM services or baseline health status not available

Study details	Sample	DV/IV Measurement	Analysis	Summary of findings √ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Dellasega & Fisher, 2001 [116] Pennsylvania, USA	Age 65+, having either a cognitive (MMSE <24) or functional impairment (need help with at least 4 of 12 ADLs/IADLs) and was treated for an acute medical or surgical problem recruited from four community hospitals, 60% participation rate, n=70	IV: self-reported use of non-professional services and type of caregiver at four weeks post-discharge DV (four weeks): <ul style="list-style-type: none"> • Self-reported health care use • Telephone Interview for Cognition 	Correlations of non-professional services with each of the outcomes	<ul style="list-style-type: none"> • Hospital readmission (0.146) • Emergency room visit (0.008) • Emergency physician visit (0.059) • Cognitive status (0.224) 	Small sample size; clients with cognitive impairment were excluded; all variables based on self-report
Fortinsky & Madigan, 1997 [246] Ohio, USA	New home care clients consecutively enrolled by 10 Medicare-certified home care agencies in Ohio (out of 306 possible agencies). Excluded if <18 years, hospice patients, early maternity discharges, sole source of payment was Medicaid waiver program (i.e., long-term home care services to delay or avoid LTC placement), n=201	IV: number of home health aide visits and total cost during home care episode (up to 62 days) DV: discharge disposition according to agency records	Bivariate ANOVA and Scheffe post-hoc tests	<ul style="list-style-type: none"> • Discharge disposition <ul style="list-style-type: none"> ○ \$95 discharged from service and remained at home ○ \$137 hospitalised ○ \$172 ongoing home care 	Small sample size; sample not representative of long-stay home care clients; under-representation of for-profit and rural home care agencies

Study details	Sample	DV/IV Measurement	Analysis	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Gené Badia, et al., 2013 [136] Catalonia, Spain	Non-institutionalised persons age 65+ who are chronically ill, unable to autonomously seek care in a primary health care centre, and receiving home care services. Each of 378 primary health care professionals recruited at least the first three eligible patients, n=1,001	IV: home help services extracted from patient's record the year before baseline assessment DV: death in next year	Chi-square test, logistic regression	<ul style="list-style-type: none"> ● Death (all patients) <ul style="list-style-type: none"> ○ 35.9% of patients who died vs. 40.2% of patients who survived used home help ● Death (patients previously hospitalised) <ul style="list-style-type: none"> ○ 35.6% of patients who died vs. 39.9% of patients who survived used home help 	IV measurement not sensitive to changes in service use during the study period; no information about the amount of services; unclear about how death was ascertained
Guerriere et al., 2015 [133] Ontario, Canada	Primary caregivers of clients with cancer who were new to receiving services from two dedicated home-based palliative care programs between July 2010–January 2012, n=302	IV: caregiver-reported resource utilisation over past two weeks (reported every two weeks until client death) DV: client death	Multiple logistic regression, adjusted for predicted probability of a preference for home death	<ul style="list-style-type: none"> ● Home death <ul style="list-style-type: none"> ○ Highest tertile of PS cost, OR=2.26 (95% CI: 1.13–4.52)* ○ Middle tertile of PS cost, OR=1.76 (95% CI : 0.93–3.35) 	Small sample size; utilisation does not include PS/HM services received from non-palliative care sources

Study details	Sample	DV/IV Measurement	Analysis	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Hansen et al., 2009 [148] Denmark	Respondents age 67, 72, and 77 who were interviewed in 1997 as part of the Danish Longitudinal Study of Elderly People. Representative samples of non-institutionalised and retired older persons living in Denmark, 29.5% lost to follow-up in 2002, n=1,267	IV: self-reported number of home help visits per month DV (5 years): <ul style="list-style-type: none"> ● Functional incapacity: Index of Incapacity ranging from 0 (full capacity) to 12 (high incapacity) ● Psychological well-being: five questions about feeling afraid, anxiety, depression, loneliness, and high spiritedness 	Multiple linear regression, adjusted for demographic, socioeconomic, and initial health status, stratified by sex	<ul style="list-style-type: none"> ✓ Well-being among men with minimum functional incapacity, $\beta=0.019^*$ × Well-being among men with higher functional incapacity, $\beta=-0.006^*$ ● Well-being among women ● Functional incapacity among men or women 	IV based on self-report; study design excluded clients discharged from home care
Health Services Utilization and Research Commission, 2000 [134] Saskatchewan, Canada	Administrative data on health care utilisation by all Saskatchewan seniors 75+ from 1989/90–1996/97. Analyses restricted to clients receiving level 1 or 2 care (supervisory and personal care), n=26,490	IV: <ul style="list-style-type: none"> ● Low PS/HM use 0.1–8.25 hr/wk ● Moderate use 8.26–17 hr/wk ● High use >17 hr/wk DV: <ul style="list-style-type: none"> ● Death ● LTC admission 	Survival analysis, adjusted for age, sex, health status, current receipt of health services, previous receipt of health services	<ul style="list-style-type: none"> ✓ LTC placement <ul style="list-style-type: none"> ○ Low use, HR=1.5* ○ Moderate use, HR=1.4* ○ High use, HR=1.6* × Death <ul style="list-style-type: none"> ○ Low use, HR=1.2* ○ Moderate use, HR=1.1 ○ High use, HR=1.1* 	Analyses were not adjusted for baseline functional limitations

Study details	Sample	DV/IV Measurement	Analysis	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Hollander & Tessaro, 2001 [137] British Columbia, Canada	Intervention group: clients in two Health Units that instituted a policy to severely cut service for low-level home care clients, n=763 Control group: low-level home care clients in other Health Units that had not instituted the policy and whose services remained the same, n=3,417	DV: health service use and cost (sum of hospital services, physician services, pharmaceuticals, LTC and chronic care facilities, home health services, home support services, adult day care services)	ANCOVA comparing year prior to cut and three years after cuts; sensitivity analysis including all Health Units found similar trend (n=7899)	<ul style="list-style-type: none"> ✓ Death after 3 years: 21.6% with cuts vs. 14.5% without cuts (no statistical test) ✓ LTC admission after 3 years: 37.9% with cuts vs. 15.0% without cuts (no statistical test) ✓ Health service cost after 2 years: \$9654 with cuts vs. \$6771 without cuts** ✓ Health service cost after 3 years: \$11903 with cuts vs. \$7807 without cuts** 	No statistical tests conducted for death and LTC admission; analyses were not adjusted for baseline health status
Hooyman et al., 1985 [152] Washington, USA	Intervention group: relatives of former home care clients receiving formal HM services but whose services were terminated due to changes in income eligibility, n=42 (out of about 2000 terminated clients) Control group: relatives of continuing home care clients receiving formal HM services, n=38	DV: <ul style="list-style-type: none"> • Types of caregiving tasks and hours per week • Perceived burden: 14-item 5-point inventory 	T-tests	<ul style="list-style-type: none"> • Number of caregivers • Average number of informal caregiving hours • Caregiver burden 	Small sample size; purposive sample of predominantly white family caregivers not generalisable; no information provided about the amount of services in either group

Study details	Sample	DV/IV Measurement	Analysis	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Hughes et al., 1984 [139] Illinois, USA	Intervention group: clients accepted to the Five Hospital Homebound Elderly Program Intervention between June 1977 and December 1979. To be accepted to FHHEP, clients must be age 60+, reside in catchment area (Chicago), homebound and medically underserved, require both medical and social services, and do not require 24-hour supervision, n=122 (out of 162 clients) Control group: non-equivalent control group of elderly and impaired clients accepted for service by an OAA Title III home-delivered meals program from same area and over similar period, n=123 (out of 167 clients)	DV (baseline and after 9 months): <ul style="list-style-type: none">• Health status: Duke/OARS Multidimensional Functional Assessment Questionnaire• Acute hospital and institutional admissions and death: OMFAQ and agency records that were verified with hospital records and/or care providers	ANCOVA comparing intervention and control groups at baseline and at 9-month follow-up	<ul style="list-style-type: none"> ✓ LTC admission rate*, 13.2% intervention vs. 22.8% control ✓ Number of LTC days*, 1722 intervention vs. 3081 control ✓ Mean LTC length of stay*, 14.2 intervention vs. 26.1 control ✓ Address unmet need for community services** × Perceived dressing ability, $\beta=-0.17^*$ × Perceived bathing ability, $\beta=-0.28^{**}$ × Perceived continence, $\beta=-0.26^*$ • Perception of physical or mental health well-being, mortality, hospitalisation rate, number of hospital days • Sum of hospital, LTC, home care, and physical care after 9 months: \$4363 intervention vs. \$3648 control (no statistical test) 	Small sample size; groups differed by ADL, home care use, and unmet need at baseline (selection bias); results were based on comparison of groups but did not further investigate amount of allocation within the intervention group

Study details	Sample	DV/IV Measurement	Analysis	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Kato et al., 2009 [149] Japan	Non-institutionalised age 65+ individuals receiving long-term care services under the government's long-term care insurance system who were enrolled in April 2005 and continued living in the community for 11 months, n=624 (out of 1,474 clients)	IV: receipt of formal home help DV: change in government care needs level ranging from 0 to 5 determined based on standardised assessment and certified by a board at baseline and at follow-up	Chi-square test	<ul style="list-style-type: none"> ● Change in care needs level (initial care levels 0 to 2) <ul style="list-style-type: none"> ○ 34% in deteriorated group vs. 32% in sustained or improved group used home help ● Change in care needs level (initial care levels 3 to 5) <ul style="list-style-type: none"> ○ 50% in deteriorated group vs. 41% in sustained or improved group used home help 	Small sample size; study of high care needs group may have been under-powered; study design excluded clients who did not use home care continuously or were discharged from home care
Kim & Shiwaku, 2012 [147] Japan	First-time clients certified for long-term care insurance as “support need” or “levels of care needs” in 2002 in a single prefecture. Excluded clients at the highest care needs level at baseline, lived in an institution, and/or died during follow-up. 67% completed the full survey, n=1,788	IV: receipt of home help and/or home visit bathing DV: change in government care needs level ranging from 0 to 5 determined based on standardised assessment and certified by a board at baseline and after two years	Binary logistic regression, adjusted for age, sex, and household structure	<ul style="list-style-type: none"> ✓ Sustained or improved care needs level (initial care level 0 or 1), OR=2.59 (95% CI: 1.38–4.87)* ● Sustained or improved care needs level (initial care level 2 to 4), OR=1.29 (95% CI: 0.80–2.08) 	Sample not representative of clients with higher degree of impairment; study design excluded clients discharged from home care; employed a simplistic adjustment for baseline care needs level

Study details	Sample	DV/IV Measurement	Analysis	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
<p>Markle-Reid et al., 2008 [146]</p> <p>Ontario, Canada</p>	<p>New home care clients age 75+ requiring assistance with personal care recruited by case managers from a single region. Excluded if unable to understand English, deemed eligible for nursing services, or lost to follow-up after six months, n=122</p>	<p>IV: average weekly use of home support services over six months obtained from computerised records → grouped into 0 (33%), <1 (39%), >1 (28%) hour per week DV (six months):</p> <ul style="list-style-type: none"> • Health-related quality of life: SF-36 Health Survey • Depression: CES-D using cut-off score ≥21 • Perceived social support: PRQ85-Part Two • Coping style: Coping Questionnaire 	<p>Difference in mean change scores of client health status: repeated measures ANCOVA</p> <p>Service cost: Kruskal-Wallis test</p>	<ul style="list-style-type: none"> × Improvement in physical functioning from baseline* <ul style="list-style-type: none"> ○ 50.5% for 0 hr/wk ○ 31.7% for <1 hr/wk ○ 16.8% for >1 hr/wk × Use of effective coping styles (i.e., active behavioural coping*, problem solving*, affective regulation*) ✓ Sum of direct health and social services cost* <ul style="list-style-type: none"> ○ \$19,238 for <1 hr/wk ○ \$16,536 for >1 hr/wk ○ \$8,249 for 0 hr/wk • Change across all other SF-36 scores: role physical, bodily pain, general health perception, vitality, social functioning, role emotional, mental health; change in depression; change in perceived social support 	<p>Small sample size; study design excluded clients eligible for nursing services or discharged from home care; clients lost to follow-up had higher baseline prevalence rates of outcomes of interest; analyses were not adjusted for baseline health status</p>

Study details	Sample	DV/IV Measurement	Analysis	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Riordan & Bennett, 1998 [141] London, UK	Clients with a dementia diagnosis and their primary family caregiver for whom residential care would be otherwise likely to requested and referred by health professionals. Control group was identified from outpatient records and matched on client age, sex, and cognitive function, and caregiver age, sex, relationship to client, and co-residency. Intervention group: standard home support services + augmented home support service for practical/emotional help and information/advice, n=19 Control group: standard home support services, n=19	DV (6, 12, 18 months): <ul style="list-style-type: none"> ● Cognition: MMSE ● Behavioural symptoms: CRBRS ● Client status (deceased, LTC placement, at home) ● Caregiver health: GHQ-28, Carer Problem Checklist, Machin Strain Scale 	Chi-square tests	<ul style="list-style-type: none"> ✓ LTC admission at 6 months*: 5% intervention vs. 50% control ✓ LTC admission at 12 months*: 26% intervention vs. 53% control ● LTC admission at 18 months: 47% intervention vs. 68% control ● Mortality ● Caregiver health 	Small sample size; study of client health status under-powered (observed trend in cognition status but sample prohibitively small to conduct statistical analysis); recruitment and/or outcomes may have been affected by knowledge that the augmented program would be withdrawn at 12 months

Study details	Sample	DV/IV Measurement	Analysis	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Sands et al., 2012 [142] Indiana, USA	Frail older adults age 65+ receiving home and community-based services through the Aged and Disabled Waiver (Medicaid program) who were enrolled between January 2001 and June 2004, and followed until December 2014, n=1,354	IV: average monthly hours of attendant care and homemaking services DV: time to LTC placement (at least 3 months' stay)	Sub-distribution hazards model according to Fine and Gray in the presence of death as a competing risk, adjusted for predisposing, enabling, and need characteristics associated with LTC placement	<ul style="list-style-type: none"> ✓ LTC placement at 24 months <ul style="list-style-type: none"> ○ Attendant care (per 5 hours), HR=0.95 (95% CI: 0.92–0.98)** ○ Homemaking (per 5 hours), HR=0.87 (95% CI: 0.77–0.99)* 	No data about the availability of informal care or changes in health status after the baseline assessment
Sussman & Regehr, 2009 [151] Ontario, Canada	Spousal caregivers actively providing care to a partner 65+ with progressive and irreversible cognitive losses, living in the community, receiving at least one publicly funded community service. Recruited by convenience sampling, n=85	IV: caregiver reported whether currently using any homemaking services paid in full or in part by government sources DV: caregiver distress measured using Zarit Burden Interview	T-tests, Pearson's correlation	<ul style="list-style-type: none"> ● Caregiver distress: mean ZBI 35.4 among HM service users vs. 33.6 among non-users 	Small sample size; convenience sample not representative of general caregiver population; baseline levels of caregiver distress not measured

Study details	Sample	DV/IV Measurement	Analysis	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Thomas, 2014 [143] USA	Annual performance reporting captured through the State Program Report (2005–2009) describing 15034 free-standing certified nursing homes linked with resident-level data. Defined “low-care residents” as residents not needing any physical assistance in any of four late-loss ADLs or not classified in the two lowest functioning RUG-III classifications, n=71,984 facility-year observations	IV: proportion of population age 65+ receiving OAA Title III services (personal care, homemaker, or chore services) DV: proportion of low-care LTC residents	Two-way fixed effects model (controlling for time and time-invariant facility characteristics)	<ul style="list-style-type: none"> ✓ Proportion of low-care LTC residents and proportion receiving personal care, $\beta = -0.76^*$ ● Proportion of low-care LTC residents and proportion receiving homemaker services 	Aggregate-level conclusions may not apply at the individual-level
Townsend et al., 1992 [247] London, UK	Admitted patients (emergency or planned) age 65+ of a single district general hospital who were recruited for a randomised controlled trial of a domiciliary discharge scheme, 96% hospital records could be retrieved, n=867 Intervention group: care attendants visited patients before discharge, on the first day at home, and up to 12 hours/week for two weeks Control group: standard in-home aftercare services	DV: emergency or planned readmissions after 18 months of discharge (coded by researchers based on patient notes)	Chi-square tests	<ul style="list-style-type: none"> ✓ Emergency or planned readmission if originally admitted as emergency case*: 73% intervention vs. 83% control ✓ Emergency readmission if originally admitted as emergency case**: 78% intervention vs. 93% control ● Emergency readmission if original admitted as planned case ● Planned readmission 	No description about how standard in-home aftercare services are provided/allocated; data on the amount of PS/HM services received not available

Study details	Sample	DV/IV Measurement	Analysis	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Washio et al., 2014 [248] Hokkaido, Northern Japan	Older disabled home care clients and their family caregivers receiving in-home nursing services and living in a city in northern Japan, n=101	DV: caregiver depression measured using CES-D (cut-off score ≥16) → 46% depressed	Chi-square tests	<ul style="list-style-type: none"> Caregiver depression: 45.7% among depressed caregivers vs. 61.8% among non-depressed caregivers used HM services 	Small sample size; no description about recruitment; baseline levels of caregiver depression not measured
Weissert et al., 1980 [249] USA	Randomised controlled trial involving patients who had been hospitalised for at least three days during two weeks prior to the study period, required health services to restore or maintain functional ability, and referred to the study. Excluded if not eligible for Medicare or required 24-hour supervision. Assessed for eligibility by multidisciplinary team, n=630 Intervention group: standard Medicare services (does not include homemaker services) + homemaker services for 1 year Control group: standard Medicare services	IV: receipt of HM services DV (initial assessment and four quarterly assessments): <ul style="list-style-type: none"> Functional ability: Katz ADL Scale Discharge disposition (LTC placement, hospitalised, death) 	Multiple classification analysis, adjusted for demographic, social, psychological, prognostic, and health service use variables; sensitivity analyses by users and non-users	<ul style="list-style-type: none"> ✓ Survival, $\beta=0.16^*$ LTC placement, hospitalisation, improve or maintain physical functioning 	Small sample size; recruitment may have been affected by knowledge that the study would withdraw services after 12 months; intervention group had higher proportion of patients with moderate functional dependency at baseline

Study details	Sample	DV/IV Measurement	Analysis	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Wilson et al., 2003 [250] New South Wales, Australia	Patients 65+ with an immediate need for basic maintenance service upon hospital discharge and enrolled in the Carrington Temporary Aged Care Program (CTACP) for up to 8 weeks while waiting for home care referral to be processed. Excluded patients with high functional or cognitive impairment, needing >7 hours/week, eligible for Community Aged Care package or Extended Aged Care in the Home, n=15 (out of 35 enrolled clients)	DV (at discharge): <ul style="list-style-type: none"> Client quality of life: AQoL (five dimensions), SF36v2 (eight sub-scales, two components) Caregiver distress: Carer Strain Index 	Paired t-test (pre- and post-service)	<ul style="list-style-type: none"> ✓ Reliance on medical aids and receipt of medical treatment* ✓ Physical senses (sight, hearing, communication)* ✓ Physical functioning sub-scale*, vitality sub-scale* ✓ Mental health component* ● Other dimensions of AQoL: independent living, social relationships, psychological well-being ● Other sub-scales and components of SF36v2 ● Caregiver distress 	Small sample size (especially for caregiver outcome); excluded persons who were eligible for home care packages

Study details	Sample	DV/IV Measurement	Analysis	Summary of findings ✓ = positive, × = negative, ● = no association *p<.05, **p<.001, ***p<.0001	Limitations
Xu et al., 2010 [144] USA	Frail older adults age 65+ receiving home and community-based services through the Aged and Disabled Waiver (Medicaid program) who were enrolled between January 2001 and June 2004, and followed until December 2014, n=1,354	IV: average monthly hours of attendant care (5, 15, 25) and homemaking services (2, 4, 6) DV: time to hospital admission	Sub-distribution hazards model according to Fine and Gray in the presence of death as a competing risk, adjusted for predisposing, enabling, and need characteristics associated with LTC placement Adjusted for demographics, comorbidities, prior use of health services, and volume of HCBS received	✓ Hospital admission after 1 month: <ul style="list-style-type: none"> ○ 5 PS hours/month: HR=0.46 (95% CI: 0.38–0.57) ○ 15 PS hours/month: HR=0.31 (95% CI: 0.20–0.42) ○ 25 PS hours/month: HR=0.25 (95% CI: 0.17–0.36) ○ 2 HM hours/month: HR=0.52 (95% CI: 0.44–0.63) ○ 4 HM hours/month: HR=0.39 (95% CI: 0.30–0.51) ○ 6 HM hours/month: HR=0.32 (95% CI: 0.23–0.44) ✓ Hospital admission after 5 and 10 months ● Hospital admission after 15 months	No data about the availability of informal care or changes in health status after the baseline assessment

APPENDIX B: Additional Tables for Chapter 6

Transition Proportions from Initial State to Follow-up State, PS Group 1, HC-Assessed Clients, HNHB LHIN January 2013–December 2017

Column %	Initial state		
	0 caregiver distress items present (n=5,661)	1 caregiver distress item present (n=410)	2 caregiver distress items present (n=53)
Follow-up state			
Next HC assessment: 0 caregiver distress items present	16.3%	4.4%	7.6%
Next HC assessment: 1 caregiver distress item present	1.9%	14.2%	3.8%
Next HC assessment: 2 caregiver distress items present	0.3%	3.7%	20.8%
Moved to cluster residence (retirement home, cluster care, assisted living)	1.3%	3.7%	0.0%
Moved to long-term care home	2.0%	2.4%	5.7%
Died	6.1%	7.6%	0.0%
Discharged because service plan complete or needs can be met in the community	56.4%	49.3%	50.9%
Discharged for other reasons	8.1%	10.5%	5.7%
Still on service but not reassessed (censored)	7.5%	4.4%	5.7%

Transition Proportions from Initial State to Follow-up State, PS Group 2, HC-Assessed Clients, HNHB LHIN January 2013–December 2017

Column %	Initial state		
	0 caregiver distress items present (n=14,714)	1 caregiver distress item present (n=3,355)	2 caregiver distress items present (n=808)
Follow-up state			
Next HC assessment: 0 caregiver distress items present	28.0%	6.4%	4.0%
Next HC assessment: 1 caregiver distress item present	4.5%	29.0%	5.0%
Next HC assessment: 2 caregiver distress items present	1.5%	7.0%	34.7%
Moved to cluster residence (retirement home, cluster care, assisted living)	3.0%	3.9%	5.8%
Moved to long-term care home	3.0%	5.5%	9.7%
Died	4.6%	4.3%	4.3%
Discharged because service plan complete or needs can be met in the community	36.0%	25.4%	21.2%
Discharged for other reasons	10.0%	11.8%	10.5%
Still on service but not reassessed (censored)	9.5%	6.7%	5.0%

Transition Proportions from Initial State to Follow-up State, PS Group 3, HC-Assessed Clients, HNHB LHIN January 2013–December 2017

Column %	Initial state		
	0 caregiver distress items present (n=11,259)	1 caregiver distress item present (n=5,014)	2 caregiver distress items present (n=1,732)
Follow-up state			
Next HC assessment: 0 caregiver distress items present	34.2%	7.1%	4.3%
Next HC assessment: 1 caregiver distress item present	6.4%	34.8%	6.2%
Next HC assessment: 2 caregiver distress items present	2.5%	7.8%	38.2%
Moved to cluster residence (retirement home, cluster care, assisted living)	2.8%	3.0%	3.4%
Moved to long-term care home	4.7%	8.2%	13.1%
Died	6.2%	6.2%	6.0%
Discharged because service plan complete or needs can be met in the community	20.0%	12.8%	9.4%
Discharged for other reasons	12.1%	11.2%	11.8%
Still on service but not reassessed (censored)	11.1%	9.0%	7.6%

Transition Proportions from Initial State to Follow-up State, PS Group 4, HC-Assessed Clients, HNHB LHIN January 2013–December 2017

Column %	Initial state		
	0 caregiver distress items present (n=3,255)	1 caregiver distress item present (n=2,037)	2 caregiver distress items present (n=950)
Follow-up state			
Next HC assessment: 0 caregiver distress items present	37.4%	7.9%	3.4%
Next HC assessment: 1 caregiver distress item present	9.4%	35.6%	4.6%
Next HC assessment: 2 caregiver distress items present	3.6%	8.5%	42.4%
Moved to cluster residence (retirement home, cluster care, assisted living)	2.6%	2.4%	2.5%
Moved to long-term care home	5.8%	10.4%	15.3%
Died	7.9%	7.2%	6.6%
Discharged because service plan complete or needs can be met in the community	9.8%	7.2%	6.3%
Discharged for other reasons	12.7%	11.6%	11.8%
Still on service but not reassessed (censored)	10.9%	9.3%	7.1%

Transition Proportions from Initial State to Follow-up State, PS Group 5, HC-Assessed Clients, HNHB LHIN January 2013–December 2017

Column %	Initial state		
	0 caregiver distress items present (n=1,671)	1 caregiver distress item present (n=2,036)	2 caregiver distress items present (n=1,370)
Follow-up state			
Next HC assessment: 0 caregiver distress items present	38.1%	6.2%	3.6%
Next HC assessment: 1 caregiver distress item present	10.4%	35.6%	4.4%
Next HC assessment: 2 caregiver distress items present	4.7%	11.2%	38.9%
Moved to cluster residence (retirement home, cluster care, assisted living)	1.7%	2.3%	2.6%
Moved to long-term care home	7.5%	13.3%	22.6%
Died	9.2%	7.9%	5.9%
Discharged because service plan complete or needs can be met in the community	7.0%	4.8%	3.9%
Discharged for other reasons	11.9%	12.1%	11.9%
Still on service but not reassessed (censored)	9.6%	6.6%	6.3%

Transition Proportions from Initial State to Follow-up State, PS Group 6, HC-Assessed Clients, HNHB LHIN January 2013–December 2017

Column %	Initial state		
	0 caregiver distress items present (n=1,062)	1 caregiver distress item present (n=1,091)	2 caregiver distress items present (n=730)
Follow-up state			
Next HC assessment: 0 caregiver distress items present	38.0%	5.7%	2.7%
Next HC assessment: 1 caregiver distress item present	7.2%	33.9%	3.8%
Next HC assessment: 2 caregiver distress items present	3.2%	7.5%	34.9%
Moved to cluster residence (retirement home, cluster care, assisted living)	1.0%	0.6%	1.4%
Moved to long-term care home	4.9%	10.2%	21.9%
Died	17.6%	18.2%	13.0%
Discharged because service plan complete or needs can be met in the community	6.3%	4.8%	4.7%
Discharged for other reasons	7.5%	9.9%	10.0%
Still on service but not reassessed (censored)	14.2%	9.3%	7.5%