Instrumental Activities of Daily Living as an Early Indicator of Transition to Residential Care: Change Point Modeling of Home Care Recipient Pathways

by

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B.A., University of Victoria, 2001
M.Ed., University of Calgary, 2008

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Supervisory Committee

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Objective: The transition to long-term care (LTC) of older adults receiving home care services is preceded by declining functional independence with basic and instrumental activities of daily living (ADL and IADL, respectively). These individual, and group, level time-dependent changes occur within unique provincial and regional policy contexts across Canada, which determine the amount and types of services received by home care recipients during this transition period. It is currently unknown whether activities of daily living (ADL) or IADL (instrumental activities of daily living) exhibit accelerated decline preceding transition to LTC, and if so, whether the onset and rate of decline differs for ADL versus IADL. This dissertation sets out to determine whether such change points exist within longitudinal data gathered from home care recipients in Ontario during the years of 2008 to 2015.

Methods: A profile likelihood method was employed to identify the best fitting change points at which the slopes of functional decline in ADL and IADL for those who transition to LTC from home care services depart from the normative age slope of those who remain in community. Data analyzed was collected at approximately 6-month intervals using the International Residential Assessment Instrument – Home Care (RAI-HC) in Ontario, Canada, and was obtained from the Canadian Institutes for Health Information (CIHI) for the period of

2006-2015. A policy review was conducted to determine whether changes had occurred to the amount or type of home care services provided during the data collection period, and subsequently data from 2008 to 2015 were retained. IADL was measured using the 21-point IADL Involvement Scale and ADL was measured using the 28-point ADL Long Form. Best fitting change point models were first identified for ADL and IADL scores in the full sample of participants who remained in community and those who transitioned to LTC and within subgroups stratified by sex. Two additional subgroups were also examined: 1) participants without a primary or secondary caregiver living in the home, and 2) participants with a primary caregiver living in the home. Each caregiver group was also stratified by sex, resulting in a total of 9 groups in which IADL and ADL change points were estimated and compared.

Results: In all groups who remained in community with home care services, age-related decline in IADL and ADL were observed. Further, IADL impairment was higher at the time of first assessment and had a greater age-related slope than ADL for those who remained in community. Both measures had discernable change points preceding discharge to LTC and the change point for IADL preceded that of ADL in all groups. Across groups, the change point for ADL had a range of 0.5 years before LTC discharge for men without a primary or secondary caregiver living in the home to 2 years for women with a primary caregiver in the home. IADL change points ranged from 2.5 years before LTC discharge for men with a primary caregiver in the home to 3.6 years for women without a primary or secondary caregiver in the home. Within the full sample, including both men and women, the onset of accelerated IADL decline for those discharged to LTC preceded the onset of home care service by 1.49 years and the time of first assessment by 1.84 years. Women in the full sample, and in both caregiver groups, experienced an earlier IADL change point relative to the availability of home care services and assessment when compared to men.

Conclusions: Both IADL and ADL have discernible change points for in the years preceding discharge from home care to LTC. The change point for IADL consistently precedes that of ADL for the entire sample, for those with or without a caregiver in the home and for both men and women. The onset of accelerated IADL decline in the presence of age normative ADL decline may be an early indicator of pending transition from home care to LTC for home care recipients identified in this study. The province of Ontario has committed to providing the *right care*, at the *right time* in the *right place*. This study demonstrates that home care policy in Ontario during this study period, which does not provide for IADL services until after patients first qualify for ADL services, may not be achieving the provinces commitment of ensuring IADL care is provided at the *right time* for recipients of home care services. Opportunities for early identification and intervention may be available through early monitoring of, and intervention with, IADL function. A stepped care model holds promise for early identification and intervention of IADL impairment in community living older adults. Future research will help to confirm if accelerating decline in IADL function in the absence of appropriate rehabilitation and support services may hasten the onset of accelerated ADL impairment and subsequent admission to LTC.

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Acknowledgments

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Introduction

Across Canada, the needs of our rapidly aging population are putting pressure on the health care system. This trend is led by the post-World War II baby boom cohort (1946-1965), with members of this age group beginning to turn 65 in 2011, culminating in “the largest increase (20%) of people 65 years of age and older in Canada in 70 years” (Statistics Canada, 2017, p. 3). As of July 1, 2019, this cohort alone accounted for the majority of adults 65 years and older (51%). It is further projected that by 2031, 22.7% of Canadians will be 65 years of age or older (Statistics Canada, 2019). Gibbard (2017) concludes that, based on aging trends and models of care, these demographic changes will result in Canada needing to nearly double the number of long-term care (LTC) beds to approximately 400,000 by 2035 at an estimated cost of 194 billion dollars. Projected future demand for long-term care beds may be mitigated by improving community based healthcare services, with recent evidence indicating many older adults are being transitioned to LTC when they may be better served in their homes and communities (CIHI, 2017).

Aging trends in the province of Ontario exceed those of Canada. In 2011, 14.6% of Ontario’s population was 65 years of age and older and it is expected this age group will double by 2031 to nearly 30%, a trend that will continue placing increased demand on home care services and long-term care facilities (Sinha, 2012). As part of Ontario’s strategy to address the accelerating medical needs of its population, the province has adopted the values of Patient Centered Care (PCC):

> A patient-centred care system is one where patients can move freely along a care pathway without regard to which physician, other health-care provider, institution, or community resource they need at that moment in time. The system is one that considers the

> individual needs of patients and treats them with respect and dignity. (Ontario Medical Association, 2010, p. 34)

This aspirational PCC goal is a cornerstone of provincial home and community care (HCC) policy and is summarized by the Ontario Ministry of Health as providing the “right care, at the right time, in the right place” (Expert Group on Home & Community Care, 2015, p. 1).

While the government of Ontario represents and upholds the values of PCC, the Ontario Medical Association, an advocacy group for doctors, has indicated further improvements are necessary as many patients continued to struggle with adapting to the current system and navigating its many complexities (Ontario Medical Association, 2010). In practical terms, barriers to PCC may result in situations where patients have unequal access to services, do not receive timely access to services necessary to treat their current medical needs, and/or poor coordination of care, which may lead to suboptimal outcomes. The challenges of providing PCC extend beyond Ontario and Canada, with many European Union and OECD countries also grappling with how to best implement high quality PCC outside of high-cost hospital and institutional settings (Hofmarcher et al., 2009). In an effort to meet the apparent challenges inherent in achieving PCC, putting patients first while simultaneously strengthening HCC has been identified as central to the Ontario government’s ongoing strategic efforts to transform health care (Ministry of Health and Long-Term Care, 2015).

The Ontario government’s PCC imperative for patients to receive care in the *right place,* and the simultaneous strengthening of HCC, aligns with the desires of older adults across Canada, with 85% preferring to age in place (CMHC, 2012). Aging in place entails “continuing to live in the same or familiar place or community for as long as possible” (Dalmer, 2019, p. 40) even with changes in needs, such as declining health and independence (Pastalan, 1990). Despite the efforts of the Ontario government, and the desires of its citizens, many factors threaten older adults' ability to remain in their homes and increase risk of transition to LTC (Aspell et al., 2019; Coward et al., 1996; Garner et al., 2018; M. Jorgensen et al., 2018). Of the multitude of risk factors which may lead to an older adult spending their final years of life in a LTC setting, declining independence with Instrumental Activities of Daily Living (IADL) is uniquely predictive (Bharucha et al., 2004; Jamieson et al., 2019; Kendig et al., 2010).

It is generally accepted that IADL skills, such as managing personal finances, grocery shopping, and booking and attending medical appointments, are necessary to maintain independent community living and without capacity or support with both basic activities of daily living (ADL) and IADL older adults will be unable to successfully age in place (Mackenzie, 2019). Despite the growing evidence indicating IADL impairment is associated with transition to residential care (Bharucha et al., 2004; Kendig et al., 2010), within Ontario access to assistance with a limited subset of home-based IADL tasks (laundry, mending and meal preparation), and access to partially subsidized assistance with community based IADL tasks support (shopping and attending appointments), continues to depend on patients first demonstrating a need for personal support services to assist with ADL, such as bathing, dressing and feeding (Ontario, 1994). This service delivery model reflects policy driven decisions by Ontario to provide care in the *right place*, i.e., by providing services to patients in their homes. However, there is insufficient evidence to conclude that waiting to provide IADL services until a patient demonstrates sufficient impairment to qualify for ADL assistance ensures services are provided at the *right time* in the developmental trajectory of older adults.

Research Opportunity

Longitudinal analysis of data collected from home care recipients using the Resident Care Assessment Instrument - Home Care (RAI-HC) (CIHI, 2021) in Ontario provides a unique opportunity to critically examine whether IADL services are being provided at the *right time*. One approach to longitudinal analysis is the estimation of change points. Change point analysis initially emerged as a strategy for identifying an inflection point where T4 cell decline began to accelerate in a group of 131 homosexual men infected with the human immunodeficiency virus (HIV) who went on to develop acquired immunodeficiency syndrome (AIDS) (Kiuchi et al., 1995). The same single group design has also been successfully used to model cognitive performance in older adults as they approach death (MacDonald et al., 2011). Change point analysis was further developed for a group of 488 older adults by identifying a time-dependent inflection point in cognitive performance when study participants who later receive a dementia diagnosis depart from the normative aging slope that characterizes the remaining participants who do not transition to dementia (Hall et al., 2000). Sliwinski et al. (2006) use this same methodology and participant sample to model a change point in cognitive performance as participants who depart from the normative aging slope approach death. This approach to change point analysis has also been used in a sample of 914 participants to identifying different inflection points at which cognitive performance enters accelerated decline for study participants preceding the onset of Alzheimer’s disease and vascular dementia, relative to participants who do not (Laukka et al., 2012).

To date, there has not been a study that estimates change points in measures of functional independence, such as ADL and IADL, for home care recipients as they approach discharge to residential care, nor has this methodology been used in a large, population-level sample. The present study engages a sample of 121,470, composed of participants who continued receiving home care services at the end of the data collection period and those who were discharged from home care services to residential care. This sample was drawn from a population of 941,029 participants, which encompasses all home care recipients assessed using the International Residential Assessment Instrument – Home Care (RAI-HC) during the data collection period of January 1, 2006, to June 30, 2015, within the province of Ontario.

The Current Study

The primary objectives of this dissertation are to determine whether change points emerge when IADL and ADL scores for participants who are discharged to residential care depart from those who remain in home care and to identify the temporal relationship between them, i.e., which occurs first. This will also allow the comparison of normative age-related change slopes for those who continue to receive home care and slopes which occur in proximity to discharge to residential care for participants who follow this path. Further exploration of these initial objectives will be conducted by stratifying the sample by sex to determine if differences emerge and by further examining subgroups of the initial sample based on the presence or absence of a caregiver in the home.

This dissertation is organized into several chapters. First, I situate the study within the broad regionalized delivery of HCC services in Ontario and how the geographic organization of service delivery has changed during the data collection period. The HCC service model and its three primary types of services, i.e., case management, professional services, and unregulated supportive care, are described and any changes that occurred during the data collection period are identified. A review of HCC policy of the number of hours and types of services home care recipients are entitled to is then conducted and relevant changes are documented. The first chapter concludes by briefly describing the history of RAI-HC deployment in Canada and how data collection, management and dissemination is currently managed.

The second chapter reviews two opposing trends in the assessment of IADL and ADL: ongoing efforts to identify hierarchical relationships between the measures of both aspects of functional independence to allow for rapid administration and epidemiological level analysis, and the trend towards expanded assessments that improve early detection of change and sensitivity to change over time. This chapter concludes with a review of associations between IADL functions and covariates such as cognitive function and outcomes such as transition to residential care. The third chapter presents the current study participant selection decisions, methods, and results. The fourth and final chapter interprets the findings of this study and discusses the possibility of accelerating IADL impairment hastening corresponding declines in ADL and subsequent residential care admission. Suggestions for early intervention strategies are then shared.

Ontario Home and Community Care

Health care in Canada is delegated as a provincial responsibility. The Canada Health Act of 1985 establishes the provision of physician and hospital services and provides transfer payments to the provinces and territories for the delivery of all health care services, including home care and residential care; however, home and residential care services for older adults and those with disabilities fall outside federal legislation and oversight (Canada Health Act, 1985). This has resulted in a mosaic of structure, policy and service models for home and residential care that fall outside national quality standards (Hirdes, 2002). The differences in the organization and delivery of home care services limits the ability to generalize research findings from one province or territory to another and necessitates that studies into both home care and residential care are situated within the unique policy and service delivery models of the province or territory from which participant data was collected.

Throughout the data collection period of January 1, 2006, to June 30, 2015, oversight for home care services in Ontario was provided by the Ontario Ministry of Health and Long-Term Care (MOHLTC). Services delivered by the MOHLTC were organized regionally through 14 geographically bounded Local Health Integration Networks (LHIN). These LHIN were conceptualized in 2004 and then established formally in 2006. The establishment of LHIN decentralized responsibility for health care from the province of Ontario to the LHIN while also centralizing influence upwards towards each LHIN from previous community-level decision making bodies such as hospitals, LTC boards and mental health agencies (Barker, 2007). In 2007, the MOHLTC extended this regionalization agenda to align Home and Community Care (HCC) services with the geographic boundaries of the LHINs and newly developed Community Care Access Centres (CCAC) (Ministry of Health and Long-Term Care, 2006). The resulting 14 geographically bounded CCAC provide home care services throughout the province of Ontario to older adults as well as adults and children with disabilities who require assistance.

Service Delivery Model

In 2015, 60% of home care recipients in Ontario were aged 65 and over, 20% were ages 18-64 years, 15% were children (<18 years) and 5% were palliative (Auditor General of Ontario, 2015). Home care services were not provided to individuals residing in long-term care homes (Ontario, 1994). During the data collection period, home care services in Ontario were delivered through a combination of case management, professional services (e.g., nursing, occupational therapy) and unregulated supportive services (e.g., personal care, home making and community support). Case management is considered a core service for HCC and all HCC case managers (CM) were directly employed by regional CCAC and required to be regulated health professionals. Within their role, CM do not provide direct services within their areas of expertise. Rather, CM provide ongoing assessment of clients' needs through observation and periodic standardized assessment at 6-month intervals using the RAI-HC. Through this assessment process, CM determine funding for services and subsequently act as service brokers by recruiting services within their networks and coordinating these services in an active and continuous manner. The following sections were drawn from publicly available policy documents and summarize of the roles and duties performed by CM, professional services, and unregulated supportive services.

Case Management Services

Patients requiring home care services were assessed by care co-ordinators, often referred to as Case Managers (CM), who were required to be regulated health professionals such as nurses, social workers, or occupational therapists, and were directly employed by provincial

CCAC. CM have no formal limits to the number of hours per month they can provide services to a specific client. CM were responsible for ongoing assessment and care coordination of patients requiring home care. Following an initial intake and observational assessment by the CM, clients were referred to one of the approximately 160 private sector for-profit or not-for-profit home care service providers dispersed across the 14 LIHN. This independent, private sector provider network also delivered professional services (e.g., nursing, occupational or physiotherapy), in addition to unregulated services (e.g., personal support for assistance with ADL and assistance with IADL that can be completed within the home). CM also provided referrals a broad network of over 800 community support service agencies across the province of Ontario.

CM maintained ongoing responsibility for assessment of client needs, eligibility for available services, planning of services (including developing a service plan and allocating resources), service coordination, ongoing reassessment, monitoring and revision of service plans and service termination (discharge). CM were required to comply with the Long Term Care Act (Ontario, 1994) while being guided by the following principles: respect for the person's rights, dignity, values and preferences; promotion of the highest level of independence possible; promoting global quality improvement; promoting a collaborative and well co-ordinated approach to service delivery; and efficient, effective and equitable use of resources (Ministry of Health and Long-Term Care, 2006). When assessing eligibility for home care services, CM were mandated to first ensure the patient was insured under the Health Insurance Act, that the place where services were provided (typically a person's home) had the features necessary for service provision and there was no significant risk of physical harm to the patient, CM or the service provider network. In addition, allied health professionals working as CM were required to maintain continuing education credits and accountability to the service delivery values and principles of their regulatory colleges.

Professional Services

Professional services were provided only when deemed necessary to enable the patient to remain in their home or to enable them to return to their home. It was required that professional services could reasonably expect outcomes that are rehabilitative, maintain functional status or are considered palliative for those in the last stages of life. These services were only provided in a place where the physical features were adequate to carry out the activities and in the absence of risks of serious physical harm to the provider. In the case of physical therapy, the patient was required to demonstrate that they are unable to attend a physiotherapy clinic before services became available in the home. Pharmacy services were provided for those taking three or more medications and was only provided in the patient's home. Professional services available included diagnostic, rehabilitation (occupational therapy, physical therapy, speech and language therapy), pharmacy, respiratory therapy and social work services. Nursing services were also available and were provided by a registered nurse, registered practical nurse or registered nurse in the extended class. Extended class registered nurses have specialized training that gives them the authority to prescribe medications, conduct procedures, and to order and interpret diagnostic tasks (Ontario, 1994).

Unregulated Care Services

Home care services in Ontario were classified as either Personal Support or Homemaking services. The scope of Personal Support services included ADL tasks such as bathing, toileting, dressing, feeding, transferring, and provided training to patients and/or their informal caregivers in ADL tasks. Homemaking services were provided only if the patient had already qualified for

Personal Support services and were restricted to aspects of care that an informal caregiver was unable or unavailable to assist with. The scope of Homemaking services included assistance or provision of in-home IADL tasks such as housecleaning, laundry, ironing, mending, banking, paying bills, planning menus, and preparing meals. Homemaking services also provided training to the patient or an informal caregiver to complete homemaking activities and child-care. CM were able to prescribe equipment, supplies or other goods relevant to both Personal Support and Homemaking services (Ontario, 1994).

Additionally, Community Support services were available to assist in areas such as meal delivery, transportation, caregiver support, adult day programs, home maintenance and repair, friendly visiting, security checks and social or recreation activities. These community support services required a co-pay by the client and were only partially funded by the LIHN. As with homemaking services, patients had to first qualify for personal support with ADL activities prior to HCC sharing in the co-pay expense. The extent to which the co-pay may create socioeconomic disparity is not known. Regional disparities in access to community support services also exist, with more community support providers and services being available for urban participants than for their rural dwelling counterparts.

Policy Changes During Data Collection Period

The services described above were constrained by funding levels that set limits to the number of hours for each type of service study participants were entitled to receive. In the context of provincial oversight of health care services, and no federal standards for the delivery of home care or residential care, the number of hours and types of services provided through these sectors is often a hotly debated political topic at the provincial level. The overall structure and funding levels for home care services is often adjusted, and sometimes completely restructured, based on the decisions and values of governing political parties.

RAI-HC data retrieved from the Canadian Institutes of Health Information (CIHI) for this study spanned the period of January 2006 to June 2015. This data collection phase occurred during a unique period of political stability in Ontario when the Ontario Liberal Party maintained leadership of the province through four general elections (occurring in 2003, 2007, 2011 and 2014). The Honorable Dalton McGuinty was the Liberal premier of Ontario during the 2006 to 2014 period, while the Honorable Kathleen Wynne led the Liberal party from 2014 to 2016. After establishing the LHIN in 2004 and subsequently aligning HCC services through regional alignment of the CCAC within each LHIN in 2007, the province wide structure and geographically bounded delivery of HCC services remained unchanged for the duration of the data collection used in this study.

Personal and Homemaking Services

Examination of the historical records of HCC policy changes (Ontario, 1994) revealed that from 2002 to 2008, the maximum number of combined personal and homemaking support hours available was 80 hours in the first 30 days, and 60 hours in any subsequent 30-day period. There was also a provision to allow the maximum 80 hours of service to continue after the first 30 days, or to be reinstated at a later date, in response to extraordinary circumstances. The provision of this enhanced service was limited to 90 days per 12-month period. In 2008, the maximum number of hours was increased to 120 hours of service in the first 30 days of service, and 90 hours in any subsequent 30-day period. Allowance for the extension, or reinstatement, of the maximum 120 hours in response to extraordinary circumstances was retained. The 90-day limit of enhanced services per 12-month period was also maintained after 2008. Both before and after 2008, extraordinary circumstances were defined as being the last stages of life or when a participant was waiting for admission to a LTC facility. The eligibility criteria, scope, and description of services for both personal support and home making services was consistent across the entirety of the data collection period (Ontario, 1994).

Professional services

From 2002 through to 2008 the maximum amount of nursing services was defined as 28 visits in a seven-day period with a total of 43 hours if provided by a registered nurse, or 53 hours if provided by a registered practical nurse. In 2008 the wording for the maximum amount of nursing services was changed to reflect a 30-day period, although the number of visits and total hours remained consistent. This level of service also remained unchanged throughout the duration of the collection period of data used in this study. The maximum amount of additional professional services such as occupational and physiotherapy is not defined, although the eligibility criteria remained consistent throughout the data collection period.

Long Term Care Admission Criteria

To qualify for admission to a LTC facility during the data collection period, the applicant must have been 18 years of age or older and insured under the Health Insurance Act. They needed to also require nursing care be available 24 hours a day, frequent assistance with ADL, frequent or ongoing supervision, and to exceed the capacity of informal and formal supports and services available within the community. The LTC facility must have also been capable of meeting the needs of the applicant. While these criteria remain consistent throughout the data collection period, in 2010 risk of financial harm, environmental conditions that can not be resolved if the applicant remains in their residence, and risk of harm to others were no longer accepted as admission criteria for LTC (Meadus, 2010). As these LTC admission criteria changes did not relate specifically to the functional domains of IADL and ADL impairment of interest in this study, participants with assessments prior to 2010 were retained.

Due to the large increase in available personal support and homemaking services in 2008, and the establishment and regional alignment of CCAC in 2007, participants with a date of first assessment prior to 2008 were not included in this analysis. The era of political stability that encompassed this data collection resulted in a remarkable, and prolonged, period during which the eligibility, scope, levels of services and descriptions of home care, nursing, and professional services remained unchanged. The 7.5-year period of stability from 2008 to 2015 provides a unique opportunity to examine longitudinal changes among HCC service recipients assessed using the RAI-HC.

Resident Care Assessment Instrument

When conducting objective assessments of a patient's need for home care services, CM were required to use the Resident Care Assessment Instrument - Home Care (RAI-HC). The RAI-HC was initially developed in 1994 with the goal of being compatible with existing systems in residential care and was revised in 1999 and again in 2007 (*InterRAI*, 2018). The revised 2007 version of the RAI-HC was used throughout the data collection period of this study. As per the Ministry of Health and the Long-Term Care Act, it was required that all RAI-HC assessments were conducted in a face-to-face manner and that a RAI-HC assessment was completed within 14 calendar days of a patient being identified as requiring long-stay home care services of more than six months. RAI-HC assessments were then conducted at six-month intervals, so long as the patient continued to require services from HCC. RAI-HC assessments were also conducted as part of hospital discharge planning and to determine patient needs for short term nursing or other professional services while in community. Following assessing patient needs during initial intakes and administering the RAI-HC, CM were then responsible for monitoring patient health status and progress while making ongoing decisions regarding the most appropriate service types, intensities, and durations. CM maintained ongoing responsibility for referring patients to and coordinating all personal support, homemaking as well as professional and community support services (Ministry of Health and Long-Term Care, 2006).

Deployment and Data Management of RAI-HC

Hirdes et al. (1999) identified a lack of standardized assessment as a barrier to continuity of care for patients transitioning between home care, hospital and LTC and to effectively track and manage outcomes and quality of services. Furthermore, this lack of standardization and quality control was identified as particularly problematic for older adults in Canada (Hirdes et al., 1999). In 2004, in response to concerns and following a request from the Ministry of Health of British Columbia (BC) to CIHI, the Home Care Reporting System (HCRS) was initiated to build a repository for CIHI home care data. The project was launched in 2006 in both BC and Ontario, becoming the national pan-Canadian data standard in the 2006-2007 fiscal year (CIHI, 2010). By 2018, the HCRS had been actively deployed in BC, Alberta, Manitoba, Ontario, Nova Scotia, Newfoundland and Labrador and the Yukon.

The HCRS uses a version of the RAI-HC that has been modified for use in Canada with permission from interRAI (the parent organization which owns the RAI-HC). Using this modified version of the RAI-HC, in Ontario information is collected by the CCAC employed CM at the point of care, entered into provincial databases and then submitted to CIHI, where it is checked for quality and appropriately anonymized. This anonymized RAI-HC data from Ontario and other provinces participating in the HCRS is made available for research and public policy purposes through requests submitted directly to CIHI. Through the HCRS system, CIHI produces annual quality reports to provide feedback to the provinces submitting RAI-HC data in an ongoing effort to promote RAH-HC data integrity on a provincial and national level.

ADL and IADL Scales and Associations

Assessment of functional independence in older adults is an active area of research that has led to the development of multiple assessment instruments in both the ADL (Lindeboom et al., 2003) and IADL (Sikkes et al., 2009) domains. Although a remarkable amount of research and development has been conducted in this area, a clear consensus regarding definitions of functional independence, and the best method for assessing this domain in older adults, has yet to emerge. To navigate this broad and at times ambiguous literature, this chapter will first review the history and early development of scales that were used to validate the Instrumental Activities of Daily Living Involvement and Activities of Daily Living Long Form scales used in the RAI-HC assessment instrument (*InterRAI*, 2018). Successes and challenges encountered by researchers in their efforts to identify hierarchical and unidimensional properties of independent and blended IADL and ADL scales are then presented. This is followed by a summary of recent research aimed at developing expanded (I)ADL instruments with improved sensitivity to change over time that can also be used to identify individuals with dementia and mild cognitive impairment. The chapter concludes with a summary of relevant research demonstrating associations of IADL with cognitive function and with adverse outcome such as admission to long-term care.

Basic and Instrumental Activities of Daily Living Scales

It is not clear from the literature, or online materials made available by InterRAI (*InterRAI Bibliography*, 2021), precisely how the IADL Involvement and ADL Long Form scales were developed for the RAI-HC. The development of these scales within the RAI-HC is further obscured by the modification of the RAI-HC for use in Canada and that the MDS-HC was utilized for the initial validation study of the IADL and ADL scales contained in the RAI-

HC (Landi et al., 2000). In this study, Landi et al. (2000) use the Pearson's Correlation Coefficient to established validity of the MDS-ADL, MDS-IADL, and MDS Cognitive Performance Scale (MDS-CPS) by establishing correlations with the Barthel ADL Index, Lawton IADL, and Mini Mental State Examination (MMSE), respectively. The authors established correlation coefficients of 0.74 for the MDS-ADL versus Barthel ADL, 0.81 for the MDS-IADL versus Lawton IADL, and 0.81 for the MDS-CPS versus the MMS, concluding that their findings "point out the overall validity of the functional and clinical data contained in the MDS-HC assessment" (Landi et al., 2000, p. 1184). Beyond this early validation study, subsequent efforts to validate the IADL Involvement and ADL Long Form scales used in the RAI-HC are absent from the literature. The issue of adequate reliability and validity testing extends beyond the subscales of the RAI-HC to include Quality Indicators (QIs) derived from these subscales and used to measure processes and outcomes expected to occur with certain frequencies (Wagner et al., 2020). Wagner et al. (2020) conclude that the available literature contained "insufficient reporting of RAH-HC QIs validation processes and reliability, as well as missing state-of-the-art methodologies" (p. 1).

With the context of these evidential shortcomings in mind, the following sections identify and review ADL and IADL scales that resemble and possibly influenced development of the RAI-HC IADL Involvement and ADL Long Form scales as well as the Barthel ADL and Lawton IADL scales used by Landi et al. (2000) in their validation study. The history of ADL and IADL assessment instrument development has progressed differently, although both constructs emerged at about the same time. There were more early ADL assessments, yet research into subsequent development and validation of those initial instruments has not seen a resurgence since. In contrast, the Lawton IADL scales tool remained largely unchallenged as the benchmark

IADL assessment instrument for many years, until efforts to expand and refine IADL assessments gained traction in the last 10-15 years. To provide balance to this review, several early ADL scales are presented, with the bulk of IADL scale review being left for more recent developments with extended IADL assessments.

Basic Activities of Daily Living

Basic Activities of Daily Living (ADL) are self-maintenance and personal-care activities such as eating, dressing, grooming, bathing, toileting, and transferring (e.g., getting in and out of bed). The construct of ADL can be traced back to the development of several seminal instruments such as the Physical Self-maintenance Scale (Lawton & Brody, 1969), Katz Index of Independence in Activities of Daily Living (Katz et al. 1963), and the Barthel Index (Mahoney & Barthel, 1965).

The Physical Self-Maintenance Scale (PSMS) was developed to create a broad and consistent rating scale for use with older adults residing in community or residential care settings (Lawton & Brody, 1969). This scale encompasses six behaviors: toileting, feeding, dressing, grooming, ambulation, and feeding, and can be administer by any health professional using informants such as the patient, family member, or health care employee who has observed the patient. These six behaviors are assigned five levels of difficulty to form a cumulative Guttman scale, where agreement with a particular level of independence indicates agreement as to the subject’s dependence with all preceding levels for each behavior. For example, with the behavior of Feeding there are five possible levels of independence, 1) Eats without assistance, 2) Eats with minor assistance at mealtimes, 3) Feeds self with moderate assistance and is untidy, 4) Requires extensive assistance for all meals, 5) Does not feed self at all and resists efforts of others to feed [them]. If a subject is rated as, 3) Feeds self with moderate assistance and is untidy, this item and the preceding two items are scored as 1, resulting in a cumulative score of 3 for the behavior of Feeding. By ranking the subject's behavior in this manner, the assessor(s) agree that the subject is unable to, 1) Eats without assistance or, 2) Eats with minor assistance. In the resulting 24 point scale, 30 indicates full dependence for all six ADL behaviors and 6 indicates full independence (Lawton & Brody, 1969).

When developing the PSMS scale, Lawton & Brody (1969) confirmed a high reproducibility coefficient of 0.96. Subsequent investigations into the reliability of the PSMS identified the interclass correlation coefficient (ICC) of inter-observer reliability using the PSMS of r = 0.96 with a rating > 0.80 considered excellent. The test-retest coefficient emerged at r = 0.56 with a rating > 0.60 considered good (Edwards, 1990). Edwards (1990) also examined the ICC between self-report (SR) and direct observation (DO), revealing a poor correlation range of 0.17-0.45 between SR and DO, with patient SR invariably higher than DO. A more recent investigation into the interrater reliability between a variety of health care professionals such as a public health nurse, psychiatrist, clinical psychologist, neurologist, and occupational therapist demonstrated excellent interrater reliability for the PSMS with all ICC values being > 0.80 or higher between all professionals (Hokoishi et al., 2001).

The Katz Index of Independence in ADL Activities, or Katz ADL, was initially developed to monitor recovery of older adults with a fractured hip and then generalized to a broader population of aging adults and those with chronic disabilities (Katz et al., 1963). To do this, Katz and his colleagues recruited 1,001 participants that were 40 years of age and older and living with a mix of disabling conditions. Of the participants, 627 were living with the outcome of a fracture of the hip, with cerebral infarction or multiple sclerosis accounting for another 627 participants. The remaining 374 were living with arthritis, malignancy, cardiovascular disease, amputation, paraplegia, or quadriplegia. Katz et al. (1963) presented the Katz ADL scales with an A-G scoring system in which A represented independence in all ADL domains and G represented dependence with all 6 ADL activities. The authors presented the construct of a predetermined hierarchy of functional decline and provided an “other” option to be used if a person was dependent with at least two Katz ADL functions but not classifiable as C, D, E, or F (Katz et al., 1963).

To support construct validity of the tool, the authors demonstrated that 93% of participants could be classified in one of two distinct hierarchical patterns of functional decline. In the final discussion of the theoretical significance of these patterns, Katz et al., (1963) postulate that older adults’ patterns of functional decline reflect the reversed order of child development processes, a process sometimes referred to as ‘last in, first out’, indicating that ADL behaviors that are last to develop in childhood are first to decline in old age. The authors conclude that 86% of participants followed a hierarchy of emerging dependence that began with bathing, followed sequentially by dressing, going to the toilet, transferring, continence, and feeding (Katz et al., 1963). There is little evidence supporting reliability and validity of the Katz ADL index beyond the development and demonstration of construct validity within early publications by Katz and his colleagues (Katz et al., 1970; Katz et al., 1962, 1963). Some more recent evidence of criterion validity has emerged, with the Katz ADL index showing strong concordance with the Barthel index (Hartig et al., 1997). Other evidence has demonstrated that the Katz ADL index predicted length of hospital stay following stroke (Mor et al., 1994).

Although the index was initially developed by Katz to be used as a generic measure of functional status for working age adults, its primary use has been with the elderly (Cohen & Marino, 2000). The challenge of accurately scoring individuals who did not meet the exact hierarchy proposed by Katz et al. also persisted and may have limited wider spread use. In response to these limitations, Lazaridis et al. (1994) conducted a comprehensive study of possible ADL hierarchies that may emerge when using the Katz ADL scale and to determine if the presumed hierarchy reported by Katz (1963) adequately summarized disability profiles. The authors demonstrate that participants in their study entered the Katz hierarchy at multiple points, that at least four hierarchies fit the data as well as the original Katz hierarchy, and conclude that a multiplicity of progressive disability profiles may exist (Lazaridis et al., 1994).

The Barthel Index (BI) was derived from an index used informally in several hospitals within the state of Maryland, USA, that had been in use since 1955, and it was first introduced as the BI in 1965 (Mahoney & Barthel, 1965). The BI was first developed to measure initial status and rehabilitation progress for patients involved in rehabilitation for stroke or other neurological disorders and the authors of the scale make no claims regarding a unitary construct or hierarchical relationships between items. The BI assesses 10 ADL items across the domains of self care and mobility, and the initial scoring of the tool was somewhat obscure as response options are weighted and range between 5 and 15, with a final score of 100 indicating full independence. The authors conclude that patients with a BI score of 100 may not require hospitalization or physical therapy (Mahoney & Barthel, 1965). Like the Katz ADL, the BI assesses participants through direct observation and review of medical records, but unlike the Katz ADL the BI measures capacity rather than disability. As the BI has been in use for an extended time, there have been many opportunities to gather reliability and validity findings and the scale has emerged as a benchmark against which other ADL scales are often measured (Cohen & Marino, 2000).

The BI was adapted to a trichotomous scoring that, in essence, provides three levels of response for each of the 10 ADL items, with 0 = unable, 1 = needs some assistance, and 2 = independent, leading to a maximum score of 20 which indicates full independence (Collin et al., 1988). An early meta-analysis of the BI and other ADL scales presents evidence that the BI has reasonable psychometric properties. Content and construct validity were rated as excellent and responsiveness validity was rated as good. Observer and test-retest reliability were also rated as excellent, although the BI falters in terms of internal consistency and is rated as poor (Law & Letts, 1989). The internal consistency shortcoming noted by Law & Letts was more recently replicated in a study of the BI's test-retest reliability, which indicated generally high agreement at >75% but considerable variation in the kappa coefficients for each of the 10 items (Green & Young, 2001).

Functional independence with ADL is assessed within the RAI-HC using the ADL Self-Performance scale that rates 10 domains of ADL, including mobility in bed, transferring, locomotion in home, locomotion outside of home, dressing upper body, dressing lower body, eating, toilet use, personal hygiene, and bathing. Participants are initially assessed on these 10 items by asking to what extent did they require assistance in the last 3 days, and rating them on a 7-point scale as: independent (0); setup help only (1); supervision (2); limited assistance (3); extensive assistance (4); maximal assistance (5); and total dependence (6), with items rated as 8 if they did not occur regardless of ability. To generate the ADL-Long Form scale, the initial 7-level rating system is transformed within the RAI-HC software to a 4-level rating system with level assistance required in the last 3 days rated as: independent (0); supervision (1); limited assistance (2); extensive assistance (3); and total dependence (4). In situations when the ADL task did not occur the item is also scored as 8. Of the initial 10 items in the ADL Self-

Performance scale, 7 are retained in the ADL-Long Form scale: bed mobility, transferring, locomotion in the home, dressing upper body/dressing lower body (combined), eating, toilet use, and personal hygiene (CIHI, 2013). The final score is derived across the 7 items and has a range of 0-28, with 0 indicating full independence and 28 indicating complete dependence on care.

Instrumental Activities of Daily Living

Instrumental activities of daily living (IADL) are complex functional skills required for independent community living and involve tasks such as financial management, meal planning and preparation, travel within the community, using technology for communication and information finding, maintaining social engagements, as well as attending to medical needs through interacting with medical professionals, following direction, and managing medications.

One of the first and most widely used assessments of IADL is the Lawton IADL scale (Lawton & Brody, 1969). Lawton & Brody (1969) recruited an initial sample of 265 subjects to compare the PSMS and IADL scales and a second group of 180 subjects to conduct the validation study. Participants were drawn from a variety of sources such as homes for the aged, county institution applicants, and psychiatric ward admissions. No descriptive information is provided about the subjects, although the language used indicates they were likely older in age.

The Lawton IADL presents 8 items, with each item having a hierarchical rating of level impairment that ranges from 1-3 for some items and 1-5 on others. The scale uses dichotomous scoring, with 0 = less able and 1 = more able. This results in a maximum score of 8 for women and 5 for men, with a lower score indicating greater dependence. The sex difference emerged in a manner keeping with the era, as authors initially imposed a gender bias by concluding that men do not normally engage in the activities of food preparation, laundry, or housekeeping. The cut points in these hierarchical ratings for each IADL item appear somewhat arbitrary. For example, within the shopping item, participants are rated as 1 if they take care of all shopping needs independently and 0 for shops independently for small purchases, needs to be accompanied on any shopping trips, and completely unable to shop. In contrast, for the ability to use the telephone item, participants are rated 1 for operates the phone on own initiative, dials a few well-known numbers, and answers the telephone but does not dial, but are rated as 0 only for does not use telephone at all. This dichotomous nature of the initial Lawton IADL scale eventually came under scrutiny, leading to a three-level rating system of 1 = unable, 2 = needs assistance, and 3 = independent, leaving the assessor to rate complex behaviors such as meal preparation without the aid of a hierarchical scale to guide them (Graf, 1999).

Lawton & Brody (1969) established the validity of the Lawton IADL by determining its correlation with three scales of the era, the Physical Classification, the Mental Status Questionnaire, and the Behavior and Adjustment rating scales. Correlations between these scales and the Lawton IADL were all significant at the 0.01 or 0.05 level (Lawton & Brody, 1969). Inter-rater reliability was later established within a team of clinicians that included a clinical psychologist, public health nurse, neurologist, and an occupational therapist, with all interrater correlation coefficients being > 0.9 and to be significant at $p < 0.0001$ (Hokoishi et al., 2001). More recent efforts to adapt the Lawton IADL scale for use in Turkey have demonstrated high internal consistency of 0.83 using Cronbach’s alpha and an interclass correlations value of 0.915, leading authors to conclude that the adapted IADL scale has excellent reliability and validity (Isik et al., 2020).

Within the RAI-HC, the IADL Involvement includes 7 items that appear to be largely unchanged from the original Lawton IADL and are drawn directly from the 7 items assessed within the IADL Involvement section of the RAI-HC. These items include meal preparation, managing finances, managing medications, ordinary housework, phone use, shopping, and transportation. Unlike the ADL Long Form, these 7 items represent the entirety of IADL items assessed within the RAI-HC assessment and there is no transformation of the rating scale. Within both the RAI-HC and the final IADL Involvement scale, participants are assessed on activities that occurred in the last 7 days using a 0-3 scale with each item as: independent (0); some help (1); full help (2), or by others (3). Participants are rated as 8 if the activity did not occur. This results in a 0-21 scale with 0 indicating no dependence and 21 indicating complete dependence for all 7 IADL items.

Although there is a large body of research examining IADL assessment and intervention, a gold standard instrument for the assessment of this functional domain has been slow to emerge (Simone Reppermund et al., 2017). This shortcoming in IADL assessment persists through the ongoing use of IADL assessment instruments that lack adequate sensitivity for clinical use, even though it may be possible to use IADL assessment as a measure of normal cognitive aging, for early detection of Mild Cognitive Impairment (MCI), and to differentiate MCI and dementia in older adults (Marshall et al., 2019; Perneczky et al., 2006). As research into the assessment of IADL and ADL advanced into its middle ages, many researchers turned their attention to developing blended IADL/ADL assessment tools that aimed to establish hierarchical relationships between items, with no less than 9 unique combined IADL/ADL scales in active use (Sikkes et al., 2009).

Hierarchical Instrumental and Basic Activities of Daily Living Scales

Hierarchical assessment instruments for use in medical and social sciences research are typically developed to reduce the subjective burden of the individual being assessed and to save time and resources for the assessor. Items in these scales are considered cumulative, to have fixed relationships to one another, and to measure a unitary construct (Kirshner & Guyatt, 1985). These properties allow the assessor to discontinue testing upon discovery of a single item of interest. For example, in a 10-item scale that is organized from least difficult to most difficult, testing can be discontinued when the first instance of ‘can not do’ is encountered. This event may occur early in the assessment process in response to the first item, thereby limiting assessment time. This assessment approach has appeal in busy clinical settings and is used to support minimal inquiry into functional status, while also bringing the advantage that two people with the same score will have impairment with the same scale items (Kempen et al., 1995). Although hierarchical assessment tools may have appeal for fast paced clinical settings such as those experienced by case managers in HCC, properties of a strong hierarchical assessment typically lack the sensitivity required for longitudinal analysis of individual differences in change over time (Kirshner & Guyatt, 1985). These competing goals create tension between administration efficiency required to reduce assessment burden and the ability to use ADL and IADL assessment instruments to guide individualized care planning and to demonstrate sensitivity to change over time.

Examination of the potential to construct an ADL/IADL hierarchical scale using data collected from 8,900 elderly respondents through the Canadian Study of Health and Aging (CSHA) led to the conclusion that “assumptions regarding ADL/IADL unidimensionality and hierarchy are not always valid, and that ADL and IADL items should be considered in combination” (Thomas et al., 1998). Further examination of these hierarchical relationships within a subset of 1,364 elderly adults from the CSHA using item response modeling provided additional evidence that the combined IADL/ADL scale performs better when separated into distinct IADL and ADL subscales (Breithaupt & Mcdowell, 2001; Spector et al., 1987).

The hierarchical nature of combined IADL/ADL scales is further challenged by the observation that while functional decline typically emerges first in IADL tasks, subsequent progression of ADL/IADL decline demonstrates considerable overlap (Lawton, 1990) and that this pattern of overlap has strong associations with declining cognitive function (Njegovan et al., 2001). Evidence of this nature has led some authors to conclude that the practical assumptions of an IADL/ADL hierarchy are limited to program planning and epidemiological research, while clinical assessment should retain sensitivity by asking all items in both scales (Kempen et al., 1995).

Within the initial RAI-HC scoring software deployed when the RAI-HC was first introduced to Canada in 2006, a 0 to 6-point ADL Self-Performance Hierarchy Scale using 4 of the 7 items in the ADL Long Form was available. More recent updates to the scoring software have provided a 0 to 6-point IADL Capacity Hierarchy Scale which uses 5 of the 7 items in the IADL Involvement Scale and a combined IADL/ADL Functional Scale which blends both the ADL and IADL hierarchy scales into a single 9-point scale (Morris et al., 2013). The combined IADL-ADL hierarchy developed by Morris et al. (2013) retains the 5 IADL items meal preparation, housework, shopping, managing finances, and managing medications, and the 4 ADL items personal hygiene, toilet use, locomotion, and eating. All these scale items are transformed into trichotomous scoring that is consistent with the IADL Involvement Scale and ADL Long Form previously reviewed. Through the process of modifying existing IADL and ADL scales to fit, Morris et al. (2013) were able to conclude that functional loss across the remaining 9 items follows a general hierarchical pattern of progression that can be measured in a valid and reliable manner when using the IADL-ADL Functional Hierarchy Scale (Morris et al., 2013).

Although it is possible to construct hierarchical IADL-ADL scales that may be helpful for epidemiological or health economics studies, their use creates challenges when conducting research into policy that directs the delivery of home care services. Within the province of Ontario, IADL and ADL services are delivered by distinct care providers and organizations, resulting in programmatic segregation of ADL and IADL services. Personal Support Workers are responsible for all ADL care, whereas Homemaking Services are responsible for in-home IADL assistance and subsidized Community Support Services external to HCC are responsible for all out of home IADL care. By combining ADL-IADL into a single hierarchical scale, policy analysts are less able to identify how specific funding and policy decisions guide the scope, level, and effectiveness of IADL and ADL services currently delivered through distinct service models. Trends in hierarchical scales to reducing the total number of items, or refitting trichotomous, or polychotomous, responses to binary scales, reduce scale ranges that may also make these instruments less sensitive to individual or group differences and to change over time. Within the context of the current study, the domains of IADL and ADL are appropriately conceptualized as being distinct factors, with each of these factors having the potential to achieve improved psychometric properties through further development.

Extended Instrumental Activities of Daily Living Scales

In contrast to combined IADL/ADL hierarchies, there are ongoing efforts to develop extended IADL scales to improve sensitivity. Extending of IADL scales can be achieved using different strategies and for use with a variety of clinical populations. For example, it is possible to extend an instrument such as the Lawton IADL scale to include basic ADL, while also adding tasks that require higher order cognitive skills. Other strategies could create an IADL scale that includes aspects of social connectedness and integration such as volunteering or involvement in community groups, or to increase specificity by inquiring about subcomponents of individual IADL tasks. It is also possible to extend IADL scales by focusing specifically on daily living activities that require complex cognitive functions to complete. Numerous examples of extended IADL scales are present in the literature and that emerged at different times, are in differing stages of development, and which are advancing towards a state of being viable for use in research and clinical settings at different rates. Several examples are presented next.

The Nottingham Extended ADL (NEADL) scale (Wu et al., 2011) extends the original 8 item Lawton IADL scale to include 22 unique self report items that cover the four domains of mobility, kitchen use, domestic activities, and leisure. The scale asks participants to record what they have actually done in the last few weeks and to choose: not at all, with help, on your own with difficulty, or on your own. Not at all or with help are scored as 0 and on my own with difficult or on my own are scored as 1. Wu et al. (2001) conclude that the NEADL is sensitive to change during rehabilitation for stroke patients, with a minimal change in score of 4.9 representing true change and a change in score of 6.1 regarded as clinically important. The authors conclude that further research using a larger sample size is recommended (Wu et al., 2011).

The Alzheimer’s Disease Cooperative Study ADL Scale (ADCS-ADL) was initially developed in 1997 to identify which activities of daily living are useful for assessment in clinical trials (Galasko et al., 1997). Galasko et al. (1997) developed the ADCS-ADL by identifying 45 ADL items through a literature review and then administering the items to 242 patients with Alzheimer’s disease and 64 elderly controls at baseline, and for several follow up periods. Within this initial pilot study, 18 items were identified as having good test-retest reliability and to demonstrate some sensitivity to change over time.

The initial developers of the ADCS-ADL did not differentiate between basic ADL and IADL, although the tool includes 4-6 basic ADL and 14 or more IADL items, depending on if the initial 18-item or subsequent 24-item version is used (Perneczky et al., 2006). Perneczky et al. (2006) used the 18-item ADCS-ADL to provide some of the first evidence demonstrating that older adults with MCI may be impaired in complex ADL. This finding was further refined using the ADCS-ADL24, and a cut-point score of 52/53 was used to classify MCI patients with a sensitivity of 0.87 and specificity of 0.87, with the authors concluding that the ADCS-AD24 holds promise to effectively discriminate between heathy older adults and those with MCI (Pedrosa et al., 2010). Although there are multiple examples in the literature of the ADCS-ADL being used as an outcome measure for clinical drug trials (Hellweg et al., 2012; Wilcock et al., 2008), issues have emerged with construct validity. Separable ADL and IADL have emerged within the items, indicating that a distinct IADL scale should be considered (Kahle-Wrobleski et al., 2014).

The IADL-extended (E-IADL) scale emerged in 2013, examining 11 leisure activities (e.g., visiting friends, playing cards, doing unpaid community work) with more traditional IADL (e.g., cooking, managing finances, and wayfinding at home and in community) for scalability, resulting in an integrated 9-item scale (Fieo et al., 2014). Fieo et al. (2014) demonstrated that the E-IADL represented a unitary construct, had moderate associations with processing speed and visual spatial ability, and overcame strong ceiling effects associated with the original 9-item IADL scale used in the study. The authors conclude that the E-IADL may be suitable for detecting early indicators of cognitive impairment in the absence of dementia (Fieo et al., 2014). Subsequent longitudinal analysis using the E-IADL has revealed that worse E-IADL scores at baseline were associated with more rapid declines in speed of processing and executive function and that worse memory at baseline was associated with more rapid decline in E-IADL scores (Fieo et al., 2018).

Another recent entrant to the field of IADL assessment is the Amsterdam IADL Questionnaire (A-IADL-Q) (Sikkes et al., 2012). The A-IADL-Q is unique in that the construct of IADL was first defined by interviewing twelve experts, including neurologists and occupational therapists, as “IADLs are complex activities with little automated skills for which multiple cognitive processes are necessary” (Sikkes et al., 2012, p. 537). A critical analysis of IADL items from several existing scales was then conducted, during which items were reviewed through an iterative process with the expert panel and additional items were generated in partnership with ten informants of dementia patients. This process resulted an initial survey of 75 IADL questions across domains such as household activities (e.g., getting groceries, cooking), using household appliances (e.g., dishwasher, microwave), managing finances, using computers and other technological devices, operating media devices (e.g., remote control or a new television), leisure activities such as playing games, and driving or otherwise accessing the community. The survey was then designed to be administered through an adaptive computerized testing procedure that took approximately 25 minutes to complete. Early validation of the test yielded positive results, with authors concluding that the 75 item A-IADL-Q measures a unitary construct and is both reliable and valid (Sikkes et al., 2013).

Further research demonstrated that the A-IADL-Q is sensitive to change over time and to be related to global cognition, memory, and executive function measures (Koster et al., 2015). The items were then refined, resulting in a 30-item version that demonstrates exceptional internal consistency and concordance with the previous 75-item version (Jutten et al., 2017). Since then, the A-IADL-Q has been validated in eight international countries, including the English speaking countries the United Kingdom and United States (Dubbelman et al., 2020). Most recently, the 30-item A-IADL-Q has been refined to include items that more accurately reflect the advancing nature of technology use in the United Kingdom, resulting in a self report version that will undergo further testing and validation, the A-IADL-A-UK (Stringer et al., 2021).

The A-IADL-Q has several advantages when compared to other extended IADL assessment instruments. The tool was developed from inception to establish a unitary IADL construct and to have adequate range in the scale to achieve sensitivity to change over time. The test also outperforms comparable tests, such as the ACDS-ADL, in its ability to accurately discriminate between older adults with healthy cognition and those with MCI and dementia. Further, the adaptive, computerized, administration of the tool allows for administration in many different clinical and research settings, and a paper and pencil version is also available.

Early detection of mild cognitive impairment prior to the onset of dementia has been an intensive area of research for many years. Recent advances in assessment tools allow for the assessment of cognitive status as it manifests in functional independence with IADL. These changes to the landscape of early detection of both cognitive impairment and associated functional limitations creates new opportunities for both early detection and intervention research and program delivery to bolster efforts to delay or prevent adverse events such as transition to residential care.

Instrumental Activities of Daily Living Associations

The associations between IADL and cognitive impairment are foreshadowed by the previous expanded IADL assessment tools and will be further described here. The existing relationship between IADL impairment and increased risk of transition to a LTC type facility will also be reviewed. Evidence is presented which supports the argument that misconceptions may exist for policy makers in Ontario who view more proximal changes in function such as advancing ADL dependency and dementia as the primary drivers of LTC placement. This section will conclude by presenting the possibility of a feed-forward, causal relationship between early onset IADL impairment and the hastening of ADL disability and transition to LTC.

IADL and Cognition

IADL exemplify day to day functional applications of a multiple cognitive processes to complete complex tasks necessary for independent living. Performance of both episodic memory and executive function (EF) is associated with longitudinal change in IADL, with each cognitive domain making unique contributions (Fariasi et al., 2009), while the self awareness necessary for effective performance monitoring of functional independence with IADL is partially mediated by cognitive reserve (Suchy et al., 2011). Further, as Koehler et al., (2011) have demonstrated in both cross section and longitudinal analysis, EF is strongly associated with complex tasks such as shopping, while episodic memory shares strong associations with independence with medication management, with EF performance accounting for up to 50% of the variance in overall IADL performance (Karzmark et al., 2012). Non-content memory processes such as temporal, prospective, and source memory also account for modest amounts of variance in overall IADL performance (Schmitter-Edgecombe et al., 2009). Of the various EF subcomponents, inhibitory control provides unique predictive capacity of independence with IADL (Jefferson et al., 2006).

The strong associations between cognitive performance and IADL function have led to an evolving literature linking IADL function to cognitive impairment. Longitudinal investigations demonstrate that IADL impairment is associated with an increased rate of cognitive decline (Rajan et al., 2013) and predicts dementia at one (Barberger-gateau et al., 1993) and two year follow-up (Sikkes et al., 2011). Subtle differences in IADL function are also associated with risk of dementia onset ten years later (Pérès et al., 2008), and small increases in cognitive impairment while in hospital are associated with higher odds of new IADL functional decline upon return to community living (Zisberg et al., 2016). IADL with high cognitive demand have further emerged as an early indicator of mild cognitive impairment (Reppermund et al., 2013). Restrictions with independent living skills can also be reported differently by men and women, with women tending to reference these difficulties as subjective memory complaints (SMC) while men tend to report their difficulties only in terms of IADL function (Pérès et al., 2011). When compared to a control group of healthy adults, those with SMC were also observed to be significantly less independent across several IADL tasks such as using the telephone, shopping, managing finances, and managing medications (Ikeda et al., 2019).

Although early efforts to use IADL assessment to predict cognitive impairment were challenging (De Lepeleire et al., 2004), the strong associations between IADL and cognition led to the development of cognitive impairment screening tools that expanded the scope of IADL definitions and assessment such as the Sydney Test of Activities of Daily Living in Memory Disorders (STAM) (Reppermund et al., 2017), the Amsterdam IADL Questionnaire (A-IADL-Q) (Sikkes et al., 2012), and the Integrated Alzheimer’s Disease Cooperative Study ADL Scale Mild Cognitive Impairment (ACDS-ADL MCI) (Wessels et al., 2015), with all of these tools having good psychometric properties and the ability to reliability differentiate between healthy older adults and those with MCI and dementia (Jutten et al., 2017; Perneczky et al., 2006b; Reppermund et al., 2017; Sikkes et al., 2013).

IADL and Long-Term Care

Considerable efforts have been made to identify predictors of LTC admission. Bharucha et al. (2004) examined comprehensive baseline data from a longitudinal study (1989-2001) collected from 1,147 working class adults from southwestern Pennsylvania, aged 66 years and older. Using admission to a nursing home as the outcome measure, Cox proportional hazards models were employed to identify predictors of admission. From the initial assessment battery, the authors determined that, in order of association, dementia, age, IADL disability, and worse/less social support emerged as being most predictive of nursing home admission (Bharucha et al., 2004).

Friedman et al. (2005) examined baseline data from a longitudinal study (1990-1998) of 4,646 participants, 55 years of age and older, who were accessing senior care programs in California. These authors also used baseline values and Cox proportional hazards models to evaluate risk over time and determined that, in order of association, age, IADL dependence, and bowel incontinence were most predictive of nursing home placement (Friedman et al., 2005). In another longitudinal study conducted at the University of Michigan, baseline data from 5,980 respondents who were 65 years of age or older was examined. Using logistic regression, the authors revealed that the odds of long-stay admission to LTC increased by 1.1 times for each year of age and by 1.1 time for each single point increase on the IADL index. They also discovered that having a psychiatric condition increased the likelihood of LTC admission by 47%, while living alone increased the likelihood by 41% (Cai et al., 2009).

A similar relationship between IADL function and risk of nursing home admission was recently replicated using baseline data from a study in France, with each point increase in IADL impairment raising risk of placement by 1.15 times (Dufournet et al., 2019). The Melbourne

Longitudinal Studies on Healthy Ageing Program used baseline data collected from 1,000 Australians. In keeping with similar findings in the U.S., the authors discovered that older age, IADL dependence, cognitive impairment, and underweight BMI were the strongest predictors of LTC admission (Kendig et al., 2010). IADL impairment and a family member living further away also emerged as predictive of LTC within a sample of 144 older adults in New Zealand, using data collected with the interRAI Minimum Dataset for Home Care (Jorgensen et al., 2009).

The Toronto Balance of Care (BoC) project was conducted by a multidisciplinary, multi-university research team in partnership with the Toronto Central Community Care Access Center (CCAC). To examine pathways for home care recipients at risk of admission to LTC, the authors stratified 1,681 individuals on the LTC waitlist as of October 2007, based on cognitive performance, ADL and IADL function, and the presence or absence of an informal or family caregiver (Williams et al., 2009). The authors discovered that while 43% of those waitlisted for LTC were fully independent with ADL, only 3% were fully independent with IADL such as meal preparation, housekeeping, and telephone use. For those with IADL impairment, 32% required some help and 65% were fully dependent on others. Through the development of patient vignettes and iterative consultation with the multidisciplinary research team, the authors conclude that:

> while it is often assumed that the LTC placements are “triggered” by cognitive decline or difficulties performing “heavy care” ADLs, “lighter care” IADLs, such as transportation, nutrition and housekeeping, emerged as a key determinant of the [LTC] pathway (p.102).

Further, Williams et al. (2009) observe that this finding is consistent with national and international evidence, suggesting that when services can be selected from a broad continuum of available service options “there is a consist tendency towards ‘downward substitution” that is, the use of lighter care IADL supports instead of healthcare” (Williams et al. 2009, p. 102).

IADL as Contributor to Physical and Cognitive Decline

The current state of the art with IADL research has yielded a new class of assessment instruments that show great promise for the early identification of both IADL restriction and mild cognitive impairment in community-dwelling older adults. Each of these new instruments identifies multiple areas of functional impairment. However, to date, none of these areas of functional impairment have been targeted for intervention to determine if the progression of IADL impairment can be altered or if intervention within the domain of IADL may stabilize, slow, or even reverse mild cognitive impairment. Capacity with IADL function supports behaviors associated with heathy aging such as physical activity (Hillman et al., 2006; Muscari et al., 2010), plasticity inducing cognitive activity (Lövdén et al., 2010b), social integration (Crooks et al., 2008), and maintaining balanced nutritional intake (Meydani, 2001). Taken together, early identification and intervention IADL impairment may provide yet unrealized opportunities to support healthy aging in older adults, to stabilize or possibly reverse cognitive decline, and to delay the eventual need for home care services and LTC placement.

Research Objectives

The primary objective of this dissertation is to compare trajectories and change points of IADL and ADL scores in the years preceding transition to residential care to determine whether (a) change points exist and (b) if there is a temporal relationship between them. To further evidence this primary objective, the main data sample will be stratified by sex and the presence or absence of a caregiver living with the participants. This approach to interpreting and subgrouping the initial sample will yield a total of 18 IADL and ADL models that are compared on 9 occasions.

Aim of Current Study

This study utilized data gathered from home care recipients using the RAI-HC (*InterRAI*, 2018) in Ontario and deployed change point models (C. Hall et al., 2000; Kiuchi et al., 1995) to identify whether IADL and ADL may enter an accelerated trajectory for those who enter LTC when compared to those who are able to continue receiving home care services. In addition to examining this phenomenon on a population level, subsamples based on sex and the presence or absence of informal caregivers in the home are also examined.

Research Questions

Question 1: Do measures of IADL and ADL exhibit a change point prior to residential care discharge, at which juncture participants discharged to residential care experienced a more rapid functional decline relative to home care recipients who remain in community?

Question 2: Do the change points for IADL precede those of ADL?

Question 3: Are there sex differences in the temporal onset of IADL and ADL change points and the related normative age and transition to residential care slopes?

Question 4: Are there differences in the temporal onset of IADL and ADL change points and normative age and transition to residential care slopes for participants with and without a caregiver living in the same home?

Methods

Data acquisition

Data for this project were made available through grant funding provided by the Canadian Frailty Network for an initial research project titled “Modeling Changes in Assessment to Predict Needs and Guide Care Planning in Home Care”. The data were acquired from the Canadian Institutes of Health Information (CIHI) and were hosted on a secure server at the University of Victoria. Approval from the Human Research Ethics Board at the University of Victoria was obtained for this study (File number: J2016-011). The RAI-HC data from Ontario, Canada, are used for this analysis. Ontario was one of the first provinces to adopt the RAI-HC assessment tool and in turn has the longest historical record for longitudinal analysis. Unlike several other provinces, including British Columbia, Ontario collects RAI-HC assessments every 6 months rather than once a year. With data collected at 6-month intervals from over 900,000 participants during the years 2006-2015, the RAI-HC data from Ontario available for this study is well suited for the proposed longitudinal analyses.

Participants

Preliminary data selection steps are shown in Table 1 with the mean, median and standard deviation values for IADL and ADL scores and age at first assessment. The initial sample of Ontario home care recipients contained 941,029 participants who were actively receiving home care services at the end of the January 1, 2006 – June 30, 2015 data collection period or had been discharged during this time for one of 10 possible reasons: 1) client no longer requires service; 2) client referred to other health service; 3) client no longer eligible for service; 4) client withdrew/terminated service; 5) client moved out of area; 6) client died; 7) agency unable to contact/reach client; 8) physical environment unsuitable for service delivery; 9) service terminated due to occupational health and safety reasons; and 10) other. Clients discharged under 2) client referred to other health service, are then referred to either 1) hospital; 2) residential care facility; 3) hospital-based ambulatory care service; 4) assisted living setting; 5) community-based health service/program; or 6) other.

The following data steps were used to select the final participant groups (quantitative descriptions of these data steps can be seen in Table 1). Participants who received their first RAI-HC assessment while in hospital were excluded as they may have been assessed only once during a hospital visit for a time limited medical issue from which they recovered fully. This decision was further informed by the systematic omission of the IADL assessment from the RAI-HC when administered in hospital and because it is well understood that those with a first assessment in hospital often have a unique trajectory through the health care system when compared to those who receive their first RAI-HC assessment at home (CIHI, 2017). Further, the practice of not assessing IADL during hospital admissions for participants who had their first assessment in community created systematic omission of IADL assessment data for these instances of assessment. This systematic imbalance between IADL and ADL assessments in the data was corrected by removing all RAI-HC assessments conducted in hospital from the record. The minimum age of first assessment was restricted to participants 65 years of age and older to limit the confounding influence of individuals who may have struggled with illness or disability that necessitated home care services as younger adults. Participants who remained in care at the end of the data collection were retained. Participants who were discharged during the data collection period were retained only if their discharge reason variable was coded as, 2) referred to other health service, and with a subsequent discharge subcode of 2) to residential care facility.

Due to geographic changes to the organization of HCC services in 2007 and subsequent changes to home and community care policies regarding hours of care and scope of services which occurred in 2008 (Ontario, 1994), inclusion was limited to participants who have a date of first assessment on or after January 1, 2008. To further align home care clients in this study with the long-stay criteria of home and community care (Ontario, 1994), study participants with a single assessment and a time in care of less than 6 months following the date their file was opened with HCC were also excluded.

Table 1 Data Steps: Age, IADL and ADL Scores at Time of First Assessment

	Total			Women			Men		
Variable	M	Md.	SD	M	Md.	SD	M	Md.	SD
Full Ontario Sample									
	N= 941,029			n = 584,438			n = 356,591		
Age	77.25	81.00	13.54	78.17	81	13.31	75.74	79	13.76
ADL Long	4.52	2.00	6.57	4.32	1.00	6.46	4.84	2.00	6.73
IADL Inv.	11.94	12.00	5.92	11.68	12.00	5.87	12.37	13.00	5.99
First Assessment in Community									
	n = 831,917			n = 519,996			n = 311,921		
Age	76.92	80.00	13.75	77.81	81	13.52	75.43	79	13.99
ADL Long	3.44	5.54	1.00	3.28	0	5.45	3.70	1.00	5.69
IADL Inv.	11.94	12.00	5.92	11.68	12.00	5.87	12.37	13.00	5.99
First Assessment at Age 65 Years and Older									
	n = 695,514			n = 442,579			n = 252,935		
Age	81.77	83.00	7.59	82.31	83	7.59	80.82	81	7.58
ADL Long	3.45	5.43	1.00	3.30	1.00	5.37	3.72	2.00	5.51
IADL Inv.	12.43	13.00	5.75	12.13	12.00	5.67	12.37	14.00	5.77

	Remained in Community and Discharged to Residential Care								
	n = 202,572			n = 136,697			n = 65,875		
Age	82.89	84.00	7.37	83.40	84	7.31	81.85	83	7.39
ADL Long	4.32	2.00	5.70	4.12	2.00	5.65	4.75	3.00	5.80
IADL Inv.	14.23	15.00	5.27	13.93	15.00	5.31	14.86	16.00	5.15
	First Assessment After December 31, 2007								
	n = 183,049			n = 122,451			n = 60,598		
Age	82.93	84.00	7.39	83.46	84	7.33	81.86	83	7.40
ADL Long	4.48	2.00	5.76	4.30	2.00	5.72	4.86	3.00	5.82
IADL Inv.	14.41	15.00	5.20	14.14	15.00	5.23	14.95	16.00	5.10
	Long Stay Home Care Client of Greater Than 6 Months								
	n = 121,470			n = 82,358			n = 39,112		
Age	82.79	83.00	7.36	83.40	84	7.31	81.85	83	7.39
N. of Obs.	2.87	2.00	1.99	2.93	2.00	2.04	2.75	2.00	1.87
ADL Long	4.28	2.00	5.61	4.04	2.00	5.53	4.79	3.00	5.75
IADL Inv.	14.17	15.00	5.24	13.83	15.00	5.28	14.88	16.00	5.75

Note: Sample selection excluded participants from outside Ontario, Canada, with a first instance of assessment while in hospital, who were under 65 years of age at the time of first assessment, who were discharged for any reason other than residential care admission, those with a first assessment date prior to January 1, 2008, and those who were not long stay clients of HCC of greater than 6 months.

N. of Obs. = Number of Observations; ADL = Activities of Daily Living; IADL = Instrumental Activities of Daily Living.

Final Sample and Subsamples

Entries at the bottom of Table 1 reveal the final sample of 121,470 participants that were deployed for this study. Within the full sample of participants represented in Table 2, there were 82,358 women and 39,112 men. At the time of first assessment, using the RAI-HC, the mean age of women (83.40 years) was 1.4 years greater than that of men (81.85 years). Women had a slightly higher mean number of observations at 2.93 compared to 2.87 for men. The mean ADL impairment score at time of first assessment is slightly higher for men than women. ADL scores within the full sample and for both men and women have strong positive skewness of 1.76 for all participants with 1.86 and 1.58 for women and men, respectively. Mean ADL scores at first assessment also have strong kurtosis for all participants of 2.93, with 3.33 and 2.27 for women and men, respectively. The mean IADL impairment score is also slightly higher for men than women and IADL scores across all groups have a moderate negative skew of -0.61, with -0.52 and -0.82 for women and men, respectively. The IADL scores also have moderate kurtosis for all participants at -0.48, with -0.62 and -0.05 for women and men, respectively. From this initial sample, two further subsamples were selected, those with a primary caregiver in the home and those without a primary or secondary caregiver in the home.

Table 2 Full Sample: Remained in Community and Discharged to Residential Care

	All Participants			Women			Men		
Variable	M	Md.	SD	M	Md.	SD	M	Md.	SD
	n = 121,470			n = 82,358			n = 39,112		
Age	82.79	83.00	7.36	83.40	84	7.31	81.85	83	7.39
N. of Obs.	2.87	2.00	1.99	2.93	2.00	2.04	2.75	2.00	1.87
ADL Long	4.28	2.00	5.61	4.04	2.00	5.53	4.79	3.00	5.75
IADL Inv.	14.17	15.00	5.24	13.83	15.00	5.28	14.88	16.00	5.75

Note: M = Mean; Md. = Median; SD = Standard Deviation; N. of Obs. = Number of Observations; ADL = Activities of Daily Living; IADL = Instrumental Activities of Daily Living.

Subsample 1: No Primary or Secondary Caregiver in the Home

The subsample of participants with no primary or secondary caregiver living in the home at the time of first assessment is represented in Table 3. At the time of first assessment, there were 49,004 women and 15,157 men and the mean age of women (84.43 years) was 1.4 years greater than that of men (83.03 years). Women have a slightly higher mean number of observations of 2.93 compared to 2.70 for men. The mean ADL score at time of first assessment is slightly higher for men than women and ADL scores across all groups had a strong positive skewness of 2.12 for all participants, with 2.16 and 1.98 for women and men, respectively. Mean ADL scores at first assessment also have strong kurtosis for all participants of 4.70, with 4.93 and 4.03 for women and men, respectively. The mean IADL score is also slightly higher for men than women and IADL scores across all participants have a moderate negative skew of -0.37, with -0.34 and -0.45 for women and men respectively. The IADL scores also have moderate kurtosis for all participants at -0.84, with -0.85 and -0.80 for women and men, respectively.

Table 3 Subsample 1: No Primary or Secondary Caregiver in the Home

	All Participants			Women			Men		
Variable	M	Md.	SD	M	Md.	SD	M	Md.	SD
	n = 64,161			n = 49,004			n = 15,157		
Age	84.10	85.00	7.16	84.43	85	7.00	83.03	84	7.54
N. of Obs.	2.88	2.00	2.01	2.93	2.00	2.05	2.70	2.00	1.86
ADL Long	3.39	2.00	5.05	3.32	1.00	5.02	3.61	2.00	5.15
IADL Inv.	12.94	14.00	5.52	12.87	13.00	5.47	13.15	14.00	5.67

Note: M = Mean; Md. = Median, SD = Standard Deviation; N. of Obs. = Number of Observations; ADL = Activities of Daily Living; IADL = Instrumental Activities of Daily Living.

Subsample 2: Primary Caregiver in the Home

The subsample of participants who had a primary caregiver living in the home at the time of first assessment are represented in Table 4. At the time of first assessment, there were 36,686 women and 25,296 men and the mean age of women (81.85 years) was 0.52 years greater than that of men (80.98 years). Women have a slightly higher mean number of observations at 3.13 compared to 2.70 for men. The mean ADL score at time of first assessment is slightly higher for men than women and the distribution of ADL scores across all groups has a strong positive skewness of 1.49 for all participants, with 1.55 and 1.41 for women and men, respectively. The distributions of ADL scores at first assessment also have moderate kurtosis for all participants at 1.86, with 2.01 and 1.67 for women and men, respectively. The mean IADL score is also slightly higher for men than women and the distribution of IADL scores across all participants has a moderate negative skew of -0.81, with -0.71 and -0.97 for women and men, respectively. The IADL scores also have small kurtosis values of 0.06 for all participants with -0.18 and 0.53 for women and men, respectively.

Table 4 Subsample 2: Primary Caregiver Lives in the Home

	All Participants			Women			Men		
Variable	M	Md.	SD	M	Md.	SD	M	Md.	SD
	n = 63,984			n = 38,686			n = 25,298		
Age	81.5	82.00	7.32	81.85	82.00	7.41	80.98	82	7.16
N. of Obs.	3.03	2.00	2.08	3.13	2.00	2.16	2.70	2.00	1.86
ADL Long	5.21	3.00	6.01	5.02	3.00	6.03	5.48	4.00	5.97
IADL Inv.	15.42	16.00	4.63	15.10	16.00	4.73	15.88	17.00	4.43

Note: M = Mean; Md. = Median, SD = Standard Deviation; N. of Obs. = Number of Observations; ADL = Activities of Daily Living; IADL = Instrumental Activities of Daily Living.

Measures

Resident Assessment Inventory-Home Care (RAI-HC).

The RAI-HC (CIHI, 2021) was developed by interRAI (*InterRAI*, 2018), an international collaborative with the goal of improving the quality of life for vulnerable persons through the development of standardized assessments instruments. InterRAI has developed these instruments for home care, developmental disability, child and youth mental health, hospital systems, palliative care and for other groups and clinical settings (*InterRAI*, 2018). The RAI-HC tool itself was developed in consultation with the provinces of British Columbia and Alberta when the Home Care Reporting System was initially developed (CIHI, 2010). It is intended to provide a standardized, minimal assessment and screening tool for clinical and research use that also aims to be user-friendly and client-centered (Morris et al., 2009). Several subscales of the RAI-HC are derived in part from other standardized measures. For example, the IADL Involvement Scale is derived from elements of the Lawton and Brody IADL Assessment (Lawton & Brody, 1969) but has been rescaled for use within the RAI-HC. Likewise, the ADL Long Form assessment tool uses elements from the Katz ADL scale (Sidney Katz et al., 1970) and the binary (0,1) ratings of the original scale were replaced in the RAI-HC tool with a 5-point scale (0-5) for each item. Elements of these rescaled instruments are also integrated into other unique assessment instruments developed by inter-RAI and its research partners to form analogous diagnostic sub-scales such as the Changes in Health End-States Disease Signs and Symptoms (CHESS) (John P. Hirdes et al., 2014) and the Method of Assigning Priority Levels (MAPLe) (John P. Hirdes et al., 2008). In the following sections, select subscales of the RAI-HC for use in this analysis are summarized.

IADL Involvement Scale. The RAI-HC IADL Involvement Scale estimates participant performance with IADL tasks around the home or in the community as they occurred in the preceding 7 days by asking to what extent they are dependent on others for assistance with meal preparation, ordinary housework, managing finances, managing medications, phone use, shopping, and transportation. The level of assistance is rated as: did on own (0); help some of the time (1); performed with help all the time (2); and, performed by others (3). In situations such as hospitalization when IADL tasks did not occur, items are scored 8. For each participant, a final summary score is derived across the 7 items, with 0 indicating full independence and a score of 21 indicating complete dependence on others for all seven IADL elements.

ADL – Long Form. The RAI-HC ADL Long Form scale estimates participants physical functioning in routine activities of daily life as they occurred in the preceding 3 days by asking to what extent they require assistance with personal hygiene, dressing upper body, dressing lower body, locomotion, toilet use, bed mobility, and eating. The level of assistance is rated as: independent (0); supervision (1); limited assistance (2); extensive assistance (3); and, total dependence (4). In situations when the ADL task did not occur the item is scored 8. For each participant, a final summary score is derived across the seven items that ranges from 0-28, with 0 indicating full independence and 28 indicating complete dependence on care.

Two Key Informal Helpers. The RAI-HC Two Key Informal Helpers scale assesses the availability of caregiver support using a series of dichotomous selections to determine availability and involvement of a primary (e.g., cohabitating spouse) and secondary (e.g., child that does not live with) caregivers. This measure assesses primary and secondary caregiver involvement across several domains such as availability for emotional support, whether the caregiver lives in the same home as the client, access to IADL and ADL support as well as capacity for the caregiver to continue and state of caregiver distress.

Statistical Analyses

The research questions were addressed by fitting a series of piecewise linear mixed models with a change point (Hall et al., 2000; Hall et al., 2009; Thorvaldsson et al., 2010), using maximum likelihood within the SAS Proc MIXED procedure (SAS Institute, Cary, NC, http://www.sas.com). The IADL Involvement Scale and ADL Long Form outcomes were modeled as a function of change in chronological age and time to residential care discharge. Models were adjusted for age at first assessment.

The discharge to residential care slope was indexed by a change point (knot), τ, which indicated the onset of this phase prior to discharge to residential care.

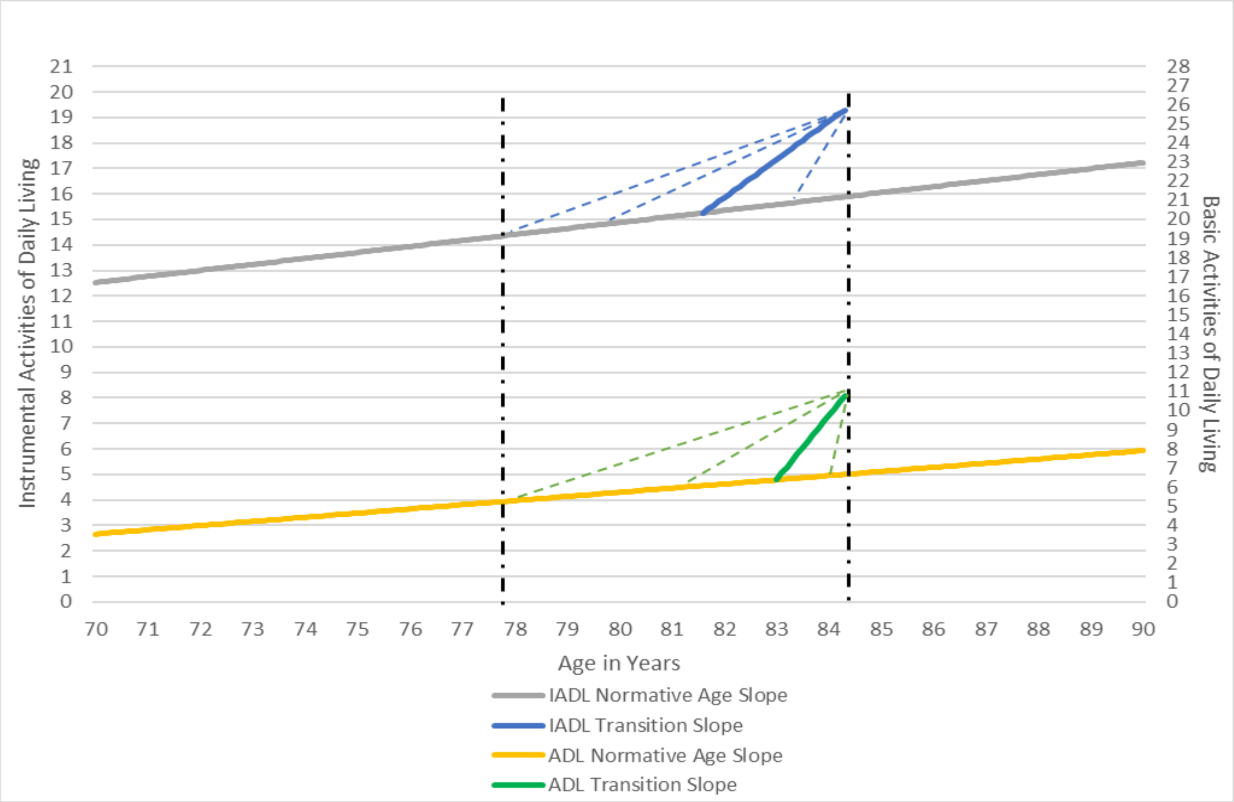
This model was parameterized as follows:

$$\mathrm{IADL}_{it} = \beta_0 + \beta_1(\min[\mathit{AgeAssess}_{it}, \mathit{AgeDischarge}_{i} - \tau]) + \beta_2(\max[0, \mathit{AgeAssess}_{it} - \mathit{AgeDischarge}_{i} + \tau]) + \beta_3\mathit{Age}_{i} + \varepsilon_{it}$$

Where the IADL score for individual *i* at the time *t* is a function of the intercept (β_0), the two slopes of interest and the control variable age at first assessment (AgeFirst). The first slope (β_1) represents rate of IADL change before and after the knot. Prior to the knot β_1 includes normative age-graded changes for participants who remained in care as well as changes that precede more rapid functional decline for participants who were discharged to residential care. After the knot β_1 includes only the normative age-graded changes for participants who remained in care. Time in β_1 is represented as age of assessment (AgeAssess) centered on 80 years. The second slope (β_2) includes only participants discharged to residential care and represents the rate of change preceding discharge to residential care where time is parameterized in 0.1-year increments which count back from the age of discharge (AgeDischarge).

The models assume there is some unknown change point prior to participants being discharged to residential care at which the rate of functional decline, indexed by IADL and ADL scores, increases relative to those who remain in community. To estimate the best fitting change point model an enumerative iteration macro function was developed in SAS. This iteration function calculated the Proc MIXED model at 0.1-year increments spanning the period of data collection of 0 to 7.5 years. A profile likelihood method was then used to select the best fitting change point using a profile likelihood methodology (Hall et al., 2000). The -2 Log Likelihood values for each iteration of the Proc MIXED model were exported as separate datasets and subsequently merged into a single dataset with 76 values (0.1-year increments spanning the entire 7.5-year follow-up) representing the entirety of each enumerative iteration of the statistical models. To identify the best fitting model, the -2 Log Likelihood values were first transformed to a Log Likelihood value and then exponentiated and transformed into values where the best fitting model equals 1 and all other models have a value between zero and one. The critical Chi squared value was then transposed in a parallel manner to identify a 95% confidence interval cut point of 0.1467. Values above 0.1467 are within this 95% confidence interval. Figure 1 illustrates how these models were estimated.

Figure 1 Example Illustration of Model Iterations



Note: The right vertical dashed black line represents the mean age of discharge to residential care for the discharged group. The left vertical black line represents the 7.5-year limit of this longitudinal data collection, beyond which it was not possible to model the data. The dashed blue and green slope lines represent several of the IADL and ADL models that were generated and compared at .1-year increments across the 7.5-year data collection period. The solid blue and green slopes represent the best fitting IADL and ADL models for participants who transitioned to residential care. Small changes to the normative aging grey and yellow IADL and ADL slopes also occurred with each successive model and, for simplicity, are not included.

An a-priori decision was made to include random effects to allow the intercepts and individual participant rates of change for both the age and transition slopes to vary independently. This allowed the model to fit both population averages for the age and transition slopes as well as individual deviations from these slopes. The inclusion of random effects, large sample size, and unbalanced group sizes of those remaining in community versus discharged to residential care informed the decision to select the Kenward-Roger method to approximate degrees of freedom (Schaalje et al., 2001). A post hoc review of Akaike information criterion (AIC) values confirmed that including random effects for intercepts and slopes and using Kenward-Roger to estimate degrees of freedom improved model fit. Missing data was assumed to be missing at random (MAR). AIC was also used to estimate the best fitting covariance structure and an unstructured covariance matrix was subsequently specified (Kincaid, 2000).

When describing the results and comparing differences between groups, an a-priori decision was made to not use statistical methods to compare group means for significant differences or to examine the Chi-squared goodness of fit. This decision was made for two primary reasons. First, the sample used in this study represents the entirety of the population of home care recipients in Ontario during the data collection period and it is not possible to accurately generalize, or infer transfer of these findings, from Ontario to another province or country due to differences in service types and levels as well as the policies which guide service delivery. Second, the sample used for this study is very large, with the smallest subsample having over 7,400 participants. In samples of this magnitude, inferential statistics and *p* values are almost always significant and thereby less meaningful (Lantz, 2013; Wasserstein & Lazar, 2016). Within output tables for the best fitting change point models, *p* values are noted to demonstrate for readers that all values are less than p=0.001 and, subsequently, of little interpretative value.

Results

Full Sample

The final sample represents 121,470 participants. During this data collection, 64,303 remained in community (Table 5) and 57,161 were discharged to residential care (Table 6). The mean age at first assessment of participants discharged to residential care (83.82 years) is 1.95 years greater than those who remain in community (81.87 years). The number of observations for those who remain in community (3.27) is 0.86 observations greater than those who are discharged to residential care (2.41). At first assessment, mean ADL scores for those discharged to residential care (4.40) is 0.22 points greater on the 28-point scale than those who remain in community (4.18). Further, mean IADL scores in the discharge group (15.17) are 1.89 points greater on the 21-point scale than those who remain in care (13.28). Patterns of skewness and kurtosis at first assessment identified in the participant descriptions continue to be present in both groups

Table 5 Final sample: Remained in Community

	All Participants			Women			Men		
Variable	M	Md.	SD	M	Md.	SD	M	Md.	SD
	n = 64,303			n =44,014			n = 20,289		
Age	81.87	83.00	7.56	82.36	83.00	7.50	80.81	81.00	7.57
N. of Obs.	3.27	3.00	2.24	3.36	3.00	2.30	3.09	2.00	2.11
ADL Long	4.18	2.00	5.58	3.88	2.00	5.44	4.82	3.00	5.81
IADL Inv.	13.28	14.00	5.36	12.85	13.00	5.36	14.21	15.00	5.23

Note: M = Mean; Md. = Median, SD = Standard Deviation; N. of Obs. = Number of Observations; ADL = Activities of Daily Living; IADL = Instrumental Activities of Daily Living.

Table 6 Final Sample: Discharged to Residential Care

Variable	All Participants			Women			Men		
	M	Md.	SD	M	Md.	SD	M	Md.	SD
	n = 57,167			n = 38,344			n = 18,823		
Age	83.82	84.00	6.98	84.39	85.00	6.89	82.65	83.00	7.02
N. of Obs.	2.41	2.00	1.53	2.43	2.00	2.04	2.37	2.00	1.48
ADL Long	4.40	2.00	5.65	4.22	2.00	5.63	4.75	3.00	5.68
IADL Inv.	15.17	16.00	4.92	14.96	16.00	4.95	15.60	17.00	4.83

Note: M = Mean; Md. = Median, SD = Standard Deviation; N. of Obs. = Number of Observations; ADL = Activities of Daily Living; IADL = Instrumental Activities of Daily Living.

Frequency of observations for all participants, remain in community and discharged to residential care groups are presented in Table 7. Differences in the mean number of observations between the discharged to residential care and remained in community groups in Tables 5 and 6 are further evidenced in the remains in community and discharged to residential care frequency columns in Table 6. In addition to the mean number of assessments being greater in the remains in community group, the tail of the frequency distribution is more pronounced and extends beyond that of the discharged to residential care group. Within the discharged to residential care group, the frequency of observations drops below 100 after the 10th time of assessment. In accord with the Ontario Home and Community Care policy, RAI-HC assessments are to be administered every 6 months. On this basis, it is possible to estimate that, by the 10th time of assessment, participants have been receiving home supports for approximately 5 years.

Table 7 Final Sample: Assessment Frequency for All Participants

	All Participants		Remains in Com.		Discharged to Res. Care	
N. of Obs.	Frequency	Cumulative Percent	Frequency	Cumulative Percent	Frequency	Cumulative Percent
1	27542	22.67	11032	17.16	16510	28.88
2	42064	57.30	20631	49.24	21433	66.37
3	20943	74.54	11554	67.21	9389	82.80
4	11860	84.31	7162	78.35	4698	91.01
5	6991	90.06	4584	85.48	2407	95.22
6	4431	93.71	3194	90.44	1237	97.39
7	2915	96.11	2212	93.88	703	98.62
8	1847	97.63	1472	96.17	375	99.27
9	1197	98.62	985	97.70	212	99.64
10	705	99.20	604	98.64	101	99.82
11	461	99.58	410	99.28	51	99.91
12	245	99.78	224	99.63	21	99.95
13	154	99.91	137	99.84	17	99.98
14	67	99.96	58	99.93	9	99.99
15	31	99.99	27	99.97	4	100.00
16	9	99.99	9	99.99		
17	3	100.00	3	99.99		
18	2	100.00	2	100.00		
19	2	100.00	2	100.00		
23	1	100.00	1	100.00		

Note: N. of Obs. = Number of Observations; Remains in Com. = Remains in Community; Discharged to Res. Care = Discharged to Residential Care.

The discharged to residential care group is further stratified by sex in Table 8. From Table 5 it is observed that there are nearly twice as many women in the discharged group as men. Although the mean number of assessments are similar, the larger sample size of women is likely responsible for the tail of the frequency distribution in this table being slightly longer and more pronounced for women than men. For men discharged to residential care, the frequency of observations drops below 100 after the 8th time of assessment and for women this occurs after the 9th assessment. With the 6-month assessment frequency, it is estimated that prior to discharge to residential care the frequency of assessments falls below 100 after approximately 4.5 years for men and 5 years for women. These values are displayed to inform the possible effects of left censoring of the data, which may constrain change points closer to the date of discharge to residential care and will be addressed in the discussion.

Table 8 Final Sample: Assessment Frequency Discharged to Residential Care

	Men Discharged		Women Discharged	
N. of Obs.	Frequency	Cumulative Percent	Frequency	Cumulative Percent
1	5493	29.18	11017	28.73
2	7241	67.65	14192	65.74
3	3010	83.64	6379	82.38
4	1509	91.66	3189	90.70
5	777	95.79	1630	94.95
6	374	97.77	863	97.20
7	196	98.82	507	98.52
8	109	99.39	266	99.22
9	64	99.73	148	99.60

10	24	99.86	77	99.80
11	14	99.94	37	99.90
12	7	99.97	14	99.93
13	1	99.98	16	99.98
14	4	100.00	5	99.99
15			4	100.00

Note: N. of Obs. = Number of Observations; Remains in Com. = Remains in Community; Discharged to Res. Care = Discharged to Residential Care.

Full Sample: Change Point Model Estimation

The estimated parameters from the best fitting change point models are shown in Table 9. The profile likelihood method was used to identify the best fitting model, as described in the methods section. The change points represent the time in years prior to discharge to residential care when the discharge group rate of functional decline with IADL and ADL skills begins to accelerate relative to the group that remains in community.

Table 9 Final Sample: Estimates from the Best Fitting Change Point Model Stratified by Sex

	Instrumental Activities of Daily Living			Basic Activities of Daily Living		
	CP Years (95% CI)	Parameters	Fixed Effects (SE)	CP Years (95% CI)	Parameters	Fixed Effects (SE)
All Part.	3.4 (*)	Intercept	17.055** (0.1784)	1.3 (*)	Intercept	17.053** (0.238)
		Age slope	0.29** (0.003)		Age Slope	0.21** (0.003)
		Transition slope	1.521** (.009)		Transition Slope	3.660** (0.029)
Men	2.7 (*)	Intercept	19.962** (0.31)	1.3 (*)	Intercept	20.865** (0.431)

		Age Slope	0.235** (0.005)		Age Slope	0.218** (0.006)
		Transition Slope	1.495** (0.017)		Transition Slope	3.369** (0.049)
Women	3.4 (*)	Intercept	15.055** (.0218)	1.7 (*)	Intercept	15.097** (0.283)
		Age Slope	0.304** (0.004)		Age Slope	0.226** (0.004)
		Transition Slope	1.647** (0.011)		Transition Slope	2.817** (0.027)

Note: All models are adjusted for age at first assessment. *CP Years* refers to the average onset (change point) of acceleration in decline of IADL and ADL functioning. Fixed effects for *Intercept* refer to estimated IADL and ADL score at the age of 80 years within the multifactorial equation. *Age slope* refers to the linear rate of change, as a function of age, both prior to and following the change point for IADL and ADL scores. *Transition Slope* refers to acceleration in decline of IADL and ADL scores relative to the age slope from the point of best fitting knot preceding discharge to residential care from community-based home support services.

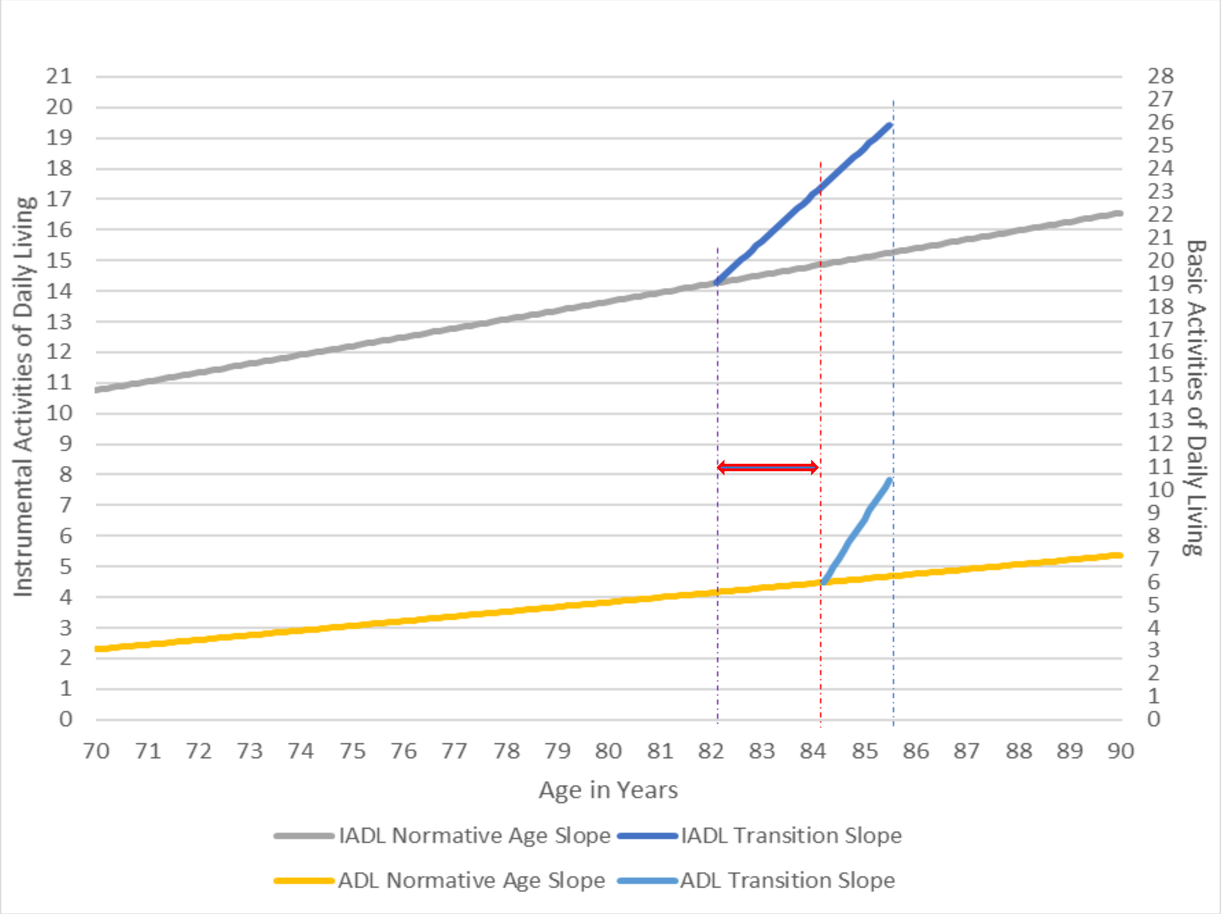
* denotes 95% confidence interval of < ± 0.1 years about the change point. ** denotes *p* value < 0.001.

For the group including both men and women, the best fitting change point prior to discharge for IADL (3.4 years) occurred 2.1 years prior to the change point for ADL (1.3 years). At the change point the slope of functional decline for IADL increased by 1.23 points per year on the 21-point scale and the ADL slope increased by 3.45 points per year on the 28-point scale for discharged participants relative to participants who remained in community (See Figure 2). For the men only group, the change point prior to discharge for IADL (2.7 years) occurred 1.4 years before the change point for ADL (1.3 years). At the change point, the slope of functional decline for men's IADL scores increased by 1.26 points per year on the 21-point scale and the functional decline for ADL score slope increased by 3.15 points per year on the 28-point scale for discharged men relative to men who remained in community (See Figure 3). For the women only group, the change point prior to discharge for IADL (3.4 years) occurred 1.7 years prior to the change point for ADL (1.7 years). At the change point, the slope of functional decline for women's IADL scores increased by 1.34 points per year on the 21-point scale and slope of functional decline for ADL score increased by 2.59 points per year on the 28-point scale for the discharged women relative to women who remained in community (See Figure 4).

Full Sample: Change Point Illustrations

Slopes for the best fitting change point model for all participants in the final sample as well as men only and women only are represented in Figures 2, 3 and 4, respectively. The IADL and ADL transition slopes for the discharge to residential care groups terminate at the mean age of discharge. Time in the discharged groups was parameterized as years to discharge and estimated in 0.1-year increments to derive the best fitting change point models. Time for the normative age slopes is parameterized as chronological age and represents the rate of age-related functional decline in IADL and ADL.

Figure 2 Final Sample: Both Men and Women



Note: IADL change point 82.1 years of age: left vertical purple line. ADL change point 84.2 years: center vertical orange line. Mean age of discharge: 85.5 years: right vertical blue line. X axis: age in years from 70-90. Left Y axis: IADL scale from 0 – 21. Right Y axis: ADL scale from 0 – 28. IADL/ADL change point difference: red double-headed arrow (2.1 years).

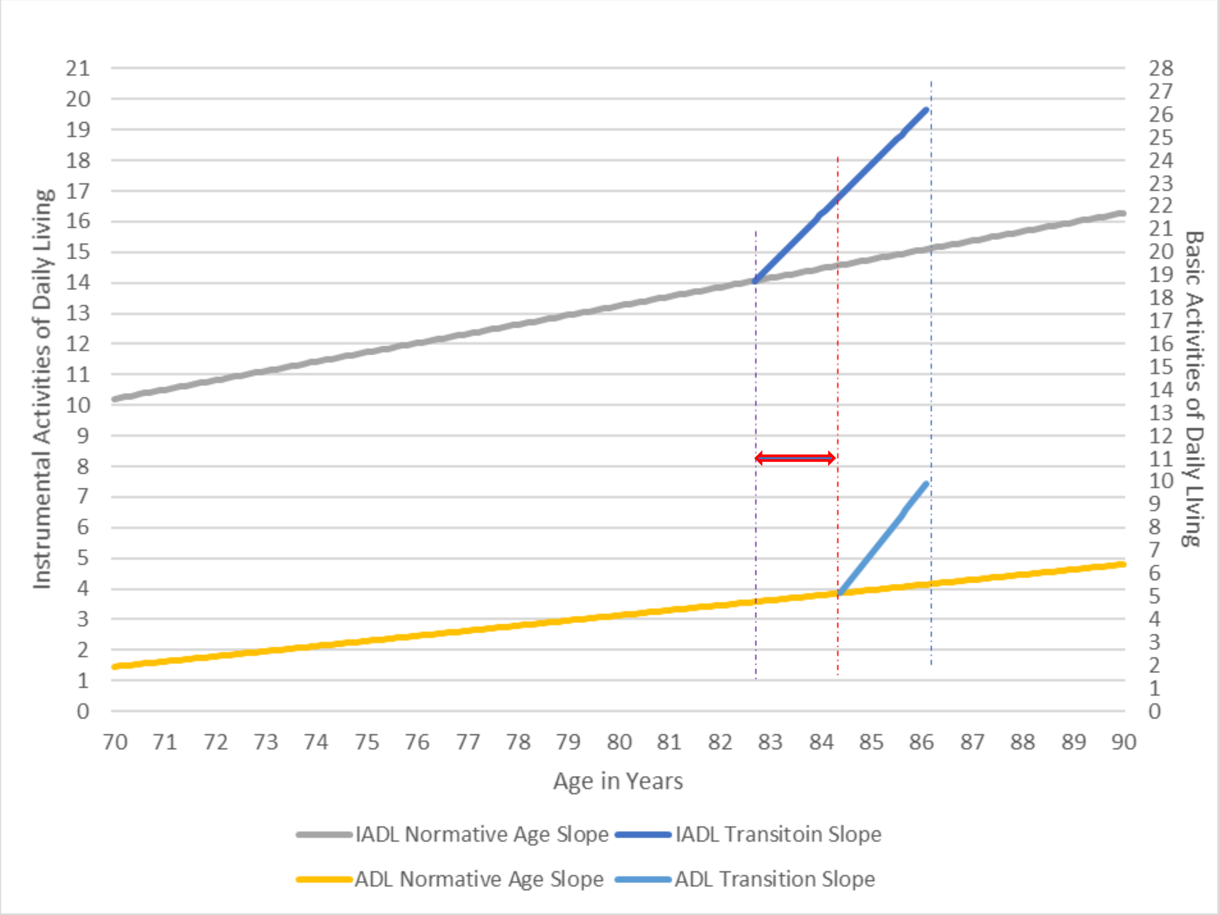
IADL and ADL models were analyzed separately and are presented together for comparison.

Figure 3 Final Sample: Men Only

Note: IADL change point 81.6 years of age: left vertical purple line. ADL change point 83 years: center vertical orange line. Mean age of discharge: 84.3 years: right vertical blue line. X axis: age in years from 70-90. Left Y axis: IADL scale from 0 – 21. Right Y axis: ADL scale from 0 – 28. IADL/ADL change point difference: red double-headed arrow (1.4 years).

IADL and ADL models were analyzed separately and are presented together for comparison.

Figure 4 Final Sample: Women Only



Note: IADL change point 82.7 years of age: left vertical purple line. ADL change point 84.4 years: center vertical orange line. Mean age of discharge: 86.14 years: right vertical blue line. X axis: age in years from 70-90. Left Y axis: IADL scale from 0 – 21. Right Y axis: ADL scale from 0 – 28. IADL/ADL change point difference: red double-headed arrow (1.7 years).

IADL and ADL models were analyzed separately and are presented together for comparison.

No Primary or Secondary Caregiver in the Home

The first subsample was drawn from the full sample and includes 64,161 participants who did not have a primary or secondary caregiver living in their home. During this data collection, 32,711 remained in community (Table 10) and 31,450 were discharged to residential care (Table 11). The mean age of those discharged to residential care (85.12 years) was 2.01 years greater than those who remained in community (83.11 years). The mean number of observations for those who remained in community (3.32) is 0.9 observations greater than those who are discharged to residential care (2.42). At first assessment, mean ADL scores for those discharged to residential care (3.88) is 0.96 points on the 28-point scale greater than those who remain in community (2.92). Further, mean IADL scores are in the discharge group (14.30) are 2.67 points greater on the 21-point scale than those who remained in care (11.63). Patterns of skewness and kurtosis identified in the participant descriptions continue to be present for both groups.

Table 10 No Caregiver in the Home: Remained in Community

	All Participants			Women			Men		
Variable	M	Md.	SD	M	Md.	SD	M	Md.	SD
	n = 32,711			n =25,274			n = 7,437		
Age	83.11	84.00	7.44	83.43	84.00	7.28	82.01	83.00	7.84
N. of Obs.	3.32	3.00	2.28	3.38	3.00	2.32	3.20	2.00	2.10
ADL Long	2.92	1.00	4.59	2.83	1.00	4.52	3.20	2.00	4.79
IADL Inv.	11.63	12.00	5.46	11.51	12.00	5.39	12.02	12.00	5.68

Note: M = Mean; Md. = Median, SD = Standard Deviation; N. of Obs. = Number of Observations; ADL = Activities of Daily Living; IADL = Instrumental Activities of Daily Living.

Table 11 No Caregiver in the Home: Discharged to Residential Care

	Women and Men			Women			Men		
Variable	M	Md.	SD	M	Md.	SD	M	Md.	SD
	n = 31,450			n = 23,730			n = 7,720		
Age	85.12	86.00	6.70	85.50	86.00	6.53	84.02	85.00	7.11
N. of Obs.	2.42	2.00	1.56	2.45	2.00	1.58	2.34	2.00	1.50
ADL Long	3.88	2.00	5.45	3.84	2.00	5.45	4.01	2.00	5.44
IADL Inv.	14.30	15.00	5.52	14.32	15.00	5.18	14.24	15.00	5.45

Note: M = Mean; Md. = Median, SD = Standard Deviation; N. of Obs. = Number of Observations; ADL = Activities of Daily Living; IADL = Instrumental Activities of Daily Living.

Frequency of observations for participants without a primary or secondary caregiver in the home for those who remained in community and those discharged to residential care are presented in Table 12. Differences in the mean number of observations between the discharged to residential care and remained in community groups in Tables 10 and 11 are further evidenced in the remains in community and discharged to residential care columns in Table 12. In addition to the mean number of assessments being greater in the remains in community group, the tail of the frequency distribution is more pronounced and extends beyond that of the discharged to residential care group. Within the discharged to residential care group, the frequency of observations drops below 100 after the 9th time of assessment. In accord with the Ontario Home and Community Care policy, RAI-HC assessments are to be administered every 6 months. On this basis, it is possible to estimate that, by the 9th time of assessment, participants have been receiving home supports for approximately 4.5 years.

Table 12 No Caregiver in the Home: Assessment frequency All Participants

	All Participants		Remains in Com.		Discharged to Res. Care	
N. of Obs.	Frequency	Cumulative Percent	Frequency	Cumulative Percent	Frequency	Cumulative Percent
1	14844	23.14	5626	17.20	9218	29.31
2	21862	57.21	10284	48.64	11578	66.12
3	10859	74.13	5728	66.15	5131	82.44
4	6295	83.95	3717	77.51	2578	90.64
5	3744	89.78	2376	84.78	1368	94.99
6	2392	93.51	1683	89.92	709	97.24
7	1580	95.97	1172	93.50	408	98.54

8	1025	97.57	810	95.98	215	99.22
9	670	98.61	535	97.62	135	99.65
10	373	99.19	321	98.60	52	99.82
11	257	99.59	227	99.29	30	99.91
12	112	99.77	99	99.59	13	99.95
13	91	99.91	80	99.84	11	99.99
14	36	99.97	33	99.94	3	100.00
15	14	99.99	13	99.98	1	100.00
16	4	100.00	4	99.99		
18	1	100.00	1	99.99		
19	1	100.00	1	100.00		
23	1	100.00	1	100.00		

Note: N. of Obs. = Number of Observations; Remains in Com. = Remains in Community; Discharged to Res. Care = Discharged to Residential Care.

The discharged to residential care group is further stratified by sex in Table 13. From Table 11 it is observed that there are more than three times as many women in the discharged group as men. Although the mean number of assessments are comparable, the larger sample size of women is likely responsible for the tail of the frequency distribution in Table 12 being slightly longer and more pronounced for women than men. For men discharged to residential care, the frequency of observations drops below 100 after the 6th time of assessment and for women this occurs after the 9th time of assessment. With the 6-month assessment frequency, it is estimated that prior to discharge to residential care the frequency of assessments falls below 100 after approximately 3 years for men and 4.5 years for women. These values are displayed to inform the possible effects of left censoring of the data, which may constrain change points closer to the date of discharge to residential care and will be addressed in the discussion.

Table 13 No Caregiver in the Home: Assessment Frequency Discharged to Residential Care

	Men Discharged		Women Discharged	
N. of Obs.	Frequency	Cumulative Percent	Frequency	Cumulative Percent
1	2385	30.89	6833	28.79
2	2945	69.04	8633	65.17
3	1168	84.17	3963	81.88
4	568	91.53	2010	90.35
5	305	95.48	1063	94.83
6	175	97.75	534	97.08
7	77	98.74	331	98.47
8	47	99.35	168	99.18
9	27	99.70	108	99.63
10	8	99.81	44	99.82
11	10	99.94	20	99.90
12	3	99.97	10	99.95
13	1	99.99	10	99.99
14	1	100.00	2	100.00
15			1	100.00

Note: N.of Obs. = Number of Observations.

No Primary Caregiver in the Home: Change point model estimation

The estimated parameters from the best fitting change point models in Subsample 1 (no primary or secondary caregiver in the home) are shown in Table 14. The profile likelihood method was used to identify the best fitting model and is represented in the preceding methods section. The change points represent the time in years prior to discharge to residential care when the discharge groups' rate of functional decline with IADL and ADL skills begins to accelerate relative to the group that remains in community.

Table 14 No Caregiver in the Home: Estimates from the Best Fitting Change Point Models Stratified by Sex

	Instrumental Activities of Daily Living			Basic Activities of Daily Living		
	CP Years (95% CI)	Parameters	Fixed Effects (SE)	CP Years (95% CI)	Parameters	Fixed Effects (SE)
No Care in Home	3.4 (*)	Intercept	9.32** (0.267)	1.2 (*)	Intercept	6.505** (0.284)
		Age Slope	0.282** (0.004)		Age Slope	0.121** (0.004)
		Transition Slope	1.77** (0.013)		Transition Slope	3.812** (0.041)
Men	2.7 (*)	Intercept	11.021** (0.551)	.5 (*)	Intercept	7.459** (0.629)
		Age Slope	0.212** (0.009)		Age Slope	0.095** (0.007)
		Transition Slope	1.812** (0.032)		Transition Slope	9.055** (.226)
Women	3.6 (*)	Intercept	8.775** (0.305)	1.2 (*)	Intercept	5.889** (0.327)
		Age Slope	0.304** (0.005)		Age Slope	0.123** (0.004)
		Transition Slope	1.77** (0.014)		Transition Slope	3.945** (0.048)

Note: All models are adjusted for age at first assessment. *CP Years* refers to the average onset (change point) of acceleration in decline of IADL and ADL functioning. Fixed effects for *Intercept* refer to estimated IADL and ADL score at the age of 80 years within the multifactorial equation. *Age slope* refers to the linear rate of change, as a function of age, both prior to and following the change point for IADL and ADL scores. *Transition Slope* refers to acceleration in decline of IADL and ADL scores relative to the age slope from the point of best fitting knot preceding discharge to residential care from community-based home support services.

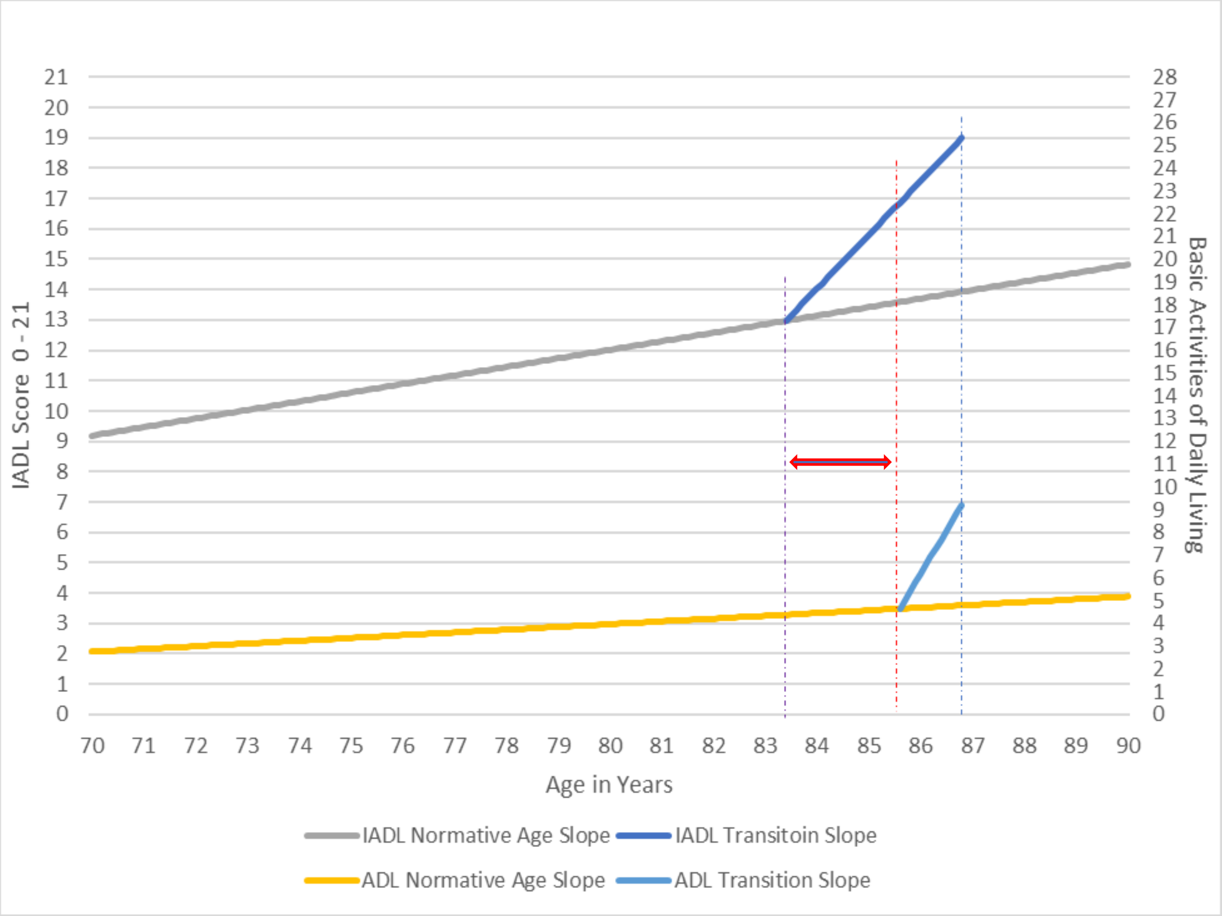
* denotes 95% confidence interval of < ± 0.1 years about the change point. ** denotes *p* value < 0.001.

For all participants in Subsample 1, the change point prior to discharge for IADL (3.4 years) occurred 2.2 years prior the change point for ADL (1.2 years). At the change point, the slope of functional decline for IADL increased by 1.49 points per year on the 21-point scale and the slope of functional decline for ADL increased by 3.69 points per year on the 28-point scale for the discharged group relative to those who remained in community. For men, the change point prior to discharge for IADL (2.7 years) occurred 2.2 years before the change point for ADL (.5 years). At the change point, the slope of functional decline for men's IADL scores increased by 1.6 points per year on the 21-point scale and the functional decline for ADL score slope increased 8.96 points per year on the 28-point scale for the discharged men relative to men who remained in community. The ADL transition slope for men discharged to residential care has the highest standard error (0.226) of any age or transition slope in this series of analyses. The men's discharge group's estimated degrees of freedom, and resultant critical T score of 1.965, were used to calculate a confidence interval about this slope with a range of 8.62-9.50. The slopes for estimated change points that bracket this change point estimate have slopes of 7.3 at 0.4 years and 11.7 at 0.6 years, indicating that the confidence interval for the slope falls within ± 0.1 years and is consistent with the change point confidence interval referenced in Table 14. For women, the change point prior to discharge for IADL (3.6 years) occurred 2.4 years prior to the change point for ADL (1.2 years). At the change point the slope of functional decline for women's IADL scores increased by 1.47 points per year on the 21-point scale and functional decline of ADL scores increased by 3.82 points per year on the 28-point scale for the discharged women relative to women who remained in community.

No Primary Caregiver in the Home: Change Point Illustrations

Slopes for the best fitting change point model for all participants in the final sample as well as men only and women only are represented in Figures 5, 6 and 7, respectively. The IADL and ADL transition slopes for the discharge to residential care groups terminate at the mean age of discharge. Time in the discharged groups was parameterized as years to discharge and estimated in 0.1-year increments to derive the best fitting change point models. Time for the normative age slopes is parameterized as chronological age and represents the rate of age-related functional decline in IADL and ADL.

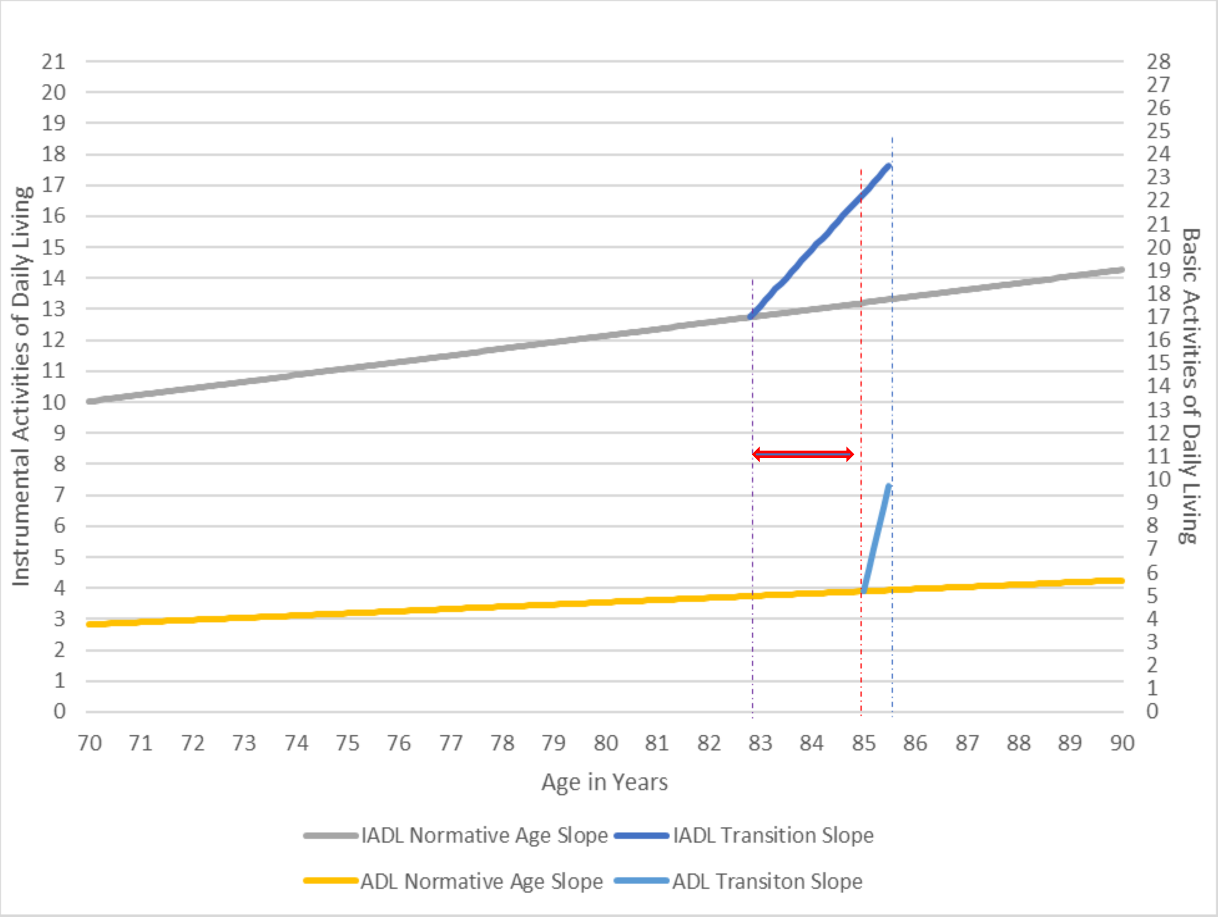
Figure 5 No Caregiver in the Home: Both Men and Women



Note. IADL change point 83.4 years of age: left vertical purple line. ADL change point 85.6 years: center vertical orange line. Mean age of discharge: 86.8 years: right vertical blue line. X axis: age in years from 70-90. Left Y axis: IADL scale from 0 – 21. Right Y axis: ADL scale from 0 – 28. IADL/ADL change point difference: red double-headed arrow (2.2 years).

IADL and ADL models were analyzed separately and are presented together for comparison.

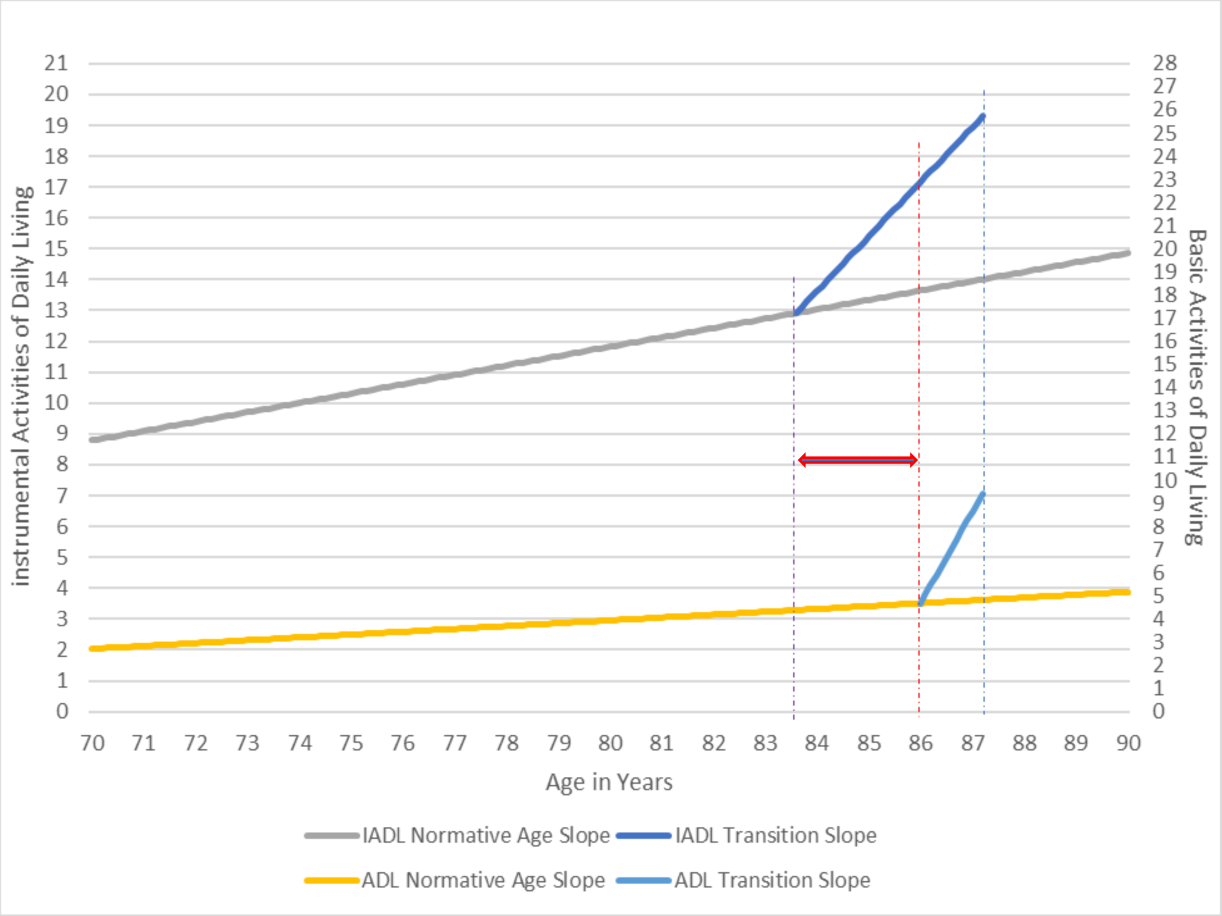
Figure 6 No Caregiver in the Home: Men Only



Note: IADL change point 82.8 years of age: left vertical purple line. ADL change point 86 years: center vertical orange line. Mean age of discharge: 85 years: right vertical blue line. X axis: age in years from 70-90. Left Y axis: IADL scale from 0 – 21. Right Y axis: ADL scale from 0 – 28. IADL/ADL change point difference: red double-headed arrow (2.2 years).

IADL and ADL models were analyzed separately and are presented together for comparison.

Figure 7 No Caregiver in the Home: Women Only



Note: IADL change point 83.6 years of age: left vertical purple line. ADL change point 86 years: center vertical orange line. Mean age of discharge: 87.2 years: right vertical blue line. X axis: age in years from 70-90. Left Y axis: IADL scale from 0 – 21. Right Y axis: ADL scale from 0 – 28. IADL/ADL change point difference: red double-headed arrow (2.4 years).

IADL and ADL models were analyzed separately and are presented together for comparison.

Primary Caregiver in the Home

The second subsample includes 63,984 participants, drawn from the full sample, who had a primary caregiver living in their home. During this data collection, 36,464 remained in community (Table 15) and 27,519 were discharged to residential care (Table 16). The mean age of those discharged to residential care (82.36 years) was 1.55 years greater than those who remained in community (80.81 years). The number of observations for those who remained in community (3.42) was 0.89 observations greater than those who were discharged to residential care (2.53). Mean ADL scores for those discharged to residential care (5.06) is 0.96 points less on the 28-point scale than those who remained in community (5.32). Mean IADL scores in the discharge group (16.33) are 4.59 points greater on the 21-point scale than those who remained in care (11.63). Patterns of skewness and kurtosis identified in participant descriptions continue to be present for both groups.

Table 15 Primary Caregiver in the Home: Remains in Community

	All Participants			Women			Men		
Variable	M	Md.	SD	M	Md.	SD	M	Md.	SD
	N = 36,465			N =22,861			N = 13,604		
Age	80.81	81.00	7.25	81.17	82.00	7.58	80.27	81.00	7.36
N. of Obs.	3.42	3.00	2.32	3.56	3.00	2.40	3.21	3.00	2.18
ADL Long	5.32	3.00	4.59	5.10	3.00	6.13	5.68	4.00	6.11
IADL Inv.	11.63	12.00	6.12	14.41	15.00	4.89	15.33	16.00	4.59

Note: M = Mean; Md. = Median, SD = Standard Deviation; N. of Obs. = Number of Observations; ADL = Activities of Daily Living; IADL = Instrumental Activities of Daily Living.

Table 16 Primary Caregiver in the Home: Discharged to Residential Care

	All Participants			Women			Men		
Variable	M	Md.	SD	M	Md.	SD	M	Md.	SD
	N = 27,519			N = 15,825			N = 11,694		
Age	82.36	83.00	6.98	82.76	83.00	7.08	81.81	82.00	6.82
N. of Obs.	2.53	2.00	1.60	2.57	2.00	1.65	2.48	2.00	1.53
ADL Long	5.06	3.00	5.86	4.90	3.00	5.90	5.28	3.00	5.80
IADL Inv.	16.22	17.00	4.28	16.00	17.00	4.36	16.52	18.00	4.16

Note: M = Mean; Md. = Median, SD = Standard Deviation; N. of Obs. = Number of Observations; ADL = Activities of Daily Living; IADL = Instrumental Activities of Daily Living.

Frequency of observations for participants with a primary caregiver in the home for those who remained in community and those discharged to residential care are presented in Table 17. Differences in the mean number of observations between the discharged to residential care and remained in community groups in Tables 15 and 16 are further evidenced in the remains on community and discharged to residential care columns in Table 17. In addition to the mean number of assessments being greater in the remains in community group, the tail of the frequency distribution is more pronounced and extends beyond that of the discharged to residential care group. Within the discharged to residential care group, the frequency of observations drops below 100 after the 8th time of assessment. In accord with the Ontario Home and Community Care policy, RAI-HC assessments are to be administered every 6 months. On this basis, it is possible to estimate that, by the 8th time of assessment, participants have been receiving home supports for approximately 4 years.

Table 17 Primary Caregiver in the Home: Assessment Frequency All Participants

	All Participants		Remains in Care		Discharged to Res. Care	
N. of Obs.	Frequency	Cumulative Percent	Frequency	Cumulative Percent	Frequency	Cumulative Percent
1	12131	19.57	5176	15.02	3957	25.00
2	21099	53.61	10699	46.06	5908	62.34
3	11235	71.74	6381	64.58	2811	80.10
4	6520	82.26	4005	76.20	1459	89.32
5	3896	88.54	2633	83.84	718	93.86
6	2570	92.69	1874	89.27	444	96.66
7	1674	95.39	1301	93.05	229	98.11

8	1086	97.14	871	95.58	135	98.96
9	701	98.27	583	97.27	72	99.42
10	447	98.99	383	98.38	44	99.70
11	279	99.44	245	99.09	23	99.84
12	179	99.73	167	99.57	8	99.89
13	89	99.87	78	99.80	11	99.96
14	43	99.94	36	99.90	4	99.99
15	22	99.98	20	99.96	2	100.00
16	6	99.99	6	99.98		
17	3	99.99	3	99.99		
18	2	100.00	2	99.99		
19	2	100.00	2	100.00		

Note: N. of Obs. = Number of Observations; Remains in Com. = Remains in Community; Discharged to Res. Care = Discharged to Residential Care.

The discharged to residential care group is further stratified by sex in Table 18. From Tables 15 and 16, it is observed there were 4,131 (35%) more women than men in the discharged group. This is the most balanced distribution of sex within the discharged to residential care groups across all three samples. The frequency distribution of assessments for men and women are also more closely matched, with the frequency of observations dropping below 100 for men beyond the 7th time of assessment and the frequency of observations for women beyond the 8th time of assessment. With the 6-month assessment frequency, it is estimated that prior to discharge to residential care the frequency of assessments falls below 100 after approximately 3.5 years for men and 4 years for women. These values are displayed to inform the possible effects of left censoring of the data which may constrain change points closer to the date of discharge to residential care and will be addressed in the discussion.

Table 18 Primary Caregiver in the Home: Assessment Frequency Discharged to Residential Care

	Men Discharged		Women Discharged	
N. of Obs.	Frequency	Cumulative Percent	Frequency	Cumulative Percent
1	2998	25.64	3957	25.00
2	4492	64.05	5908	62.34
3	2043	81.52	2811	80.10
4	1056	90.55	1459	89.32
5	545	95.21	718	93.86
6	252	97.37	444	96.66
7	144	98.60	229	98.11
8	80	99.28	135	98.96
9	46	99.68	72	99.42
10	20	99.85	44	99.70
11	11	99.94	23	99.84
12	4	99.97	8	99.89
13	0	99.97	11	99.96
14	3	100.00	4	99.99
15			2	100.00

Note: N. of Obs. = Number of Observations

Primary Caregiver in the Home: Change Point Model Estimation

The estimated parameters from the best fitting change point models in Subsample 2 (primary caregiver in the home) are shown in Table 19. The profile likelihood method was used to identify the best fitting model and is represented in the preceding methods section. The change points represent the time in years prior to discharge to residential care when the discharge groups' rate of functional decline with IADL and ADL skills begins to accelerate relative to the group that remains in community.

Table 19 Primary Caregiver in the Home: Estimates from the Best Fitting Change Point Models Stratified by Sex

	Instrumental Activities of Daily Living			Basic Activities of Daily Living		
	CP Years (95% CI)	Parameters	Fixed Effects (SE)	CP Years (95% CI)	Parameters	Fixed Effects (SE)
Care in Home	3 (*)	Intercept	18.589** (0.212)	2 (*)	Intercept	22.392** (0.367)
		Age Slope	.252** (0.004)		Age Slope	0.303** 0.006)
		Transition Slope	1.346** (0.012)		Transition Slope	2.118** (0.0286)
Men	2.5 (*)	Intercept	20.7** (.3361)	1.9 (*)	Intercept	25.268** (0.576)
		Age Slope	0.211** (0.006)		Age Slope	0.289** (0.009)
		Transition Slope	1.387** (0.02)		Transition Slope	2.164** (0.045)
Women	3.1 (*)	Intercept	16.857** (0.289)	2	Intercept	20.292** (0.474)
		Age Slope	0.269** (0.005)		Age Slope	0.308** (0.007)
		Transition Slope	1.404** (0.015)		Transition Slope	2.164** (0.038)

Note. All models are adjusted for age at first assessment. *CP Years* refers to the average onset (change point) of acceleration in decline of IADL and ADL functioning. Fixed effects for *Intercept* refer to estimated IADL and ADL score at the age of 80 years within the multifactorial equation. *Age slope* refers to the linear rate of change, as a function of age, both prior to and following the change point for IADL and ADL scores. *Transition Slope* refers to acceleration in decline of IADL and ADL scores relative to the age slope from the point of best fitting knot preceding discharge to residential care from community-based home support services.

* denotes 95% confidence interval of < ± 0.1 years about the change point. ** denotes *p* value < 0.001.

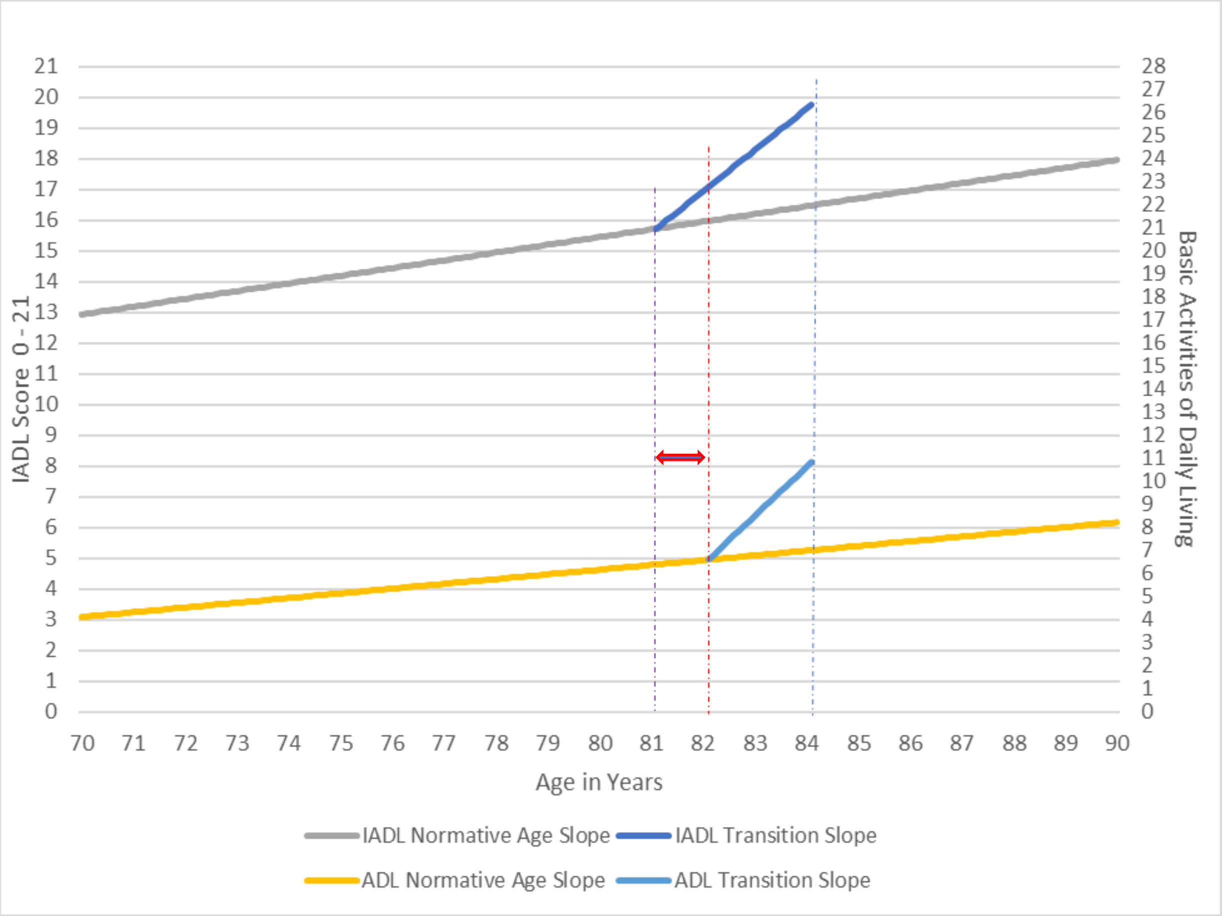
For all participants in Subsample 2, the change point prior to discharge for IADL (3 years) occurred 1 year prior to the change point for ADL (2 years). At the change point, the slope of functional decline for IADL increased by 1.09 points per year on the 21-point scale and the slope of functional decline for ADL increased by 1.82 points per year on the 28-point scale for discharged participants relative to participants who remained in community. For men, the change point prior to discharge for IADL (2.5 years) occurred 1.6 years before the change point for ADL (1.9 years). At the change point, the slope of functional decline for men's IADL scores increased by 1.18 points per year on the 21-point scale and the functional decline for ADL score slope increased by 1.88 points per year on the 28-point scale for discharged men relative to men who remained in community. For women, the change point prior to discharge for IADL (3.1 years) occurred 1.1 years prior to the change point for ADL (2 years). At the change point, the slope of functional decline for women's IADL scores increased by 1.14 points per year on the 21-point scale and functional decline of ADL score increased by 1.86 points per year on the 28-point scale for discharged women relative to women who remained in community.

Primary Caregiver in the Home: Change Point Illustrations

Slopes for the best fitting change point model for all participants in the final sample as well as men only and women only are represented in Figures 8, 9 and 10, respectively. The

IADL and ADL transition slopes for the discharge to residential care groups terminate at the mean age of discharge. Time in the discharged groups was parameterized as years to discharge and estimated in 0.1-year increments to derive the best fitting change point models. Time for the normative age slopes is parameterized as chronological age and represents the rate of age-related functional decline in IADL and ADL.

Figure 8 Primary Caregiver in the Home: Both Men and Women



Note. IADL change point 81.1 years of age: left vertical purple line. ADL change point 82.1 years: center vertical orange line. Mean age of discharge: 84.1 years: right vertical blue line. X axis: age in years from 70-90. Left Y axis: IADL scale from 0 – 21. Right Y axis: ADL scale from 0 – 28. IADL/ADL change point difference: red double-headed arrow (1 year).

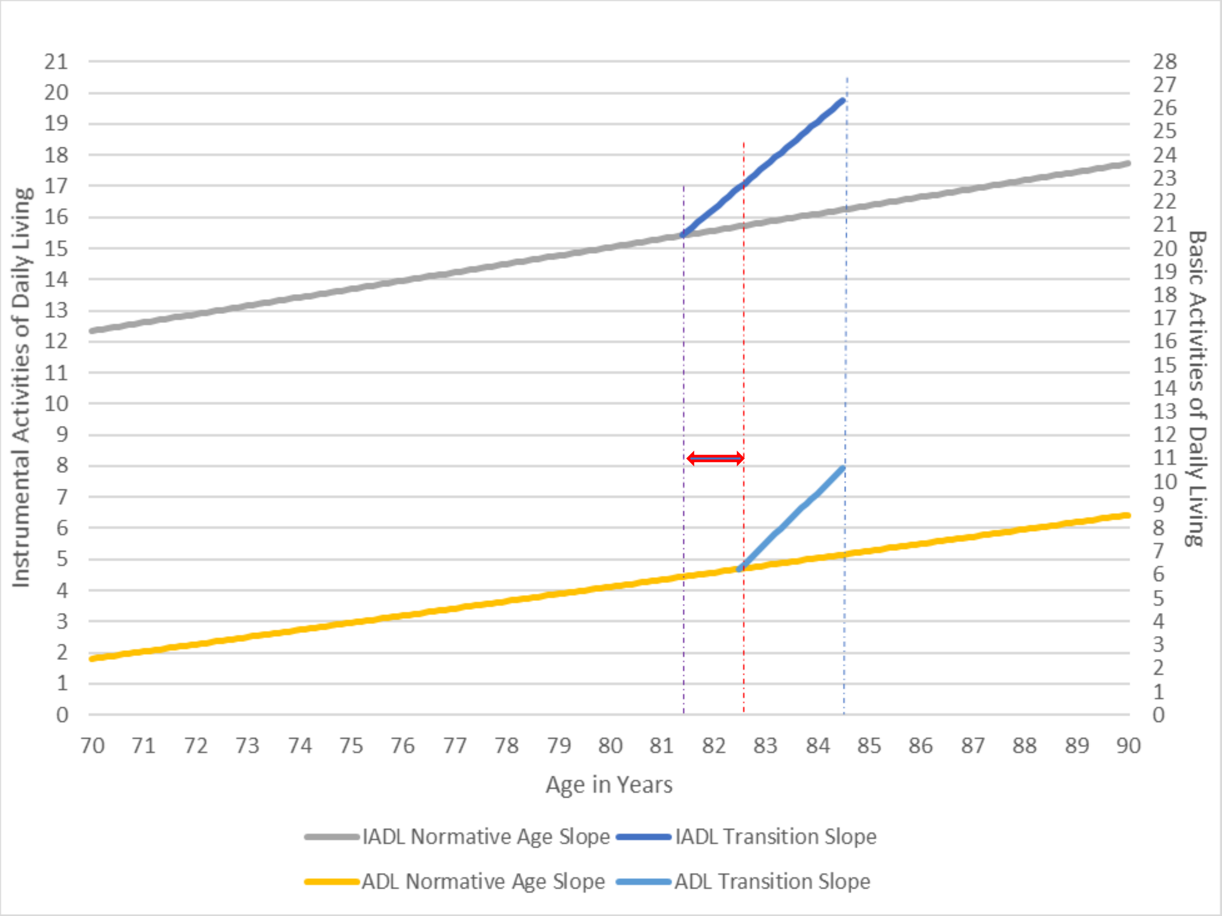
IADL and ADL models were analyzed separately and are presented together for comparison.

Figure 9 Primary Caregiver in the Home: Men Only

Note. IADL change point 81 years of age: left vertical purple line. ADL change point 81.6 years: center vertical orange line. Mean age of discharge: 83.5 years: right vertical blue line. X axis: age in years from 70-90. Left Y axis: IADL scale from 0 – 21. Right Y axis: ADL scale from 0 – 28. IADL/ADL change point difference: red double-headed arrow (0.6 year).

IADL and ADL models were analyzed separately and are presented together for comparison.

Figure 10 Primary Caregiver in the Home: Women Only



Note. IADL change point 81.4 years of age: left vertical purple line. ADL change point 82.5 years: center vertical orange line. Mean age of discharge: 84.5 years: right vertical blue line. X axis: age in years from 70-90. Left Y axis: IADL scale from 0 – 21. Right Y axis: ADL scale from 0 – 28. IADL/ADL change point difference: red double-headed arrow (1.1 year).

IADL and ADL models were analyzed separately and are presented together for comparison.

Time to Service and Assessment, Magnitude of Change, and Level of Impairment

Table 20 presents the magnitude of change between the normative and transitions slopes, the time between initial IADL change points and the onset of services and assessment, and mean age of discharge values. The Ass. columns were calculated by differencing the mean Time to Discharge value and the change point (CP). Participants included in this study were assessed with the RAI-HC within 14 calendar days of being identified as requiring home care services of at least 6-months (Ontario, 2007). Through consideration of the minimum assessment frequency of 6-months, and that many participants would be identified as requiring long stay home care services during the first meeting with the HCC CM, it was estimated that the duration of time participants received home care services prior to a first assessment was less than 6-months, or 0.5 years. Within Table 20, the value of 0.35 years is added to the Ass. columns, and displayed in the Ser. columns, to represent a conservative estimate of the time between onset of home care services and the IADL and ADL change points.

Within Table 20, date of service (Ser.) and first assessment (Ass.) can be interpreted using the change point values provided in tables 9, 14 and 19. For example, within the full sample from table 9, the IADL change point occurred 3.4 years prior to discharge, 1.49 years prior to the mean time of first service and 1.84 years prior to the mean time of first assessment. For ADL within the full sample, the mean estimate of service onset and first assessment occurred -0.61 and -0.26 years, respectively, prior to the ADL change point which occurred at 1.3 years prior to discharge to LTC. This pattern indicates that, for the full sample, IADL change points occurred prior to the mean onset of services and first assessment while ADL change points occurred after the mean onset of services and first assessment. Positive values for mean time to service (Ser.) and first assessment (Ass.) columns relative to ADL change points for participants who had a primary caregiver living in the home indicate that the ADL change points occurred prior to the mean time to service onset and first assessment for these participants.

Table 20 Magnitude of Change and Time to Service and Assessment

Group	Discharge			IADL Change Point					ADL Change Point				
	Age	M	Est.	Ser.	Ass.	A.S.	T.S.	Per.	Ser.	Ass.	A.S.	T.S.	Per.
Full	82.1	1.56	1.91	***1.49***	1.84	0.29	1.52	*424*	***-0.61***	-0.26	0.21	3.66	*1643*
M	81.6	1.46	1.81	***0.89***	1.24	0.24	1.49	*536*	***-0.51***	-0.16	0.22	3.67	*1445*
W	82.7	1.61	1.96	***1.44***	1.79	1.30	1.67	*441*	***-0.26***	0.09	0.23	2.82	*1146*
N.C.	83.4	1.18	1.53	***1.87***	2.22	0.282	1.77	*528*	***-0.33***	0.02	0.12	3.81	*3050*
M	82.8	1.02	1.37	***1.33***	1.68	0.212	1.81	*755*	***-0.87***	-0.52	0.10	9.06	*9432*
W	83.6	1.23	1.57	***2.03***	2.37	0.304	1.77	*482*	***-0.37***	-0.03	0.12	3.95	*3107*
Care	81.1	1.27	1.54	***1.46***	1.73	0.252	1.35	*433*	***0.46***	0.73	0.30	2.19	*600*
M	81.0	1.22	1.57	***0.93***	1.28	0.211	1.39	*559*	***0.33***	0.68	0.29	2.16	*651*
W	81.4	1.3	1.65	***1.45***	1.8	0.269	1.40	*424*	***0.35***	0.7	0.30	2.16	*612*

Note. All numeric values are in years.

Discharge: Age = mean age of discharge; M = Mean time in care from date of first assessment; Est. = Estimated mean time to discharge plus 0.35 years to indicate approximate time to when service started.

IADL Change Point: Ser. = Difference between change point and estimated onset of home care services; Ass. = Difference in years between change point and first assessment; A.S. = Normative aging slope for home care recipients who remained in care; T.S. = Transition slope for participants who were discharged to residential care; Per. = percentage change between A.S. and T.S.

ADL Change Point: Ser. = Difference between change point and estimated onset of home care services; Ass. = Difference in years between change point and first assessment; A.S. = Normative aging slope for home care recipients who remained in care; T.S. = Transition slope for participants who were discharged to residential care; Per. = percentage change between A.S. and T.S.

Full = All participants included in study; N.C. = Subsample of participants without a primary or secondary caregiver in the home; Care = Subsample of participants with a primary caregiver in the home.

Table 21 presents differences in level of impairment and rate of change between participants with a primary caregiver in the home and those without a primary or secondary caregiver in the home.

Table 21 Caregiver Group Level and Slope Differences

	IADL				ADL			
	CP	80	A.S.	T.S.	CP	80	A.S.	T.S.
No Caregiver	3.4	***12.0***	0.282	**1.77**	1.2	***4.0***	0.12	**3.81**
No Care Men	2.7	***12.1***	0.212	**1.81**	0.5	***4.7***	0.10	**9.06**
No Care Women	**3.6**	***11.8***	0.304	**1.77**	**1.2**	***3.9***	0.12	**3.95**
Caregiver	3.0	***15.4***	0.252	**1.35**	2.0	***6.2***	0.30	**2.19**
Care Men	**2.5**	***16.2***	0.211	**1.39**	**1.9**	***6.26***	0.29	**2.16**
Care Women	3.1	***15.0***	0.269	**1.40**	2.0	***5.5***	0.30	**2.16**

Note. CP = Change point; 80 = IADL and ADL scores from the normative aging slope at 80 years of age; A.S. = Normative aging slope; T.S. = Transition slope after the change point for participants who transitioned to residential care.

No Caregiver = Subsample of participants without a primary or secondary caregiver in the home; Caregiver = Subsample of participants with only a primary caregiver in the home (no secondary).

Discussion

This chapter will first summarize findings pertinent to the research questions posed in the preceding Research Objectives section. This is followed by a consideration of how early-onset IADL impairment may have a feed-forward effect on subsequent ADL impairment and eventual discharge to LTC. The relationships between these areas of functional independence are then contextualized within two anecdotal case examples. A description of how future applied research and development could be framed within a stepped-care model is then presented. The discussion concludes by addressing pertinent limitations of this study and presenting areas of future research.

IADL and ADL Change Points Prior to Residential Care Discharge

Do measures of IADL and ADL exhibit a change point prior to residential care discharge, at which juncture participants discharged to residential care experienced a more rapid functional decline relative to participants who remain in community?

This study documented change points for both IADL and ADL measures within the full sample and for both men and women when these groups were drawn from the full sample. Change points also emerged for participants with a primary caregiver in the home, for participants without a primary or secondary caregiver in the home, and within sex stratified subgroups derived from the caregiver groups. The discovery of this primary finding demonstrates that participants who are discharged to LTC have unique trajectories of IADL and ADL function when compared to participants who remained in community and allows for all subsequent stages of this study to proceed. The percentage increase in slope following the change point was substantial for all groups included in this study, with percentage increases in the discharge slopes for IADL ranging from 424% for women with a primary caregiver in the home to 755% for men without a caregiver in the home (see Table 20). Percentage increases in ADL slopes ranged from 600% for the full group (both men and women) of participants with a primary caregiver in the home, to 9432% for men without a caregiver in the home.

Temporal Onset of Change Points for IADL Versus ADL

Do the change points for IADL precede those of ADL?

This study found that the change points for IADL preceded those of ADL within the full sample and for both men and women when these groups were drawn from the full sample. The same temporal relationship emerged within the caregiver subgroups and within the sex stratified groups drawn from the caregiver subsamples (see Figures 2 through 10). The difference between IADL and ADL change points ranged from a minimum of 0.6 years for men with a primary caregiver in the home to 2.4 years for women without a caregiver in the home.

In addition to confirming that all IADL change points preceded those of ADL, Table 20 presents the time (in years) from the change points to when services were likely initiated (Ser.) and when data collection began at the time of first assessment (Ass.). Note in Table 20 that the beginning of home care services, and subsequent availability of in-home IADL support and subsidized community based IADL support, occurred well after the onset of accelerated IADL impairment for all study participants who transitioned to residential care. Within the full sample, the time-lag from the IADL change point was 1.49 years to onset of home care services and 1.84 years until the time of first assessment. Within this same sample, the ADL CP occurred -0.61 years after the onset of services and -0.26 years after the first assessment, indicating that participants who transitioned to residential care were receiving home care services prior to the onset of accelerated ADL decline. The delay between the onset of accelerated IADL impairment and the instance of first data collection is of particular interest. Across the entire sample, earlier assessment of IADL function could have allowed for 2-3 additional points of data collection. This information might have permitted early identification of participants in rapid IADL function decline and adequate time to implement interventions and services to mitigate decline and possibly delay transition to LTC.

The ADL change point for the entire sample occurs 1.3 years prior to discharge to residential care versus 3.4 years prior to discharge for the IADL change point. When viewed in the context of LTC admission planning, it is likely that the last point of assessment for those discharged to LTC was used to assess participant eligibility for LTC and to determine if increased levels of home care services were required while they awaited placement. This would leave at most one year to identify and intervene with rapidly declining ADL function and one or two opportunities to gather change information using the RAI-HC. Based on this short timeline, the limited ability to gather relevant change data, and that decisions regarding placement in LTC occur during this period, it is unlikely that monitoring for the onset of declining ADL function permits interventions that will further delay transition to LTC beyond the 1.3-year ADL change point. In contrast, the onset of accelerated IADL decline occurs 3.4 years prior to discharge. Monitoring and responding to this early IADL change provides a unique opportunity to intervene with participants at risk of transition to LTC well in advance of the rapid decline in ADL function that occurs in closer proximity to LTC discharge.

Sex Differences in Temporal Onset of IADL Versus ADL Change Points

Are there sex differences in the temporal onset of IADL and ADL change points and the related normative age and transition to residential care slopes?

Within the full sample, the mean Age of Discharge was 84.3 years for men and 86.14 years for women (see Table 20). In addition to having a LTC discharge age nearly two years greater than their male counterparts, women in this group also demonstrated earlier IADL change points (3.4 years), 0.7 years prior to men (2.7 years). Further, the ADL change points experienced by women (1.7-years) occurred 0.4 years before that of men (1.3 years). These change point differences extend to the time lag between the estimated start of home care services and the onset of data collection, with women waiting 1.79 years from the onset of acerated IADL impairment to time of first assessment while men waited 1.24 years. The closer proximity of the ADL change point for men discharged to LTC demonstrates that attempts to intervene at the onset of accelerated ADL decline may be an even less reasonable strategy for men when compared to women.

Within the normative aging slope of the best fitting sex stratified models derived from the full sample, at 80 years of age women scored 13.2 for IADL and 4.2 for ADL. At the same age in the normative aging slope, men scored 14.9 for IADL and 5.7 for ADL, indicating that men experienced greater impairment in both IADL and ADL at age 80. This observation of men having greater impairment with IADL and ADL than women extends across the entirety of the normative aging slopes for sex stratified subgroups derived from the full sample. In addition to having an ADL change point which occurred in closer proximity to discharge, the ADL transition slope value for men (3.67) was 0.85 greater than that for women (2.82) within sex stratified subgroups drawn from the full sample (see Table 20). Women had greater normative aging slope values for IADL (1.30) than men (0.24). Women also had greater IADL transition slopes (1.67) compared to men (1.49). Normative aging slope values for ADL were similar for women (0.23) and men (0.22).

Live-in Caregiver Status Differences in Temporal Onset of IADL versus ADL Change Points

Are there differences in the temporal onset of IADL and ADL change points and normative age and transition to residential care slopes for participants with and without a caregiver living in the same home?

Analysis of this final question was undertaken to explore available data and to identify future research and model refinement of caregiver subgroups. Specifically, this analysis aimed to identify smaller subgroups with unique trajectories that may be suitable for early assessment and intervention. Beyond information about the presence or absence of a primary or secondary caregiver in the home, the available dataset contains several other relevant caregiver variables. These variables contain inconsistencies with regards to presence of a caregiver in the home, caregiver health and emotional well-being, and/or caregiver capacity to provide assistance to the participant, all of which may change over time and across assessments. While the initial results presented here are of value, interpretation should be tempered pending further exploration and model development that is beyond the scope of this project.

The mean Age of Discharge to residential care for participants with a primary caregiver in the home was 83.5 years for men and 84.5 years for women. Seemingly counterintuitive, the mean age of discharge to residential care for participants without a primary or secondary caregiver in the home was 85 years for men and 87.2 years for women. The reason for this difference is unknown, but it may represent a longevity selection bias for older adults who outlived their spouses or an unknown type of resilience that may select for, or emerge in response to, living independently to an advanced age.

Notably, both men and women with a primary caregiver in the home had positive values in the Ser. and Ass. columns for both IADL and ADL (see Table 20). The IADL change point occurred 0.93 years before the onset of services for men and 1.45 years prior for women, and the change point occurred 1.28 years before the fist instance of assessment for men and 1.8 years prior to first assessment for women. The ADL change point occurred 0.33 years before the onset services for men and 0.35 years prior for women, and 0.68 years before the time of first assessment for men and 0.7 years prior to first assessment for women (see Table 20). This indicates that participants discharged to residential care who had a primary caregiver in the home entered accelerated decline in both IADL and ADL prior to home care services starting and likely managed this accelerating impairment in both domains with the assistance of their primary caregiver until services began. The IADL and ADL change points for both sexes with a primary caregiver also occur in closer proximity to each other, with the IADL and ADL change point difference for men occurring in the closest proximity of any group (0.6 years apart). It is possible these change point differences represent a protective effect of having a primary caregiver in the home, by allowing these home care recipients to tolerate advancing ADL impairment in the presence of concurrently advancing IADL impairment.

Assessment scores for ADL and IADL at age 80 within the normative age slopes for women and men without a caregiver in the home are considerably lower than the commensurate scores for those with a primary caregiver in the home (see Table 21), a finding that extends across the entirety of the normative aging slopes. The normative aging and discharge IADL slopes for those with and without a caregiver are somewhat comparable, with a trend towards earlier change points and greater values for both the normative aging and discharge slopes for participants without a caregiver in the home. However, the normative aging ADL slopes for both men and women have a lower value at Age 80 and a more gradual slope for those without a caregiver in the home; this slope also advances at less than half the rate of participants with a primary caregiver in the home. These shallow ADL normative aging slopes are contrasted by a more rapid functional decline in ADL preceding discharge to LTC and a change point that is in closer proximity to discharge when compared to those with a primary caregiver in the home (see Table 20). These lower normative aging values and slopes may indicate that participants without a primary caregiver in the home are less able to remain in community with ADL impairment when compared to participants with a primary caregiver in the home.

The ADL CP for both men and women without a caregiver occur in closer proximity to LTC discharge than for those with a primary caregiver in the home (see Table 21). This is most pronounced for men, for whom the ADL CP occurs (0.5-years) prior to LTC discharge, leading to a LTC transition slope with the greatest percentage change relative to the normative aging slope (9435% increase) for any group (See Table 20). In keeping with arguments about the late onset of ADL change points, it seems unlikely that interventions aimed at further delaying discharge to LTC could be initiated for men without a primary caregiver in the home once the onset of accelerated ADL decline begins. It also indicates that for many male participants without a caregiver, the HCC CM would have been able to provide at most one RAI-HC assessment after the ADL change point and prior to discharge to LTC. It is difficult to envision how such a rapid increase in ADL impairment, occurring in immediate proximity to LTC placement, could be experienced as a voluntary and positive life transition that is free from risk of trauma.

Level of Impairment and Onset of Change Points

For all participants and subgroups, the ADL change points occurred in close proximity to when participants reached 17 out of 21 on the IADL scale. However, those with a primary caregiver in the home had more gradual ADL transition slopes, and the ADL change points occurred further away from LTC discharge. This allowed men with a primary caregiver in the home to remain in community 1.4 years longer than men without a caregiver after the onset of an IADL score of 17 and the co-occurring ADL change point. Women with a primary caregiver were able to remain in community for 0.8 years beyond the same transition point than those without. Taken together, the transition to LTC for both men and women is delayed after the onset of advanced IADL impairment and the ADL change point for those with a primary caregiver in the home, with men potentially realising the greatest advantage from this support.

A score of 17 out of 21 on the IADL scale indicates that, at the ADL change point, participants were unable to complete or participate in at least 3 of the 7 IADL scale items and required others to do these activities for them. It is likely they also required help all the time to complete the remaining 4 activities. It is possible that participants without a caregiver in the home were unable to effectively manage the onset of accelerating physical disability in the presence of such advanced IADL impairment, leading to more rapid discharge to LTC after reaching this level of IADL impairment. Beyond the restricted scope of the IADL scale, these combined functional impairments may have also limited participants’ ability to engage in rehabilitation following injury, follow medical instructions to maintain health, adapt to mobility aids, and to problem solve in a manner that allowed them to remain safe in their homes as their mobility deteriorated.

The relatively low normative aging slope of ADL scores, and shallow normative ADL aging slopes, of participants without a primary or secondary caregiver in the home, may indicate that they initially began receiving home care services closer to the minimal ADL care needs threshold required to access services. This observation could also indicate that those without a primary or secondary caregiver in the home entered home care services at the minimal ADL impairment criteria required to permit early access to in-home and community based IADL services. Within the second scenario, HCC CM may experience moral or ethical tension when assessing someone with advanced IADL who does not fully meet the required ADL disability to receive services. In some instances, this may motivate a CM to identify minimal ADL needs in some home care clients with the undocumented primary goal of providing access to assistance with IADL.

The IADL change point for those discharged to LTC occurred earlier for both men and women without a caregiver in the home. This was most pronounced for women without a caregiver, for whom the IADL change point occurred 3.6 years prior to LTC admission. This resulted in women without a caregiver having an estimated wait time of slightly more than 2 years beyond the onset of rapidly deteriorating IADL function before home care services started (See Table 20). They also waited 2.27 years until the first instance of assessment and data collection, time lags that are the longest of any group. If RAI-HC assessments had begun for this group at, or around, the time of the IADL change point, it would have been possible to gather multiple instances of assessment and to generate reliable slopes to identify those most at risk of LTC admission and to muster a rehabilitation or support services response. Of all the subgroups examined in this study, onset of accelerated IADL impairment for women without a primary caregiver in the home may hold the most promise as an early indicator of transition to LTC and as an early intervention target.

Interpretation of IADL and ADL Change Point Onset

This study presents strong evidence that change points exist for both IADL and ADL scores as older adult home care recipients of Ontario approach discharge to residential care. Sex differences are present within the full sample and within the caregiver subgroups. This study also reveals that the onset of accelerated IADL impairment for those who go on to LTC precedes the availability of home care services for all participants. This lag between the onset of IADL decline and availability of services is most prominent for all women within this study and for both men and women without a primary caregiver in the home. Men without a primary caregiver in the home may experience an abrupt, and precipitous, decline in ADL function preceding discharge to LTC. Women without a caregiver may endure accelerated IADL impairment in the absence of publicly funded home care services for 2 or more years, the longest of all groups.

Examining the time between the onset of ADL change points and discharge to residential care reveals that efforts to initiate rehabilitation or other forms of intervention responses to address accelerating ADL decline, and to subsequently avoid or delay LTC admission, are unlikely to be successful. This is especially true for men without a primary caregiver in the home, as the ADL change point occurs a mere 0.5 years prior to the mean age of LTC admission. Conversely, the change points and onset of accelerated IADL impairment occur well in advance of LTC admission and prior to the onset of home care services for all participants in this study. This provides evidence that the inflection of IADL impairment occurring at the change point may be a viable early indicator of impending transition to residential care and may provide a unique opportunity to identify and intervene, using a variety of methods such as education, peer support, as well as rehabilitative and supportive interventions. These types of early assessments and interventions may hold promise of delaying, or in some instances preventing, transition to LTC.

Case Examples of IADL Impairment

There is value in anecdotal case examples to describe how a particular client's trajectory through home care services and to residential care may unfold. Case examples are useful to readers who may not have direct experience observing functional decline in older adults. In the context of IADL and ADL change points, these case examples may foster appreciation for how, in the absence of appropriate supports and services, early onset IADL impairment may hasten subsequent ADL impairment and eventual admission to LTC. Given the unique trajectories and potential vulnerability of men and women without a caregiver in the home, case examples for a man and woman without a primary caregiver in the home are presented next and corresponding implications are then discussed.

Case example 1: Female with no Caregiver in the Home

Jane recently turned 80 years old. During her working career she was initially a high school teacher and later worked in her local school district as an administrator. Her husband passed away 10 years ago. She has two adult children from their time together and an adult daughter with children lives in the same city. As Jane aged, she experienced a combination of frailty and impaired cognition. Over the last few years her difficulties with executive function and memory as well as reduced mobility and endurance due to frailty led to increasing difficulty with maintaining her IADL. The adult child who lives in town attempted to assist her mother, but she does not have the skills or knowledge about how best to help her mother. Their interactions are often stressful and tiring for them both. The daughter also has young children and is limited in how much time she can spare, which leads to inconsistency in her ability to help her mother.

Over the last two or more years her family observed Jane is having increasing difficulty keeping up with managing her medications, attending medical appointments, consistently preparing healthy meals, staying active in a manner that maintains social connections, and maintaining a level of physical activity necessary to slow progressing symptoms of frailty. Although Jane's independence with basic personal care did not seem to change much, she became increasingly dependent on her daughter for IADL support. When not receiving help, Jane spent more time alone in her apartment and there were signs of her being less able to access the community and to maintain social contacts.

One night, following several days of not eating well, Jane made a mistake with her medication which caused symptoms of vertigo. The vertigo caused Jane to fall and seriously sprain her ankle, requiring a hospital visit. As an outcome of the hospital visit, a letter was sent to her family doctor to advise that a referral to home and community care had been initiated.

Although a file had been opened with HCC, it took 8 days for a CM to arrange a first visit with Jane and assess her needs for home care. During this time, Jane struggled with basic personal care and was increasingly dependent on her daughter for all IADL. At the time of the CM's first visit, Jane's personal hygiene had deteriorated and she had begun losing weight. It was recommended that Jane receive personal support services to supervise her transfers in and out of the shower, medication monitoring, meal preparation, laundry, and assistance with lower body dressing. Other homemaking services to assist with IADL in the home and community were not approved due to the history of her daughter helping in these areas. Jane also received in-home physiotherapy as she was unable to get to a clinic independently.

Although the services seem robust at first, Jane and her family soon discovered that personal support services were quickly reduced once her ankle began to heal. Services were left in place to supervise Jane when bathing twice a week and for medication monitoring, but assistance with laundry, meal preparation, and dressing were discontinued. Jane returned to spending most of her time sedentary and isolated in her apartment, her diet continued to be poor, and her cognition and mood seemed to also deteriorate. What were initially stressful and tiring interactions with her daughter began to evolve into points of interpersonal conflict, which Jane found distressing.

About a year after the first fall, Jane tripped over some clothing she had left on the floor and had a second fall. Due to poor diet and limited physical activity she had become increasingly frail, and the second fall was more serious. Jane reinjured her ankle, fractured her right wrist, and experienced a concussion. This fall led to a hospital stay of seven days during which Jane was again assessed with the RAI-HC. Upon discharge, Jane experienced increasing difficulty with memory and required additional personal support services to assist with lower body dressing, transfers, bathing, and medication monitoring in addition to the full compliment of in home IADL services available through home making services. Community-based IADL services continued to be denied as the CM had identified Jane’s daughter as being responsible for these tasks. In-home physiotherapy was attempted, but Jane was not able to fully participate so the service was discontinued prematurely. By this time Jane’s daughter was in a state of heightened caregiver distress and exhausted from managing nearly all of Jane’s community based IADL needs. Jane became increasingly hopeless and despondent that she had become a burden to the people she loved. After about eight months of struggling, Jane agreed to be transferred into a LTC facility.

Within this case example, Jane experienced an early onset of cognitive decline and IADL impairment. This change in IADL independence led to Jane not eating well, not regularly attending medical appointments, and making mistakes with her medications, all of which had adverse consequences. Extending beyond the basic elements of IADL impairment, Jane also became less active and increasingly deconditioned, behavior changes which increased her level of frailty and led to social isolation. For Jane, all these aspects of IADL functioning and community access preceded and increased the likelihood of the two falls she experienced and the physical disability and dependence on personal support services that ensued. It is possible that with early assessment, identification of, and supports to mitigate IADL impairment, the onset of ADL dependency and subsequent LTC admission could have been delayed.

Case example 2: Male with no Caregiver in the Home

Bob was married during middle age but divorced before having children. During his career he worked in various blue-collar occupations and needed to reinvent himself several times in response to changing economic conditions. As a young man he worked in fisheries, then later in the logging industry, and for the last part of his career in residential housing construction. In his youth and early 20’s, Bob was a competitive football player with dreams of playing professionally. Unfortunately, several concussions and recurring knee injuries ended his athletic career. Throughout most of his adult life Bob drank frequently and casually used drugs such as cannabis and cocaine, as was the norm for his peer group. After retiring, Bob’s physical activity levels declined dramatically and his lifestyle choices that were previously offset by daily physical exercise through his work soon caused him to become diabetic. The diabetes exacerbated the historical concussion injuries, leading to increasing memory difficulties, accelerated arthritis progression in his injured knee, and exacerbated chronic back pain he began to experience towards the end of his working career. Bob rarely sought medical attention and instead continued to use alcohol and other drugs to self medicate and manage pain and increasing mood instability.

Bob often ate out when employed and found it difficult to maintain a diabetes-healthy diet on a fixed budget after retirement. By his mid-70’s Bob became insulin dependent; however, his mobility challenges and persistent alcohol and drug use lead to him often going days at a time without refilling his insulin prescription and his blood glucose levels were poorly managed. By his late 70’s Bob began to develop peripheral neuropathy in his feet and hands, which brought more pain to his life and further limited his mobility and physical activity, leading to an increasing dependency on insulin and increasingly poor blood glucose management. Bob continued to struggle with budgeting on a fixed income and was evicted from his apartment for late rent payment at 79 years of age. Thankfully, Bob had a distant brother who was able to give him the money needed for a deposit and first month’s rent and agreed to co-sign on a rental application. The new accommodation was much smaller, in an area of town Bob was not familiar with, and not within walking distance to a grocery store. Bob had never used the public transit system and due to his poor financial situation was no longer able to afford to maintain a vehicle. With considerable effort, he did manage to learn a bus route to a grocery store, but he found the trip exhausting and stressful and avoided going out for groceries until he could no longer delay it. Bob struggled in this environment for several more years.

At the age of 82, during a rare visit to his family doctor, Bob’s physician suggested a referral for home support services for assistance with bathing, transfers, and ongoing nursing care for advancing diabetic ulcers that had begun developing on his feet due to the peripheral neuropathy and reduced peripheral blood circulation. The doctor also mentioned that Bob may qualify for assistance with meal preparation and possibly support with getting groceries. After some resistance, Bob eventually agreed to be assessed for home care services.

During the in-home assessment, Bob demonstrated his independent spirit and pushed through the pain to prove to the HCC CM that he was an independent and capable person. This led to him being assessed as being quite independent on the ADL scale, although supportive medical care for his foot ulcers and supervision with a bath twice a week were recommended. Bob was also adamant that he was fully able to prepare his own meals, but eventually agreed to assistance once a week for a grocery shopping outing. However, when presented with the co-pay costs of the community support services, it was obvious he could not afford the service. The CM was able to contact Bob's distant brother who agreed to fund two grocery shopping outings a month. When the community support worker began regular visits for the grocery outings, they soon discovered that Bob was often out of money by the second monthly visit, having spent his fixed monthly income on food delivery services and alcohol. As Bob was still considered competent of finance, and budgeting was outside the scope of the community support worker's job role, Bob often spent the last part of each month under-nourished. His poorly controlled diabetes continued to deteriorate and the ulcerations on his feet showed little sign of recovering.

Bob's mood continued to deteriorate and when receiving ADL and nursing services he would occasionally show responsive behaviors and was intoxicated on two occasions when personal support workers arrived. This quickly led to services being pulled back to a minimum level not adequate to sustain Bob's medical and support needs. Bob often sat with soiled bandages on his feet for days at a time and rarely bathed. Despite these challenges, Bob continued to identify as a strong and independent person and pushed through the pain and discomfort to manage much of his ADL care independently, albeit poorly.

Due to the limited ability to provide direct services, Bob was carefully monitored by the HCC CM. During a home visit the HCC CM noticed that Bob was doing poorly and that his blood glucose was so low that he was struggling to remain conscious and at imminent risk. After supporting a dietary intervention to stabilize his blood glucose, the CM assessed Bob with the RAI-HC to provide supporting evidence of his need for a LTC placement. The CM then communicated to Bob's family doctor and the local health unit that his needs exceeded the capacity of HCC and his refusal to accept appropriate services was placing him at imminent risk of harm. An emergency intervention was organized, and Bob was involuntarily admitted to a locked and secure behavioral stabilization unit at a regional hospital, where his medical and behavioral challenges were addressed while awaiting LTC placement. Bob's distant brother was contacted to handle the disposal of his personal items and to end tenancy at his apartment.

Bob's experiences demonstrate how specific elements of IADL impairment, namely diabetes management, budgeting, and meal planning, can have a feed-forward effect which leads to subsequent ADL impairment and eventual admission to LTC. As Bob transitioned into retirement, he lacked the skills to prepare budget-friendly, healthy meals at home. He also did not adapt to his increasing medical needs as an older adult by attending more frequent medical appointments and appropriately managing his blood glucose, insulin, and other medications. It is possible that Bob's developmental trajectory could have been altered had he received early IADL education and resources about how to plan for and prepare inexpensive, healthy meals and to better manage his diabetes. Prior to his need for home care service, Bob may have also responded to a skilled support worker who could have worked along side Bob to provide training with the use of public transit and assistance with budgeting, meal planning, shopping, and meal preparation. This skilled worker could have also monitored Bob's diabetes management and supported him to seek out medical attention prior to the development of foot ulcers and related mobility impairment. This, in turn, could have delayed or prevented the need for home care services and the eventual admission to hospital and LTC.

Early IADL Impairment Onset Implications

The preceding case examples demonstrate how early onset of IADL impairment can have a feed-forward effect and lead to subsequent ADL impairment and eventual transition to LTC. When combined with findings of this study, these anecdotal lived experiences of older adults can expand the current understanding of associations between IADL impairment, cognition, and transition to residential care within Ontario (Williams et al., 2009) and across other settings (Bharucha et al., 2004; Friedman et al., 2005; Kendig et al., 2010). While the scientific community does not have firm evidence of a causal link between IADL impairment and the hastening of ADL impairment, it may emerge that IADL impairment plays a causal role in the onset of ADL impairment for some older adults which may also lead to LTC placement.

There is considerable opportunity to improve the scope and availability of IADL services within Ontario, and across Canada. Improvements in scope and availability could better support quality of life for older adults and may prevent suffering associated with rapidly declining IADL function that may be occurring between the onset of rapidly declining IADL function and when older adults qualify for home care services. A stepped care model could be used to develop early assessment and intervention and serve as a framework to inform different stages of IADL intervention research and program development.

As presented here, the stepped care model also provides unique opportunities for patient partnering in the development and delivery of services and for the establishment of partnerships between current home care programs and existing community services to promote person-centered care, continuity of care, and a fluid transition through the stages of the stepped care model. The strong association between IADL function and cognition, and recent development of IADL assessment instruments that can identify those with mild cognitive impairment, creates an additional opportunity to pair IADL education and services with early detection and intervention for those with mild cognitive impairment. The nature of currently available IADL assessment instruments also identify IADL impairment targets that could be exploited to inform education, rehabilitation, and participatory support intervention research. To date, there are no research findings indicating whether interventions aimed at rehabilitating or maintaining IADL function stabilize, or possibly improve, cognitive function in older adults.

Stepped care for IADL assessment and intervention

Stepped care models are grounded within a person-centered (Goodwin, 2016), individualized model of care and with the understanding that not all people require the same type of service or intensity of intervention (Haaga, 2000). Stepped care models should be evidence based, low barrier, and accessible through both self and clinician referral processes, while being well integrated with increasingly intensive intervention strategies made available in a manner that promotes fluid transition of participants through progressive steps of care (Sobell & Sobell, 2000). The evidence necessary for the development of a stepped care approach to IADL services is based in a strong and evolving literature reviewed earlier and which identifies associations between IADL impairment and adverse outcomes, emerging knowledge about the time course of IADL and ADL impairment, the recent evolution of expanded IADL assessment instruments, and the ability to utilize IADL assessment to identify and intervene with older adults experiencing mild cognitive impairment.

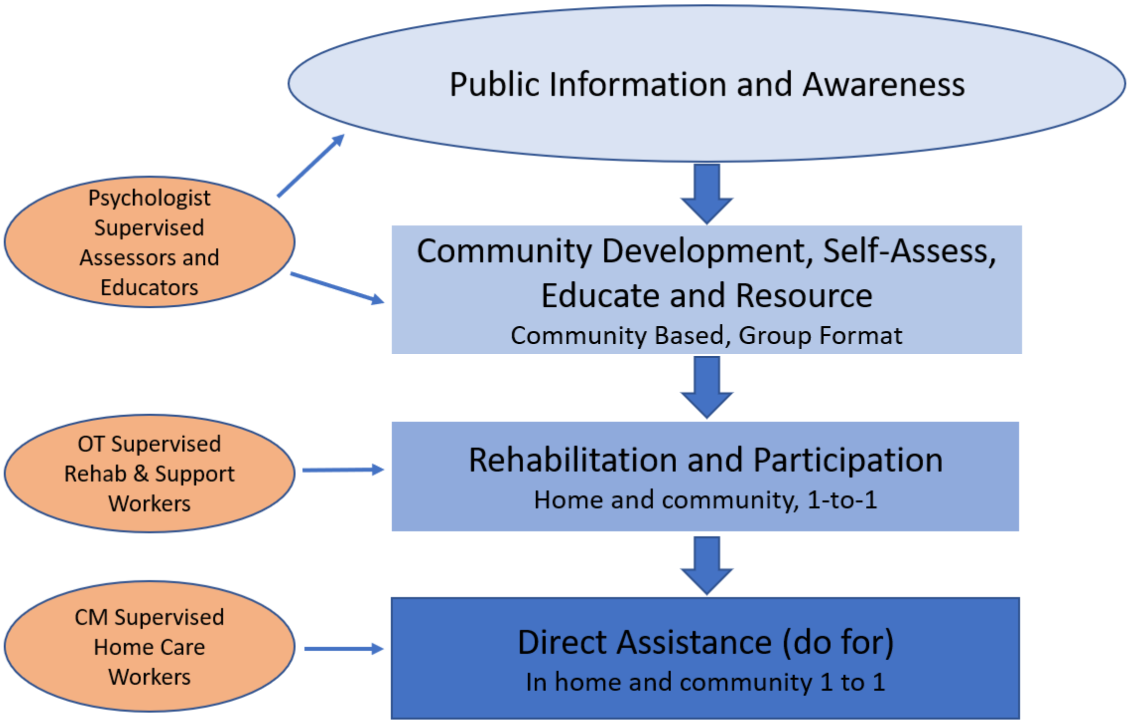
The strong evidence of relationships between IADL function and cognition provide links to the cognitive training literature. Early efforts to exploit cognitive training as an intervention for older adults held great theoretical and applied promise for improving daily function in older adults (Lövdén et al., 2010a; Lustig et al., 2009). However, the field of cognitive training has since been criticized for lacking a cohesive theoretical framework (Willis & Schaie, 2009) and for failing to demonstrate meaningful transfer to everyday cognitive skills (Owen et al., 2010). Despite these shortcomings, this area of research has consistently demonstrated improvements in the performance of older adults on the specific cognitive tasks trained (Ball et al., 2002; Smith et al., 2009), with some showing modest transfer to other tests of cognitive function (Schmiedek et al., 2010) and daily living skills (Ball et al., 2007; Willis et al., 2006). This disparity has led to the development of new theories that argue for direct training of every day cognitive tasks (Bielak et al., 2017) and compensatory strategies (Chandler et al., 2017). IADL exemplify every day cognitive tasks that may also benefit from compensatory strategies.

When viewing cognitive training and rehabilitation within the context of adult development, early intervention is further supported by the understanding that older adults who engage in higher levels of cognitive activity experience slower cognitive decline (Hall et al., 2009) and that reduced learning abilities in older adults precedes the onset of dementia (Royall et al., 2003) and death (Laukka et al., 2006; Wilson et al., 2007). Taken together, the associations between IADL and independent living skills with cognition, evolution of cognitive training literature, and knowledge that advancing cognitive impairment impedes new learning and adaptive behaviors, all lead to the conclusion that early assessment and intervention with IADL and other cognitively complex independent living skills may emerge as best practice when providing care and supports for older adults. Interventions in this area of functional independence have two potential outcomes: positive changes with functional independence and/or positive changes in cognitive performance, with improvements in either domain having broad reaching implications for improving capacity to age in place.

IADL stepped care model

Figure 11 presents a flowchart representation of a possible stepped care model for IADL interventions. The orange ellipses on the left identify personnel who may be appropriate for the delivery of each stage in the stepped care model and what may be an appropriate level/type of supervision. The top blue ellipsis symbolizes a broad reaching public information and awareness campaign targeted to older adults, their caregivers, and family members. Each subsequently darker blue rectangle below this ellipsis represents interventions of increasing intensity.

Figure 11 Flow Chart of IADL Stepped Care Model



Note: Figure depicts steps and stages of IADL assessment and intervention (blue) and type of supervision and direct service staffing (orange).

The public information and awareness component of this model includes activities such as public presentations, development of a resource and self assessment website, distribution of resource and educational materials at places older adults and their caregivers frequent, and possibly media advertisements to garner attention to the initiative. These community outreach activities could also be used to generate referrals to other steps of care in the model. The first of these steps included the group-based delivery of workshops for participants and their caregivers to support interpretation of self assessment instruments and to provide group-based training regarding skills and adaptive strategies specific to IADL and independent living. This initial step could also be used to develop social networking and peer support elements with the aim of creating a self-sustaining community of older adults and volunteers who may be able to independently maintain aspects of the group-based training program.

The second step in the model opens access to clinician supervised rehabilitative IADL and independent living skills services that are delivered by community rehabilitation workers (CRW). Within this step, participants are engaged in a participatory activation model where the CRW provides a “do with, not for” approach that is person centered, strength based, and which integrates principle of progressive goal attainment. This participatory model encourages participants to self-direct service through the co-creation of a person-centered goal plan, identifies strengths and capacity to determine appropriate start points for service, and subsequently engages participants to set realistic and achievable, stepwise, goals that build upon current strengths and capacity. Goal and rehabilitation outcomes are achieved through active participation with older adults to complete IADL activities as independently as they are able and through the ongoing interventions of the CRW to ensure safety, create and implement adaptive strategies, and to monitor and revise goal plans while celebrating achievements and newly identified strengths as they are realized. This integrated approach promotes activation and direct training with cognitively complex independent living skills while providing opportunities to implement adaptive strategies and to otherwise promote independence.

The third, and most intensive, step of this program is delivered by existing HCC home care programs to provide in-home and community-based assistance with IADL tasks in the absence of co-pay requirements. As participants transition to no longer being able to actively participate with the CRW program, and it is agreed to by the participant and their caregiver(s) that another party needs to take responsibility for these tasks, a traditional home care model that uses a “do for, not with” approach to service delivery is integrated. Wherever possible, participants remain engaged with the CRW participatory activation services to promote independence, engagement, community access and integration.

Study Limitations

When modeling data for this study, the best fitting change points and slopes are estimated from 0-years prior to discharge to residential care to the limit of the longitudinal data at 7.5-years. However, not all participants or subgroups who are discharged to residential care have longitudinal data that traverses the entirety of the 7.5 years. For example, from the assessment frequency tables in the preceding results sections, it can be observed that the subsample for men without a primary caregiver in the home is the smallest and has the most limited number of assessments, with the number of observations dropping below 100 participants by the 7th observation (approximately 3.5 years before discharge) and trailing off below 10 participants by the 11th observation (approximately 5.5 years before discharge). When modeling data for the men without a caregiver, the models failed to converge beyond 7 years prior to discharge to residential care, while larger samples demonstrated successful convergence through to 7.5 years.

Although the limited number of assessments in the smaller subsamples was initially a concern, the model estimates converged well beyond the best fitting change point models. For example, the IADL change point for men without a caregiver was 2.7 years prior to discharge and the models estimated for this group converged up to 7 years prior to discharge. The standard error about the best fitting change point is also consistent across all models, with the exception of the ADL slope for men without a caregiver in the home, and the confidence intervals remain exceptionally well contained. There is also no systematic pattern across the best fitting change point models that would indicate a pattern of IADL change points (those which occurred earliest) being constrained towards discharge to residential care. Initial concerns about the number of assessments distal to residential care discharge may have been partially mitigated by the average time between assessments being greater than 6 months, a value that was likely increased through the omission of in-hospital assessments. Furthermore, if left censoring in this data is constraining the IADL slopes towards discharge, it does not do so in a manner that interferes with the ability to support the research questions, as the IADL slopes occur prior to those of ADL and well in advance of the onset of home care services across all groups.

Although the group and population findings in this study are compelling, it is important to keep in mind that while the slopes and change points may resemble the lived experiences of many participants, they are not representative of the lived experiences of all participants. The sample used in this study is exceptionally heterogenous and spans many thousands of people, all of whom have unique elements to the onset and type of disability they may experience, the trajectory of their adult developmental processes, and the availability of supports and services.

While it is possible to conceptualize a prototypical, or average, experience of a person who follows the exact change points and slopes fit to the data, this study was not designed to identify or describe individual differences. Rather, the intent is to identify population trends and phenomena that may inform home and community care policy that directs the onset, type, scope, and level of services home care recipients receive.

Generalizing findings from this study to other provinces in Canada, or regions in the world, can only be done through a comparative analysis of the participant demographics and regional home care policy that directs the onset, type, scope, and level of services home care recipients receive. This study describes the entire population of home care recipients in Ontario who met the inclusion criteria and received services during the data collection period. The methods used, and findings derived, do not rely on inferential assumptions nor do they imply an ability to apply these findings directly to a different provincial or regional context.

Skew and kurtosis present in the distributions of IADL and ADL variables used in this study are also worth noting, as these values were generally high. Explorations conducted, but not included in here, indicate that skew and kurtosis values changed, and in some cases were moderated, by the time of last assessment when compared to the first assessment values reported here. Violations of homoskedasticity in the variance of error terms is of critical importance when using inferential statistics to identify *p* values, determining variance accounted for, and when making arguments which support the generalization of findings to other individuals or groups. This study does not rely on inferential statistics to interpret findings or to develop arguments for the generalization of findings from this study to other provinces or territories. Distribution concerns in the key variables are further mitigated by the decision to use a full information maximum likelihood method for all model estimations, an analytic approach which down-weights outlying values.

The caregiver variables available within the dataset are complex and contain inconsistencies. In addition to values identifying the presence or absence of primary and secondary caregivers living within the home, values are present for information such as the type of care, if the caregiver can continue providing assistance, caregiver distress, and hours of informal help. Further, the presence or absence of a caregiver within the home, and other variables available that inform the capacity of a caregiver to provide assistance, are likely to change over time and between assessments. It can be observed within the total number of assessments for both caregiver groups that the sum of these values exceeds the total sample size for the full sample, indicating that these subgroups are not entirely mutually exclusive. Although the caregiver subgroup results presented provide an interesting and useful initial exploration, initial interpretation and dissemination of these results should be tempered. In contrast, the caregiver status results do provide compelling support for further exploration and refinement of these models as they may allow for the identification of smaller subgroups of home care recipients who may benefit from targeted interventions of a suitable scope for research interventions and policy driven pilot projects.

Three variables estimated in this analysis, i.e., birth date, long stay status, and date accepted for service, were not available in the dataset. The exclusion of birth date is a standard procedure to ensure participant anonymity. It is uncertain why the date participants were accepted for service and their status as a long stay client were not included in this dataset, as both variables are present within the data dictionary and appear to be values that are routinely collected. Although the file opened date is available, the date an administrative file is opened for a home care client represents the date the application was received and precedes the date services are approved and started. Birth date was estimated using a standardized procedure for all participants to ensure consistent age of assessment values applied in all instances. From Table 20, the average time between onset of services and change points were also estimated. Status as a long stay home care participant was also estimated. In the context of the 6-month assessment interval of the RAI-HC in Ontario, it was concluded that participants with 2 or more assessments received care for at least 6 months and all participants with 2 or more assessments were retained. Participants with a single assessment who received care for less than 6 months from the date their file was opened were removed from the study.

Future Research

More information about the rate of change and subjective experience of older adults experiencing accelerated functional decline with IADL is required. It may be possible to employ a burst assessment design within a cohort of older adults who are recruited for subjective cognitive concerns or complaints or who have received a diagnosis of mild cognitive impairment (MCI). Shorter initial assessment intervals would allow for the assessment of individual rates of IADL decline and to identify those who are experiencing more rapid functional decline with IADL. Rapid decliners could then be recruited for qualitative interviews or focus group informed self report surveys. Such an investigation would provide valuable information about older adults' experiences of rapid IADL decline and aid in better understanding if they experience negative affect such as stress or fear about their changing capacity, if they have concerns about pending physical limitations, and if their cognitions and emotions about these issues vary by the presence or absence of a caregiver in their home or life. IADL training, rehabilitation and support interventions could then be deployed to determine whether older adults are able regain independence or stabilize decline with IADL activities and whether stabilization or improvement in IADL function is associated with positive changes in cognitive performance.

Change point findings for the full sample and initial sex stratifications from this study would benefit from replication in other provinces in Canada. As indicated in the study limitations, this will require corresponding reviews of policy to determine the scope, type, and level of IADL and ADL services and to identify potential confounds to the models such as abrupt changes in the policies directing these services. It is well known that RAI-HC assessment frequency varies across the country with provinces such as British Columbia requiring assessment frequencies of one year while Ontario provides assessments every six months. These assessment frequency differences will be an important consideration when determining if an adequate number of assessments exist within the datasets of other provinces to accurately information slopes and change points. In situations where this is not possible, policy comparison and other types of quantitative exploration may be necessary to establish comparability between provinces.

A unique feature and strength of a stepped care approach is the opportunities it provides for partnership and collaboration when developing research and program interventions. Researchers in this area are presented with considerable opportunities to establish public and private partnerships with organizations (such as home and community care departments within regional health authorities, provincial ministries of health, the Alzheimer’s Society of Canada, and local community and resource organizations) when developing grant applications for Canadian Tri-Agency financial support. Further, the participatory nature of the early community-based elements of the stepped care model provides a unique opportunity for patient partnering, both in the development of research and programs and with long term program delivery. Patient partnering with older adults will also be valuable when gathering information about current knowledge and public awareness regarding links between IADL and cognition, IADL adaptive strategies, and other topics necessary to inform content and scope for the initial public information and awareness campaign and the education and self assessment step identified in the model.

Finally, the ongoing availability of RAI-HC through CIHI provides considerable opportunities for future quantitative analyses with more recent data from within Ontario and other provinces across Canada. More specifically, future efforts to refine the caregiver status analysis in this study, and to bolster the overall findings with additional quantitative analyses, may be best examined with more current data that extends to the onset of the COVID-19 pandemic in early 2020. Additional quantitative analyses could include approaches such as multi-level modeling that uses slope rate for IADL as a predictor of residential care and joint growth-survival analysis that stratifies IADL and ADL by slope rate.

Conclusion

Change points occur for both IADL and ADL across all groups in this study, with the magnitude of change in the slope following the knot indicating a meaningful acceleration in functional decline in both IADL and ADL for those who are discharged to LTC. Sex differences also emerge, with women being slightly older and exhibiting earlier change points than men for those who are discharged to LTC. These sex differences are most pronounced when comparing men and women without a caregiver in the home.

Change points for IADL occur well in advance of the onset of home care services and the time of first assessment for all groups in this study. For those with a caregiver in the home, the ADL change point also occurs before this time, indicating that they may be relying on support from informal caregivers in the interim. As with sex differences, those without a caregiver in the home experience the earliest change point for IADL, with this being most pronounced for women. These observations bring the question of whether advancing IADL impairment in the absence of adequate supports and services may hasten the onset of ADL impairment and eventual transition to LTC.

Advances in the development of extended IADL assessment instruments creates a new opportunity for researchers to conduct public education and early detection of IADL restriction and related cognitive impairment such as MCI within community settings well in advance of change points observed in this study and that are associated with accelerated functional decline and transition to LTC. These research opportunities fit exceptionally well within current funding mandates to develop community and industry partners and with the important goal of partnering with patients and their family members.

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