Title	Economic perspectives on the boundary of care for people with dementia in Ireland
Author(s)	Carter, Laura
Publication Date	2022-08-24
Publisher	NUI Galway
Item record	http://hdl.handle.net/10379/17300

National University of Ireland, Galway

Doctoral Thesis

Economic perspectives on the boundary of care for people with dementia in Ireland

Author:
Laura Elizabeth Carter

Supervisors:
Professor Eamon O'Shea (NUI Galway)
Dr. Stephen O'Neill (London School of Hygiene & Tropical Medicine, University of London)

A thesis submitted in fulfilment of the requirements for the degree of
Doctor of Philosophy in the
J.E. Cairnes School of Business and Economics

March 2022

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Declaration

I, Laura Carter, declare that this thesis, submitted to the National University of Ireland, Galway for the degree of Doctor of Philosophy (Ph.D.) has not been previously submitted as an exercise for a degree at this or any other University. All research is entirely my own.

Signature: Laura Carter Date: 28/03/2022

Acknowledgements

Firstly, I would like to thank my supervisor Professor Eamon O'Shea for your unwavering support and encouragement throughout my Ph.D. journey. You have always been so generous with your time, offering helpful advice and practical suggestions based on your wealth of experience. You are a leader in this field, and I have learned so much from you over the past few years. Thank you for believing in my abilities and for offering me the opportunity to pursue this research. I also wish to thank my other supervisor, Dr. Stephen O'Neill, for your motivation and encouragement. Your statistical expertise has taught me so much, you have always been so willing to share your knowledge and skills with myself and so many others. Nothing was ever too much trouble. I appreciate your guidance and advice over the past few years, you have become a dear friend.

Many thanks to the Hardiman scholarship at NUI Galway for financially supporting this work. I would also like to extend my deepest gratitude to the study participants who took part in this research.

To my GRC committee, Brendan Kennelly, Professor Kieran Walsh, and Dr. Fiona Keogh, thanks for your continued support and guidance. Your valuable suggestions, insights, and advice were of huge benefit as my thesis developed. I appreciate the commitment you have shown towards my research.

To my team at CESRD, Christine De Largy, Dr. Patricia Carney and Dr. Tom Pierse. Your knowledge and expertise have greatly contributed to the development of my skills over the past few years. Thanks for all of your ideas, help, and encouragement throughout my Ph.D.

I would also like to express thanks to my colleagues and friends at the Discipline of Economics, NUI Galway, who always had a kind word of encouragement, particularly Dr. Edel Doherty, Professor Paddy Gillespie, Dr. John Cullinan, Dr. Michelle Queally, Dr. Anna Hobbins, Dr. Tom McDermott and Dr. Danny Norton. A special thanks to Brendan Kennelly, who has been a very important part of my academic journey. Finally, a word of thanks to Dr. Gerard Turley, who taught me microeconomics in my first semester as an undergraduate at NUI Galway, the impact of your teaching inspired me to proceed with studying economics. My deepest gratitude to Claire Noone and Imelda Howley, thanks for always making me feel so welcome, and for helping me out on so many occasions.

Thanks to my fellow Ph.D. students for your friendship and support: Shikha Sharma, Áine Teahan, Niamh Hennelly, Dan Kelleher, Diarmaid O'Ceallaigh, and Kashie Prendergast. A special word of thanks to past Ph.D. student Padraic Ward; your friendship has been so important throughout this journey.

A word of thanks to my very first teacher, Nollaig Osbourne, you had a significant influence on my education. I think back fondly on your excitement when I began university and the helpful advice you shared.

Mom, thank you for your love, support, and dedication throughout my life. You always encouraged my learning; this Ph.D. is both of ours, and I know Dad would be incredibly proud. To my family, in particular my best friend and sister Olivia, thank you for being by my side every step of the way, I couldn't have done this without you. Aunty Breege, I'm very thankful for all the memories and laughs, you were one of a kind. Finally, to my partner Anil, thank you for your love, kindness, help, and encouragement throughout this journey, I will be forever grateful.

Dedication

This thesis is dedicated to Mimi

Abbreviations and Acronyms

A&E	Accident and Emergency
ADL	Activities of Daily Living
AIDS	Acquired Immunodeficiency Syndrome
AME	Average Marginal Effect
ATT	Average Treatment Effect on the Treated
BIC	Bayesian Information Criteria
BoC	Balance of Care
CEA	Cost-Effectiveness Analysis
CEM	Coarsened Exact Matching
CI	Confidence Interval
CIF	Cumulative Incidence Function
CPI	Consumer Price Index
CSHR	Cause-Specific Hazard Ratio
CSO	Central Statistics Office
CUA	Cost-Utility Analysis
DRG	Diagnosis-Related Group
ECH	Extra Care Housing
GLM	Generalized Linear Model
GP	General Practitioner
HCP	Home Care Package
HIPE	Hospital In-Patient Enquiry
HIQA	Health Information and Quality Authority
HIV	Human Immunodeficiency Virus
HSCP	Health and Social Care Professional
HSE	Health Service Executive
IADL	Instrumental Activities of Daily Living
ICD-10-AM	International Classification of Disease and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM)
IHCP	Intensive Home Care Package
ICPOP	Integrated Care Programme for Older Persons
IQR	Interquartile Range

LOS	Length of Stay
LSRC	Long-Stay Residential Care
NUI	National University of Ireland
NDS	National Dementia Strategy
NDSIP	National Dementia Strategy Implementation Programme
NESF	National Economic and Social Forum
NHS	National Health Service
NHSS	Nursing Home Support Scheme
NIS	National In-patient Sample
OECD	Organisation for Economic Co-operation and Development
ONS	Office for National Statistics
PCRS	Primary Care Reimbursement Service
PH	Proportional Hazards
Ph.D.	Doctor of Philosophy
PPI	Public Patient Involvement
PSSRU	Personal Social Services Research Unit
QALY	Quality-Adjusted Life Year
RIP	Rest in Peace
RUD	Resource Utilisation in Dementia
SCU	Specialist Care Unit
SES	Socioeconomic Status
SHR	Sub-distribution Hazard Ratio
UK	United Kingdom
US	United States

Abstract

As the population ages, the expected increase in the number of people living with dementia will have significant budgetary implications on the health and social care system over the coming years. Therefore, from an economic standpoint, there is considerable incentive to make the best possible use of service provision for people with dementia in Ireland. The main focus in this thesis is the cohort of people with dementia who are on the margin of admission to residential care and/or acute care facilities. Keeping people with dementia at home, postponing admission to long-stay residential care (LSRC) and reducing length of stay (LOS) in acute care may yield significant cost savings for the Irish government, as well as enhance the quality of life for those affected. Reform is currently in train to shift care away from the acute and residential settings and towards the delivery of care at home, where appropriate. During that process, it is inevitable that policy-makers will face the complex task of identifying local needs, determining priorities, and allocating resources within a fixed budget constraint.

The objective of this thesis is to inform resource allocation decision-making at key transition points for people with dementia in Ireland. The thesis uses a broad balance of care (BoC) framework to examine placement decision-making between home care and residential care and between acute care and home care, with the main emphasis on costs rather than outcomes. More specifically, this thesis seeks to support resource allocation at local and national levels and to address identified gaps in the literature relating to costs and, where possible, consequences of placement decision-making for people with dementia on the margins of home care, residential care, and acute care in Ireland.

This thesis consists of three published papers completed over the past four years. The first paper analyses the cost of intensive home care packages (IHCPs) through an examination of resource utilisation of formal, informal, and private care for people with dementia who are living at home but are on the margin of LSRC. Importantly, this analysis facilitates the comparison between the cost of home care and alternative placement in public and private residential care alternatives. While the first study offers valuable insights into community care costs, it is important to consider factors that may affect transition towards LSRC and mortality for IHCP recipients, thereby enhancing our understanding of the specific characteristics of people who may benefit most from home-based care. For this reason, the second paper uses a competing risks survival analysis technique to examine predictors of admission to LSRC and mortality for IHCP recipients living at home who are on the boundary of residential care. Some people with dementia inevitably are admitted to acute care, and there is evidence that many of them spend a longer time as inpatients than might be reasonably expected, even when admitted for non-dementia reasons. The third paper considers the resource implications of dementia in the acute care setting and uses generalized linear modelling on a matched data set to estimate inpatient LOS for patients with a principal or secondary diagnosis of dementia in Irish acute hospitals. Related unit costs are estimated to give an overall additional cost of care for people with dementia in acute hospital settings.

The thesis is a novel contribution to the Irish and international BoC empirical and policy literature, given the paucity of information currently available on costs and/or consequences of alternative care settings for people with dementia. This thesis has significant implications for the recalibration of care towards greater support of people with dementia living at home. The results of the three studies undertaken for the thesis will be particularly useful for the Department of Health to address current and future challenges in relation to placement decision-making for people with dementia in Ireland. The work has already impacted on the provision of home care packages for people with dementia and will help to shape the form and structure of new legislation on home care for people with dementia in the future.

Chapter 1: Introduction

1.1 Research context

Dementia is a loss of cognitive functioning that impacts on memory, language, mood, personality, and the ability to carry out everyday activities (Cahill et al., 2012; National Institute of Health, 2020). Among older people, dementia is the most common cause of functional and cognitive decline (Wübker et al., 2015). Populations are ageing rapidly around the world (United Nations, 2019). Globally, there are over 55 million people who have dementia (World Health Organization, 2021). In Ireland, approximately 55,266 individuals were living with a diagnosis of dementia in 2016. Based on projections in Table 1.1, this figure is expected to almost treble by 2046 (O'Shea et al., 2017). Due to the deteriorating nature of the condition, the care needs of people with dementia increase throughout the trajectory of the disease, therefore imposing significant costs on the health and social care system. In 2018, it was estimated that the worldwide yearly cost of dementia was in the region of $1 trillion (Alzheimer's Disease International, 2018). In Ireland, the cost of caring for people with dementia was estimated to be €1.69 billion per annum (Connolly et al., 2014). Due to the ageing population, the forecasted growth in the number of individuals with dementia will have significant budgetary implications. Therefore, from an economic standpoint, there is considerable incentive to find the most appropriate and cost-effective ways to care for those affected by dementia (Tucker et al., 2008).

Table 1.1: Projected growth in the number of people with dementia in Ireland by age group, 2016-2046

Age group	2016	2021	2026	2031	2036	2041	2046
30-59	2,992	2,933	2,871	2,854	2,847	2,879	2,991
60-64	1,319	1,449	1,615	1,738	1,905	2,044	1,896
65-69	3,377	3,681	4,108	4,586	4,986	5,438	5,774
70-74	5,689	6,842	7,575	8,518	9,543	10,395	11,381
75-79	8,451	10,206	12,564	14,055	15,925	17,971	19,693
80-84	12,621	14,015	17,861	22,348	25,375	29,104	33,195
85+	20,817	26,514	32,427	41,764	54,845	68,632	82,953
Total	55,266	65,641	79,021	95,863	115,426	136,462	157,883

Source: O'Shea et al., 2017.

Recently, the policies of many developed countries have evolved to support dependent older people to remain living in their own homes for as long as possible and practicable (Donnelly et al., 2016; Gage et al., 2015; Verbeek et al., 2012). Keeping older dependent people living at home is based on a number of considerations, such as cost and cost-effectiveness, but the underlying belief is that older people, including those with complex needs, have a strong preference to remain living in their own home (Browne, 2016; Department of Health and Children, 2001; Keogh et al., 2018a; Knapp et al., 1997). An Irish survey conducted by Browne (2016) on future care requirements found that 81% of respondents would most prefer to receive long-term care in their own home, whereas care in a nursing home (29%) was found to be one of the least preferred options.

Many European countries, such as Norway, Sweden, and Denmark, have published dementia strategies that aim to support people with dementia to remain living in their own homes for as long as possible, rather than in residential care (O'Shea & Monaghan, 2016). The Irish National Dementia Strategy (NDS), published in 2014, was the starting point for a national response to dementia care in Ireland. Crucially, the strategy outlines a key action for the delivery of appropriate supports and services for people with dementia that can be accessed in people's own homes and local communities in Ireland (Department of Health, 2014). An important issue in all health and social care systems is how to keep very dependent people with dementia who are on the boundary of residential care living at home for longer, rather than being admitted to acute care or expensive long-stay residential care (LSRC) facilities. Not only is this in keeping with what people want (Browne, 2016; Keogh et al., 2018b; Tucker et al., 2008), but keeping people living at home for longer, or delaying admission to hospital or LSRC facilities, may lead to significant cost savings for governments.

1.2 Motivation

Over the coming years, as the population in Ireland ages, there will be a significant increase in the number of people living with dementia; consequently, this will have implications for public health expenditure (O'Shea et al., 2017). In the context of government reforms in Ireland that seek to move towards the delivery of care at home, where appropriate (Department of Health, 2019; Government of Ireland, 2018; Houses of the Oireachtas Committee on the Future of Healthcare, 2017; PA Consulting, 2018), it is inevitable that policy-makers will face the complex task of identifying local needs, determining priorities, and allocating resources within a fixed budget constraint. The key motivation for the work was the desire to bring economic calculus into the decision-making process on the placement of people with dementia along the continuum of care, especially at key transition points on the dementia journey. This is achieved using a balance of care framework (BoC) to inform resource allocation for people with dementia on the boundary of care in Ireland. More specifically, this thesis seeks to support resource allocation at local and national levels and to address identified gaps in the literature relating to costs and, where possible, consequences of placement decision-making for people with dementia on the margins of home care, residential care, and acute care in Ireland. The findings from this thesis will provide important information on formal home care costs, family care provision, placement decision-making, key transition points, and dementia in acute care settings.

1.3 Home care in Ireland

Currently, the Health Service Executive (HSE) manages the public health care system and is responsible for providing health and social care services in hospitals and communities across Ireland (Health Service Executive, 2019a). Entitlement to home care services is determined based on need; insofar as resources allow, services are usually free at the point of use and are not means-tested (Citizens Information, 2020). At present, home care services are provided by a mix of HSE employees, private care providers, or voluntary organizations. Recent estimates suggest private care companies are the largest providers of care in Ireland, having delivered 58% of total care hours in 2019 (Walsh & Lyons, 2021). The amount of public funding received by private care providers has increased from €3 million in 2006 to €176 million in 2019 (Mercille & O’Neill, 2021). Under the Home Help scheme, the HSE typically provides an individual with up to 5 hours of home care per week (Keogh et al., 2018a).

Enabling people to remain living at home for as long as possible and practicable has been a long-standing objective of government policy in Ireland, dating as far back as the 1960s. However, dementia care in Ireland, and home care, in particular, has traditionally been underfunded and under prioritised (Cahill, 2010). Social care in Ireland has only slowly moved away from institutionalisation, workhouses for the destitute, and large-scale unregulated county homes to newer, more enlightened models with a stronger focus on community care (Timonen & Doyle, 2008). The Care of the Aged report (Government of Ireland, 1968) was the first policy document that explicitly referenced older people remaining in their own homes. The 1970 Health Act then introduced formal home care provision funded by the State in the form of the home help scheme (Walsh & Lyons, 2021). This scheme was established to provide recipients with domestic assistance, such as help with cleaning, cooking, and personal hygiene (O'Shea & Carney, 2016).

These commitments to community care were magnified in The Years Ahead: A Policy for the Elderly report (Robins, 1988). This seminal policy document highlighted the importance of keeping older people in dignity and independence at their own home as an alternative to residential care. The Years Ahead report also contained some of the first dementia specific policy recommendations. These are centred on elements such as screening for dementia, the need for dementia specific carers, additional day care, and day hospital facilities, specialist hostels to support people with severe dementia, and developing the provision of psychiatry in old age. Unfortunately, the shift to community-based care signalled in The Years Ahead report was not followed up by an ongoing commitment to funding the new model. Resource allocation towards home care continued to be piecemeal and fragmented, and nothing much changed for dependent older people in Ireland. Families continued to provide the bulk of care for people living at home (Cahill et al., 2012). Moreover, very few, if any, specific provisions were developed for people with dementia and their carers. Diagnosis was sporadic, information systems were poor, post-diagnostic provision was weak, and dementia remained off the policy radar in Ireland (O'Shea & Carney 2016; O'Shea et al., 2017; O'Shea et al., 2018).

An Action Plan for Dementia (O'Shea & O'Reilly, 1999), commissioned by the National Council for Ageing and Older People, was Ireland's first non-governmental dementia plan. It envisioned a person-centred, best practice social model of dementia care, highlighting the need for major improvements in care in the community. It prioritised several key areas: increased public awareness, earlier diagnosis, psychosocial approaches to complement existing care, community-based services, and small-scale residential care units. The government's 2001 Health Strategy (Department of Health and Children, 2001) pledged to implement the Action Plan for Dementia, but again this hope was never realised. Despite pressure from various stakeholder groups, the setting up of two National Dementia Working Groups, and the publication of a call for implementation (O'Shea, 2007), dementia did not become a priority for the government, nor was there any new investment in home care services or facilities.

The attention of policy-makers at that time was focused mainly on the regulation of nursing homes in Ireland, including establishing the statutory provision of long-term care with the Nursing Homes Act (1990) and the subsequent development of National Quality Standards for Residential Care settings for older people in Ireland (Health Information and Quality Authority, 2008). The Nursing Home Support Scheme (NHSS), commonly known as the ‘Fair Deal,’ was established in 2009 to provide financial support to eligible residents towards the cost of their nursing home care (Office of the Comptroller and Auditor General, 2020). This was a major piece of legislation that required residents to make a contribution towards care costs, depending on their means, with the HSE contributing the balance.

A modest home care package (HCP) scheme was introduced in 2006 with the aim of supporting dependent older people to stay at home for longer through the provision of enhanced home supports and rehabilitation services (Walsh & Lyons, 2021). These packages were typically targeted towards people on the margin of residential care, especially people who needed additional supports following discharge from acute care (Keogh et al., 2018a). In truth, they were designed to facilitate faster discharge from acute care beds than to prevent admission in the first instance. Currently, the weekly hours for HCPs typically range between 6 to 21 hours (Keogh et al., 2018a). In 2018, The Home Help Service and Home Care Package Scheme were combined into what is now called the Home Support Service (Health Service Executive, 2021). The home support service scheme delivered home care services to over 53,000 individuals, costing over €440 million in 2019 (Walsh & Lyons, 2021).

In 2011, a promise was given by the incoming government to develop a specific National Dementia Strategy (Department of Health, 2014). This was initially signalled as a *no-cost strategy* due to the precarious condition of the State’s finances at that time. Fortunately, from 2011 to 2016, dementia care in Ireland benefited from a substantial philanthropic investment of over €33 million from The Atlantic Philanthropies (O’Shea & Carney, 2016). This money helped to finance major multi-sectoral programmes throughout the country in key areas such as service transformation, including end-of-life care; advocacy and awareness; education and training; brain health, prevention, and diagnosis; and measurement, research, and evaluation (Carney & O’Shea, 2020). The money also helped to partially fund the Irish National Dementia Strategy, especially the development of intensive home care packages (IHCPs) for people with dementia to allow them to remain living in their own homes for as long as possible.

IHCPs are designed to keep people with dementia out of acute care and residential care and to support people with very high levels of need who might otherwise be unable to live at home (Keogh et al., 2018a). The IHCP initiative is closely aligned with a priority action of the National Dementia Strategy Implementation Programme (NDSIP) involving the further development of integrated services for people with dementia, particularly in respect of home supports (Department of Health, 2014; Keogh et al., 2018a). In practice, those receiving IHCPs receive more visits and significantly more hours of care from public health nurses and home help workers than those not in the scheme, including more personalised provision that reflects individual circumstances, family care networks, and housing conditions. Encouragingly, investment in the IHCP initiative indicates support for change regarding the reorientation of resources towards community-based care. However, due to budget constraints, the allocation of IHCPs has been slow. Approximately 200 IHCPs are approved each year (Keogh et al., 2018a).

As in many other countries, informal carers for people with dementia are a significant part of the support system in Ireland, with the majority of home care provided by family and friends (O'Shea et al., 2017). In 2016, it was estimated that there are over 195,000 family carers in Ireland who provide an average of 38.7 hours of caring per week (Central Statistics Office, 2016a). Approximately 60,000 family carers provide care to people with dementia (Gillespie et al., 2013). There is evidence that informal carers bear most of the carer burden and financial cost of dementia care (O'Shea et al., 2019). Connolly et al. (2014) report just under half (48%) of the total annual cost of caring for people with dementia is attributable to informal care provided to those with dementia living in the community setting in Ireland. While the vast majority of family carers are committed to caring for their loved ones, it is evident that more financial and social support is needed for this group (Teahan et al., 2021). Recent evidence also shows there is an increase in privately purchased home care to supplement HSE publicly funded home care hours. Wren et al. (2017) report that private out-of-pocket expenditures are attributable for up to one-quarter of all home help hours in Ireland. Therefore, it must be recognised that an inadequate supply of publicly funded home care in Ireland is likely to lead to a diversion of demand for private home care provision and other care alternatives such as admission to residential settings and hospital care (Walsh & Lyons, 2021).

1.4 Irish policy context

1.4.1 Home care within the Irish context

Various policies such as the Sláintecare report (Houses of the Oireachtas Committee on the Future of Healthcare, 2017), the National Carers' Strategy (Department of Health, 2012a), and the National Positive Ageing Strategy (Department of Health, 2013) have emphasised home care as being the preferred care option over residential care for older people in Ireland. However, the policy commitment to developing community care services in order to support this goal has not always been successful (Keogh et al. 2018a; O’Shea et al., 2019). In Ireland, community care services for people with dementia remain underdeveloped, under-resourced, unevenly distributed, and inflexible; offering a small range of services with inconsistent availability (Cahill et al., 2012; Keogh et al., 2018a; O’Shea et al., 2017; Walsh & Lyons, 2021).

At present, in Ireland, there is no statutory scheme in place for the provision of home care services in the community setting (Browne, 2016; O’Shea & Carney, 2016). This differs to countries such as the United Kingdom (UK), Norway, Denmark, France, and Australia (O’Shea et al., 2019). The lack of statutory entitlement for the provision of home care services in Ireland has led to eligibility and entitlement issues across the country (Kiersey & Coleman, 2017). Keogh and O’Shea (2019) describe home care in Ireland as being a ‘supply-led’ service, meaning that home care is determined by the amount of funding allocated each year. This leads to a situation where home care is rationed, for example, by means of a waiting list or by spreading hours sometimes quite thinly across recipients. As a result, home care provision in Ireland is, for the main part, determined based on the needs of the provider as opposed to the needs of the recipient (O’Shea et al., 2019). Due to the scarcity of care hours available, Ireland currently operates a task-based model of home care, which is largely generic in orientation (Keogh et al., 2018a). Whereby the focus of home care is largely on the provision of essential domestic and personal care assistance with little focus on the delivery of personalised care services such as providing companionship or accommodating individual preferences and wishes (O’Shea et al., 2017).

It is evident that the current model of home care is recognised as far from ideal. Dempsey et al. (2016) studied the preferences of both home care recipients and home care workers in Ireland. Their findings showed that the current task-based model of home care placed time constraints on home care workers, resulting in the recipients feeling their visit was too short and home care workers being unhappy with the length and quality of visit provided. According to Harty (2018), considerable travel time, overflowing rotas, and a high volume of short calls have been identified as reasons for home care workers arriving late to calls, not staying for the allocated length of time, or missing calls entirely. Factors such as insufficient rates of pay, zero-hour contracts, low status, and valuation have led to difficulties recruiting and retaining staff within the private home care sector (Prince et al., 2013), and thus, are amongst the issues greatly threatening a move towards the personalization of care for individuals with dementia living in the community.

The need for personalised care services has long been recognised in Ireland (National Economic and Social Forum, 2005). The Institute of Public Health (IPH) report published in 2018 showed that a number of respondents proposed that services should be designed around the needs of the user, with the users having a central role in shaping the type and quality of the service that they receive. Furthermore, continuity of service and building a relationship between carers were identified as being important to users also. At present, there is no statutory regulation or quality assurance mechanisms for home care in Ireland; importantly, these are needed to measure outcomes as well as processes of home care in the community setting (Keogh & O'Shea, 2019). While the delivery of essential domestic and personal care assistance continues to be a focal point of home care in the Irish context, social, psychological, and emotional needs must also be recognised in a new personalised approach to care (Keogh et al., 2018a). It is estimated that there are at least 11,175 people with dementia living at home who have a serious functional impairment, 1,876 of whom are chair or bedbound (Pierse et al., 2019). Thus, it must be acknowledged that the generic nature of care delivery in Ireland may have a significant impact on people with dementia who specifically require a more personalised approach to care in the home, which promotes personhood (Keogh et al., 2018a).

Despite calls over the past number of years, Ireland has been very slow to develop alternatives to the traditional nursing home model of care (Cahill, 2021; O'Shea & O'Reilly, 1999). In terms of resource allocation, one of the longstanding criticisms of government policy for dependent older people in Ireland is the imbalance in public spending between residential care and community-based care (Donnelly et al., 2016; Keogh et al., 2018a; O'Shea, 2017). Thirty years ago, The Years Ahead: A Policy for the Elderly report highlighted the need for the development and practice of home-based care for older people and recommended greater state involvement to support community-based care (Robins, 1988). In 2005, the National Economic and Social Forum (NESF) called on the then government to spend an additional €500 million to bring long-term care expenditure up to the Organisation for Economic Co-operation and Development (OECD) average, arguing for a disproportionate spend on home care in the country (National Economic and Social Forum, 2005). In the past, even when public resources were relatively plentiful, resource allocation and prioritisation of community-based care have been poor (O'Shea & Carney, 2016). Currently, the government is spending more than twice as much on residential care as on community-based care, over €1 billion relative to €446 million annually (Dáil Éireann, 2019). In practice, only two care options exist for the majority of older people in Ireland, home care and conventional nursing home care (O'Shea et al., 2019). Evidence from other countries shows that poor access to home care increases admission to residential care (De Meijer et al., 2015; Guo et al., 2015). Given the inadequacy of home support services in Ireland, nursing home admission may be the only option for some people with dementia. This leads to a situation where some people end up in residential care prematurely.

The most recent Health Service Capacity Review for the government (PA Consulting, 2018) highlights the need for significant investment in home care provision in Ireland. Based on there being no service reconfiguration between 2016 and 2031, it is anticipated that approximately 82,000 dependent older people will be in need of home help hours by 2031, an increase of 71% (Table 1.2). Meanwhile, the demand for HCPs will increase to 26,600 people by 2031 (70% increase), while the demand for IHCPs will increase to 330 packages by 2031 (70% increase). Unfortunately, there has been no work published that estimates the number of those individuals with a diagnosis of dementia.

Table 1.2: Capacity requirement in Ireland, with no service reconfiguration

Setting	2016	2031	% change
Community-based Home Help hours	48,000	82,000	71%
Community-based Home Care Packages	15,600	26,600	70%
Community-based Intensive Home Care Packages	200	330	70%

Source: PA Consulting, 2018.

1.4.2 Residential care within the Irish context

Transition to residential care is needed when care at home is no longer practicable, and the level of care required does not necessitate an acute hospital admission (Walsh et al., 2019). In Ireland, LSRC is provided by a mixture of public, voluntary, and private care providers. The private sector is the largest provider, supplying about three-quarters of all long-term care beds (Daly, 2018). The majority of providers are funded by the state, with the Exchequer funding approximately three-quarters of the cost of long-term care (Daly, 2018). Over the past number of years, it has been argued that a policy bias exists which supports residential care over home-based care (Cahill, 2021), and this is evident from the statutory entitlement to nursing home care delivered through the NHSS established in 2009, which involves a co-payment arrangement between the state and a contribution from the resident based on a financial assessment of income and assets, including their family home (Wren et al., 2017). In 2019, there were 23,629 residents supported by the NHSS in Ireland (Doyle & Timoney, 2021).

Some family caregivers have reported that gaining access to nursing homes for a relative with dementia is not straightforward, even with the NHSS in place, citing a number of issues such as long waiting lists, high nursing home costs, and difficulties with regard to finding an appropriate dementia-friendly facility (Cahill et al., 2012). Recent estimates suggest that 19,530 people with dementia are living in nursing homes in Ireland (Pierse et al., 2019), representing approximately 70% of total residents (O'Shea et al., 2017). The vast majority of those with dementia in nursing homes are likely to have high levels of functional impairment (Pierse et al., 2019). Research has shown that most people with dementia who are living in nursing homes are being cared for in generic care facilities, which do not accommodate for many of the complex and unique caring needs of people with dementia (O'Shea & Carney, 2016). In the Irish context, very often, the building layout of nursing homes is not suitable for a person with dementia, and this makes it difficult for staff to deliver care in a personalised manner (Cahill et al., 2021). A recent report published by O'Shea et al. (2019) explains that good environmental design is extremely important for people with dementia living in a residential care setting, as is engagement and connectivity. The authors describe that the creation of a more homelike psychosocial environment and maintaining engagement and connection with the outside world, for example, by integrating into community life with neighbourhoods, can enhance the personhood dimension of care within residential settings (O'Shea et al., 2019).

In order to accommodate for the special caring needs of dementia in long-term residential care facilities, many countries such as the UK, France, Norway, Sweden, and Germany are moving towards the provision of specialist care in small-scale care units (Cahill et al., 2012). A number of studies have reported a positive impact of small-scale care units on the quality of care received and quality of life for the person with dementia (Cioffi et al., 2007; Day et al., 2000; Doody et al., 2001; Morgan et al., 2004; Sloane et al., 2005). Due to limited availability in Ireland, very few people (approximately 11%) gain access to dementia specialist care units (SCU) (O'Shea et al., 2019). Furthermore, the absence of a standard definition for what constitutes an SCU or a 'dementia specific bed' within a generic long-term care facility augments concern regarding the lack of dementia specific long-term residential care facilities in Ireland as it is more difficult to discern where and how people with dementia are being cared for in residential care settings (O'Shea & Carney, 2016). The report by O'Shea et al. (2019) recommends that future investment in nursing home facilities in Ireland must include dementia specific design principles and should provide small-scale units which are homelike and therefore promote the personhood of people with dementia (O'Shea et al., 2019).

Due to a number of factors such as the ageing population, an increase in dementia prevalence rates, and the decline in the availability of informal carers, we can expect to see a significant increase in the demand for long-term residential care in the medium to long term (Wren et al., 2017). Based on the findings of the Health Service Capacity Review, approximately 10,100 (39%) more long-term care beds will be required between 2016 and 2031 (PA Consulting, 2018). No doubt this will place significant costs on the Exchequer. As a result, the government needs to consider the sustainability of long-term care funding systems and to examine whether expanding community-based home care services or developing alternative models of care will reduce future demand for long-term care nursing home beds. Arguably, there is a need for the government to shift the BoC away from the traditional residential care setting towards potentially more cost-effective home-based care. The extent to which future demand for long-term residential care can be mitigated by strengthening and developing community-based services will only be determined after new approaches are evaluated (Department of Health, 2012b).

1.4.3 Acute care within the Irish context

The inadequate supply of publicly funded home care services also places pressure on acute hospitals in Ireland (O'Shea et al., 2019). A recent study conducted in Ireland found that hospital LOS was longer for inpatients living in regions with a lower supply of formal home care (B.Walsh et al., 2020). Worryingly, when people with cognitive impairment and/or dementia are admitted to hospital, they typically experience a longer LOS than other patients (King et al., 2006; Möllers et al., 2019; Motzek et al., 2018; Tropea et al., 2017). Not surprisingly, costs are also found to be significantly higher among hospitalised patients who are cognitively impaired (Connolly & O'Shea, 2015). An Irish study by Briggs et al. (2016) found that the average LOS for those with a diagnosis of dementia aged 65 years and over was 31.0 days compared to 14.1 days for the non-dementia group. This led to hospital care costs being almost three times higher for the dementia group (€13,832 versus €5,404). Moreover, studies have shown poorer outcomes for hospitalized patients with dementia, placing this group at an increased risk of morbidity, mortality, institutionalization, falls, and functional decline while in the hospital setting (Fogg et al., 2018; George et al., 2013; Sampson et al., 2009; Tropea et al., 2017; Watkin et al., 2012). It is not surprising, therefore, that in many countries, reducing hospital LOS for dementia patients is a prospective strategy designed to improve health outcomes, decrease health care costs, and to ensure the sustainability of health care systems (Jensen et al., 2019; Vetrano et al., 2014).

Out of all OECD countries, Ireland allocates the largest proportion of health care spending to acute hospitals (Organisation for Economic Co-operation and Development, 2018a). The government has acknowledged the need to move away from the current hospital-focused model of care and towards treating people as close to their homes for as long as possible and practicable (Department of Health, 2019; Government of Ireland, 2018). Encouragingly, for the first time, the most recent Health Service Capacity Review has taken a broader approach to considering acute bed capacity only and has now recognised the importance of examining interdependencies within the health care system, including the expansion of home supports to relieve the pressure off overburdened hospitals (PA Consulting, 2018). Furthermore, the Sláintecare Implementation Strategy has identified that significant additional investment is required in the area of home support in order to reduce acute hospital pressures (Government of Ireland, 2018). Reform of home care will undoubtedly alleviate pressure on an overburdened hospital sector in the country, some of which is also caused by low bed-to-population ratios and high bed occupancy rates relative to other countries (Organisation for Economic Co-operation and Development, 2018a). Equally, however, expanding home care supports will not completely address excessive LOS for people with dementia in acute hospitals; in particular, a lack of staff training and an absence of dementia specific knowledge in hospitals is likely to contribute to extending stays beyond efficient levels (Bracken-Scally et al., 2020; Jensen et al., 2019).

1.4.4 New home care scheme in Ireland

To overcome shortcomings in the current health care system, a new statutory home care scheme was proposed by government in the 2017 Sláintecare report (Houses of the Oireachtas Committee on the Future of Healthcare, 2017). Within the context of the broader implementation of Sláintecare reform, the Department of Health is currently committed to establishing and progressing a new statutory scheme for the financing and regulation of home care services in Ireland (Keogh & O'Shea, 2020). The importance of developing such a scheme has been recognised by the Department of Health's Sláintecare Implementation Strategy (Government of Ireland, 2018), which recognises the expansion of community-based care being closer to home as a strategic priority (Keogh & O'Shea, 2020).

Under the new home care scheme, the recalibration of care towards greater support of people at home is described as being central to the reform process. To advance Sláintecare's vision of delivering "the right care in the right place at the right time" (Keogh & O'Shea, 2019), some objectives of the new statutory home care scheme include: provision of services that are determined based on a care needs assessment; cost not being a barrier to accessing services; integration of the new home care scheme with other health and social care services (including the NHSS fair deal) along the continuum of care; and, the development of a system that delivers home care in an equitable, fair and consistent manner across the country (Keogh & O'Shea 2019; Walsh & Lyons, 2021). The development of the new home care scheme will build on international best practice, as well as lessons learned from the current health and social care system with respect to the delivery of home care services in the Irish context (Walsh & Lyons, 2021). However, at the time of writing, the commitment to the new home care legislation has not yet been realised, and stated targets have not been met, complicated by recent resignations of key personnel driving change in this area. While the Department of Health's Sláintecare Implementation Strategy (Government of Ireland, 2018) had committed to the introduction of the new statutory home care scheme by the end of 2021, progress has stalled, undoubtedly impacted by COVID-19 (Walsh & Lyons, 2021), but not fully explained by the latter either.

1.4.5 Key elements of the proposed new home care scheme

A recent Policy Dialogue of the new home care scheme published by the Centre for Economic and Social Research on Dementia (Keogh & O'Shea, 2020) identified four themes to emerge from the Stakeholder Dialogue regarding future home care provision in Ireland: the home care continuum, family carers, care planning and organisation of care delivery, and regulating for quality and funding. Some of the key findings from the Policy Dialogue are outlined below:

Home care continuum

- A lack of clarity exists in relation to the purpose of home care. There is a need to define outcomes required from a home care service
- Home care is currently reactive, for example, in times of crisis, whereas a more proactive approach is needed to maintain the current health of individuals

- There is a need to personalise and individualise home care, with a focus on flexibility

Family carers

- There is a greater need to explicitly recognise carers within the provision of care, for example, by providing blocks of formal care if requested
- An increase in the provision of home care hours is needed. After addressing physical needs, the importance of social needs was highlighted

Care planning, organisation, and delivery

- A proactive approach is needed to keep older people active, mobile, and independent; this will support disease prevention and will help older people to live independently for longer
- Older people have a right to autonomy, meaning that home care recipients must be given responsibility and choice in relation to home care services
- Consultation such as public patient involvement (PPI) should be built into the new home care scheme

Quality, regulation, and financing home care

- There is a need to regulate home care and home care workers
- Home care workers need to be valued in order to make caring a more attractive career option. This could be helped by creating better pay and working conditions
- There is a need to measure outcomes as well as processes in the regulatory system
- In the short term, a combination of the current general taxation system supported by a co-payment system could be used to fund a new model; in the longer term, a new social insurance scheme could potentially be an option.
- Given the demand for limited resources, there was a consensus that cost sharing is necessary whatever model of financing existed

The findings from the Policy Dialogue (Keogh & O’Shea, 2020) demonstrate the importance of an evidence base for building and developing the new home care scheme in Ireland. This thesis is a contribution to that evidence base, providing important information on the continuum of care and decision-making along the continuum. The results of the three studies in this thesis will be particularly useful for the Department of Health to address current and future challenges in relation to placement decision-making. The work undertaken in the thesis is a recognition of the need to address current challenges faced by the home care system in Ireland and to create a platform for the development of home care services in the future (Keogh & O’Shea, 2020). The success of the new home care scheme will depend in part on lessons learned within the

Irish context but also on the strength of new evidence for the development of the new scheme. The data and analysis from this thesis will provide important information on formal home care costs, family care provision, placement decision-making, key transition points, and dementia in acute care settings.

1.5 Overview of the balance of care approach

As governments seek to move away from the provision of care in acute hospitals and residential care settings to focus on the development of community-based care for older people, it is inevitable that policy-makers in Ireland will face the complex task of identifying local needs, determining priorities, and allocating resources within a fixed budget constraint. Although economic evaluations such as cost-effectiveness analysis are frequently used at the national level for providing evidence on costs and outcomes of drugs, technologies, etc., the literature suggests economic evaluations are not commonly used at the local level to determine optimal placement decisions (Tucker, 2020). A transparent system for allocating resources between home, residential and acute care is often lacking at the local level highlighting the importance of practical information on costs and outcomes (Tucker et al., 2013). Very often, health care planners make resource allocation decisions without robust evidence, leading to inappropriate placement for some older people (Challis et al., 2014; Donnelly et al., 2017). For example, a UK study found that up to half of new residential care home entrants could be cared for in alternative settings. For these individuals, nursing home care could be delayed by 3-12 months if adequate community supports were made available (Challis et al., 2014).

BoC is a strategic planning tool that can be used to support resource allocation at the national or local level (Challis et al., 2014). This framework focuses on identifying the types of dependent older people on the margin of care whose care needs could be met in more than one setting, such as the community, residential or acute care setting (O'Shea & Monaghan, 2016). Of course, it is difficult to identify *a priori* people on the margins of care without the support of local administrative systems that, in turn, mostly rely on the ex-post judgements of health care providers. Identifying people on the margin of care is not an exact science for sure. However, once the relevant population has been identified, BoC is a systematic framework for exploring the potential costs and/or consequences of changing the mix of resources in a defined geographical area (Challis et al., 2014). At the core of this approach is the idea that when funding is limited, shifting the balance of resources from one group/service to another can increase benefits and/or reduce costs (Arthur Anderson & Company, 1981; Mooney &

Drummond, 1982, as cited in Tucker, 2020). In this thesis, the BoC framework is used to examine the costs and, where possible, consequences of placement decision-making for people with dementia on the margins of home care, residential care, and acute care in Ireland, with the focus predominantly on costs rather than outcomes. This framework will be discussed in further detail in Chapter 2.

1.6 Overview of research objectives

The purpose of this thesis is:

To inform resource allocation decision-making for people with dementia across the continuum of care in Ireland, especially at the intersections between home care, residential care, and acute care, using a BoC approach/framework.

Based on this broad purpose, three specific research objectives are outlined below, corresponding to the three main studies/papers in the thesis:

- **Research objective one**: To conduct a cost analysis of HSE-Genio intensive home care packages for people with dementia living on the boundary of home care and residential care in Ireland
- **Research objective two:** To examine admission to long-stay residential care and mortality for intensive home care package recipients living at home but on the boundary of residential care in Ireland
- **Research objective three:** To explore length of stay and related costs for people with dementia in Irish acute hospitals

Using a BoC framework, this research seeks to support resource allocation at local and national levels and to address identified gaps in the literature relating to costs and, where possible, consequences of placement decision-making for people with dementia on the margins of home care, residential care, and acute care in Ireland. Due to data limitations in Ireland, the main focus of this thesis is predominantly on costs and cost drivers rather than outcomes. When analysing costs, the perspective of the study should first be determined (Byford & Raftery, 1998). The perspective commonly adopted throughout the literature is that of the health service, which considers the costs originating in that sector, such as nursing and medical care provision (Connolly et al., 2014). The broadest perspective is societal, which includes all costs, where possible, regardless of who pays those costs. Such a perspective includes not only the costs falling on the health care service but also social care costs such as the opportunity cost of informal caring, for example (Connolly et al., 2014).

In relation to the first research objective, a cost analysis is conducted from a societal perspective, including family care costs, to determine the average weekly cost of home care for people with dementia on the boundary of care who are receiving enhanced home supports in the form of IHCPs. The costs of community care and residential care facilities are then compared. While the first research objective offers valuable insights into community care costs, it is important to consider factors that affect the transition towards LSRC and mortality for IHCP recipients, as such information can enhance our understanding of the specific characteristics of people who may benefit most from home-based care. To address research objective two, a competing risks survival analysis technique is used to examine predictors of admission to LSRC and mortality for IHCP recipients who are on the boundary of care in Ireland. The third research objective considers resource implications of dementia in the acute care setting and uses generalized linear modelling on a matched data set to estimate inpatient LOS for patients with dementia in Irish acute hospitals for those with a principal and secondary diagnosis of dementia. Related care costs are then estimated and valued from a health service perspective.

The three research objectives are inter-linked as they seek to consider the costs and, where possible, consequences of changes in placement decision-making at key transition points using a BoC framework. The analysis and findings should be seen as a contribution to the international BoC literature, which is relatively sparse on economic analysis of placement decision-making, and to ongoing policy deliberations on the role and potential of home care for people with dementia in Ireland.

1.7 Structure of thesis

This thesis follows an article-based format. The empirical chapters (3,4,5) contain each of the journal article submissions. The thesis is structured as follows:

Chapter 2 presents a discussion of the theoretical underpinnings and key elements of the BoC approach. This chapter will also present an overview of the findings from empirical studies in this area, and it will discuss where my Ph.D. research fits into the theoretical background.

Chapter 3 provides an overview of home care supports and a discussion of the policy context in Ireland. A cost analysis method is employed to analyse the first comprehensive cost estimation of IHCPs for people with dementia living on the boundary of home care and residential care facilities in Ireland. The cost of community-based services and supports, including informal care and private out-of-pocket expenditure, are compared to the cost of public and private residential care. The main findings from this study are discussed and concluding remarks on the key findings of this study are presented.

Chapter 4 employs a competing risks survival analysis method to compare the experiences of people with and without dementia in relation to admission to LSRC and mortality in the presence of additional IHCP community-based provision. The data also allows consideration of the role that family carers play in influencing admission to LSRC and mortality.

Chapter 5 begins with an overview of the findings from a literature review that identified excess LOS in the acute care setting for people with dementia. A generalized linear modelling technique is used on a matched national data set (Hospital-In-Patient Enquiry (HIPE)) to estimate inpatient LOS for patients with a principal or secondary diagnosis of dementia in Irish acute hospitals relative to similar patients without dementia. Subsequent care costs attributable to extended LOS for people with dementia in the acute care setting are also estimated. For people with a secondary diagnosis of dementia, heterogeneity in differences by principal diagnosis is also explored. This paper extends previous research (Briggs et al., 2016; Connolly & O'Shea, 2015) by controlling for the influence of case-mix on LOS.

Chapter 6 provides a detailed overview and interpretation of the key results from the three papers. Furthermore, key policy implications arising from this research are discussed in light of ongoing deliberations on the new home care scheme for dependent older people in Ireland. This chapter will outline the contributions and limitations of this work as well as recommended areas for future research. An overall conclusion will be presented, in addition to a personal reflection on my Ph.D. journey.

1.8 Research data and methodology

This thesis covers three main papers/studies. An overview of data and methodology is presented below, while a more detailed description can be found in each of the three papers. For papers one and two (see Chapter 3 and Chapter 4), I used anonymised routine data collected administratively by the HSE on all dependent older people who received an IHCP in Ireland between November 2014 and December 2017. For paper three (Chapter 5), I used national Hospital In-Patient Enquiry (HIPE) data on discharges from acute public hospitals in Ireland. HIPE collects demographic, clinical, and administrative data on discharges from, and deaths in, acute public hospitals nationally. Ethical approval was required for the data used in papers one and two, while a complex application and authorisation process was required to access the HIPE data for use in paper three.

1.8.1 Research paper one

In paper one, I undertook a comprehensive cost analysis to examine the cost of IHCPs for people with dementia living on the boundary of home care and residential care facilities in Ireland. The cost of community-based services and supports, including informal care and private out-of-pocket expenditure, was compared to the cost of public and private residential care. This cross-sectional study recruited 42 persons with dementia and/or their family caregivers, who were living on the boundary of home care and residential care, to an in-depth study on the cost of care in Ireland. The Resource Utilisation in Dementia (RUD) questionnaire (Wimo et al., 2010) was used to collect data on the utilisation of standard formal care and informal care by people with dementia in receipt of an IHCP. Data on intensive home care support hours were collected by the HSE for all participants. Information on private out-of-pocket expenditure on care was also collected from participants through a schedule of care form, which was specially developed to record this information during interviews with study participants (Keogh et al., 2018b). I assigned unit costs to the relevant averaged resource utilisation across all elements of provision to value formal and private care provision, while I applied the opportunity cost methodology to value informal caring time (Gillespie et al., 2015). The opportunity cost of informal caring can be considered as the financial loss incurred by engaging in the provision of care (Hassink & Van den Berg, 2011). Estimates of the opportunity cost of informal caring were calculated separately for caregivers in employment and for caregivers not available for employment (Connolly et al., 2014).

The costing process in this study was made significantly more complex given there is no common, uniform database that covers unit costs in community-based care in Ireland. Consequently, information on unit costs came from a variety of mainly Irish data sources, and where necessary, UK sources, with relevant adjustments based on inflation and exchange rate indices from the Central Statistics Office (CSO), Office for National Statistics (ONS), and the OECD (Central Statistics Office, 2018; Office for National Statistics, 2018; Organisation for

Economic Co-operation and Development, 2018b). The paucity of unit cost data was especially evident in relation to dementia; hence generic cost estimates were predominantly used instead of dementia specific cost estimates (Connolly et al., 2014).

1.8.2 Research paper two

The objective of the second study was to examine factors affecting transition towards LSRC and mortality among people with and without dementia who were living at home with intensive formal care support. By virtue of receiving intensive support, these people were deemed to be on the margin of care between home and residential care; otherwise, local decision-makers and providers would not have authorised or supported additional expenditure. This was a cross-sectional study based on administrative data collected on 429 dependent older people in Ireland, 269 of whom were people with dementia. For the purposes of this research, two outcomes were of interest: the first was admission to LSRC, and the second was mortality. Ignoring one of these events may lead to incorrect conclusions regarding the likelihood of the other event, so I used a competing risks approach to overcome this problem.

A competing risk is an event whose occurrence either prevents the observation of the primary event of interest or modifies the chance of the event occurring (Noordzij et al., 2013; Pintilie, 2007). When examining admission into LSRC as the outcome of interest for participants in this study, mortality is a competing risk since, if an individual dies while in the community, they are no longer at risk of entering LSRC. Alternatively, when examining mortality in the community as the outcome of interest, admission into LSRC is a competing event because admission into residential care precludes the occurrence of mortality in the community. To manage the presence of competing risks, I used the cause-specific hazard model to analyse time to event outcomes.

I first used a cause-specific hazard model to examine time to admission to LSRC when mortality is treated as a competing risk. This allowed me to examine the hazard of admission to LSRC for those recipients who are currently event-free (i.e., alive and not in LSRC). Next, I used a cause-specific hazard model to investigate time to mortality while treating admission into LSRC as a competing event. This allowed me to consider the hazard of mortality in those recipients who are currently event-free (i.e., who are alive and not in LSRC). I then regressed the hazard of admission to LSRC and mortality on a number of covariates.

A core assumption of the cause-specific hazard model is that hazards are proportional, which suggests that variables have a constant effect on the hazard function over time (Bradburn et al., 2003). In each of the models, I tested for violations of the proportional hazards (PH) assumption. Unfortunately, there were some violations of the PH assumption which further complicated the analysis; however, it was possible to correct for non-proportionality by interacting the covariate that violated the PH assumption with the natural log of time (Bradburn et al., 2003; Cleves, 2010).

The identification of competing risks in this study undoubtedly made the data analysis significantly more challenging as I did not have previous experience of using survival analysis competing risks techniques. In order to overcome this obstacle, I availed of training opportunities both online (via Stata) and at NUI Galway. In order to further my learning, I was the recipient of funding for a research trip in 2019 to visit Professor Peter Austin, who is a world-class research leader in survival analysis techniques based at the University of Toronto. On this trip, I gained practical experience in using competing risks techniques and learned how to overcome data issues relating to this study, such as how to deal with a violation of the Cox proportional hazards assumption. This trip greatly enhanced my methodological skills and was of fundamental importance to my learning of competing risks survival analysis techniques.

1.8.3 Research paper three

The third study estimated the impact of a diagnosis of dementia on inpatient LOS and related care costs in Irish acute hospitals. Both principal and secondary diagnosis effects were estimated and valued. This was a cross-sectional study based on administrative data collected on all public hospital inpatient discharges in Ireland for people aged 65 years and older in 2019. During this time period, there were a total of 221,415 inpatient discharges for this age cohort. For the purposes of this study, I conducted three comparisons. The first comparison was between patients discharged with a principal diagnosis of dementia and those without a principal or secondary diagnosis of dementia (Comparison 1). Comparison 2 focused on patients discharged with a secondary diagnosis of dementia and those discharged without a secondary diagnosis of dementia across all discharges, excluding the group with a principal diagnosis of dementia. Discharges were also analysed separately for a number of principal diagnosis disease categories to examine heterogeneity in the impact of a secondary diagnosis of dementia on LOS and related care costs (Comparison 3).

Information was available on a range of covariates, including ICD-10-AM codes (National Centre for Classification in Health, 2000), on up to 29 additional diagnoses. One methodological challenge I had to overcome while conducting this analysis was solving how to generate comorbid conditions from the ICD-10-AM codes. Building on a study by Tropea et al. (2017), I used a ‘comorbidity’ package (Gasparini, 2018) available in R software to generate the Elixhauser Comorbidity Index, which is a method for categorizing comorbidities of patients using ICD-10-AM codes found in administrative data (Elixhauser et al., 1998; Quan et al., 2005). The use of the ‘comorbidity’ package meant it was possible to generate a number of dichotomous comorbid conditions that indicated whether a comorbidity was present or not (Elixhauser et al., 1998; Quan et al., 2005). I did not have experience in using the R software package prior to this, but I enhanced my quantitative skills by taking an online course to learn how to use this computer software package.

In this study, when comparing LOS between dementia and non-dementia groups, it was important to consider that the characteristics of the groups may be different, thus possibly biasing results (Zhao & Percival, 2017). A strength of the data is that it offered a much larger number of observations in the control group (non-dementia) relative to the treated group (dementia), thereby allowing me to perform coarsened exact matching (CEM) on a large selection of covariates to account for observed confounders between dementia and non-dementia groups. Importantly, the use of such an approach improves the estimation of causal effects in observational data (Blackwell et al., 2009).

Given the dependent variable in this analysis, LOS had a non-normal distribution with a long, heavy right tail; I used generalized linear modelling to analyse variation in LOS between the groups. For each of the models, I used the Modified Park Test to identify the most suitable family and used the Pregibon Link Test, the Modified Hosmer Lemeshow Test, and Pearson’s Correlation to choose the appropriate link (Deb et al., 2017). To estimate LOS for each comparison, I used a generalized linear model (GLM) on the pre-processed data using the weights generated as an output from CEM (Jones et al., 2020). Average treatment effects on the treated (ATTs) were then obtained as the average marginal effect (AME) of the treatment variable included in the GLM model, estimated using the matched sample. Finally, a generic unit cost for Ireland, representing the average cost across all nights in all Irish hospitals and in all types of inpatient cases, of €938 (Hospital In-Patient Enquiry, 2019) was used to calculate the costs attributable to LOS for patients with dementia.

1.9 Thesis outputs

Three peer-reviewed journal articles have been generated from my thesis. Furthermore, I have contributed to three peer-reviewed publications outside of my own Ph.D. and to four major policy reports, two of which addressed the evaluation of IHCPs for the HSE in Ireland. Although these publications were not directly linked to my thesis, the research experience I have gained on these projects has been instrumental in developing my methodological and analytical skills. I have delivered two significant conference presentations, as well as given many internal seminars as part of the Ph.D. programme at NUI Galway. My work has also been reviewed by external reviewers as part of the Health Research Board leader grant award held by my supervisor Professor Eamon O'Shea.

Ph.D. peer-reviewed journal article publications

Carter, L., O'Neill, S., Keogh, F., Pierce, M., & O'Shea, E. (2019). Intensive home care supports, informal care and private provision for people with dementia in Ireland. *Dementia, 20*(1), 47-65. https://doi.org/10.1177%2F1471301219863580.

Carter, L., O'Neill, S., Keogh, F., Pierce, M., & O'Shea, E. (2020). Admission to long-stay residential care and mortality among people with and without dementia living at home: a competing risks survival analysis. *Aging & Mental Health, 25*(10), 1869-1876. https://doi.org/10.1080/13607863.2020.1857698.

Carter, L., Yadav, A., O'Neill, S., & O'Shea, E. (2022). Extended length of stay and related costs associated with dementia in acute care hospitals in Ireland. *Aging & Mental Health*, 1-10. https://doi.org/10.1080/13607863.2022.2068128.

Other peer-reviewed publications

Gillespie, P., **Carter, L.,** McIntosh, C., & Gethin, G. (2019). Estimating the health-care costs of wound care in Ireland. *J Wound Care, 28*(6), 324-330. https://doi.org/10.12968/jowc.2019.28.6.324.

Murphy, S., **Carter, L.,** Al Shizawi, T., Queally, M., Brennan, S., & O'Neill, S. (2022). Exploring the impact of breastfeeding on the incidence of infant illnesses: Evidence from a nationally representative cohort study. Submitted to *BMC Public Health.*

Al Shizawi, T., Murphy, S., **Carter, L.,** Murphy, S., Queally, M., Brennan, S., & O'Neill, S. (2022). A systematic review on the impact of breastfeeding on maternal health outcomes in Ireland. Submitted to *Social Science and Medicine*.

Policy reports

Perry, I. J., Millar, S.R., Balanda, K.P., Dee, A., Bergin, D., **Carter, L.,** Doherty, E., Hamilton, D., & Jaccard, A. (2017). *What are the estimated costs of childhood overweight and obesity on the island of Ireland.* Cork: Safefood.

Keogh, F., Pierce, M., Neylon, K., Fleming, P., **Carter, L.,** O'Neill, S., & O'Shea, E. (2018). *'Supporting Older People with Complex Needs at Home: Report 1: Evaluation of the HSE Intensive Home Care Package Initiative'.* Dublin: HSE-Genio.

Keogh, F., Pierce., Neylon, K., Fleming, P., O'Neill, S., **Carter, L.,** & O'Shea, E. (2018). '*Supporting Older People with Complex Needs at Home: Report 2:'What Works for People with Dementia'.* Dublin: HSE-Genio.

Akasheh, N., **Carter, L.,** Dimla, E., Domijan, K., Kieran, J., O'Neill, S., & Walsh, C. (2022). *'Socioeconomic cost of food hypersensitivity on the island of Ireland*. Cork: Safefood.

Conference presentations

Carter, L. (2019). An economic analysis of intensive home care packages for people with dementia in Ireland. Irish Postgraduate Early Careers Economics Workshop. 7th of June, 2019.

Carter, L., O'Neill, S., Keogh, F., Pierce, M., & O'Shea, E. (2021). Admission to long-stay residential care and mortality among people with and without dementia living at home but on the boundary of care: a competing risks survival analysis. European Union Health Economics Association Ph.D. conference. 3rd September 2021, online.

Chapter 2: The Balance of Care Approach

2.1 Introduction

2.1.1 Continuum of care for people with dementia

The continuum of care for people with dementia typically ranges from mainstream housing to long-term residential facilities with a number of care options in between. Many European countries offer a wide range of care alternatives to people with dementia along the care continuum, including shared housing, sheltered housing, and housing with care (O'Shea & Carney, 2016). For example, in Norway and Sweden, assisted living or small-scale group living facilities are commonplace for people with dementia (Cahill et al., 2021). These dwellings are integrated into the heart of the community and are situated close to public transport networks, parks, shopping centres, etc. (Cahill et al., 2021). In these countries, the care models are built on social rather than medical models of care, which are underpinned by values such as personal autonomy, identity, and connectivity (O'Shea et al., 2019; Verbeek, 2011).

In contrast to Europe, a recently published review on the care for people with dementia in Ireland (O'Shea et al., 2019) suggests that the continuum of care is much narrower in Ireland. Very often, the choice is between home care and residential care with little in-between. Even at home, the reliance on families outweighs any formal community-based statutory services and supports. Housing with care options suitable to accommodate the complex caring needs of people with dementia are also underdeveloped in Ireland. There are a small number of schemes, but there is no tradition of this type of support in the country. In terms of resource allocation and prioritisation, long-term residential care is supported over all other care options in Ireland (O'Shea et al., 2019). The reality is that few care alternatives exist outside of residential care for people with dementia who can no longer remain living in their own homes. This leads to a situation where some people with dementia end up in LSRC sooner than is required. Moreover, there has been little investment or innovation in the residential care sector to develop autonomy-enhancing units that give privacy and more homelike living to residents in that sector.

2.1.2 Key transitions into long-stay residential care and hospital for people with dementia

Admission to residential care is needed when the care needs of a person with dementia can no longer be adequately met at home. Reasons that prompt transition into long-term care for people with dementia has been the subject of much research investigation over the past number of years. International research has found that caregiver burden and a decline in caregiver and care-receiver health are key factors precipitating admission to residential care for people with dementia (Cahill, 1997; Etters et al., 2008; Horttana et al., 2007; Luppa et al., 2010). The absence or lack of informal care support has also been linked to LSRC admission (Caron et al., 2006; Sussman & Regehr, 2009). For example, a UK study conducted by Banerjee et al. (2003) found that the presence of a co-resident caregiver over a one-year period made admission into residential care for people with dementia twenty times less likely. Other determinants associated with admission to LSRC include the presence of challenging behaviours, the severity of dementia, cognitive and functional decline, and old age (Cepiou-Martin et al., 2016; Gaugler et al., 2007).

In the Irish context, a small-scale qualitative study conducted by Argyle et al. (2010) suggested that a number of factors were responsible for influencing admission to LSRC. These reasons included: declining health of both the caregiver and person with dementia, the demands of caregiving, and a lack of both formal and informal support available. Another Irish study identified different factors such as challenging behaviours, concerns around safety, and poorly adapted housing as being reasons for admission to SCUs for people with dementia (Bobersky, 2013). A recently published study found that a myriad of factors such as psychosis, severe functional impairment, caregiver age and gender, and geographical location increased the likelihood of admission to LSRC for people with dementia in Ireland (Walsh et al., 2021). Furthermore, Donnelly et al. (2017) identified health care system factors as being important in the Irish context, citing under-resourced, inequitable, and ineffective community care service provision as factors affecting admission to long-term care settings for people with dementia.

Research has also been conducted on factors that may prompt hospital admission for people with dementia living in either the community or LSRC settings. A recently published systematic review and meta-analysis found that age, multimorbidity, polypharmacy, and lower functional ability were predictors of hospital admission for people with dementia (Shepard et al., 2019). While another systematic review by Toot et al. (2013) suggested risk factors for admission to hospital included behavioural problems, changes to routine and environment, and dependency problems relating to specific activities of daily living (ADLs). Furthermore, conditions such as a urinary tract infection or pneumonia have been found to precipitate unplanned acute hospital admissions for people with dementia (Sampson et al., 2009). In the Irish context, a study by Timmons et al. (2015) on six acute hospitals in Ireland found that patients admitted to hospital with dementia were older, frailer, and malnourished. They also had a lower functional status and higher comorbidity compared to those without dementia. Fragmented community care provision also increases the potential for acute hospital admissions for people with dementia living at home; under-resourced community care services sometimes means that admission to acute care is the only option for families unable to cope with the needs of the person with dementia (Donnelly et al., 2017).

Not surprisingly, some people believe that enhanced community-based care provision and better support for informal carers can help delay or reduce admission to LSRC or acute care facilities for a proportion of individuals whose needs determine them to be on the ‘margin/boundary of care’ between home and alternative settings (Challis et al., 2014; Tucker et al., 2016). Most studies that have asked people about their placement preferences have found that staying at home is the preferred care option for older dependent people, including those with complex cognitive care needs such as dementia (Tucker et al., 2008). Home care is also generally favoured for economic reasons. ‘Ageing in place’ can potentially lead to greater cost savings for the government (O’Shea & Monaghan, 2017). Therefore, reducing the use of LSRC and acute care in favour of a ‘home first’ approach should continue to be a policy goal for people with dementia in Ireland (O’Shea et al., 2019; Walsh & Lyons, 2021).

2.1.3 Balance of care approach in this thesis

As the population ages, dementia is expected to represent a significant economic and societal challenge in Ireland (Walsh et al., 2021). Therefore, as referenced above, from an economic standpoint, it is imperative that the government make the best possible decisions on service provision for people with dementia (Tucker et al., 2015b). The cohort of people with dementia who are on the boundary of admission to LSRC, or acute care facilities is in the vanguard of the policy argument on resource allocation. Keeping these people out of more expensive facilities, or even postponing admission, may yield significant cost savings for budget-constrained governments. However, evidence is often incomplete on the characteristics of those people who benefit most from different services or the relative costs of community-based, residential, and hospital-based care (Challis et al., 2014). This thesis uses a BoC approach to act as an integrative holding framework to examine the costs and, where possible, consequences of placement decision-making for people with dementia on the margins of home care, residential care, and acute care in Ireland. The focus is firmly on the margin, on the transition between home and residential care, and home and acute care for people with dementia. In the context of significant expansion of home care services and supports in the coming decade (Department of the Taoiseach, 2020; Houses of the Oireachtas Committee on the Future of Healthcare, 2017), this thesis has significant implications for the recalibration of care towards greater support of people living at home with dementia. The results of the three studies will be particularly useful for the government and the Department of Health to address current and future challenges in relation to placement decision-making for people with dementia in Ireland.

2.2 Origins and theoretical framework of balance of care approach

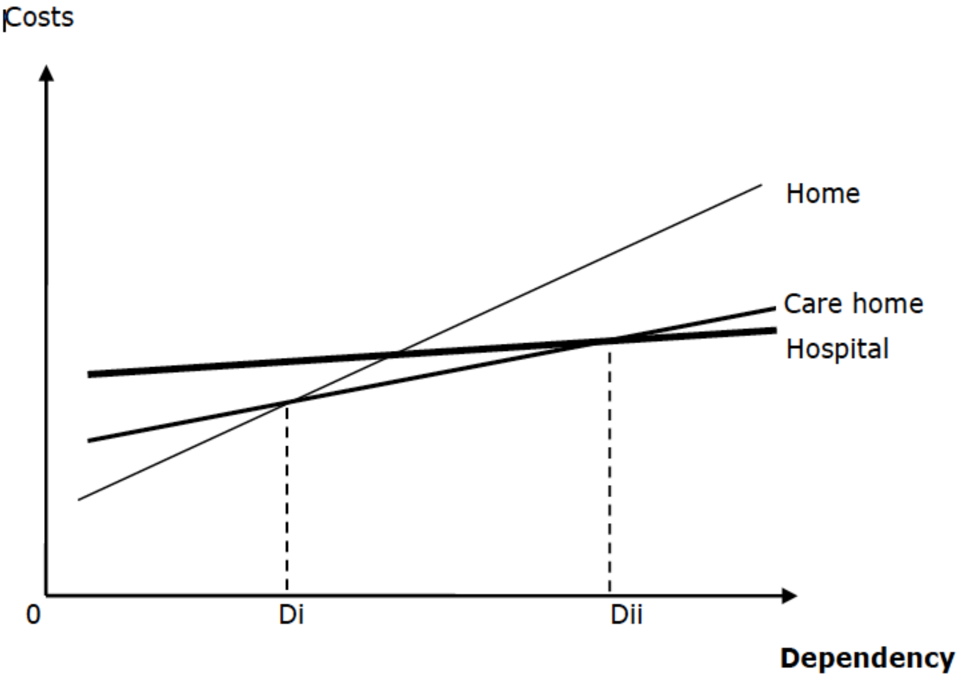
The BoC framework was originally developed as a national policy analysis tool by the Department of Health and Social Security in Britain during the early 1970s (McDonald et al., 1974; Tucker et al., 2016). The approach has taken on different forms over the years in the UK (Challis et al., 2014) in response to local needs, sectoral challenges, and geographical differences in need and supply. However, the general premise is that the BoC framework can be used as a means of identifying client groups who could receive care in more than one type of setting (e.g., at home or in a nursing home, or in a hospital bed). Coverage usually implies people living ‘on the margins/boundary of care’ and explores the potential resource consequences of alternative options (Hughes & Challis, 2004; Mooney, 1978; Tucker et al., 2016).

Importantly, the BoC approach can be used to answer questions such as who currently gets what in terms of care provision; would it be possible to provide more appropriate care for some of these people; and, if so, what would be the cost of this? (Tucker et al., 2013). The framework does not try to identify total need but instead can be used by decision-makers to examine the costs and/or consequences of redeploying available resources (Challis et al., 2014). The four defining features of BoC studies are thus: the identification and measurement of client characteristics (typically sociodemographic, clinical, functional) that affect decisions about the most appropriate setting in which to support them; the specification of inputs/resources required; some means of allocating clients to the most appropriate setting; and a determination of the relevant costs (and ideally outcomes) in different settings (Challis et al., 2014; Tucker et al., 2015b). It has to be said, however, that the focus on outcomes, including mortality, has been much less than the focus on costs.

The health economist Gavin Mooney was an early proponent of the BoC approach; his work primarily focused on exploring the most effective use of resources among care in the home, residential facilities, and the hospital setting for older people on the margins across the three settings (Mooney, 1978). A central objective of his early work was to provide cost data and information on the dependency of older people who were likely to be impacted by changes in service supply. His work was designed to encourage policy-makers to be more explicit regarding the opportunity costs and trade-offs associated with redeploying available resources for older people. In the context of this thesis, the methodology for the BoC framework set out in Mooney's (1978) study, as discussed below, is particularly relevant given the focus on placement decision-making for people with dementia on the margins of home care, residential care, and acute care in Ireland. Moreover, the use of data, where possible in this thesis, on client characteristics, service use, costs, and outcomes contributes important findings to a critical debate on the redeployment of resources for those on the margin of care.

Drawing on Mooney's (1978) initial presentation and subsequent interpretations (Challis et al., 2014), the central components of the BoC model are represented below in Figure 2.1. Whereby, the three upward sloping lines show the relationship between the costs and characteristics (e.g., dependency) of people supported at home, in residential care homes, and in the hospital setting. Each line assumes there is a positive correlation between costs and dependency, meaning that both variables move in the same direction (e.g., if dependency increases, costs will also increase). It is evident the position and slope of the lines differ, suggesting that for people with low dependency, receiving care at home costs less than residential care homes, which in turn is cheaper than receiving care in the hospital setting. Whereas, for people with high dependency, the order reverses, meaning that hospital care becomes cheaper than residential care homes, which in turn costs less than home care, mainly due to scale efficiencies. If the outcomes for people in all three settings were equally acceptable, Figure 2.1 indicates the most cost-effective place to support people with low levels of dependency (between 0 and Di) would be in their own homes, whereas for people with moderate levels of dependency (between Di and Dii) residential care would be selected, and finally for those with dependency levels greater than Dii, hospital would be the most cost-effective care option (Challis et al., 2014).

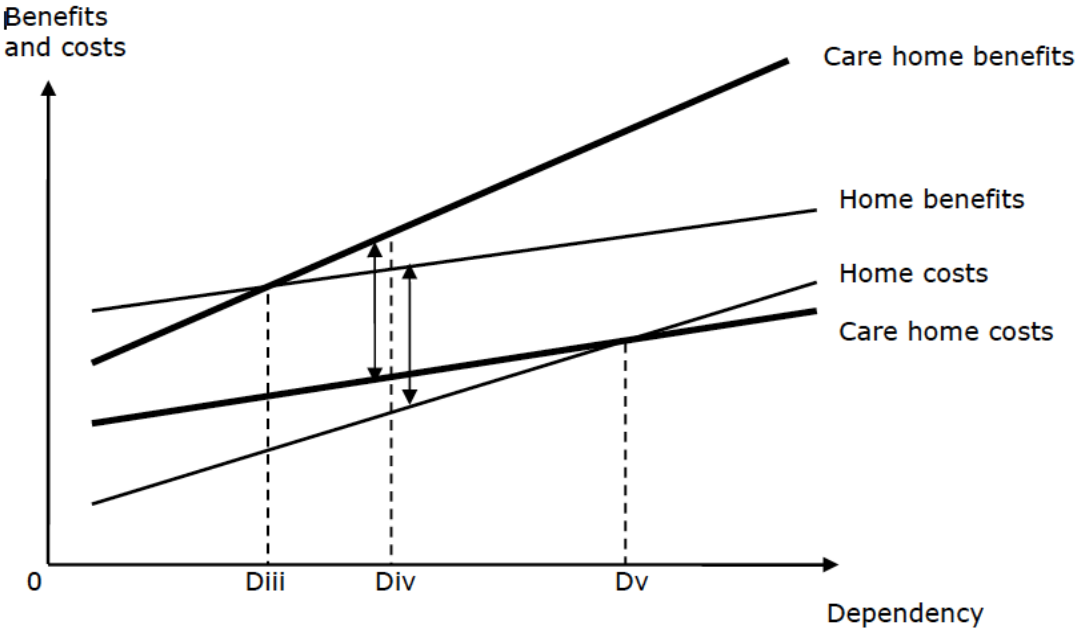
Figure 2.1: Costs by dependency for people at home, in residential care, and in hospital



Source: Challis et al., (2014).

The explanation above is a simplistic version of the BoC approach. In reality, people's preferences for different care options may differ, depending on the benefits on offer. Figure 2.2 below, therefore, considers marginal costs and benefits as well as dependency. For simplicity purposes, just two care options are shown – care at home and care in residential homes. In this diagram, two new lines have been added which represent the relationship between benefit and dependency. These lines are assumed to be positively correlated and cross, similar to the cost-dependency lines. Therefore, people with dependency between 0 and Diii gain more benefit from home care, whereas people with dependency higher than Diii gain more benefit from residing in residential care. While the situation becomes more complex when considering both costs and benefits, the diagram shows that for people with dependency levels beneath Diii, the most cost-efficient care option is home since the benefits are greater and the costs are lower than residential care. Alternatively, for people with dependency levels above Dv, the most cost-efficient care option is clearly residential care. Challis et al. (2014), describe that for people with dependency levels between Diii and Dv, residential care is both more beneficial and more expensive, and it is the point at which marginal social cost equals marginal social benefit (Div) which determines the most cost-effective placement. For people with dependency below Div, home care is the optimal choice, whereas, for people with dependency above Div, residential care is most favourable (Challis et al., 2014). The difficulty, of course, is whether these costs and benefits can be estimated with any reasonable degree of certainty.

Figure 2.2: Costs and benefits by dependency for people at home and in residential care



Source: Challis et al., 2014.

2.3 Measuring costs and outcomes

Although economic evaluation techniques such as cost-effectiveness analysis (CEA) and cost-utility analysis (CUA) are commonly used tools of choice at the national level for providing evidence on costs and outcomes of drugs, technologies, etc. (Drummond et al., 2015; Morris et al., 2007), such evaluations are not commonly used at the local level to determine optimal placement decisions (Tucker, 2020). For example, while an intervention or service offered at the local level may offer many benefits, including non-health outcomes, CEA only examines the cost associated with one type of health outcome at a time (e.g., life years gained). Although CUA does allow several health outcomes to be combined into a single composite summary measure, such as the quality-adjusted life year (QALY), the outcomes of many interventions and services, particularly regarding placement decisions, often extend beyond patient health. For example, Tucker (2020) described how both carers and patients, who were part of an initiative to move long-stay patients with dementia from the hospital to the community setting, prioritised being treated respectfully and kindly over health outcomes. Kitwood (1997) recognised the importance of personhood in dementia and so too, more recently, has the focus shifted to capabilities measured for older people that include non-health elements (Coast et al., 2008; Coast et al., 2015). The dilemma is finding measures that incorporate these types of outcomes in ways that make sense to care recipients and can be calibrated by researchers. While both CEA and CUA are useful methods for the evaluation of health care interventions, it can be argued that these techniques are of limited value to decision-makers when considering the potential costs and/or outcomes of changes in service mix across a wide spectrum of local health and social care provision (Tucker et al., 2013). By way of contrast, the BoC approach can be used to examine how shifting the balance of resources from one group/service to another can increase benefits and/or reduce costs (Arthur Anderson & Company, 1981; Mooney & Drummond, 1982, as cited in Tucker, 2020).

2.3.1 Measurement issues in past applications of the balance of care approach

Over the decades, the BoC framework has been used to generate data to inform resource allocation at the local (Challis & Hughes, 2002; Wager,1972) and national level (Kavanagh et al., 1995; Wright et al., 1981). Not all studies, however, have explicitly applied the framework in the same way, as there is no fixed template or manual for carrying out this work (Hughes & Challis, 2004; McClenahan et al., 1987; Mooney, 1978; Tucker et al., 2008). Therefore, identifying studies that have used the BoC framework is challenging, as this work spans over several decades and has been produced for a wide variety of different client groups in different circumstances (Tucker et al., 2013). Nonetheless, a systematic review by Tucker et al. (2015a) identified 38 studies that applied the BoC framework in the previous 40 years. Each of the studies included in the review was considered to have applied the BoC framework if they took the future strategic planning of health and/or social care into account; and used data on client characteristics, service use, or costs to examine resource allocation options for those on the margin of care.

The vast majority of studies have been conducted in the British Isles, which is most likely due to the origins of the BoC approach, having been developed by the British government (Challis et al., 2014; Tucker et al., 2013). However, there is nothing to limit the geographical application of the BoC framework, as demonstrated by a number of studies conducted in Italy (Tramarin et al., 1997) and Canada (Kuluski, 2010; Kuluski et al., 2012; SHS Consulting & Balance of Care Research Group, 2009; Williams et al., 2009; Williams & Watkins; 2009). Nor are there any limitations with regard to policy context, as a number of studies have applied the BoC approach to inform resource allocation at both the local (Challis & Hughes, 2002; Wager,1972) and national level (Kavanagh et al., 1995; Wright et al., 1981).

Although the original BoC model had an interest in the provision of services across multiple client groups, the majority of BoC studies have focused on the provision of services to one client group only, which is usually older people (Bebbington et al., 1990; Challis & Hughes, 2002). However, there is nothing that restricts the use of the BoC approach to a particular client group, as this approach has been applied to a number of different populations, including adults with mental illness and learning difficulties (Challis & Shepherd, 1983; Knapp et al., 1997), individuals with renal impairment (Rutherford & Forte, 2003), and people with HIV/AIDS (Rizakou et al., 1991; Rosenhead et al., 1990; Tramarin et al., 1997). More than one-half of BoC studies identified by Tucker et al. (2015a) have examined the potential for shifts between hospitals, LSRC facilities, and community services (Forte & Bowen, 1997; McCallion, 1993; Tucker et al., 2008). More recently, post the 2015 review, settings have included the margin between ECH and LSRC settings (Verbeek et al., 2019) and alternative care arrangements within or outside of prison (Forsyth et al., 2019).

While the comparison of costs in alternative care settings is a defining feature of BoC studies, not all studies have reported on the full range of costs, with many failing to carry out a comprehensive costing exercise that examined not only formal health care costs but housing, personal consumption, and informal care. According to Challis et al. (2014), the latter is least likely to be examined in BoC studies, something which is addressed in paper one of this thesis. Even when family care costs are measured, there has been variation in the methodology used to calculate costs. For example, some studies have used a replacement valuation (Wanless et al., 2006), while other studies have considered the opportunity cost of foregone paid work, nonmarket work, and leisure time for carers (O’Shea & Corcoran, 1989; O’Shea & Corcoran, 1990). Furthermore, a significant number of BoC studies failed to report the year to which costs were applied and whether adjustments for inflation were carried out (Keogh et al., 2021; Pierse et al., 2021; Verbeek et al., 2019).

To improve the quality of BoC studies going forward, more evidence will be required on local unit cost data (Challis et al., 2014). This dictum certainly applies to Ireland, where there has been no systematic analysis of the supply of primary and community-based services and supports, thereby making it difficult to estimate unit costs in any consistent manner. In this thesis, I used a mixture of ‘bottom-up’ and ‘top-down’ costing approaches to estimate baseline unit costs and expenditure. Unfortunately, my analysis was completed before recent comprehensive work by Smith et al. (2021), which estimated unit costs for non-acute care in Ireland.

While the identification of outcomes in different care settings is another defining feature of the BoC approach, the availability of evidence on outcomes from studies that have been completed is not compelling. Tucker et al. (2013) reported in a systematic review which predominantly explored services for frail older people, that objective outcome data were collected in only four of the identified studies (Challis et al., 2000; District Auditors, 1981; Plank, 1977; Tramarin et al., 1997). One of these studies used information on how people's needs were met and how satisfied they were to act as a measure of care quality (Plank, 1977). More studies drew inference from existing outcome data (Kavanagh et al., 1993; Kavanagh et al., 1995; Wager, 1972; Wanless et al., 2006; Wright et al., 1981). For example, the latter discussed plans to increase home support, referring to previously published research on the relative benefits of community and residential care. Other BoC studies relied on health and social care professionals (HSCPs) to make explicit judgements regarding alternative placements (Forsyth et al., 2019; Keogh et al., 2021; Pierse et al., 2021; Verbeek et al., 2019). One study simply presented information to decision-makers on relevant costs and an explanation of those likely to be affected by changes in the mix of resources, thus leaving decision-makers to make judgements on optimal care placements (O'Shea & Monaghan, 2017).

It is evident from the literature that data is needed on the relative effectiveness of care in different settings going forward, as policy-makers need information on both costs and outcomes to make resource allocation decisions. There are, of course, even more, practical difficulties associated with measuring outcomes for people with dementia, which include but are not limited to difficulties with communication, recall, processing of complicated information, and time perception (Gridley et al., 2016). The collection of outcome data is further complicated by the heterogeneity of dementia as a condition, meaning that people have diverse and fluctuating needs. Since the systematic review published by Tucker et al. (2015a), further studies using the BoC framework have been published. These include a small number of studies that have applied the BoC approach to the care of people with dementia (Forsyth et al., 2019; Giebel et al., 2019; Keogh et al., 2021; O'Shea & Monaghan, 2017; Pierse et al., 2021; Tucker et al., 2016; Verbeek et al., 2015; Verbeek et al., 2019).

2.4 Balance of care and dementia

The main application of the BoC approach to dementia has occurred relatively recently (Table 2.1), with the exception of two studies that looked at cost and outcome measures for people with dementia in the 1990s (Kavanagh et al., 1993; Kavanagh et al., 1995). One has to be careful in making such pronouncements, however, since many of the studies using BoC did include older people, some of whom may have had cognitive impairment or dementia but were not listed as such. An international study on BoC for people with dementia was recently carried out across eight European countries as part of the *RightTimePlaceCare* project (Tucker et al., 2016). This study used data on client characteristics such as ADLs, living situation, and cognition to formulate dementia case types so that practitioners could identify whose needs could be met in more than one type of care setting, thereby facilitating analysis of the costs of various care alternatives. In practice, formulating case types consists of dividing the population into categories based on similar characteristics. The paper used a public sector costing perspective focussing on the most common health and social care costs. Although a comprehensive costing approach would have been better, the authors described that such an approach wasn't possible as there were difficulties in obtaining comparative unit costs across the various countries. Very often, cost data voids in the various countries were filled with information from a BoC study previously conducted in the UK (Challis et al., 2014). The findings from this study suggested that a notable minority of entrants to residential care could be more appropriately supported at home. Four factors were found to be particularly important in relation to decision-making on the margin of care: individual circumstances/care needs, costs/finances, informal care availability, and formal care availability. Potential cost savings attributable to community care were also identified in all eight countries. However, community care was not always found to be cheaper than residential care, as the ability to release resources differed across countries (Tucker et al., 2016).

Table 2.1: Summary table of dementia-related balance of care studies

Study No.	Author(s)	Year	Country	Population of interest	Settings explored
1	Kavanagh et al. Kavanagh et al.	1993 1995	England	Older people with cognitive impairment	Hospital, LSRC facilities, own home
2	Verbeek et al.	2015	Eight European countries	Older people with dementia	LSRC facilities, own home
3	Tucker et al.	2016	Eight European countries	Older people with dementia	LSRC facilities, own home
4	O'Shea & Monaghan O'Shea & Monaghan	2016 2017	Ireland (multiple sites)	Older people with dementia	LSRC facilities, own home
5	Verbeek et al.	2019	England	Older people with dementia	LSRC facilities, ECH
6	Giebel et al.	2019	England	Older people with dementia	LSRC facilities, own home
7	Forsyth et al.	2019	England	People with mild cognitive impairment or dementia in prison	Alternative care arrangements within or outside of prison
8	Keogh et al.	2021	Ireland	Older people with dementia	LSRC facilities, own home
9	Pierse et al.	2021	Ireland	Older people with dementia	LSRC facilities, own home

Another study conducted as part of the *RightTimePlaceCare* European project utilised data on functional, clinical, and sociodemographic characteristics to explore inter-country variation in factors affecting institutionalization for people with dementia on the margin of care (Verbeek et al., 2015). The findings from statistical analyses conducted in this study showed there was considerable variation, across the eight countries, in the characteristics of people with dementia who were admitted to LSRC. However, caregiver burden and independence in activities of daily living (ADLs) were the two common predictors of institutionalization across all eight countries. Given the variation across countries, the authors suggested that factors affecting institutionalization may be country-specific, and consequently, more information is needed in European countries not included in this study.

Giebel et al. (2019) applied the BoC framework to explore the balance of informal and formal home care support for people with dementia, and their associated costs, from the viewpoint of both informal carers and paid staff in the UK. Based on a subset of the larger UK national data set associated with the *RightTimePlaceCare* project, dementia case types were formulated based on client characteristics, including cognition, dependency, challenging behaviours, and caregiver burden. Formal care recommendations by both informal carers and paid staff were costed using nationally representative unit cost data sourced from Personal Social Services Research Unit (PSSRU) 2013/2014 unit costs in the UK. Informal care costs were calculated using a market value approach, meaning the cost applied to informal caring was based on the cost of a paid staff member providing a similar service. The findings from this study showed that day care and personal and domestic home care were the most frequently suggested formal care services by both informal carers and paid staff. Furthermore, both groups did recommend nursing home admission for some dementia case types that required more care inputs. However, disparities were evident between the two groups. For example, informal carers placed greater significance on formal paid care than informal care. Importantly this research highlights the need to include the perspective of informal carers in the resource allocation decision-making process in order to identify the individual needs of people with dementia and their caregivers.

Another study by Verbeek et al. (2019) used the BoC approach to examine the appropriateness of extra care housing (ECH) as a care model for people with dementia living in LSRC. In this study, dementia case types were formulated based on case types drawn from data collected as part of another BoC study conducted in North-West England (Challlis et al., 2014; Tucker et al., 2015b). Front-line workers and social care managers were asked to make judgements on the appropriateness of ECH for the various dementia case types. A comprehensive costing approach was used to calculate the weekly costs of proposed community care packages. However, information wasn't provided on the source of unit costs, the year in which costs were applied, and whether adjustments for inflation were made. The findings from this study showed that there was consensus from front-line workers that ECH was an appropriate care alternative for a significant minority of LSRC entrants, particularly those with dementia or cognitive impairment who were living alone. However, ECH was not recommended as appropriate for people who needed care at night, as the extent of care needed may exceed what is available from ECH. Despite social care managers being in support of ECH as a care model, they voiced support for maintaining people in their own home as they saw few advantages of ECH.

More recently, Forsyth et al. (2019) applied the BoC framework to the care of people with dementia or mild cognitive impairment residing in prisons in the UK. This work relied on explicit judgements of multidisciplinary staff and carers from both the prison and community settings to develop an appropriate care pathway to meet the needs of several case types who were representative of the data set. A public sector costing perspective was adopted to represent the costs associated with delivering various treatment pathways. Prison specific unit cost data were not available, so data were obtained from multiple sources such as the PSSRU unit costs of Health and Social Care 2018 and the NHS Reference Costs 2017/2018, among others. Information was provided on the year in which costs were applied and whether adjustments for inflation were made. Despite a lack of unit cost data available in this study, the authors provided detailed information on how they overcame such data limitations.

Recommendations to emerge from this research included the need to make prisons more ‘dementia friendly’ by including bright coloured rooms, clear signage, use of labelling, contrasting colours, maximum use of light, and having access to interventions and activities such as book clubs, arts, and crafts, etc. The delivery of care packages on a prison wing, similar to what is delivered in the community setting, was also suggested by participants. The development of training packages in dementia awareness, assessment, and treatment was also suggested for prison staff. For those with more severe dementia, including high ADL impairment or complex comorbidities, a purpose-built specialist wing was recommended, where a dedicated therapeutic regime would be provided for those affected. In the case of prisoners who were at risk of harming others, participants recommended transfer to secure forensic hospitals. While the care pathway developed from this work has yet to be implemented, this research importantly used the experience and knowledge of multidisciplinary staff and carers to provide information on how changing the mix of resources will impact prisoners with dementia or mild cognitive impairment in the UK.

In Ireland, O’Shea and Monaghan (2017) used the BoC approach to highlight the economic potential of enhanced individualised supports for keeping people with dementia living in their own homes for longer rather than being admitted to LRSC. The cost of community-based care was estimated using a comprehensive costing approach which included formal health and social care services, personalised project supports, informal care, personal consumption, and housing costs. Given there was no database that covered unit costs in community-based care in Ireland at the time of the study, unit costs were sourced from a variety of mainly Irish data sources. Information was provided on the year in which costs were applied and whether adjustments for inflation were made. The estimates from this study suggested that investment in personalised supports can postpone admission to LSRC. However, when informal care provision was monetized, the cost of community-based care nearly trebled.

A recent study by Keogh et al. (2021) applied the BoC framework to examine resource allocation decision-making on optimal care across the dementia continuum in Ireland. Data was utilised on characteristics such as dependency level, living situation, and comorbidities to formulate different dementia case types so that HSCPs could make explicit judgements on the allocation of services under constrained and unconstrained budget scenarios. Unit costs for services were costed based on HSE staff pay scales and a review of the Irish literature. However, information wasn't provided on the year in which costs were applied and whether adjustments for inflation were made. The findings from this study showed that HSCPs allocated resources to address a wide range of needs for both the person with dementia and their caregiver. However, once a resource constraint was introduced, there was a much greater emphasis placed on meeting physical and clinical dependency needs rather than on psychosocial care. The authors explain that the difference in resource allocation decision-making when a budget constraint is introduced demonstrates that budgets for people with dementia in Ireland are not adequately funded relative to the needs of this group. Importantly, this research facilitated the inclusion of HSCPs into the decision-making process and subsequently provided valuable information on how HSCPs balance factors in the resource allocation decision-making process for people with dementia across the care continuum.

Pierse et al. (2021) used the BoC framework to examine resource allocation across the dementia care continuum not only from the viewpoint of HSCPs but also from the perspective of people with dementia and caregivers. In this study, the three groups were asked to make explicit judgements on what represents optimal care for a range of dementia case types under constrained and unconstrained budget scenarios. Similar to the study by Keogh et al. (2021), unit costs provided for services in this research were estimated based on the Irish HSE staff pay scales and unit cost data drawn from the Irish literature. However, information wasn't provided on the year in which unit costs were applied and whether inflation adjustments were carried out. The findings from this study showed that while resource allocation was broadly similar between the three groups, people with dementia and their caregivers allocated more resources to psychosocial supports than HSCPs. Furthermore, carers also placed greater significance on the provision of in-home respite. Importantly, this study found that even when extensive community-based care was provided under an unconstrained budget, family carers more frequently viewed LSRC as a more suitable care option for people with dementia with high levels of need. This work by Pierse et al. (2021) is one of the very few studies to include the perspectives of people with dementia and caregivers in the resource allocation process. Importantly the inclusion of such groups in this study demonstrates how the BoC framework has evolved over the past 40 years to facilitate greater patient and family engagement, particularly in dementia research. Currently, in Ireland, people with dementia and their caregivers are not a part of the resource allocation decision-making process. Therefore, the findings from this research highlights that both groups have an important role in influencing priority setting in relation to the delivery of dementia care in Ireland.

With regard to the BoC approaches employed, a number of recent studies on dementia have relied on practitioners to make explicit judgements on alternative care placements using case types generated from data (Keogh et al., 2021; Tucker et al., 2016; Verbeek et al., 2019). Other studies have used data on client characteristics to examine factors associated with costs and/or outcomes using various econometric modelling techniques (O'Shea & Corcoran, 1989; Verbeek et al., 2015). A number of other BoC studies have simply presented information to decision-makers on relevant costs and an explanation of those likely to be affected by changes in the mix of resources, thus leaving decision-makers to make judgements on optimal care placements (O'Shea & Monaghan, 2017).

The literature shows that many BoC studies did not consider cost shifting and failed to undertake a broader approach to costing, encompassing not only formal care costs but also housing and informal care costs especially. Comparing only public expenditure items leads to a partial understanding of care costs. Disappointingly, informal care costs were not commonly examined within the literature, something which is dealt with in the first paper of this thesis. Furthermore, it is evident that a significant number of BoC studies didn't report the year to which costs were applied and whether adjustments for inflation were undertaken (Keogh et al., 2021; Pierse et al., 2021; Verbeek et al., 2019). To improve the quality of BoC studies going forward, more evidence will be required on local unit cost data (Challis et al., 2014). This is particularly pertinent in the Irish context, where there is a paucity of unit cost data currently available despite recent improvements (Smith et al., 2021), specifically within the community care setting. In order to contribute to the evidence base in Ireland, this thesis applied a mixture of 'bottom-up' and 'top-down' costing approaches to estimate baseline unit costs and expenditure.

Importantly, the first study in this thesis considered cost shifting between the community and residential care settings. The comprehensive costing exercise facilitated the inclusion of not only formal health care costs but also informal care and private care costs, therefore providing important information on public-private mix elements for IHCP recipients living in the community setting. The second study used more sophisticated competing risks survival modelling to consider factors affecting placement in LSRC and mortality for recipients of

IHCPs living at home, thus, identifying the specific characteristics of IHCP recipients who benefit most from home-based care. Additionally, this data allowed for consideration of the role family carers play in influencing admission to LSRC and mortality. The final study in this thesis incorporated a BoC framework to examine LOS for dementia patients in Irish acute hospitals. Related costs were then estimated and valued from a health service perspective. The analysis and findings of all three studies will add to the evidence base by providing important information on the cost of care and, where possible, the consequences of placement decision-making between the home, residential, and acute care settings. From an economic viewpoint, the provision of such information will be particularly useful to inform the resource allocation process for people with dementia on the boundary of care in Ireland.

2.5 Strengths and weaknesses of the balance of care approach

The appeal of the BoC approach is that it offers planners a strategic framework for examining the costs and/or consequences of changing the mix of resources in a defined geographical area (Challis et al., 2014). The pragmatic approach has many benefits as it facilitates a mix of local data, research findings, and the views of front-line staff to be integrated into the decision-making process (Tucker et al., 2015b). A key strength of BoC studies is their ability to produce detailed information on client groups that are likely to be affected by resource allocation changes (Tucker et al., 2013). Importantly, the strategic planning tool motivates us to look beyond existing service patterns of care by providing high-quality information to underpin service planning and development (Tucker et al., 2015b).

Nonetheless, there are limitations to this approach which arguably focuses on intermediary outputs of care rather than on final outputs of care such as quality of life measures, psychological well-being, etc. (Hughes & Challis, 2004). This could be due to the framework originating from the field of economics and subsequently being applied to social science (Hughes & Challis, 2004), although much of the quality-adjusted life year (QALY) measurement also originated in economics but has had some success in influencing resource allocation decision-making. In recent years, two systematic reviews were published with the purpose of highlighting methodological lessons to inform the future application and development of BoC studies. The research identified that future work should incorporate a broader approach to costing (e.g., housing, informal caring costs), examine more alternative care options, include outcomes for clients and caregivers, and involve local practitioners and clients in the planning process (Tucker et al., 2013; Tucker et al., 2015a).

In relation to the application of the BoC framework, Tucker et al. (2015a) acknowledged that three main barriers currently exist: data demands (particularly on client characteristics), complexities related to costing, and the paucity of information available on comparative outcomes. With regard to demands for data on client characteristics, this information is typically obtained from surveys completed by practitioners (Keogh et al., 2021; Mooney, 1978), researchers (Boldy et al., 1981; Boldy et al., 1982), or clients (Knapp et al., 1997; Pierse et al., 2021), and is very often a time-consuming exercise. Moreover, due to a lack of information provided in some studies, it can be difficult to determine whether case types are based on adequate numbers to be broadly typical of the population of interest. Data demands also exist in relation to service use, as very often individual-level data collection is required, again highlighting the demand for data when applying the BoC approach. However, the use of routinely collected electronic data in health care should make data demands less of a barrier in the future.

In relation to the complexities of costing, it is evident from the literature that the majority of BoC studies rarely examined cost shifting and failed to carry out a comprehensive costing exercise encompassing not only formal care costs but also housing, personal consumption, and informal care costs. This has led to an underestimation of the cost of community care. Encouragingly, other cost modelling templates have recently been developed to facilitate a comprehensive costing exercise and to model projections of cost shifting (Brand et al., 2015a; Brand et al., 2015b). Finally, although the identification of outcomes in different care settings is a defining feature of the BoC approach, the availability of evidence on outcomes remains weak. The literature shows that little progress has been made in this regard and that evidence on the effectiveness of different care settings remains a priority for future research.

Nevertheless, despite certain shortcomings of the approach, the use of these data, where possible, on client characteristics, service use, costs, and outcomes contributes important findings to a critical debate on the redeployment of resources for those on the margin of care. Furthermore, the application of the BoC framework allows policy-makers to explore the cost and consequences of alternative care options while facilitating diverse stakeholder judgements in the decision-making process (Tucker et al., 2015b). Therefore, the strengths and opportunities provided by the BoC approach are of much benefit (Tucker et al., 2015b). In future, possible applications of the BoC approach could potentially shift the focus from what is often considered as diversion to prevention. For example, this would consist of delivering services needed earlier in the care pathway to prevent/delay admission to LSRC or the acute care setting (Tucker, 2020). With regard to the acute care setting, another potential application of the BoC approach would be to formulate several dementia case types from data so that practitioners, for example, could make explicit judgements on who could be appropriately discharged earlier from hospital. It must be noted, however, that the demand for data on client characteristics is significant when formulating case types, and this is one of the reasons it was not possible for me to conduct such an exercise as part of my Ph.D. research. Moreover, dementia is a heterogeneous and changing condition, meaning that people with dementia have diverse and flexible needs. As a result, it is questionable if the development of case types for people with dementia whilst in hospital is the best approach, given that changing circumstances can have temporary effects that are not always easy to predict.

2.6 Application of balance of care approach to research objectives in this thesis

This thesis draws on three of the four defining features of the BoC approach set out in section 2.2 of this chapter. The first paper in the thesis specified the resources required for dementia-IHCP recipients to remain living at home and determined the relevant costs of care in the community setting versus alternative placement in public and private LSRC alternatives. The second paper focused on the identification and measurement of client characteristics that are likely to affect decisions about the most appropriate care setting in which to support IHCP recipients. Both papers used localised data gathered from the HSE-Genio 'real-world activity and practice' IHCP initiative. Data were collected from a number of pilot sites around Ireland and were subsequently aggregated to allow inferences to be drawn at the national level. The final paper in the thesis utilised national level data on inpatient discharges to determine LOS and the relevant costs of care for people with dementia in Irish acute hospitals. Although the consideration of outcomes in alternative care settings is a key element of the BoC framework, due to data limitations in Ireland, the focus of this thesis was mainly on costs and cost drivers rather than outcomes. Further information on the application of the BoC framework to my specific research objectives is presented below.

In paper one of this thesis, IHCP recipients were living at home but were likely to be on the boundary of admission to LSRC; such was their level of need relative to conventional and usual home support in Ireland. In the absence of an IHCP, it is likely, though not certain, that most of these people would be admitted to LSRC. For this analysis, I applied the BoC framework to examine service utilisation data in order to determine the average weekly cost of home care for people with dementia on the boundary of care in Ireland who were receiving enhanced home supports in the form of IHCPs. Very importantly, the comprehensive costing approach adopted in this study examined not only formal health care costs but also informal care costs, housing, and personal consumption costs. In the Irish context, this research contributes new information on local unit costs, where an absence of data currently still exists despite recent improvements (Smith et al., 2021), specifically in relation to community-based psychosocial care. Furthermore, the cost comparison of alternative care settings presented in this study allows policy-makers to consider the cost of IHCPs in the context of the care continuum in Ireland.

As part of the BoC framework, in the second paper of this thesis, I used data on client characteristics (e.g., living alone, physical dependency, level of informal care) to examine factors affecting outcomes such as admission to LSRC and mortality among people with and without dementia who were living at home with intensive formal care support. Again, the recipients of IHCPs were likely to be on the boundary of admission to residential care, such was their level of need relative to conventional and usual home support in Ireland, as determined by local practitioners and decision-makers. While the first research paper offers valuable insights into community care costs, this paper concentrates more on the specific characteristics of people who potentially benefit most from home-based care. Importantly, such information will help to focus policy attention on the key factors and recipient attributes that can prolong living at home and extend life for dependent older people who are in receipt of IHCPs in the community setting in Ireland.

In the final paper of this thesis, I applied the BoC framework by utilising data on patient characteristics (e.g., age group, socioeconomic status, comorbidities) to examine LOS as an outcome, as well as care costs for people with dementia in Irish acute hospitals. Getting people out of hospitals faster, especially when they are discharged back to their own home, can have an important positive impact on the BoC for people with dementia, as well as on the overall cost of care in relation to the disease. Both principal and secondary diagnosis dementia effects were examined for all hospital discharges aged 65 years and over in public hospitals in Ireland. Although the information was not available to determine if patients with dementia (principal or secondary) were on the margin of home care/acute care or LSRC/acute care, undoubtedly, admission to hospital is a key transition point along the care pathway for people with dementia. So, while the application of the BoC approach is less explicit in the third paper, it still addresses important resource allocation implications of dementia in acute care hospitals.

By looking at extended LOS for people with dementia, it is possible for health care planners to determine where changes to care practice can be made in order to improve care and save costs in the acute setting. While hospital beds are a fundamental part of the health care system and will always be needed, there may be opportunities to reduce LOS for people with dementia who are admitted through dementia-led training and education (Tucker et al., 2017). Moreover, in relation to wider BoC issues, previous research has shown that an important reason for extended LOS for people with dementia in the acute care setting is the lack of alternative care options available, both in the home and in LSRC (Connolly & O'Shea, 2015). There is good evidence nationally, and internationally that personalised community-based services can reduce hospital admission for people with dementia (Cahill et al., 2012).

2.7 Conclusion

The allocation of resources for people with dementia is undoubtedly one of the most challenging tasks facing policy-makers, now and in the future. The BoC approach can be used to support resource allocation at the national or local level. The framework examines the costs and/or consequences of shifting the balance of resources from one group/services to another (Arthur Anderson & Company, 1981; Mooney & Drummond, 1982, as cited in Tucker, 2020), thus, providing detailed information to policy-makers about client groups that are likely to be affected by changes to resource allocation (Tucker et al., 2013). There are limitations to the BoC approach, however, which include but are not limited to demands for data, complexities related to costing, and a scarcity of information available on comparative outcomes for different care settings (Tucker et al., 2015a). Nonetheless, despite shortcomings of the approach, information on client characteristics, service use, costs, and outcomes contributes important information to ongoing policy discussions on the allocation and distribution of resources for people with dementia on the boundary of care across different settings.

The three research studies, and subsequent published papers, completed for this thesis are linked as they seek to consider the costs and, where possible, consequences of placement decision-making for people with dementia, particularly at key transition points, using a BoC approach. The latter is an integrative holding framework to examine the costs and/or consequences of placement-decision-making for people with dementia on the margins of home care, residential care, and acute care in Ireland, with the focus on costs more than outcomes. While the first and second papers in this thesis explicitly use the BoC approach to look at the interface between home care and residential care, the third paper applies the BoC approach in a less explicit manner by utilising data on patient characteristics to consider the resource implications of dementia in Irish acute care hospitals addressing LOS and costs. Given that there is a paucity of information available on costs and/or outcomes of alternative care settings for people with dementia nationally and internationally (Cahill et al., 2012; Tucker 2020), this work is an important and novel contribution to the literature. Moreover, in the context of upcoming new home care legislation in Ireland, which is intended to lead to a considerable expansion of home care services for people with dementia in the coming years, the findings from the three studies are timely and relevant. This work contributes important information that will support the development of a new model of care, particularly in relation to formal home care provision, unit costs, family care provision, placement decision-making, key dementia transition points, and dementia in acute care settings.

Chapter 3: Intensive home care supports, informal care and private provision for people with dementia in Ireland[1]

3.1 Introduction

Chapter 1 showed that the Irish government is increasingly seeking to recalibrate resource allocation towards home care (Department of Health, 2019; Government of Ireland, 2018; Houses of the Oireachtas Committee on the Future of Healthcare, 2017; PA Consulting, 2018). As part of a process of further expansion of home care in Ireland, particularly for people with dementia, the HSE established an intensive home care package (IHCP) initiative to augment usual care for highly dependent older people at risk of admission to residential or acute care settings (Keogh et al., 2018b). This chapter used the BoC approach, as discussed in Chapter 2, to analyse the cost of IHCPs through an examination of resource utilisation of formal, informal, and private care for people with dementia who are living at home but are on the margin of residential care. Importantly, this analysis facilitates the comparison between the cost of home care and alternative placement in public and private residential care alternatives. This chapter, therefore, provides important information on costs across different care settings that can be used to inform the new home care scheme being developed by the Department of Health. The research makes it possible for policy-makers to consider the cost of IHCPs in the context of the broad continuum of care for people with dementia in Ireland, including the most comprehensive information set on resource use available to date in the country.

3.2 Background

Dementia is a neurodegenerative disease that results in the loss of cognitive and social functioning (Health Service Executive, 2018a). Due to the progressive nature of the condition, the care needs of people with dementia increase throughout the trajectory of the disease, therefore, imposing significant costs on the health and social care system. In 2015, it was estimated that the worldwide yearly cost of dementia was $818 billion (Prince et al., 2015). In

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[1] This chapter is based on: Carter, L., O'Neill, S., Keogh, F., Pierce, M., & O'Shea, E. (2019). Intensive home care supports, informal care and private provision for people with dementia in Ireland. *Dementia*, *20*(1), 47-65. https://doi.org/10.1177/1471301219863580. I was lead author on the paper, taking primary responsibility for all sections including the study design and data analysis.

Ireland, the cost of caring for people with dementia was estimated to be €1.69 billion per annum (Connolly et al., 2014).

As the population ages, the predicted increase in the number of people with dementia will have significant budgetary implications (O'Shea et al., 2017). In recent years, the policies of many developed countries have broadly converged, with each concerned to achieve a movement away from the provision of long-stay residential care (LSRC) and towards the greater support of people at home (Challis & Hughes, 2003; Howe & Kung, 2003). Such plans have been motivated by a number of considerations, including cost and cost-effectiveness, but the underlying belief is that for older people, including those with complex needs, staying at home for longer is the preferred care option (Department of Health and Children, 2001; Knapp et al., 1997).

Therefore, a major issue in all health and social care systems is how to keep very dependent people with dementia who are on the boundary of LSRC living at home for longer, rather than being admitted to acute care or expensive long-stay care facilities. Not only is this in line with what people want, but keeping people living at home for longer, or postponing admission to hospital or long-stay facilities, may reduce the potential cost of care to the government (O'Shea & Monaghan, 2016; Wübker et al., 2015).

One of the enduring criticisms of government policy for dependent older people in Ireland is the imbalance in public spending between LSRC and community-based care (Donnelly et al., 2016; O'Shea, 2017). Thirty years ago, The Years Ahead: A Policy for the Elderly report highlighted the need for the development and practice of home-based care for older people and recommended greater state involvement to support community-based care (Robins, 1988). In 2005, the National Economic and Social Forum (NESF) called on the then government to spend an additional €500 million to bring long-term care expenditure up to the Organisation for Economic Co-operation and Development (OECD) average, arguing for a disproportionate spend on home care in the country (National Economic and Social Forum, 2005). Historically, even when public resources were relatively plentiful, investment in community-based care has been poor (O'Shea & Carney, 2016).

Currently, the government is spending more than twice as much on LSRC as on community-based care, €962m relative to €408 million annually (O'Shea, 2017). At present, there is a statutory entitlement to nursing home care in Ireland delivered through the Nursing Home

Support Scheme (NHSS), which involves a co-payment arrangement between the state and a contribution from the resident based on a financial assessment of income and assets, including their family home (Wren et al., 2017). However, there is currently no statutory scheme in place for the provision of home care services in the community setting (Browne, 2016). Given the inadequacy of home support services, nursing home admission may be the only option for some people with dementia. It is estimated that there are at least 11,175 people with dementia living at home who have a serious functional impairment, 1,876 of whom are chair or bedbound (Pierse et al., 2019). Estimates from the same source suggest 19,530 people with dementia are living in nursing homes in Ireland, the vast majority of whom are likely to have high levels of functional impairment.

In Ireland, the Health Service Executive (HSE) manages the operation of the Irish health service and is responsible for the provision of public health and social care services (Health Service Executive, 2019a; Wren et al., 2017). The home help service has been the most important community-based support system for dependent older people living at home. Home help services traditionally consisted of domestic assistance, such as help with cleaning, cooking, and personal hygiene. However, since 2012, greater emphasis has been placed on assisting with personal care services (bathing, dressing, etc.). The HSE provided approximately 49,000 older people with home help services in 2017, amounting to 10.6 million home help hours in that year (Timoney, 2018), suggesting that the average number of home help hours was just over 4 hours per week.

Recent innovations in community care in Ireland have focused on the introduction of designated home care packages (HCPs) for older dependent people living at home. The latter are additional supports over and above existing community-based services and are designed to maintain an older person at home for longer through the provision of enhanced home supports and rehabilitation services. They are typically targeted towards people on the margin of LSRC or those who need additional supports following discharge from acute care. The most recent data available suggests that 16,450 older people in Ireland benefited from an HCP during 2016 (Department of Health, 2018). The average weekly hours for standard HCPs are 6.5 hours at an average cost of €165 per week (Health Service Executive, 2018b).

As part of a process of further development of home care, particularly for people with dementia, the HSE introduced an intensive home care package (IHCP) initiative in 2014. The initiative is closely aligned with a priority action of the National Dementia Strategy Implementation

Programme (NDSIP) involving the further development of integrated services for people with dementia, particularly in respect of home supports (Department of Health, 2014; Keogh et al., 2018a). IHCPs consist of support hours that are greater in range and level than those provided as part of a standard HCP or current community services (Institute of Public Health, 2018; Keogh et al., 2018a). IHCPs are designed to keep people with dementia out of acute care and residential care and to support people with very high levels of need who might otherwise be unable to live at home (Keogh et al., 2018a).

As part of the investment to support the implementation of the National Dementia Strategy (NDS), a fund of €20.5m from Atlantic Philanthropies, the HSE, and the Department of Health was made available to deliver IHCPs for individuals with dementia over a three-year period. Given the vagaries of the budget system in Ireland, there are no guarantees that IHCPs will be sustained in the longer term, especially since the support of Atlantic Philanthropies for the NDS was a once-off contribution to the budgetary process in Ireland (O'Shea & Carney, 2016). As part of the NDSIP, the HSE commissioned an evaluation of the overall IHCP initiative for people with dementia. This paper is part of the cost evaluation of IHCPs and was conducted through an in-depth study of a small sample of IHCP recipients with dementia. The objective is to analyse the cost of IHCPs through an examination of resource utilisation of formal, informal, and private care for people with dementia living at home on the boundary of community and residential facilities. The analysis facilitates the comparison between the cost of home care and alternative placement in public and private residential care alternatives.

The BoC approach can be used to identify the types of dependent older people who might equally be cared for at home or in a nursing home if resources for the former were of sufficient scale and quality (Challis et al., 2014; O'Shea & Monaghan, 2017; Tucker et al., 2016). A large UK BoC study found that up to half of new care home entrants could be cared for in alternative settings if adequate resources were made available (Challis et al., 2014). For these case types, nursing home care could be delayed by 3-12 months due to the provision of appropriate community supports. Similarly, for Ireland, O'Shea and Monaghan (2016) highlighted the economic potential of enhanced individualised supports for keeping people with dementia living in their own homes for longer. Their estimates suggest that the weekly average cost of community care for those on the boundary between community and residential care, including formal care provision, new personalised supports, consumption, and housing, was less than half the cost of potential nursing home care. However, monetizing informal care provision nearly trebled the cost of community-based care.

The resource constraint is crucial in relation to the potential of community-based care to delay or reduce admission into LSRC. Additional resources are required for community-based care to make a difference to placement decision-making, including IHCPs. Keeping people at home in the absence of sufficient community-based care is not an easy task (Rothera et al., 2008; Spijker et al., 2008; Toot et al., 2017). Therefore, from an economic standpoint, any new investment in IHCPs must be costed and compared to other care alternatives in order to inform the resource allocation process for individuals with dementia living on the boundary of care.

3.3 Data and methods

3.3.1 Data

A total of 505 individuals received an IHCP at some point between 2014 and 2017; 297 of those recipients were individuals with dementia who had either a confirmed formal diagnosis of dementia (i.e., from their own GP or another clinician) or had evidence of moderate to severe cognitive impairment based on an assessment by nursing staff or allied therapists. All those approved for dementia-IHCPs were invited to participate in the in-depth study between October 2016 and January 2018. Potential participants who responded to the invitation were contacted directly by a member of the research team. A total of 42 persons with dementia and/or their family caregivers, as characterized in Table 3.1 below, were recruited for this study. Over half of the study sample had dementia that was at a severe stage, 38% had moderate dementia, and 10% had mild stage dementia (using the Dementia Severity Rating Scale). ‘Process consent’ was adopted to obtain consent from people with dementia to participate in the study (Dewing, 2008). This approach comprises of five parts: background and preparation; establishing a basis for capacity and other abilities; initial consent; ongoing consent and monitoring; and feedback and support.

Data were collected at baseline and at follow-up. Not everyone completed the baseline questionnaire; hence the focus, in terms of resource use, is primarily on the follow-up data set, which was collected after IHCPs had been in place for some time. This study allows us to take advantage of a novel and comprehensive data set on current resource allocation for individuals with dementia receiving an IHCP who are currently living at home but are also likely to be on the boundary of admission to LSRC. In the absence of the IHCP, it is likely, though not certain, that most of these people would be admitted to LSRC, such is their level of need relative to conventional and usual home support in Ireland. Ethical approval for the study was obtained through the Royal College of Physicians of Ireland Research Ethics Committee in September 2016.

Table 3.1: Descriptive analysis

Variable	In-depth study	Larger study
Number of people with dementia	42	297
Age in years: median (interquartile range)	82.5 (74-88)	82 (75-87)
Male	43%	39%
Female	57%	61%
Living with spouse/partner	57%	53%
Living alone	24%	29%
Main informal caregiver: spouse/partner	48%	42%
Barthel Index dependency (0-20): median (interquartile range)	4.5 (2-7)	6 (3-10)
IHCP support hours per week: median (interquartile range)	33 (30-42)	38 (29-48)

Table 3.1 presents a comparison of summary statistics on the characteristics of recipients from both the in-depth study and the larger study. With respect to sociodemographic variables, the in-depth study is largely representative of the whole group of people with dementia who received an IHCP. Additional descriptive analysis was carried out on data collected for the in-depth study only, which suggests that it is the spouse/partner and children who provide the majority of informal care to persons with dementia. The average age of carers was 63.0 (IQR: 54.5 to 74) years, and the majority of these were female; just over a quarter of carers were engaged in full-time employment. The findings on caregivers are consistent with a number of previous studies, which supports the representativeness of the admittedly limited sample (Argyle et al., 2010; Brennan et al., 2017; Gillespie et al., 2015; Lafferty et al., 2014; O'Shea et al., 2017). The Resource Utilisation in Dementia questionnaire (Wimo et al., 2010) was administered face-to-face to persons with dementia and/or their caregivers by an HSE-Genio project leader in order to collect data on formal resource utilisation and informal care provision in the previous 30 days. Data on intensive home care support hours were collected from the HSE for all participants in the in-depth study. Information on privately funded care was

collected from participants through a schedule of care form, which was specially developed to record this information during interviews (Keogh et al., 2018b).

3.3.2 Methods

Formal care costs

IHCP costs were calculated by multiplying the number of support hours provided to each individual by the unit cost of a support hour. Under the IHCP scheme, support hours can be provided by HSE employees and/or HSE approved private care providers. For those individuals who received home support hours from approved private care providers, a unit cost of €22.64 per hour was applied; this was the average cost of a home care hour based on four approved private care providers in Ireland. For those individuals who received home support hours from both an approved private care provider and directly through the HSE, a unit cost of €23.71 was applied; this was the average cost of a home care hour based on approved private care providers in Ireland and the HSE salary scale of a home help, including associated non-pay costs.

The cost of standard community-based service provision was calculated by attaching the appropriate unit cost to the relevant averaged resource use across all elements of provision. There is no common, uniform database that covers unit costs in community-based care in Ireland. Consequently, information on unit costs comes from a variety of mainly Irish data sources (Table 3.2). Where necessary, unit cost data obtained prior to 2017 were adjusted using an appropriate inflation index (Central Statistics Office, 2018) to reflect costs for 2017. Labour costs were calculated using consolidated salary scales available from the HSE for public-sector employees, with associated non-pay costs estimated according to the methods outlined by the Health Information and Quality Authority (Health Information and Quality Authority, 2018). Duration of visit was calculated according to the methods outlined in the Regulatory Impact Analysis guidelines issued by the Department of the Taoiseach (2009).

Table 3.2: Source of unit cost estimates

Resource Activity	Activity	Unit Cost	Source of Estimates
General practice	Per visit	€54	Connolly et al., 2014
Public health nurse	Per visit – 30 mins	€24	Public health nurse salary, consolidated salary scales, (HSE, 2018c)
Community mental health nurse	Per visit – 30 mins	€25	Community mental health nurse salary, consolidated salary scales, (HSE, 2018c)

Allied health therapies	Per visit – 30 mins	€21	HSE consolidated salary scales, (HSE, 2018c)
Day care	Per visit	€112	O'Shea & Monaghan, 2016
Meals on wheels	Per meal	€8	O'Shea & Monaghan, 2016
Geriatrician (outpatient visit)	Per visit	€148	Brick et al., 2015
Psychiatrist (outpatient visit)	Per visit	€148	Brick et al., 2015
Neurologist (outpatient visit)	Per visit	€148	Brick et al., 2015
Psychologist (outpatient visit)	Per visit – one hour	€62	Psychologist salary, consolidated salary scales, (HSE, 2018c)
A&E attendance	Per visit	€271	HIPE, 2015
Anti-dementia medication	Per week	€14	PCRS (HSE, 2018f); NCPE, 2016; Connolly et al., 2014
Anti-psychotic medication	Per week	€28	PCRS (HSE, 2018f); NCPE, 2016; Connolly et al. 2014
Anti-depressant medication	Per week	€7	PCRS (HSE, 2018f); NCPE, 2016; Connolly et al., 2014
Acute hospital admission	Per night	€878	HIPE, 2017
Emergency acute hospital admission	Per night	€878	HIPE, 2017
Psychiatric admission	Per night	€364	Connolly et al., 2014
Day hospital	Per visit	€153	Green et al., 2014
Home help: nonmarket value	Per visit – one hour	€28	Home help salary, consolidated salary scales, (HSE, 2018c)
Health care assistant: nonmarket value	Per visit – one hour	€30	Health care assistant salary, consolidated salary scales, (HSE, 2018c)
Health care assistant: market value	Per visit – one hour	€22.64	HSE approved private care providers
Night duty (non-live)	Per night - 9 hours	€160	HSE approved private care providers
Home help: nonmarket value and Health care assistant: market value	Per visit – one hour	€23.71	Home help salary, consolidated salary scales, (HSE, 2018c) & HSE approved private care providers
Opportunity cost method: caregivers in employment	Per hour	€22.34	Average Hourly Earnings, Q2 2017, CSO
Opportunity cost method: caregivers not in employment	Per hour	€5.58	Leisure time: (25% of Average Hourly Earnings)
Public nursing home	Per week	€1,526	HSE, 2018d
Private nursing home - Dublin area	Per week	€1,149	HSE, 2018e
Private nursing home - rest of country	Per week	€909	HSE, 2018e
Personal consumption	Per week	€144	O'Shea & Monaghan, 2017
Capital	Per week	€92.61	O'Shea & Monaghan, 2017

Standard public and private outpatient visit costs were sourced from Brick et al. (2015), the average of both costs was calculated and adjusted to 2017 prices using an appropriate inflation index. A unit cost of €271 was applied to an accident and emergency (A&E) attendance; this estimate was sourced from Hospital In-Patient Enquiry (HIPE) and was adjusted to 2017 prices (Hospital In-Patient Enquiry, 2015). The cost of a psychologist visit was calculated using the consolidated salary scales available from the HSE for public-sector employees, with associated non-pay costs estimated according to the methods outlined by HIQA (2018). A unit cost of €878, which is the average cost across all nights in all hospitals and in all types of inpatient cases, was applied to acute hospital admission and emergency hospital admission (Hospital In-Patient Enquiry, 2017). A unit cost of €153 per day was applied to day hospital admission; this cost was sourced from UK data generated by the Personal Social Services Research Unit (PSSRU). Consumer Price Index (CPI) data from the origin country and the purchasing power parity index was used to convert the unit cost to local currency (Green et al., 2014; Health Information and Quality Authority, 2018; Organisation for Economic Co-operation and Development, 2018b; Office for National Statistics, 2018).

Information was collected on the use of anti-dementia, anti-psychotic, and anti-depressant drugs by people with dementia in the study. For people on medication, it was assumed that they were taking the most commonly used drug: Memantine for dementia, Risperidone for psychosis, and Citalopram for depression. The unit costs reflect normal dosage levels taken from the Monthly Index of Medical Specialities (MIMS), adjusted to 2017 prices using an appropriate inflation index.

Private care costs

A unit cost of €22.64 per hour was applied to private expenditure on care, based on the average cost of a private out-of-pocket care hour across various HSE approved providers in Ireland. An average nightly rate of €160 was applied to instances where individuals purchased care from private providers at night. No data is available on the types of services purchased out-of-pocket from private providers. It is likely that private out-of-pocket care consists mainly of more of the same type of home care hours available through IHCPs, perhaps delivered outside of normal business hours, whereby the focus of care remains largely on the provision of essential domestic and personal care assistance (such as cleaning, cooking, bathing, and dressing). Future work will be necessary to tease out what people spend on private care, for what purpose, and at what times.

Informal care costs

Informal care inputs were estimated from data provided by family carers on the total hours of informal support provided to the person with dementia in an average day in respect of each type of support: activities of daily living; instrumental activities of daily living*;* and supervision. The labour force participation status was available for the carers of individuals with dementia; information was also available on whether people gave up paid work entirely or reduced their hours of paid work in order to care. An opportunity cost methodology was used to measure the baseline cost of informal care (Gillespie et al., 2015). The opportunity cost of time for caregivers categorized as having given up paid work time to care is valued at €22.34 per hour, which is the average hourly wage across all industrial sectors in Ireland in 2017 (Central Statistics Office, 2017). For those categorized as retired or not available for work, the opportunity cost of time was valued at a percentage (25%) of the average hourly wage, equating to €5.58 per hour (Central Statistics Office, 2017).

Personal consumption costs

People living in their own homes in the community expend resources on the personal consumption of items such as food, fuel, light, and household maintenance. If those identified as being on the margins of LSRC were admitted to LSRC, these costs would be included as part of the direct costs of care by the institution. Wübker et al. (2015) suggest that the exclusion of personal consumption for people living in their own homes would diminish some of the differences between community care and residential care costs, as this consumption could amount to 15% or more of nursing home outlays. Personal consumption costs must, therefore, be calculated when comparing costs between the two settings. Weekly personal expenditure for people living at home in the community is €144, based on the Household Budget Survey 2010 (most recently available) estimates of expenditures of a retired household, inflated to 2017 prices using the CPI (Central Statistics Office, 2018).

Housing costs

Capital costs are normally included in the pricing structure of private nursing homes. Hence the cost of housing for people with dementia living in the community must also be calculated when making comparisons between the cost of home care and residential care. The two components of capital cost are the opportunity cost of keeping the capital item another year, in this case, the house, and the depreciation over time of the asset itself. One method of valuing major capital costs is to calculate the equivalent annual cost by annuitizing the initial capital outlay over the useful life of the asset itself. In calculating the opportunity cost of housing in this study, the current average price of housing is used to determine the replacement value of the house (Lyons, 2018). The analysis assumes a 0% discount rate to calculate the equivalent annual housing cost over a 50-year period, implying that the increasing value of the house is offset by depreciation over the lifetime of the asset. The cost of capital for an individual living in the community per week is estimated at €92.61.

Nursing home costs

In order to compare the cost of care for people with dementia had they been institutionalized rather than cared for at home through the delivery of IHCPs, it was necessary to calculate the average cost of public long-stay facilities in Ireland, private nursing homes in the Dublin area and private nursing homes in the rest of the country, given that the sample of IHCP recipients in the study is distributed across the country. Public and private long-stay cost estimates are based on the average cost of agreed prices available from the HSE under the NHSS. Average weekly costs were €1,526 in a public long-stay facility (Health Service Executive, 2018d), €1,149 for private nursing homes in Dublin, and €909 for nursing homes in the rest of the country (Health Service Executive, 2018e).

3.4 Results

Resource use

Resource utilisation among people with dementia is presented below in Table 3.3. The average number of additional support hours provided through the HSE-Genio Dementia Programme to people with dementia and their informal carers was 34 hours per week (ranging from 13 hours to 56 hours per week). In general, despite a relatively high risk of institutionalization, a large number of participants in the study were not in receipt of standard community-based formal provision. The most frequently used standard services include public health nurse visits (61%), GP visits (51%), day care (28%), and occupational therapy (21%), with a low proportion of individuals receiving community mental health nurse visits (8%) and social work visits (5%). The overall picture is one of scarcity in regard to standard public community-based care provision for people with dementia living at home in Ireland.

Resource utilisation for outpatient and inpatient visits among people with dementia is also presented in Table 3.3. Psychiatrist (13%) and geriatrician (10%) visits were the most commonly used outpatient service for people with dementia living in the community. Only 5% of participants experienced an inpatient acute hospital admission in the last month, while only 3% had an emergency admission to an acute hospital. It should be noted, however, that one person had spent all of the last 30 days in acute care. Only one other person was reported as having been admitted to hospital, but no data was available on their length of stay. A length of stay of 12 days was assumed for this person, based on previous findings from a generic study on hospital admissions and discharges for people with dementia by Connolly and O'Shea (2015). Just over half (56%) of people with dementia living in the community were prescribed an anti-dementia drug in the last 30 days (Table 3.3). A smaller proportion of individuals were prescribed anti-depressant medication (33%) and anti-psychotic medication (27%).

In 35% of cases, private out-of-pocket care hours were purchased in order to supplement IHCP support and standard public care for individuals with dementia living in the community setting. An average of 19 hours of private care was bought per week. Not everyone purchased private care, as is clear from the range of the data (0 hours to 168 hours per week). On average, carers of people with dementia reported providing 80 hours of informal care per week (ranging from 2 hours to 133 per week), or just over 11 hours per day. Even with IHCP provision, there is a considerable reliance on families to support people with dementia in Ireland.

Table 3.3: Resource utilisation and costs of care among people with dementia

Activity	Resource Utilisation, n (%)	Average cost per week, €
Intensive home care package	42 (100)	€774.18
Primary and community care		
GP	20 (51)	€7.11
Nursing		
Public health nurse	23(61)	€7.66
Community mental health nurse	3 (8)	€0.63
Allied health therapies		
Physiotherapist	4 (10)	€0.88
Occupational therapy	8 (21)	€1.26
Speech and language therapy visit	5 (13)	€0.63
Chiropodist	6 (15)	€0.75
Social worker	2 (5)	€0.38
Other health professional	8 (21)	€1.13
Services		
Day care	11 (28)	€75.05
Meals on wheels	2 (5)	€2.33
Outpatient visits		
Geriatrician	4 (10)	€3.54
Psychiatrist	5 (13)	€4.43
Neurologist	0 (0)	€0.00
Psychologist	1 (3)	€0.37
A&E attendance	2 (5)	€3.24
Inpatient visits		
Acute hospital admission	2 (5)	€220.63
Emergency admission to acute hospital	1 (3)	€5.25
Psychiatric hospital	0 (0)	€0.00
Day hospital	2 (5)	€1.79
Prescribed medication		
Anti-dementia medication	22 (56)	€7.90
Anti-psychotic medication	10 (27)	€7.57
Anti-depressant medication	13 (33)	€2.33
Private care	14 (35)	€390.63
Informal care	38 (100)	€593.34

Note: Not everyone who received an IHCP responded to each subsequent resource use question. The percentage value reflects actual respondents for each item of resource use.

Cost of home care

Table 3.3 also shows the average weekly costs of care for people with dementia. The average cost of support hours provided through the HSE-Genio Dementia Programme to people with dementia and their informal carers was €774 per week. The variation in provision is evident, with weekly costs ranging between €294 and €1,268. The total average weekly cost of standard primary and community care for people with dementia per week was €97.81, almost 77% of which was accounted for by day care activity. This was followed by public health nurse visits which accounted for approximately 8% of the total average cost. Allied health therapies (i.e., physiotherapist, occupational therapist, etc.) contributed approximately only 5% of the overall average cost.

The average costs of outpatient visits per person living in the community setting are also presented in Table 3.3. Visiting rates were very low overall; for example, only one person attended a psychologist, resulting in average costs of aggregate outpatient visits in the community of only €11.58 per week. With regard to inpatient care, only two people incurred costs, but one of them spent the previous 30 days in hospital, accounting for 71% of the entire acute hospital admission costs. The total average weekly cost of medications was €17.80, of which 44% is accounted for anti-dementia drugs.

With regard to private out-of-pocket home care hours, the average cost was €391 (range €0 to €3,497) per week. Some people did not purchase any private care, while others bought significant amounts. Informal care costs in the community setting were valued using an opportunity cost methodology; the average cost of informal care was estimated to be €593 (€33 to €1,354) per week. The average weekly capital cost of housing for people with dementia living in the community was €93. Over a one-week period, the average estimated cost of personal consumption was €144.

Table 3.4 shows the overall average care costs for people with dementia living in the community setting. The estimated average cost of home care for a person with dementia, which includes IHCP hours, primary and community care, medications, consumption, and housing, is €1,127 per week. Costs rise to €1,720 per week when informal costs using an opportunity cost methodology are included and rise further to €2,111 per week when private out-of-pocket care costs are taken into account. The average cost per week for home care when all care costs are included (i.e., adding inpatient and outpatient costs) is €2,351. On average, informal care and private care account for 42% of overall care costs for people with dementia living in a community setting and just under half the cost of care if inpatient and outpatient costs are excluded.

Table 3.4: Overall care costs for people with dementia

Activity	Average costs per week, €	% of overall cost of care
Intensive home care package	€774	33
Primary and community care	€98	4
Outpatient visits	€12	1
Inpatient visits	€228	9
Medications	€18	1
Private care	€391	17
Informal care (opportunity cost method)	€593	25
Capital	€93	4
Personal consumption	€144	6
All	€2, 351	100

Note: Numbers have been rounded.

We are interested in comparing the potential cost of care for people with dementia if they had been institutionalized rather than cared for at home in the community. Comparing costs in this way is not straightforward, given the often complex case-mix in long-stay facilities associated with different levels of dependency and need among residents with dementia. The use of an average cost for residential care is, therefore, not ideal, but it is the only figure available to us, as marginal costs are not routinely published and, in any case, are not always easy to compute. If the comparison is only with IHCP support hours, primary and community care, medications, consumption, and housing, the average home care cost of €1,127 per week is almost comparable to the average cost of a private nursing home in the Dublin area, which costs €1,149, on average, per week. When compared to the average cost of a public long-stay facility (€1,526 per week), there is a cost saving of €399 per week. However, when informal care costs are included, community care is more expensive than any type of residential care for people with dementia in Ireland.

Sensitivity analysis

The impact of uncertainty in relation to costs was explored using sensitivity analysis. In order to assess variation in the average weekly cost of IHCPs and private out-of-pocket expenditure on care, a 5% trimmed mean was calculated. This removes the lowest and highest 5% of cases from the analysis (i.e., the outliers). With regard to informal care costs, an alternative replacement cost method was used, whereby each hour of informal care was valued using the HSE salary scale and associated non-pay costs of a health care assistant, which is €30 per hour

(Health Service Executive, 2018c). This method is viewed as being less conservative than the opportunity cost approach, which may lead to an underestimation of informal caregiving costs. For capital costs, instead of using a zero percent discount rate in order to calculate the equivalent weekly housing cost over a 50-year period, discount rates of 2% and 5% were assumed, respectively.

Following the removal of outliers, the 5% trimmed mean for the average cost of IHCP support hours was €775 (€379 to €1,176), which remained almost unchanged from the full mean. With regard to private out-of-pocket expenditure on care, the average is reduced to €245 per week (€0 to €2,332), €146 less than the full mean. When a replacement valuation is applied to informal care, costs quadruple to an average of €2,389 (€60 to €3,990) per week. Applying a discount rate of 2% in order to calculate the equivalent annual housing cost over a 50-year period increases the cost of capital to €147 per week. When a 5% discount rate is assumed, costs increase further to €254 per week.

3.5 Discussion

This study examined data from the HSE-Genio Dementia Programme on resource utilisation of formal, informal, and private care in order to analyse the cost of care for people living at home but who are on the boundary of LSRC. The average weekly cost of community-based care, funded through public expenditure and comprising of standard community-based provision, and IHCPs is cheaper than residential care alternatives, especially public long-stay care settings - €872 per week compared to €1,526 per week. Including housing and personal consumption costs raised the cost of community-based care, but home care remains below public long-stay care facilities and around the same cost as private nursing homes in Dublin.

The results suggest that even with increased public spending on IHCPs, significant informal care and, increasingly, private care are needed to keep people with dementia living at home rather than in residential care facilities (O'Shea & Monaghan, 2016). If traditional community-based care is characterized by its absence in this study, family care is the opposite and is the main bulwark of care for people with dementia, as well as being a major contributor to costs. Informal care comprises 25% of the total cost of care. Adding family care inputs to care, valued using an opportunity cost methodology, raises the average cost of home care by €593 per week. Therefore, when measured from a societal perspective, home care may be more expensive than LSRC, both public and private facilities. But then it is possible to see this differential as the price people are willing to pay to support home care over residential care (O’Shea et al., 2008). Adding private out-of-pocket expenditure on care further inflates the cost of home care.

However, it is important to consider that private out-of-pocket expenditure and informal care costs might also be incurred in a residential care setting. For example, the Irish De-Stress study found that over half of caregivers whose spouse had moved into LSRC visited their spouse every day (Brennan et al., 2017). Some carers continue to play an important caring role in the residential care setting where they offer emotional support, companionship, and assistance with daily activities (Timonen, 2009). A recently published systematic literature review found that for people with dementia living in residential care facilities, informal care continued to be important (Boumans et al., 2019). But, whatever about comparisons with residential care, even with all costs accounted for, keeping people with dementia living in their own homes is less than half of the weekly cost of care in an acute hospital.

Previous cost studies internationally have identified higher costs in institutional long-term care settings compared to formal, exchequer-funded community care provision. Data from a study involving eight European countries found that residential costs were higher than basic home care costs (Wübker et al., 2015). However, the results suggest that community-based care can be just as expensive as residential care and more if informal care costs and private out-of-pocket expenditure on care are included. Similarly, Leicht et al. (2013) suggest that the societal cost of caring for people in the community can be considerably higher than nursing home costs if informal care is taken into account. Wübker et al. (2015) also found that home care costs are sensitive to the valuation of informal care, confirming the results and subsequent sensitivity analysis in this paper. This research also reflects previous cost estimates for people with dementia on the boundary between community and residential care in Ireland (O’Shea & Monaghan, 2016), whereby high family care costs were identified irrespective of the additional supports received.

From an international perspective, this research contributes to a growing field of research on the costs of care for people with dementia and therefore contributes towards informing future health care service planning and provision for individuals with dementia living on the boundary between home care and residential care. There are, however, limitations to the present study. The sample size was small, making it possible that the results of the study are not generalizable to the wider dementia population. The results, therefore, should be viewed with caution, although Table 3.1 suggests that the sample is largely representative of the whole group of people with dementia who have received an IHCP in Ireland. In most cases, data on resource utilisation was reported by caregivers giving rise to a possibility of bias, as this information was not validated by another source; it should also be acknowledged that difficulties in recall can occur in relation to resource use in the previous 30 days. Given that reliable data on costs in Ireland are generally limited, unit cost data for the majority of services had to be drawn from a variety of sources, including outside of the country. This is likely to have had a negative impact on the accuracy of some of the cost estimates.

Future research with more participants is required on resource utilisation and costs of care associated with different care settings, both in Ireland and elsewhere. With regard to private out-of-pocket expenditure on care, it would be useful to gain an understanding of what types of resources are being purchased in the community setting. Predicting factors that influence admission to LSRC or mortality would also add to our knowledge of the resource allocation process, as it would help focus policy attention on the key factors and policies that prolong living at home and extend life for dependent older people. The use of statistical methods such as survival analysis, which focuses on modelling time to event data, would also be useful from a policy viewpoint in order to consider both the rate and incidence associated with admission to LSRC and/or mortality.

3.6 Conclusion

In conclusion, this study has shown that it is possible to increase the availability of publicly provided intensive home care supports to augment existing formal provision in the community and still cost the exchequer less than 60% of weekly public residential care costs. Investment in intensive supports for people with dementia is good value for money for the public sector, especially for people on the boundary between home care and residential care. New legislation currently going through the Irish parliament is intended to provide designated rights for home care in Ireland for the first time ever. It is not known yet what that will actually mean in terms of scale, provision, and cost sharing. But there is evidence from Scotland that free personalised care, while expensive, may prevent even higher levels of cost inflation by keeping people out of LSRC facilities (Bell et al., 2013). New investment in community-based care may also take some of the care burden off family carers, even if the evidence of this study is that the latter still contribute significantly to care in the home. Additional public support may be necessary anyway in the future, as there may be fewer adult children available to help care for their elderly parents, should they become dependent. The growing importance of private out-of-pocket expenditure on care for some people should also be noted, particularly the potential for inequities to develop as that market evolves. What has been confirmed is that family care costs remain high even in the presence of IHCPs; what is emerging is the increase in private out-of-pocket payments for care.

Chapter 4: Admission to long-stay residential care and mortality among people with and without dementia living at home but on the boundary of residential care: a competing risks survival analysis[2]

4.1 Introduction

The previous chapter determined the average weekly cost of home care for people with dementia on the boundary of care who are receiving enhanced home supports in the form of IHCPs. Even with increased public spending on IHCPs, family care costs and private out-of-pocket expenditure remain high for some people with dementia, sometimes higher than the residential care alternative. Therefore, from a societal perspective, keeping highly dependent people with dementia living at home is costly, making it important to know whether increased investment in home care prolongs living at home, for whom, for how long, and in what circumstances. The focus of this chapter is on predictors of admission to long-stay care and mortality for IHCP recipients currently living at home. The provision of such information will focus attention on the specific characteristics of people who potentially benefit most from home-based care. From a resource allocation viewpoint, such information can help to focus attention on the key factors that prolong living at home and extend life for dependent older people who are in receipt of IHCPs in the community setting. Moreover, the consideration of factors affecting the transition towards LSRC is useful for health care planners to examine if delaying admission to a long-term care setting is the best approach for some individuals on the boundary of care.

4.2 Background

Health policy for dependent older people in many countries continues to be underpinned by a commitment to support them to remain living in their own homes for as long as possible and practicable (Donnelly et al., 2016; Gage et al., 2015; National Health Service, 2016; Verbeek et al., 2012). Keeping older dependent people living at home is motivated by a number of

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[2] This chapter is based on: Carter, L., O'Neill, S., Keogh, F., Pierce, M., & O'Shea, E. (2020). Admission to long-stay residential care and mortality among people with and without dementia living at home: a competing risks survival analysis. *Aging & Mental Health, 25*(10), 1869-1876. https://doi.org/10.1080/13607863.2020.1857698. I was lead author on the paper, taking primary responsibility for all sections including the study design and data analysis.

considerations, especially cost and cost-effectiveness (Tucker et al., 2008), as preventing or postponing admission to hospital or long-stay residential care (LSRC) may reduce the potential cost of care to the government (O'Shea & Monaghan, 2016; Wübker et al., 2015). There is also the underlying belief that staying at home is the preferred care option for the vast majority of older people, including those with complex cognitive care needs such as dementia (Tucker et al., 2008). As the population in Ireland ages, the predicted increase in the number of older people with dementia will have significant budgetary implications for the health and social care system (Wren et al., 2017). Therefore, from an economic standpoint, there is considerable incentive to find the most appropriate and cost-effective ways to care for those with significant care requirements. Of particular interest is the cohort of people with dementia who are on the boundary of admission to LSRC. Keeping these people out of residential care, or even postponing admission, may yield significant cost savings for governments.

The Health Service Executive (HSE) in Ireland is responsible for the provision of community-based formal care, which is delivered directly through the HSE, or by private and voluntary agencies in receipt of HSE funding (Health Service Executive, 2019a; O'Shea & Monaghan, 2016). Home help provision has traditionally been the most important community-based, formal home support service in Ireland, providing domestic assistance with cleaning, cooking, and other light household tasks. In recent years, however, home helps have also provided assistance with personal care services, such as bathing, dressing, mobility assistance, toileting, etc. (Carter et al., 2019; Kiersey & Coleman, 2017). In 2014, as part of a process of further enhancement of home care, particularly for people with dementia, the HSE introduced an intensive home care package (IHCP) initiative to augment usual care for highly dependent older people at risk of admission to residential care (Keogh et al., 2018a). In practice, those receiving IHCPs receive more visits and significantly more hours of care from public health nurses and home help workers than those not in the scheme, including more personalised provision that reflects individual circumstances, family care networks, and housing conditions. The initiative was closely aligned with a priority action of the National Dementia Strategy Implementation Programme (NDSIP) relating to the further development of integrated services for people with dementia to enable them to continue to live at home rather than be admitted to LSRC (Carter et al., 2019; Genio, 2016; Keogh et al., 2018a).

Balance of care (BoC) is often used to describe a systematic framework for exploring the potential costs and consequences of changing the mix of community and institutional services in a defined geographical area (Challis et al., 2014). This approach focuses on identifying the types of dependent older people whose care needs can potentially be met through the provision of enhanced supports in the community setting instead of being admitted to LSRC if resources for the former were of sufficient scale and quality (Challis et al., 2014; O'Shea & Monaghan, 2017; Tucker et al., 2016). A large BoC study carried out in the UK found that up to half of new residential care home entrants could be cared for in alternative settings if adequate resources were made available (Challis et al., 2014). People with dementia may be at a higher risk of admission to LSRC, particularly in later stages of the disease or when significant behavioural problems occur (Alzheimer's Association, 2010; Gage et al., 2015; Verbeek et al., 2012). In Ireland, Aspell et al. (2019) report that higher levels of cognitive dysfunction are a predictor of admission to long-stay care, alongside being in receipt of high levels of formal community care hours. However, time to admission, rates of institutionalization, and mortality along the continuum of care vary considerably among different countries (Brodaty et al., 2009; Feldman et al., 2009; Ribbe et al., 1997). It is also ambiguous whether delaying admission to a long-term care setting is the best approach for all individuals with significant dependency, as evidence to support the optimal timing of placement decision-making is lacking, including the relationship to mortality (Verbeek et al., 2012).

This paper is based on administrative data generated in response to a policy decision by the Irish government to introduce a limited number of IHCPs for people with dementia to allow them to remain in their own homes rather than be admitted to residential care, even when faced with significant physical and cognitive challenges. The data allows us to explore factors that impact on subsequent admission to LSRC and mortality over a three-year period, taking account of both contingencies. It was possible to compare the experiences of people with and without dementia in relation to admission to LSRC and mortality in the presence of additional community-based provision. Whether and how dementia affects placement and mortality is particularly important in a country like Ireland, where there is a three-fold increase expected in the number of people with dementia in the next twenty-five years (Pierse et al., 2019). The data also allows consideration of the role that family carers play in influencing admission to LSRC and mortality.

4.3 Data and methods

4.3.1 Data

The IHCP scheme was a national initiative, originally focused on the appropriate discharge of dependent older people from acute hospitals, but evolving to cover the prevention of admission in the first place, including keeping older people out of residential care for as long as possible and practicable. Once an older person was identified by care staff as potentially benefiting from an IHCP, a formal assessment was made of their care needs and social circumstances, followed by an application to the relevant Clinical Lead and the Local Manager for Older Person's Services for monetary support to fund an appropriate package. Anonymised routine data collected administratively on all dependent older people who received an IHCP in Ireland between November 2014 and December 2017 was made available for analysis by the HSE. The data covers 429 recipients of these packages, on which complete information was available; 160 (37.30%) of recipients were individuals with significant physical dependency (non-dementia-IHCPs), and 269 (62.70%) were individuals with dementia (dementia-IHCPs). The latter had either a confirmed formal diagnosis of dementia (i.e., from their own GP or another clinician) or symptoms of moderate to severe cognitive impairment based on an assessment by nursing staff or allied therapists. Ethical approval for the study was granted by the Royal College of Physicians of Ireland Research Ethics Committee in September 2016.

Two outcomes were of interest in this study: the first was admission to LSRC, and the second was mortality. Ignoring one of these events may lead to misleading conclusions regarding the likelihood of the other event, so a competing risks approach was used to overcome this problem. For each recipient, information was recorded on the date of IHCP commencement and the date and cause for IHCP cessation. Time to each event was measured in days. If an individual had not experienced an event of interest over the study period, the observation was censored at the date of last follow-up/study end. Whether the individual was a non-dementia-IHCP recipient or a dementia-IHCP recipient was expressed as a binary variable.

Data were collected on additional independent variables such as gender, age, marital status, living arrangement (alone versus not alone), and the referral source for the IHCP (community or hospital) of each recipient. Information was also collected on the relationship between the IHCP recipient and their main informal carer, in addition to the amount (level) of care provided by the main informal caregiver per day measured in three time blocks: 0-8 hours; 8-12 hours; and 12+hours. Physical dependency was measured using the Barthel Index (Mahoney &

Barthel, 1965), which is used to measure performance in terms of activities of daily living (Hopman-Rock et al., 2019). The Barthel Index is scored from 0 to 20, with lower scores indicating increased disability or dependency. Finally, the number of care hours provided per week as part of the IHCP was also recorded.

4.3.2 Methods

In survival analysis, outcomes may be censored, a situation that arises when, at the end of the study period (or at the end of follow-up), the outcome has not been observed to occur for a given subject. Censoring may occur for various reasons, such as loss to follow-up, withdrawal from the study, or reaching the end of the study period (Feakins et al., 2018; Noordzij et al., 2013). Commonly used standard survival analysis methods are the non-parametric Kaplan-Meier model, which estimates survival functions, and the semi-parametric Cox proportional hazards model, which is used to estimate the effect of predictors on the hazard function (Austin et al., 2016; Despa, 2010). Both approaches make the assumption that censoring is independent of the time to the outcome, i.e., non-informative. This implies that subjects who are censored at a certain time point are representative of those still under observation at that point in time (Feakins et al., 2018; Noordzij et al., 2013). In some circumstances and settings, however, individuals are at risk of experiencing more than one type of outcome (Feakins et al., 2018).

A competing risk is an event whose occurrence either prevents the observation of the primary event of interest or modifies the chance of the event occurring (Noordzij et al., 2013; Pintilie, 2007). Therefore, at any time before experiencing the first event, individuals should be at risk of both events (Noordzij et al., 2013). In this scenario, a competing risk considers censoring to be informative. When examining admission into LSRC as the outcome of interest for participants in this study, mortality is a competing risk since, if an individual dies while in the community, they are no longer at risk of entering LSRC. Alternatively, when examining mortality in the community as the outcome of interest, admission into LSRC is a competing event because admission into residential care precludes the occurrence of mortality in the community. In the presence of competing risks, the cause-specific hazard model can be used to analyse time to event outcomes. This model estimates the effect of covariates on the cause-specific hazard function, which is defined as:

$$h_k(t) = \lim_{\Delta t \to 0} \frac{\mathrm{Prob}(\mathrm{t} \leq \mathrm{T} < \mathrm{t} \ + \Delta\mathrm{t}, \text{failure from cause k } |\mathrm{T} \geq \mathrm{t})}{\Delta\mathrm{t}}$$

The cause-specific hazard $h_k(t)$ is the instantaneous rate of failure from a specified cause k in those subjects who are currently event-free at time t (Austin & Fine, 2017; Cleves et al., 2010), where T is equal to the time to first failure from any cause (Austin & Fine, 2017; Cleves et al., 2010; Hinchliffe & Lambert, 2013). A central assumption of this model is that hazards are proportional, which implies that variables have a constant effect on the hazard function over time (Bradburn et al., 2003).

For the purpose of the analysis, a cause-specific hazard model was initially chosen in order to examine time to admission to LSRC, when mortality is treated as a competing risk. This allowed the hazard of admission to long-term care for those recipients who are currently event-free (i.e., alive and not in LSRC) to be examined. This was followed by the application of a cause-specific hazard model to investigate time to mortality while treating admission into LSRC as a competing event. This allowed the hazard of mortality in those recipients who are currently event-free (i.e., who are alive and not in LSRC) to be considered. The hazard of admission to LSRC and mortality was regressed on the set of independent variables described above (Culliford et al., 2013; Feakins et al., 2018; Ferraz & Moreira-Filho, 2017). In each of the models, violations of the proportional hazards (PH) assumption were tested and corrected for non-proportionality by interacting the covariate that violated the PH assumption with the natural log of time (Bradburn et al., 2003, Cleves et al., 2010). The sensitivity of results to the inclusion of irrelevant variables using backwards variable selection based on the Bayesian Information Criteria (BIC) was also assessed. Results are very similar to those using the full set of variables and hence are not reported. The analyses were performed using Stata 16 (StataCorp, 2019).

4.4 Results

Table 4.1 presents a comparison of summary statistics on the characteristics of both non-dementia and dementia-IHCP recipients, using medians and interquartile range (IQR) for continuous variables and percentages (%) for categorical variables. With respect to sociodemographic variables, the median age of non-dementia-IHCP recipients was 78 (IQR: 69 to 84) years and 81 (IQR: 75 to 87) years for dementia-IHCPs. Over half of the participants were female (59.21%). The two groups (non-dementia-IHCP recipients and dementia-IHCP recipients) were similar with regard to the proportion of individuals living alone and the proportion of those being cared for by their spouse/partner. The median level of dependency, as measured by the Barthel Index (which ranges from 0 to 20), was 5 (IQR: 2.5 to 7) for non-dementia-IHCP recipients and 6 (IQR: 3 to 10) for dementia-IHCP recipients. The median number of home support hours provided to non-dementia-IHCPs was 42 (IQR: 35 to 50) hours per week, while dementia-IHCPs received 38.5 (IQR: 28 to 48) home support hours per week. IHCP provision is approximately six to seven times greater than usual weekly care support hours for older people in Ireland (Houses of the Oireachtas, 2019). Of the 429 individuals who commenced an IHCP at some point between November 2014 and December 2017, 19% (n=80) were admitted to LSRC, and 33% (n=142) died while living in the community; 46% (n=197) of recipients were still receiving an IHCP at the end of the study period (active).

Table 4.1: Descriptive analysis for non-dementia-IHCP and dementia-IHCP recipients

Variable	Non-dementia-IHCP recipients (n=160)	Dementia-IHCP recipients (n=269)
Status, n (%)		
Active (receiving an IHCP at the end of the study period)	63 (39.38)	134 (49.81)
Ceased (admission/readmission to hospital/respite)	1 (0.63)	0 (0.00)
Ceased (admission to acute care)	3 (1.88)	5 (1.86)
Ceased (admission to LSRC)	21 (13.13)	59 (21.93)
Ceased (RIP)	72 (45.00)	70 (26.02)
Ceased (HSE provided alternative service)	0 (0.00)	1 (0.37)
Gender, n (%)		
Male	70 (43.75)	105 (39.03)
Female	90 (56.25)	164 (60.97)
Age at approval, median (interquartile range)	78 (69, 84)	81(75, 87)
Age groups, n (%)		
65 years or under	29 (18.12)	18 (6.69)
66-74 years	36 (22.50)	48 (17.84)
75-84 years	56 (35.00)	105 (39.03)
85+ years	39 (24.38)	98 (36.43)
Married, n (%)		
Yes	82 (51.25)	148 (55.02)
No	78 (48.75)	121 (44.98)
Living alone, n (%)		
Yes	45 (28.13)	73 (27.14)
No	115 (71.88)	196 (72.86)
Barthel score, median (interquartile range)	5 (2.5, 7)	6 (3, 10)
Dependency level (BI), n (%)		
High and Maximum dependency	144 (90.00)	214 (79.55)
Medium dependency	8 (5.00)	46 (17.10)
Low dependency and Independent	8 (5.00)	9 (3.35)
Main informal caregiver, n (%)		
None	4 (2.50)	7 (2.60)
Other	85 (53.13)	146 (54.28)
Spouse/Partner	71 (44.38)	116 (43.12)
Level of care by carer, n (%)		
>12 hours of care daily	39 (24.38)	95 (35.32)
8 -12 hours of care daily	31 (19.38)	60 (22.30)
< 8 hours of care daily	90 (56.25)	114 (42.38)
IHCP hours per week, median (interquartile range)	42 (35, 50)	38.5 (28, 48)

We first used a univariate cause-specific model to regress the hazard of admission to LSRC on whether the individual was a non-dementia-IHCP recipient or a dementia-IHCP recipient while accounting for mortality as a competing risk. The time-dependent covariate test (Cox, 1972) showed that the proportional hazards assumption was met (p=0.08). The estimated unadjusted cause-specific hazard ratio (CSHR) was 2.52 (Table 4.2), suggesting that the hazard of admission to long-term care was significantly higher for dementia-IHCP recipients than for non-dementia-IHCP recipients (95% CI: 1.51 to 4.19; p<0.001). Dementia-IHCP recipients still had a significantly higher hazard of admission to LSRC compared to non-dementia-IHCP recipients after the model was modified to include a range of covariates to control for observable differences between the groups (CSHR 2.45, 95% CI: 1.39 to 4.33; p<0.001).

With regard to the level of care provided by the main informal family caregiver, the results show that the hazard of admission to LSRC was higher for dependent older people receiving between 0-8 hours (CSHR 3.21, 95% CI: 1.56 to 6.61; p<0.001) and 8-12 hours (CSHR 2.67, 95% CI: 1.21 to 5.87; p<0.05) of informal care per day, compared to those receiving more than 12 hours of informal care per day. None of the other covariates were statistically significant at the 5% level.

Table 4.2: Cause-specific hazard model regression coefficients (and 95% confidence intervals) for admission to long-stay residential care, accounting for competing risk of mortality

	Long-term care			***Long-term care, adjusted***		
Variable	**Coefficient**	**CSHR (95% CIs)**	**P-value**	**Coefficient**	**CSHR (95% CIs)**	**P-value**
Dementia-IHCP	0.925	2.52 (1.51, 4.19)	<0.001***	0.898	2.45 (1.39, 4.33)	<0.001***
Male				0.061	1.06 (0.65, 1.73)	0.80
Age at approval						
66-74 years				-0.102	0.90 (0.32, 2.48)	0.84
75-84 years				0.522	1.68 (0.66, 4.25)	0.26
85+ years				0.255	1.29 (0.47, 3.48)	0.61
Married				0.259	1.29 (0.57, 2.92)	0.53
Community				0.027	1.02 (0.56, 1.87)	0.92
Living alone				0.150	1.16 (0.57, 2.35)	0.67
Barthel Index						
Medium dependency				-1.327	0.26 (0.01, 4.32)	0.35
Medium dependency x ln(time)				0.311	1.36 (0.80, 2.31)	0.24
Low dependency and Independent				-8.198	0.00 (<0.0001, 4.69)	0.09*
Low dependency and Independent x ln(time)				1.576	4.83 (0.92, 25.33)	0.06*
Main informal caregiver						
Other				0.806	2.23 (0.51, 9.72)	0.28
Spouse/Partner				0.712	2.03 (0.43, 9.56)	0.36
Level of care by carer						
8-12 hours per day				0.984	2.67 (1.21, 5.87)	0.02**
0-8 hours per day				1.167	3.21 (1.56, 6.61)	<0.001***
IHCP hours per week				-0.008	0.99 (0.97, 1.00)	0.30

* p<.1; ** p<.05; ***p<.01

In the second model, the cause-specific hazard of mortality was regressed on the main independent variable of interest, indicating whether an individual was a non-dementia-IHCP or a dementia-IHCP recipient while accounting for admission to LSRC as a competing risk (Table 4.3). Initially, the calculation of the CSHRs (Exp ($\beta_1 + \beta_2 * \ln(t)$)) showed that the hazard of mortality increased over time for dementia-IHCP recipients compared to non-dementia-IHCP recipients, and this difference was statistically significant ($p<0.05$). After adjusting for covariates, the proportional hazards PH assumption did not hold for the dementia-IHCP variable. The multivariable model was modified to include a time-dependent covariate by interacting the relevant covariate with the natural log of time, therefore, allowing the effect of the relevant covariate to change over time (Bradburn et al., 2003). While the subsequent calculation of the CSHRs again suggested that the hazard of mortality increased over time for dementia-IHCP recipients compared to non-dementia-IHCPs (year one: 1.13; year two: 1.32; year three: 1.44), the difference was no longer statistically significant at the 5% level.

Based on the CSHRs presented in Table 4.3, the hazard of mortality was found to be significantly higher for individuals aged 85 years and over compared to those aged 65 years and under, with a CSHR of 2.01 (95% CI: 1.03 to 3.93; $p<0.05$). The cause-specific hazard of mortality was lower for individuals with a medium level of dependency (CSHR 0.28, 95% CI: 0.12 to 0.66; $p<0.001$) on the Barthel Index compared to those with a high/maximum level of dependency. Finally, mortality was also lower for those receiving 8-12 hours (CSHR 0.49, 95% CI: 0.28 to 0.85; $p<0.05$) of informal care per day, compared to those receiving more than 12 hours of informal care per day. None of the other covariates were found to have a statistically significant effect at the 5% level.

Table 4.3: Cause-specific hazard model regression coefficients (and 95% confidence intervals) for mortality, accounting for competing risk of admission to long-stay residential care

	Mortality			***Mortality, adjusted***		
Variable	**Coefficient**	**CSHR (95% CIs)**	**P-value**	**Coefficient**	**CSHR (95% CIs)**	**P-value**
Dementia-IHCP	-1.461	0.23 (0.06, 0.77)	0.02**	-1.14	0.31 (0.09, 1.09)	0.07*
Dementia-IHCP x ln(time)	0.261	1.29 (1.01, 1.65)	0.03**	0.21	1.24 (0.97, 1.58)	0.08*
Male				0.06	1.07 (0.75, 1.52)	0.70
Age at approval						
66-74 years				0.63	1.89 (0.95, 3.73)	0.06*
75-84 years				0.21	1.24 (0.64, 2.40)	0.51
85+ years				0.70	2.01 (1.03, 3.93)	0.04**
Married				0.26	1.30 (0.73, 2.31)	0.37
Community				-0.20	0.81 (0.50, 1.32)	0.40
Living alone				0.02	1.02 (0.62, 1.68)	0.93
Barthel Index						
Medium dependency				-1.25	0.28 (0.12, 0.66)	<0.001***
Low dependency and Independent				-1.12	0.32 (0.09, 1.04)	0.06*
Main informal caregiver						
Other				-0.19	0.82 (0.28, 2.38)	0.71
Spouse/Partner				-0.59	0.55 (0.18, 1.62)	0.28
Level of care by carer						
8-12 hours per day				-0.70	0.49 (0.28, 0.85)	0.02**
0-8 hours per day				-0.15	0.85 (0.57, 1.26)	0.43
IHCP hours per week				0.00	1.00 (0.99, 1.01)	0.09*

* p<.1; ** p<.05; ***p<.01

Given the importance of the effect of covariates on the probability of events occurring over time (Austin & Fine, 2017), the effect of covariates on the cumulative incidence function was estimated using the Fine-Gray sub-distribution hazard model (see Appendix A). The results from the sub-distribution hazard model support the general findings. In addition, the Fine-Gray model found that the cumulative incidence of mortality was also lower for individuals classified as having low dependency/independent on the Barthel Index (SHR 0.30, 95% CI: 0.10 to 0.93; $p<0.05$). The cumulative incidence of mortality was also found to be higher for those receiving an additional hour of formal care provided as part of an IHCP (SHR: 1.01, 95% CI: 1.00 to 1.02, $p<0.05$), suggesting that higher levels of need, proxied by additional formal provision, may impact on mortality, confirming the finding of Aspell et al. (2019).

4.5 Discussion

Our findings suggest that people with dementia had a significantly higher admission rate to LSRC than people without dementia during the time frame of the study. In a systematic review and meta-analysis by Cepoiu-Martin et al. (2016), the authors suggest that having severe dementia was a significant predictor of admission to long-term care. Irish data on placement also highlights, more broadly, the importance of cognitive impairment and dementia for admission into residential care (Aspell et al., 2019; S.Walsh et al., 2021). These findings were confirmed using more sophisticated competing risks survival modelling. Even with enhanced community care provision delivered through IHCPs, people with dementia remain more disposed to admission to LSRC than people without dementia. Providing people with dementia with more hours of formal care may not be enough to keep them out of LSRC. Intensity is more complex than simply the provision of more care hours. The form, structure, and quality of those hours are also important (S.Walsh et al., 2020). Meeting the needs of people with dementia may be more difficult because of the denial of personhood in their lives and the consequent absence of a person-centred approach among formal care providers (Kitwood, 1997; Trahan et al., 2014; S.Walsh et al., 2020).

The results also indicate that dependent older people who were receiving less informal care hours had significantly higher admission to long-term care. This finding suggests that admission to LSRC is affected by the availability of family care provision. While this finding is not novel, it is interesting that families still matter even when additional formal care resources, in the form of IHCPs, are provided. Substitution may eventually occur at very high levels of state provision, but this study has shown that even with mean formal support hours of up to 42 hours per week (Table 4.1), six times that of usual care, families still matter for placement outcomes. Therefore, should informal care be absent, or reduced by choice or through demography in the future, the state may have to invest much more to support dependent older people living at home than currently envisaged by policy-makers.

Mortality was significantly higher for people aged 85 years and over relative to younger recipients aged less than 65 years of age. This raises the issue of resource allocation at the end-of-life, including the question of whether chronological age should be taken into account in deciding on eligibility for IHCPs. The argument that additional resources, delivered through IHCPs, should be rationed for people aged 85+ may be attractive, on the basis that any additional investment might be better allocated to people in younger age categories who have better chances of survival, but there are other issues to consider. In particular, it is not methodologically sound to argue on the basis of one cross-sectional study that age should, or indeed should not, be used to ration scarce community-based resources. Moreover, there is a countervailing normative argument that dependent older people should have the same access to care and treatment as younger age cohorts (O'Shea, 2020), implying that resources should never be allocated on the basis of age alone.

Mortality was lower for individuals classified as having a medium dependency on the Barthel Index relative to those with high/maximum dependency. It should also be noted that mortality was also lower for those classified as having low dependency/independent on the Barthel Index, but the results did not arguably reach statistical significance (p=0.06). These results corroborate a recently published study for Ireland, which found that high levels of physical dependency were predictors of mortality for dependent older people living in a community setting (Aspell et al., 2019). There is also evidence from other countries that reduced baseline activities of daily living (ADL) are associated with functional deterioration and mortality among older people (Na et al., 2017; Stineman et al., 2012). People with higher levels of physical dependency and limitation appear to have a higher risk of death when capacity becomes severely compromised (Kurichi et al., 2017). In general, therefore, a high level of physical dependency is a risk factor for mortality, highlighting the importance of movement, mobility, and exercise programmes for older people living in the community. Unfortunately, formal movement and exercise programmes are scarce in Ireland, reflecting a disablement approach to ageing that impacts negatively on dependent older people living in all care settings (Kelly et al., 2017).

Older people receiving between 8 and 12 hours of informal care per day had significantly lower mortality than those receiving more than 12 hours of informal care per day. This is not surprising as the *a priori* expectation would be that higher informal care provision, incorporating night-time care, implies a higher level of dependency and poorer health on the part of the recipient. A significantly lower hazard rate of mortality for individuals receiving between 0 and 8 hours of informal care per day might have been expected, presuming, in general, that those receiving minimum amounts of informal care would be in better health. The model suggests that this is not necessarily the case, signalling a potential influence on mortality from too little or too much informal care. It may be that people receiving low levels of informal care are more vulnerable simply because they have less informal care available to them. The relative absence of family in the care relationship may precipitate mortality, or, at least, not reduce the risk of mortality, through complex psychological and emotional pathways (Aneshensel et al., 2000; Santini et al., 2015). Unfortunately, the data is not available to explore this question any further in this paper. However, it is reasonable to speculate that there may be an optimal mix of family and formal care that is sensitive to the psychological and emotional needs of care recipients for family engagement in the care process.

There are limitations to the present study. The number of study participants who switched from home care to LSRC or died over the study period was relatively small, therefore, the results should be viewed tentatively. Information was not available on important variables of interest such as prior resource utilisation of usual formal care in the community setting (therefore, there was no baseline provision), caregiver work status, private care provision, and important outcome measures such as quality of life and caregiver burden. While data were gathered on the level of care provided by the caregiver, there was no differentiation with regard to the type of care provided (i.e., supervision vs. providing assistance with IADLs, for example). Data was not formally collected on the socioeconomic status (SES) of IHCP recipients in this study. However, SES is likely to have been incorporated indirectly into the decision-making process under social circumstances when considering need, particularly in relation to housing conditions and housing quality.

Other uncertainties surround the measurement of informal caring, as there is potential for carers to overestimate informal caring time in the way the data was collected. The use of the Barthel Index as a measure of dependency has limitations (Sainsbury et al., 2005; Yi et al., 2020). Moreover, very little is known, if anything, about how health professionals in Ireland use the

Barthel Index when conducting their assessments, raising issues of reliability. The results may also be subject to the influence of unobserved confounding. For example, predictors which may influence admission to LSRC or mortality, such as caregiver burden, income, quality of life, or comorbidities, were not included in the analysis, as information was not collected on these variables. Therefore, results should be viewed as descriptive rather than causal (Huang et al., 2020). Finally, it is unclear if predictors of institutionalization are country-specific; therefore, further research is required across countries in order to examine the specific characteristics of people who benefit most from institutional as opposed to home-based care.

4.6 Conclusion

This paper uses competing risks survival analysis to provide important insights into factors associated with admission into LSRC and mortality for people with dementia in Ireland, with important lessons for other countries. Dementia is an important predictor of admission to LSRC, even when additional formal care hours are available to keep people living at home. Therefore, increasing care hours through IHCPs for people with dementia living at home, while welcome, is not enough. The focus should be as much on the quality of care hours provided as the quantity of hours provided to people with dementia on the boundary of residential care. The needs of people with dementia are different and must be recognised as such by practitioners and policy-makers. Informal care continues to be important for placement decision-making and mortality among people with and without dementia, with the findings pointing to the importance of complementarity rather than substitutability between families and the state for keeping people out of residential care. Physical dependency matters for mortality, suggesting a role for ongoing reablement and mobility programmes for dependent older people along all stages of the continuum of care.

Chapter 5: Extended length of stay and related costs associated with dementia in acute care hospitals in Ireland[3]

5.1 Introduction

The previous chapter provided important information on factors affecting transition towards LSRC and mortality among people with and without dementia who were living at home with intensive formal care support. Thus, giving us an improved understanding of the specific characteristics of people who benefit most from care delivered in the home. The BoC focus now shifts to the acute sector. Much of the current policy focus on home care is driven by what happens in acute care, specifically a desire to ensure that discharges from hospital are not constrained by poor or inadequate community-based care for dependent older people. This was exemplified by the recent inclusion (for the first time) of social care as a factor in modelling future capacity in hospitals in Ireland (PA Consulting, 2018). The main objective of this chapter is to investigate the resource implications of dementia in the acute care setting by examining inpatient LOS and related costs for patients with dementia in Irish acute hospitals. Importantly, both principal and secondary diagnosis effects were estimated and valued. This research directly addresses the economic impact of extended LOS for patients with dementia in Irish acute hospitals. It contributes new evidence on those specific principal diagnosis disease categories that are more susceptible to increased LOS for people with dementia. From a policy perspective, the provision of information on costs and consequences of placement in the acute care setting is important, as reducing hospital LOS for dementia patients is a prospective strategy in many countries, designed to reduce health care costs, with a potential for the reallocation of resources to primary care settings and community-based care (Jensen et al., 2019; Vetrano et al., 2014).

5.2 Background

Ireland has one of the fastest rates of population ageing in Europe, with significant increases in older age cohorts expected in the coming decades (Kane et al., 2015). Population projections

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[3] This chapter is based on: Carter, L., Yadav, A., O'Neill, S., & O'Shea, E. (2022). Extended length of stay and related costs associated with dementia in acute care hospitals in Ireland. *Aging & Mental Health*, 1-10. https://doi.org/10.1080/13607863.2022.2068128. I was lead author on the paper, taking primary responsibility for all sections including the study design and data analysis.

from the Central Statistics Office (2016b) in Ireland suggest that the older population (i.e., those aged 65 years and over) will increase significantly from 629,800 persons in 2016 to between 1.51 and 1.60 million by 2051. The impact of future demographic ageing on the demand for health and social care and on capacity requirements will, therefore, be more keenly felt in Ireland than in many other countries, especially in the acute care sector, where bed numbers, occupancy rates, and waiting lists are an ongoing concern for the government (Department of Health, 2019; Houses of the Oireachtas Committee on the Future of Healthcare, 2017; Organisation for Economic Co-operation and Development, 2018a). Approximately 1 in 3 patients aged 70 and older admitted to Irish hospitals are estimated to have dementia, and this figure will increase annually as the population ages in the coming years (Bracken-Scally et al., 2020). Quantifying the clinical and financial implications of dementia in the acute care sector is, therefore, an important, if difficult task, given that many people with dementia remain undiagnosed before, during, and after their hospital admission (Connolly & O’Shea, 2015).

There is evidence from different countries that people with cognitive impairment and/or dementia experience a longer length of stay (LOS) in hospital (King et al., 2006; Möllers et al., 2019; Motzek et al., 2018; Tropea et al., 2017). A study by Tropea et al. (2017) on inpatient admissions at a Melbourne hospital showed that adjusted median LOS was longer for patients with cognitive impairment compared to those without cognitive impairment. Not surprisingly, costs were also found to be significantly higher among hospitalised patients who were cognitively impaired. Another Australian study found that mean LOS for dementia patients was double that of non-dementia patients (King et al., 2006). More recently, a systematic review of observational studies on length of hospital stay and dementia found that fifty-two of the sixty included studies reported longer LOS for people with dementia compared to those without dementia (Möllers et al., 2019). In Ireland, Connolly and O’Shea (2015) reported that people with a recorded diagnosis of dementia (either principal or secondary) had a significantly longer LOS in hospital than those without a recorded diagnosis of dementia. Similarly, Briggs et al. (2016) examined LOS over a 3-year period, from 2010 to 2012, in one 600-bed university hospital in Ireland for people with and without a diagnosis of dementia and found significant differences in LOS and costs of care.

Multiple studies have shown poorer health outcomes for hospitalized patients with dementia, which inevitably leads to an increase in LOS, resulting in significant additional costs on the health care system. Hospitalisation is associated with higher risks of morbidity, mortality, and an increased risk of institutionalization (Fogg et al., 2018; Sampson et al., 2009; Tropea et al., 2017). More specifically, patients with dementia are at an increased risk of falls, pressure ulcers, and functional decline while receiving treatment in acute hospital settings (George et al., 2013; Tropea et al., 2017; Watkin et al., 2012). It is not surprising, therefore, that, in many countries, reducing hospital LOS for dementia patients is a prospective strategy designed to decrease health care costs and to ensure the sustainability of health care systems (Jensen et al., 2019; Vetrano et al., 2014). Part of the problem is that dementia is not always acknowledged or recognised within acute care settings. Only 40% of dementia patients in Ireland have cognitive testing carried out during their hospital admission, while only 22% of hospitals have a dementia recognition system in place so that staff is aware of a person's dementia while in hospital (Bracken-Scally et al., 2020).

The objective of this paper is to estimate inpatient LOS and related costs of care for patients with dementia in Irish acute hospitals relative to similar patients without dementia. This paper builds on previous research (Briggs et al., 2016; Connolly & O'Shea, 2015) by controlling for the influence of case-mix on LOS and incorporating predictors that were not previously controlled for, including source of admission, proxy measures for socioeconomic status, and whether or not the patient was treated by a consultant geriatrician. Moreover, the paper estimates the impact of both a principal and secondary diagnosis of dementia on LOS and related care costs, with extensive efforts to match dementia and non-dementia patients. Heterogeneity in the impact of a secondary diagnosis of dementia on LOS is also addressed by separately considering a number of principal diagnosis disease categories identified using ICD-10-AM codes (National Centre for Classification in Health, 2000). This will help to identify those specific principal diagnosis disease categories that are more susceptible to increased LOS for people with dementia.

5.3 Data and methods

5.3.1 Data

Setting and participants

This study analyses anonymised individual patient-level data obtained from the Hospital In-Patient Enquiry (HIPE) administrative data set, which captures data on all public hospital inpatient discharges in Ireland (Hospital In-Patient Enquiry, 2021). HIPE is a national health information system that collects demographic, clinical, and administrative data on discharges and deaths in public acute hospitals (Healthcare Pricing Office, 2020). In this study, inpatient discharges in 2019 for patients aged 65 years and older are examined in detail. While much of the policy concern is often focused on resource allocation activity on the margin between home care and acute care settings (Gaughan et al., 2015; B.Walsh et al., 2020), patients who died while in hospital were also included in the analysis for this paper since proximity to death has been identified as a significant driver of health care costs among older people (Breyer & Lorenz, 2021). Moreover, in the Irish context, a recently published paper by Matthews et al. (2021) found that serious life-limiting conditions ending in death accounted disproportionately for LOS in Irish acute hospitals. Unfortunately, the absence of a unique patient identifier in the HIPE data means it is not possible to analyse certain parameters of potential interest, such as the number of hospitalizations per patient, nor to consider information on historic admissions that may be informative in relation to the patients' health status. The analysis is conducted at the discharge-level rather than patient-level.

Ethics

Accessing HIPE data requires a detailed application to be made by researchers to the Healthcare Pricing Office (HPO), which is under the auspices of the Health Service Executive in Ireland. The HPO will only supply data if they deem that the request conforms with their obligations of confidentiality under the Data Protection Acts 1988 to 2018 and the General Data Protection Regulation. The application process is comprehensive and is similar in form and structure to a conventional ethics application, with questions on the use of the data, aggregation, disclosure, risk, safety, and dissemination. All applicants, including the authors of this paper, have to demonstrate that their use of data will not be disclosive or harmful to individual patients before an application is successful.

Diagnosis and dependent variables

The dependent variables in the analysis were LOS for patients with (i) a principal or (ii) a secondary diagnosis of dementia, measured in days for each inpatient episode of care. For all inpatient discharges, HIPE records information on up to 30 diagnosis codes (one principal and up to 29 additional diagnosis codes) using the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification (ICD-10-AM) coding system (National Centre for Classification in Health, 2000). HIPE only records hospital stay, so the principal diagnosis is the hospital-acquired diagnosis (Healthcare Pricing Office, 2021).

It is the responsibility of the hospital clinician to record and provide accurate principal diagnosis and procedures. However, if the clinical information is deemed inadequate, the hospital coder responsible for transferring the information to HIPE is required to get clarification from the clinician before assigning the diagnosis code primarily responsible for causing the episode of admission to hospital. Secondary diagnosis refers to conditions or complaints, either coexisting with the principal diagnosis or arising during the episode of admitted patient care. These are interpreted in HIPE reporting as conditions that affect patient management. Patients with a secondary diagnosis represent the most common scenario of patients with dementia hospitalized for organic issues, for example, congestive heart failure, while the group with a principal diagnosis of dementia are, more than likely, patients hospitalized because of agitation and other behavioural and psychological symptoms of dementia (we cannot tell precisely from the data available). Thus, these groups may describe very different patients, but for this study, the focus is on LOS and associated costs only.

Patients with a principal or secondary diagnosis of dementia were identified using the ICD-10-AM codes F00 (dementia in Alzheimer’s disease), F01 (vascular dementia), F02 (dementia in other diseases classified elsewhere), F03 (unspecified dementia), G300 (dementia in Alzheimer’s disease with early-onset), G301 (dementia in Alzheimer’s disease with late-onset), G308 (dementia in Alzheimer's disease, atypical or mixed type) and G309 (dementia in Alzheimer's disease, unspecified). Those without such diagnoses were categorised as non-dementia patients.

Three comparisons were undertaken in the paper. The first comparison was between patients with a principal diagnosis of dementia and those without a principal or secondary diagnosis of dementia (Comparison 1). After observations with incomplete information on the variables of interest were excluded, there were 803 (0.45%) inpatient discharges with a principal diagnosis of dementia and 177,491 (99.55%) inpatient discharges without a principal diagnosis of dementia. Comparison 2 focused on patients with a secondary diagnosis of dementia and those without a secondary diagnosis of dementia across all discharges, excluding the group with a principal diagnosis of dementia. Before matching, there were 9,859 (5.23%) patients with a secondary diagnosis of dementia and 178,704 (94.77%) patients without a secondary diagnosis of dementia. Discharges were also analysed separately for a number of principal diagnosis disease categories to examine heterogeneity in the impact of a secondary diagnosis of dementia on LOS and related care costs (Comparison 3). In order to examine the subgroups of diagnoses, total discharges for the year 2019 were grouped into a number of principal diagnosis categories using the first letter and first two digits from each ICD-10-AM diagnosis code (Healthcare Pricing Office, 2020) (See B.1 in Appendix B for further details).

Independent variables

In this study, a range of potential influences on LOS were controlled for, including gender, age group (65-74, 75-84, >85), marital status (married or not), admission source (admitted from home, admitted from long-stay accommodation, transferred from other source), consultant specialty (geriatric or other), whether the admission was emergency or elective, and whether or not time was spent in an intensive care environment during the hospital admission. As there are no explicit measures of socioeconomic status within the HIPE data set, medical card status was used as a proxy for socioeconomic deprivation, on the basis that medical card holders in Ireland are more likely to come from lower income households (Walsh et al., 2019). The variable discharge status (whether treatment was carried out by a consultant on a private or public basis) was also used to act as a proxy for whether or not a patient is covered by private health insurance (Keegan & Smith, 2013; Walsh et al., 2019). Using ICD-10-AM codes on additional diagnoses provided by HIPE, it was possible to use the Elixhauser Comorbidity Index (excluding dementia) to generate comorbid conditions (Quan et al., 2005). This index is commonly used to predict in-hospital mortality, hospital resource utilisation, LOS, and adverse events (Chang et al., 2016; Elixhauser et al., 1998; Menendez et al., 2014).

It was not feasible to control for all comorbid conditions generated by the Elixhauser Comorbidity Index due to the small number of observations present in some of the comorbidities, which creates potential problems of identifiability. Therefore, the focus is on the comorbid conditions with a sufficient sample size (N > 5). For Comparison 1 (principal diagnosis) and Comparisons 2 and 3 (secondary diagnosis; and subgroups of diagnoses), the comorbid conditions controlled for are outlined in Table 5.1. For all Comparisons (1, 2, and 3), the Elixhauser non-weighted comorbidity score was included; this is a simple sum of the number of Elixhauser comorbidities recorded for each observation in the data set, i.e., it is a comorbidity count (Elixhauser et al., 1998; Quan et al., 2005). While the weighted version of the Elixhauser comorbidity score assigns risk weights to each comorbidity (Sharma et al., 2021), the use of such weighting systems are generally based on a specific region (predominantly the US), health system, and patient group, raising concerns about generalizability to the Irish context, where there have been no comorbidity weighting adjustments specifically designed for use on a national data set such as HIPE. The study results are unlikely to be sensitive to the use of the non-weighted comorbidity score since matching incorporates a number of individual comorbidities, thereby achieving good balance. Furthermore, the use of individual comorbidities tends to have better predictive discriminative ability (Goltz et al., 2019).

Table 5.1: List of comorbid conditions included as independent variables in Comparisons 1, 2 and 3

Comparison 1 (principal diagnosis)	**Comparisons 2 and 3 (secondary diagnosis; and subgroups of diagnoses)**
Congestive heart failure	Congestive heart failure
Cardiac arrhythmias	Cardiac arrhythmias
Peripheral vascular disorders	Valvular disease
Hypertension, uncomplicated	Hypertension, uncomplicated
Other neurological disorders	Paralysis
Chronic pulmonary disease	Other neurological disorders
Diabetes, uncomplicated	Chronic pulmonary disease
Diabetes, complicated	Diabetes, uncomplicated
Hypothyroidism	Diabetes, complicated
Renal failure	Renal failure
Solid tumour without metastasis	Metastatic cancer
Weight loss	Solid tumour without metastasis
Fluid and electrolyte disorders	Weight loss
Psychoses	Fluid and electrolyte disorders
Depression	Deficiency anaemia
	Alcohol abuse

5.3.2 Methods

When comparing LOS between dementia and non-dementia groups, it should be recognised that the composition of the two groups may differ, leading to potential biases (Zhao & Percival, 2017). Therefore, it is important to account for potential confounders to the extent possible when making such comparisons. A feature of the data in this paper is that it offers a much larger number of potential controls (non-dementia) than treated units (dementia). It is possible, therefore, to identify patients among the control group that are similar to those in the treated group, *ceteris paribus*. Matching patients allows for a more robust comparison between the groups, allowing for greater balance in the distribution of covariates across the treated and control groups (Macchioni Giaquinto et al., 2021). As a result, model dependence is reduced, and subsequent parametric regression modelling is less dependent on restrictive assumptions about the model specification and is more likely to identify causal effects (Jones et al., 2020).

Although there are many available matching approaches, such as propensity score matching or nearest neighbour matching (Rosenbaum & Rubin, 1983; Rubin, 1973), coarsened exact matching (CEM) (Blackwell et al., 2009) was used to match on the covariates described above. This approach aims to locate exact matches by sorting the data into strata (Jones et al., 2020), whereby an observation in strata *i* of the treatment group is matched to at least one observation in strata *i* from the control group, which has an identical value. All unmatched observations within any stratum are then discarded from the analysis (Blackwell et al., 2009). Importantly, CEM has a monotonic imbalance bounding property, meaning that the balance of each covariate can be adjusted without having any effect on the others (Blackwell et al., 2009; Macchioni Giaquinto et al., 2021). Furthermore, balance is achieved in the full joint distribution of the confounding variables, which includes interactions and non-linearities (Jones et al., 2020). This approach removes extreme observations and restricts the matched data to common areas of empirical support (Blackwell et al., 2009). In the context of the study, this could imply that more complex/high burden dementia patients would be excluded from the study if individuals with similar covariates in the broader population of admissions are not available.

Since the dependent variable LOS (count) is positively skewed and strictly positive, a Generalized Linear Model (GLM) was chosen to analyse predictors of LOS (Deb et al., 2014). The model estimates the mean of y, conditional on covariate (X), which is defined as:

$$g\{E(y_j)\} = X_j\beta, y_j \sim F$$

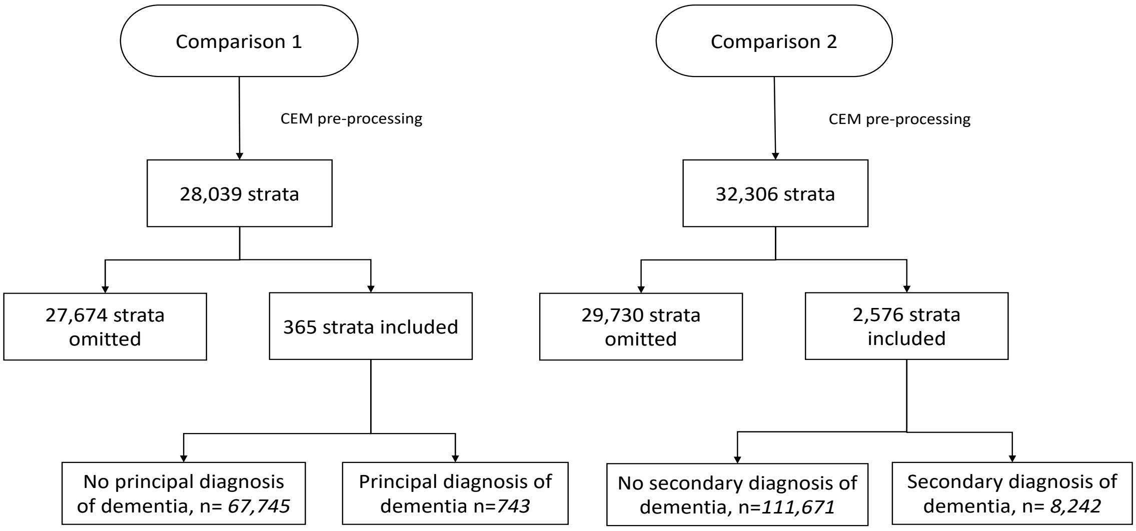
The link function (g) characterises how the linear index is related to the conditional mean. The family, F, specifies a distribution from the exponential family that reflects the mean-variance relationship of the data (Deb et al., 2014; StataCorp, 2021). The key covariate of interest was an indicator for whether the unit was in the treatment or control group, furthermore the set of independent variables described above were controlled for, in addition to using CEM.

For each of the models, the Modified Park Test was used to identify the most suitable family (Deb et al., 2017). The appropriate link was chosen using a combination of three tests, namely, the Pregibon Link Test, the Modified Hosmer Lemeshow Test, and Pearson's Correlation (Deb et al., 2017). For Comparison 1, the preferred GLM model used a gamma distribution with a power 0.5 link function. For Comparisons 2 and 3, the tests identified the power 0.2 link as the most appropriate. To estimate LOS for each comparison, a GLM was used on the pre-processed data using the weights obtained as an output from CEM (Jones et al., 2020). Average treatment effects on the treated (ATTs) were then obtained as the average marginal effect (AME) of the treatment variable included in the GLM model, estimated using the matched sample, although these should not be interpreted as causal effects. Instead, they can be viewed as differences between the groups that are not explained by differences in the groups' covariates. Finally, a generic unit cost for Ireland, representing the average cost across all nights in all Irish hospitals and in all types of inpatient cases, of €938 (Hospital In-Patient Enquiry, 2019) was used to calculate the costs attributable to LOS for patients with dementia. The analyses were performed using Stata 16 (StataCorp, 2019).

5.4 Results

In Comparison 1, pre-processing through CEM resulted in the stratification of the sample into 28,039 strata. For 365 of these strata, there were 743 (1.08%) patients with a principal diagnosis of dementia (treatment group) and 67,745 (98.92%) with no principal diagnosis of dementia (control group). The remaining 27,674 strata were omitted from the analysis since they had characteristics that differed from those of the treatment group (Figure 5.1).

Figure 5.1: Sample stratification after coarsened exact matching



In Comparison 2, CEM led to a stratification of the sample into 32,306 strata. For 2,576 of these strata, there were 8,242 (6.87%) patients with a secondary diagnosis of dementia (treatment group) and 111,671 (93.13%) patients with no secondary diagnosis of dementia (control group). The remaining 29,730 strata were omitted from further analysis (Figure 5.1).

Tables B.2 and B.3, in Appendix B, show the means of each group for each comparison before and after CEM. Reassuringly, equality of the sample means for all covariates is evident between the treated and control groups, suggesting that comparisons between groups should not be affected by any observed confounding post-CEM. Comparing the means before and after matching (Tables B.2 and B.3 in Appendix B) indicates that the retained pool of treated units tends to have better health than the full treated pool (e.g., having lower Elixhauser scores).

Table 5.2 presents key descriptive statistics for each group in Comparisons 1 and 2 after CEM[4], using medians and interquartile range (IQR) for continuous variables and (%) for categorical variables. The median LOS for patients with a principal diagnosis of dementia was 20 (IQR: 5 to 40) days, while patients with no principal diagnosis of dementia had a median LOS of 5 (IQR: 2 to 10) days. For patients with a secondary diagnosis of dementia, the median LOS was 8 (IQR: 4 to 19) days compared to 2 (IQR: 6 to11) days for patients with no secondary diagnosis of dementia. In each group, over half of the discharged patients were female, with the largest proportion of inpatient discharges aged between 75-84 years. Across all groups, between 42% and 44% were married. With regard to the proxy variables for socioeconomic status, over 80% of patients were in receipt of a medical card (free public care, including general practitioner visits), while approximately 90% of patients were treated by a consultant on a public basis.

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[4] Table B.1, in Appendix B, presents key descriptive statistics for each group in Comparisons 1 and 2 before CEM.

Table 5.2: Descriptive statistics for inpatient discharges with and without a principal or secondary diagnosis of dementia

Variable	Principal diagnosis of dementia (n=743)	No principal diagnosis of dementia (n=67,745)	Secondary diagnosis of dementia (n=8,242)	No secondary diagnosis of dementia (n=111,671)
Length of stay in hospital, median (interquartile range)	20 (5, 40)	5 (2,10)	8 (4, 19)	2 (6,11)
Gender, n (%)				
Male	337 (45.36)	30,727 (45.36)	3,534 (42.88)	47,882 (42.88)
Female	406 (54.64)	37,018 (54.64)	4,708 (57.12)	63,789 (57.12)
Age 65-74, n (%)				
Yes	120 (16.15)	10,941 (16.15)	981 (11.90)	13,292 (11.90)
No	623 (83.85)	56,804 (83.85)	7,261 (88.10)	98,379 (88.10)
Age 75-84, n (%)				
Yes	393 (52.89)	35,833 (52.89)	3,755 (45.56)	50,877 (45.56)
No	350 (47.11)	31,912 (47.11)	4,487 (54.44)	60,794 (54.44)
Age 85+, n (%)				
Yes	230 (30.96)	20,971 (30.96)	3,506 (42.54)	47,503 (42.54)
No	513 (69.04)	46,774 (69.04)	4,736 (57.46)	64,168 (57.46)
Married, n (%)				
Yes	327 (44.01)	29,815 (44.01)	3,471 (42.11)	47,029 (42.11)
No	416 (55.99)	37,930 (55.99)	4,771 (57.89)	64,642 (57.89)
Medical card holder, n (%)				
Yes	634 (85.33)	57,807 (85.33)	6,951 (84.34)	94,179 (84.34)
No	109 (14.67)	9,938 (14.67)	1,291 (15.66)	17,492 (15.66)
Public patient status, n (%)				
Yes	689 (92.73)	62,821 (92.73)	7,452 (90.41)	100,967 (90.41)
No	54 (7.27)	4,924 (7.27)	790 (9.59)	10,704 (9.59)

In Comparison 1, LOS between patients with a principal diagnosis of dementia and patients with no principal, or any other, diagnosis of dementia was examined (Table 5.3). The estimated AME for dementia suggests that patients with a principal diagnosis of dementia spent on average 17.6 (95% CI: 14.99 to 20.28; p<0.001) days longer in hospital than similar patients without any diagnosis of dementia. This finding reduced marginally after the model was adjusted to control for a range of covariates (AME: 17.5, 95% CI: 15.42 to 19.56; p<0.001). Age, being treated by a consultant geriatrician, and time spent in intensive care had significantly positive marginal effects on LOS. A number of comorbidities also had significant positive marginal effects on LOS. The AMEs for the individual comorbidities is the additional effect of that condition, above the effect one would see for a person with the same score without the condition. So, for example, a person with congestive heart failure would have a LOS of 7.7 days longer, all other things equal to a person without this condition. The AME of the

Elixhauser score is the effect of a one unit increase in the Elixhauser score on LOS, holding all other variables constant, including the comorbid conditions.

Table 5.3: Average additional length of stay (days) for inpatient discharges with a principal diagnosis of dementia (Comparison 1)[5]

	Unadjusted model		**Adjusted model**	
Variable	**Average marginal effect (95% CIs)**	**P-value**	**Average marginal effect (95% CIs)**	**P-value**
Principal Dementia	17.64 (14.99, 20.28)	<0.001***	17.49 (15.42, 19.56)	<0.001***
Male			0.42 (0.20, 0.64)	<0.001***
Age 75-84			0.99 (0.72, 1.27)	<0.001***
Age 85+			3.31 (2.95, 3.66)	<0.001***
Married			-1.28 (-1.50, -1.06)	<0.001***
Medical card holder			1.12 (0.84, 1.39)	<0.001***
Admission source: home			-3.51 (-4.45, -2.57)	<0.001***
Admission source: long-stay accommodation			-2.77 (-3.55, -2.00)	<0.001***
Public patient status			-1.51 (-1.96, -1.05)	<0.001***
Emergency admission to hospital			-5.51 (-6.65, -4.37)	<0.001***
Treated by consultant geriatrician (1=Yes, 0=No)			3.38 (3.08, 3.69)	<0.001***
Time spent in intensive care environment (1=Yes, 0=No)			4.28 (2.44, 6.12)	<0.001***
Elixhauser comorbidities				
Congestive heart failure			7.71 (3.70, 11.72)	<0.001***
Cardiac arrhythmias			7.63 (4.11, 11.15)	<0.001***
Peripheral vascular disorders			17.11 (11.23, 22.98)	<0.001***
Hypertension, uncomplicated			13.24 (8.97, 17.51)	<0.001***
Other neurological disorders			18.50 (13.85, 23.14)	<0.001***
Chronic pulmonary disease			6.41 (2.81, 10.00)	<0.001***
Diabetes, uncomplicated			4.54 (1.40, 7.69)	<0.001***
Diabetes, complicated			5.42 (2.06, 8.79)	<0.001***
Hypothyroidism			6.34 (2.62, 10.06)	<0.001***
Renal failure			6.66 (3.13, 10.19)	<0.001***
Solid tumour without metastasis			13.75 (9.09, 18.42)	<0.001***
Weight loss			7.40 (3.66, 11.15)	<0.001***
Fluid and electrolyte disorder			10.11 (6.29, 13.92)	<0.001***
Psychoses			9.29 (4.97, 13.61)	<0.001***
Depression			18.95 (13.48, 24.41)	<0.001***
Other comorbidities			12.05 (7.75, 16.34)	<0.001***
Elixhauser comorbidity score			-4.62 (-7.27, -1.96)	<0.001***

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[5] The base category for admission source is transferred from other source. The base category for age is 65-74 years. The base category for Elixhauser comorbidities is those patients with no comorbidities. ***Denotes significant at 1% level; **Denotes significant at 5% level.

Table 5.4: Average additional length of stay (days) for inpatient discharges with a secondary diagnosis of dementia (Comparison 2)[5]

Variable	Average marginal effect (95% CIs)	P-value	Average marginal effect (95% CIs)	P-value
Secondary Dementia	6.73 (6.28, 7.18)	<0.001***	6.73 (6.31, 7.14)	<0.001***
Male			-0.08 (-0.27, 0.11)	0.41
Age 75-84			1.15 (0.85, 1.44)	<0.001***
Age 85+			2.94 (2.62, 3.25)	<0.001***
Married			-0.63 (-0.82, -0.44)	<0.001***
Medical card holder			0.50 (0.25, 0.75)	<0.001***
Admission source: home			-5.24 (-5.95, -4.52)	<0.001***
Admission source: long-stay accommodation			-5.18 (-5.66, -4.71)	<0.001***
Public patient status			-0.66 (-1.00, -0.32)	<0.001***
Emergency admission to hospital			-4.89 (-5.77, -4.01)	<0.001***
Treated by consultant geriatrician (1=Yes, 0=No)			4.59 (4.25, 4.93)	<0.001***
Time spent in intensive care environment (1=Yes, 0=No)			7.40 (6.34, 8.46)	<0.001***
Elixhauser comorbidities				
Congestive heart failure			-1.55 (-4.51, 1.41)	0.31
Cardiac arrhythmias			-2.80 (-5.63, 0.01)	0.05**
Valvular disease			-4.61 (-6.80, -2.42)	<0.001***
Hypertension, uncomplicated			-3.82 (-6.32, -1.32)	<0.001***
Paralysis			-1.21 (-4.28, 1.85)	0.44
Other neurological disorders			0.65 (-2.77, 4.07)	0.71
Chronic pulmonary disease			-2.92 (-5.54, -0.29)	0.03**
Diabetes, uncomplicated			-5.31 (-7.52, -3.11)	<0.001***
Diabetes, complicated			-3.00 (-5.68, -0.33)	0.03**
Renal failure			-4.18 (-6.61, -1.75)	<0.001***
Metastatic cancer			-2.99 (-5.62, -0.35)	0.03**
Solid tumour without metastasis			-1.98 (-4.84, 0.86)	0.17
Weight loss			-1.85 (-4.76, 1.06)	0.21
Fluid and electrolyte disorders			-2.10 (-5.06, 0.86)	0.17
Deficiency anaemia			-1.55 (-4.51, 1.40)	0.30
Alcohol abuse			-2.22 (-5.08, 0.62)	0.13
Other comorbidities			-0.56 (-3.81, 2.67)	0.73
Elixhauser comorbidity score			5.71 (2.44, 8.99)	<0.001***

Comparison 2 examines LOS for patients with a secondary diagnosis of dementia compared to patients with no secondary diagnosis of dementia (Table 5.4). The results of this model indicate that patients with a secondary diagnosis of dementia spent on average 6.7 (95% CI: 6.28 to

7.18; p<0.001) days longer in hospital than similar patients with no secondary diagnosis of dementia. The difference in LOS (AME: 6.7, 95% CI: 6.31 to 7.14; p<0.001) remained unchanged when other factors were taken into account. The covariates should again be interpreted with caution as they represent associations, but time spent in an intensive care environment had a significant positive marginal effect on LOS of 7.4 days, perhaps reflecting differences in severity of the patients. In interpreting AMEs for a particular comorbidity profile, both the AME for the comorbidities of interest and the AME for the Elixhasuer score corresponding to that profile should be considered. For instance, for a patient with one comorbidity, the impact on LOS would be the AME on the Elixhauser score plus the AME on that comorbidity; thus, for those with fluid and electrolyte disorders, the LOS is 3.6 days longer than patients with no fluid and electrolyte disorders.

Comparison 3 analysed subgroups of fifteen principal diagnosis disease categories to examine the impact of a secondary diagnosis of dementia on LOS. Based on the AMEs from the adjusted models presented in Table 5.5, a secondary diagnosis of dementia increased LOS for all principal diagnosis disease categories (all statistically significant at 1%). The effect of a secondary diagnosis of dementia varied from 1.6 (95% CI: 0.49 to 2.75; p<0.001) days for patients with ‘diseases of the digestive system’ to 24.7 (95% CI: 17.36 to 31.99; p<0.001) days for patients with ‘factors influencing health status and contact with health services.’ In regard to the latter, the highest volume of cases is in the dialysis, chemotherapy, and radiotherapy categories. The results also show that patients with a principal diagnosis of ‘mental and behavioural disorders’ and a secondary diagnosis of dementia spent on average 15.8 (95% CI: 7.61 to 23.97; p<0.001) days longer in hospital than similar individuals without a secondary diagnosis of dementia.

Table 5.5: Category description, length of stay median, and average additional length of stay (days), for selected inpatient discharges with and without a secondary diagnosis of dementia (Comparison 3)[6]

Category description	Secondary dementia, (n) – before matching	Secondary dementia, (n) – after matching	LOS, median (interquartile range)	No secondary diagnosis of dementia, (n) - before matching	No secondary diagnosis of dementia, (n) – after matching	LOS, median (interquartile range)	Average marginal effect (95% CIs)	P-value
Certain infectious and parasitic diseases | A00–B99	330	178	7 (4,15)	4,767	1,118	6 (3,11)	3.14 (1.56, 4.72)	<0.001***
Neoplasms | C00–D48	274	148	10.5 (4.5, 23.5)	15,458	2,275	7 (3,14)	9.16 (6.35, 11.96)	<0.001***
Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism| D50–D89	64	33	8 (3,13)	1,966	289	2 (1,9)	6.60 (3.51, 9.69)	<0.001***
Endocrine, nutritional and metabolic diseases | E00–E89	291	158	8 (4,16)	4,106	1,011	4 (2,10)	6.42 (4.41, 8.43)	<0.001***
Mental and behavioural disorders | F00–F99	168	71	14 (7,35)	1,424	346	7 (2,27)	15.79 (7.61, 23.97)	<0.001***
Diseases of nervous system | G00–G99	421	281	9 (4,26)	4,274	1,568	4 (1,9)	11.39 (8.74, 14.04)	<0.001***
Diseases of the circulatory system | I00–I99	1,013	607	8 (3,19)	29,906	8,478	5 (2,11)	6.65 (5.38, 7.91)	<0.001***
Diseases of the respiratory system | J00–J99	2,342	1,723	7 (4,14)	31,416	15,585	3 (6,10)	4.61 (3.96, 5.27)	<0.001***
Diseases of the digestive system | K00–K93	557	372	6 (3, 12.5)	13,166	4,831	5 (2,10)	1.62 (0.49, 2.75)	<0.001***
Diseases of the skin and subcutaneous tissue | L00–L99	123	78	7.5 (3, 17)	3,188	667	7 (3, 12)	8.66 (5.32, 12.01)	<0.001***
Diseases of the musculoskeletal system and connective tissue | M00–M99	198	124	9 (4, 28.5)	8,438	1,928	4 (1, 11)	13.69 (9.97, 17.42)	<0.001***
Diseases of the genitourinary system | N00–N99	1,288	849	8 (4, 19)	12,626	5,340	6 (3, 10)	6.67 (5.45, 7.90)	<0.001***
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified | R00–R99	1,123	877	5 (2, 13)	22,500	13,097	2 (0, 6)	6.25 (5.20, 7.30)	<0.001***
Injury, poisoning and certain other consequences of external causes | S00–T98	1,373	1,034	10 (4, 23)	18,258	10,011	6 (2, 14)	6.83 (5.64, 8.03)	<0.001***
Factors influencing health status and contact with health services | U00–U49, Z00–Z99	272	173	25 (9, 54)	5,378	1,108	14 (5,35)	24.68 (17.36, 31.99)	<0.001***

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[6] ***Denotes significant at 1% level.

Hospital care costs

Applying a generic unit cost of €938 to an inpatient day suggests that the estimated cost associated with extended LOS for patients with a principal diagnosis of dementia was, on average, €16,415 more than similarly matched patients without a diagnosis of dementia in 2019. The results also indicate that patients with a secondary diagnosis of dementia had an average excess cost of €6,285 compared to similarly matched patients with no secondary diagnosis of dementia. If excluded dementia patients are assumed to be equally as costly as those dementia patients retained after matching, the additional annual total cost of those presenting with a principal diagnosis of dementia in acute hospitals in 2019 was estimated to be €13.2 million. The additional annual total cost of those presenting with a secondary diagnosis of dementia in acute hospitals was estimated to be €62.0 million. The findings from the subgroup analyses suggest that the additional average cost associated with having a secondary diagnosis of dementia varied from €1,501 for patients with 'diseases of the digestive system' to €23,169 for patients with 'factors influencing health status and contact with health services.' The annual additional total cost for these two categories were, therefore, €0.8 million and €6.3 million, respectively.

Sensitivity analysis

Uncertainty associated with the vagaries of the health and social care system in relation to balance of care decision-making was explored by including discharge destination as an additional predictor variable. In Comparison 1, LOS for patients with a principal diagnosis of dementia decreased by 3.9 (AME: 13.6, 95% CI: 11.65 to 15.51; p<0.001) days on average (Table B.4 in Appendix B) when compared to the main analysis. Similarly, LOS reduced by an average of 1.9 (AME: 4.8; 95% CI: 4.41 to 5.28; p<0.001) days for Comparison 2 (Table B.5 in Appendix B). Assuming the excluded dementia patients have the same additional LOS as those dementia patients retained after matching, the additional annual cost of care for patients in hospitals with a secondary diagnosis of dementia decreased to €44.4 million and €10.2 million for those with a principal diagnosis.

5.5 Discussion

The findings from this study are consistent with previous research, which has found that people with a diagnosis of dementia experience significantly longer LOS (King et al., 2006; Möllers et al., 2019; Tropea et al., 2017) and higher care costs while in the hospital setting (Briggs et al., 2016; Connolly & O'Shea, 2015; Jensen et al., 2019). Patients with a principal diagnosis of dementia spent on average 17.5 (95% CI: 15.42 to 19.56; p<0.001) days longer in hospital than similar patients with no principal diagnosis of dementia. LOS was 6.7 days longer (95% CI: 6.31 to 7.14; p<0.001) for patients with a secondary diagnosis of dementia compared to similar patients with no secondary diagnosis of dementia. The additional annual cost of care for patients in hospitals with a secondary diagnosis of dementia was €62.0 million and €13.2 million for those with a principal diagnosis. Given that Ireland has one of the fastest rates of ageing population in Europe (Kane et al., 2015; O'Shea et al., 2017), the costs identified in this paper will grow rapidly and persistently over the coming decade.

These findings have implications for the process of care within the hospital setting, especially the importance of identifying and addressing cognitive impairment across all patients in hospitals, given the importance of dementia as a secondary diagnosis (Turner et al., 2017). The HIPE data does not, however, facilitate forensic examination of processes in acute care settings, leaving some questions unanswered. For example, one curiosity was that emergency admission to hospital had a significant negative marginal effect on LOS relative to those who had an elective admission. The proportions being transferred out of hospital to other hospitals, home and residential care from the emergency and elective admissions group were checked, but nothing notable emerged. However, emergency admissions tend to have more comorbidities requiring more intensive resource use that may lead to these patients being discharged from hospital quicker due to more concentrated care relative to those with elective admission. Some emergency admissions with comorbidities may also only require short-term observation before being discharged again relatively quickly. More generally, much more information is needed on the relationships between dementia, comorbidities, and LOS in acute care, including a deeper understanding of clinical and *a priori* theoretical associations, incorporating care pathways, and balance of care decision-making.

There is evidence that inadequate staff training and an absence of dementia specific knowledge within acute care settings may contribute to extended LOS for patients with dementia (Bracken-Scally et al., 2020; George et al., 2013; Jensen et al., 2019). Jurgens et al. (2012) found that carers of people with dementia attributed changes in the condition of their loved one, particularly deterioration, to the quality of hospital care received, and, more specifically, linked poor outcomes to staff education and training in relation to dementia. Ultimately, the needs of people with dementia are complex, requiring an increased level of awareness and better response from hospital staff to heterogeneity amongst a patient group who may not be able to fully communicate their needs (Røsvik & Rokstad, 2020). For example, people with dementia find it more difficult to maintain nutrition and hydration while in the hospital setting (Fogg et al., 2018), while it is also common for people with dementia to experience difficulties while eating or swallowing. Relatively straightforward improvements in communication could help to alleviate some of these problems, for example, better knowledge sharing at handovers among staff working on different shifts (Jensen et al., 2019). The creation of a more homelike psychosocial environment around the person with dementia might also enhance the personhood dimension of care within an acute setting and contribute to a reduction in LOS (Grey et al., 2018; Hung et al., 2017; Pinkert et al., 2018; Prato et al., 2019).

Expertise in dementia care within the acute care setting also matters, particularly for those in medical and nursing leadership roles. The 2006 'A Vision for Change' mental health policy framework for Ireland recommended that '*everybody aged 65 years and over with primary mental health disorders or with secondary behavioural and affective problems arising from dementia, should be cared for by a mental health services for older people team*' (Expert Group on Mental Health Policy, 2006). Unfortunately, that recommendation has not yet been implemented, and expertise on dementia is not as strong as it should be in the acute hospital sector. A National Audit of Dementia Care in Irish Acute Hospitals published in 2014 highlighted significant gaps in service provision for older people with mental health issues in acute care (De Siún et al., 2014). Shortcomings included inadequate representation of old age psychogeriatric expertise on multidisciplinary teams, as well as an absence of specialised dementia assessment and treatment in many acute care settings in the country.

Finally, it is impossible to reflect on dementia in acute care without considering wider balance of care issues (Carter et al., 2019; Carter et al., 2020). In response to an acknowledged weakness of community-based care for older people (Walsh & Lyons, 2021), the Irish government has committed to a significant expansion of home care services and supports in the coming decade (Department of Health 2018; Department of Health, 2019; Houses of the Oireachtas Committee on the Future of Healthcare, 2017). There is good evidence that personalised community-based services can reduce hospital admission for people with dementia (Cahill et al., 2012). Additional funding for the provision of intensive home care packages has also been shown to support people with very high levels of need who might otherwise be unable to live at home; especially people recently discharged from acute care settings (Keogh et al., 2018a; Timmons et al., 2016).

Caregiver burden and the associated stress have been identified as predictors of prolonged LOS in acute hospitals (Lang et al., 2010; Toh et al., 2017). In addition, admission to acute care may lead to a major change in the relationship between the carer and person with dementia in a way that directly impacts on discharge. Sometimes, people with dementia remain in the acute care setting for longer than necessary in order to alleviate some of the stress for overburdened caregivers (Hickey et al., 1997), or, in the extreme, carers sometimes use admission as an opportunity to stop caring entirely. Therefore, ongoing support for carers may impact positively on LOS for people with dementia in acute care settings by relieving burden and allowing home-based caring to recommence on discharge (Teahan et al., 2021).

Strengths and limitations

This is the first study in Ireland to robustly account for observed differences in patients when assessing inpatient LOS and related care costs for patients with dementia in Irish acute hospitals. A major strength of this study is the relatively large number of observations in the control group, thereby allowing us to perform CEM on a richer set of covariates than previously explored, making it more likely that comparisons between groups are not affected by observed confounding. The inclusion of people with a comprehensive secondary diagnosis of dementia allows differential analyses on the impact of dementia on the cost of care across a wide range of conditions.

There are, however, limitations to the present study. First, in the HIPE instruction booklet (Healthcare Pricing Office, 2021), the definition for those with a principal diagnosis is as follows: *'the diagnosis established after study to be chiefly responsible for occasioning the episode of admitted patient care.'* However, it should be acknowledged that several factors related to hospitalization and clinical status, for example, delirium, may cause potentially transient cognitive impairment in acute hospitals. Ideally, the person should be examined after several weeks in an appropriate setting to determine if a diagnosis of dementia is warranted.

Undiagnosed dementia remains an issue in both the community and acute care settings (Briggs et al., 2016; Connolly & O'Shea 2015; Jensen et al., 2019). Moreover, researchers have been critical in the past of incomplete coding on HIPE's part in relation to capturing people with dementia (Curley, 2003, as cited in Health Service Executive, 2019b). As a result, it is likely that a number of undiagnosed patients with dementia have been placed into the control group; therefore, estimates are likely to be lower bounds and under-represent the true impact of LOS and related care costs in Irish acute hospitals.

The total annual cost estimates produced in this study assume that excluded dementia patients had the same additional LOS and thus were equally as costly as those dementia patients retained after matching. Since comparable control units with which to compare dementia patients excluded from the analysis are not available, it is impossible to be confident how many (if any) additional days these admissions would have generated relative to a person with dementia included in the analysis. Therefore, it is possible that costs are overestimated. Equally, however, the excluded group of dementia patients may be the more difficult cases, leading to an underestimation of the total annual cost of hospital care for people with dementia in Ireland.

It is important to remember that the purpose of covariates was to act as controls, and one should be cautious in over-interpreting their AMEs as causal effects. Moreover, despite controlling for a rich set of covariates in this study, the results may be subject to the influence of unobserved confounding as information was not available on important variables such as physical dependency, cognitive functioning, disease severity, caregiver burden, and private care provision. Therefore, the estimated differences between groups cannot be causally attributed to the dementia diagnosis.

5.6 Conclusion

This paper highlights an additional cost of care of €13.2 million for people with a principal diagnosis of dementia in acute hospitals in Ireland. Extended LOS, associated with a secondary diagnosis of dementia, also places significant additional costs on the health care system, estimated to be €62.0 million in 2019. Dementia has differential LOS effects across a wide range of illnesses and conditions for those with a secondary diagnosis. Dementia care in acute hospitals is undoubtedly professionally challenging, and there are many structural and environmental obstacles to ensuring a positive hospital experience for patients with the condition. At the very least, this paper highlights the need for greater attention to be paid to dementia within acute hospitals, given the impact on LOS and costs. Change is required in the form of the delivery of more person-centred care by staff trained in the nuances and complexity of dementia care. The likely benefit would be a reduction in LOS for patients with principal and secondary diagnoses of dementia in acute care settings and an associated reduction in the cost of care.

Chapter 6: Conclusion

6.1 Introduction

This chapter provides a summary of each chapter in the thesis and discusses the key findings that have arisen from the empirical work undertaken for the thesis. Section 6.2 contains a summary of the key findings in relation to the core research objectives of the thesis and the BoC framework that facilitated the work. This section also uses the findings of the three empirical chapters to suggest potential policy interventions for the care of people with dementia on the margins of care across home care, residential care, and acute care, including support for family carers. Section 6.3 reports on the value added of the work and contribution to the literature. Section 6.4 draws attention to the limitations of each study and asserts certain caveats for interpretation of the results. Section 6.5 recommends future avenues of research, taking stock of the findings and limitations of the research undertaken for the thesis. Concluding remarks are made in section 6.6. And finally, personal reflections on the work and the thesis journey are outlined in Section 6.7.

6.2 Key findings and policy implications

The purpose of this thesis was outlined in Chapter 1:

To inform resource allocation decision-making for people with dementia across the continuum of care in Ireland, especially at the intersections between home care, residential care, and acute care, using a BoC approach/framework.

Based on the broad purpose of this thesis, three specific research objectives were undertaken, which correspond to the three main studies/papers in this thesis:

- **Research objective one**: To conduct a cost analysis of HSE-Genio intensive home care packages for people with dementia living on the boundary of home care and residential care in Ireland
- **Research objective two:** To examine admission to long-stay residential care and mortality for intensive home care package recipients living at home but on the boundary of residential care in Ireland
- **Research objective three:** To explore length of stay and related costs for people with dementia in Irish acute hospitals

Using a BoC framework, as discussed in Chapter 2, this research sought to support resource allocation at local and national levels and to address identified gaps in the literature relating to costs and, where possible, consequences of placement decision-making for people with dementia on the margins of home care, residential care, and acute care in Ireland. The provision of such information is important in the Irish health care context, where resources are limited, and allocation has traditionally been biased towards the residential care setting. With regard to the upcoming new home care legislation in Ireland, which is intended to provide designated rights for home care for the first time ever, the work presented in this thesis will contribute new evidence for the development of home care services in the future.

Chapter 3 addressed the first research objective by presenting a cost analysis to determine the average weekly cost of home care for people with dementia on the boundary of care who are receiving enhanced home supports in the form of IHCPs. The costs of community care and LSRC facilities were estimated in order to compare the costs of alternative care settings for this group. This study estimated that the average weekly cost of home care, including the IHCP, standard formal community care provision, medications, consumption, and housing was €1,127. This is lower than the average weekly cost of public long-stay care facilities (€1,526) and around the same as for private nursing home fees in the Dublin region (€1,149). When the opportunity cost valuation of informal care was included, the cost of home care was higher than all types of residential care. Adding private care expenditure further inflated the cost of home care. The cost of home care is clearly significant, but citizens may see the differential to residential care costs as a price they are willing to pay through taxation to keep dependent older people living at home (O'Shea et al., 2008). Equally, however, it points to the need to ensure that expanded services and supports are given to those who need them most and can get the most benefit from them.

At present in Ireland, the parameters of the proposed new home care scheme for dependent older people are not yet fully determined. Given that IHCPs are a potential care alternative to residential care placement, it may mean a significant expansion in the number of packages provided to older people living in the community. IHCPs will also impact admission to, and discharge from, acute care facilities. Thus, from a policy viewpoint, any new investment in IHCPs must be costed and compared to other care alternatives in order to inform the resource allocation process for individuals with dementia living on the boundary of care. Importantly, this analysis facilitates the comparison between the cost of home care and alternative placement in public and private residential care alternatives. Therefore, it will be possible for policy-makers to consider the cost of IHCPs in the broader context of the continuum of care.

The first paper has shown that it is possible to increase the availability of publicly provided intensive home care supports to supplement existing formal provision in the community and still cost the government less than 60% of weekly public residential care costs. Investment in intensive supports for people with dementia is good value for money for the public sector, especially for people on the margin between home care and residential care. However, adding family care costs and private out-of-pocket expenditure means that overall spending can exceed even the most expensive residential care alternative. Therefore, from a societal perspective, keeping highly dependent people with dementia living at home is not cheap and raises questions about optimal resource allocation on the boundary of home care and residential care. Families contribute so much care, and their role has largely been under-represented in BoC studies and undervalued by the state. Comparing only public expenditure between home care and residential care provides a partial understanding of resource use at the margin between home and residential care. Similarly, ignoring out-of-pocket contributions by people with dementia and their families can serve to distort overall expenditure trends, as well as contribute to a change in the public-private mix of care by stealth, with potential consequences for access and equity.

Supporting home care provision will always raise practical questions relating to the level of support, for example, whether IHCP values should be capped? And, if so, at what level? The most common approach when supporting home care is to take the average weekly cost of nursing home care as the absolute upper limit and work downwards, thereby generating savings for the exchequer *ceteris paribus*. But this study has shown that formal community care provision does not tell the whole story, even when it is significantly expanded using IHCPs. Therefore, should packages be funded above the average cost of nursing home care, given all the additional resource use, especially informal care provision? If that were to happen, should this be considered an explicit acknowledgement of the role of informal carers, as well as an implicit public valuation of the additional benefits of home care relative to nursing home care? Another question relates to acute care and the role that expanded home care provision plays in influencing costs in hospitals. This study found that even with all public and private costs accounted for, keeping people with dementia living in their own homes is less than half of the weekly cost of care in an acute hospital. Thus, IHCPs may be important in both reducing hospital admission and/or accelerating discharge leading to significant cost savings for the Irish government.

Chapter 4 addressed the second research objective by employing a sophisticated competing risks survival analysis technique to examine factors that may affect transition towards LSRC and mortality for IHCP recipients living on the margin of care in Ireland. The findings from this study showed that admission to LSRC was higher for people with dementia relative to people without and for those receiving lower amounts of informal care. The hazard of mortality was significantly higher for older people aged 85+, whereas it was lower for individuals with a medium level of dependency relative to those with high levels of dependency. The hazard of mortality was also influenced by the amount of informal care provision, reinforcing the role that carers play in the care of dependent older people.

From a policy perspective, examining factors that affect transition towards LSRC and mortality places greater attention on the specific characteristics of people who may benefit most from home-based care. In a world where resources are finite, from a resource allocation viewpoint, such information can help to focus attention on the key factors that can prolong living at home and extend life for dependent older people who are in receipt of IHCPs in the community setting. Moreover, the consideration of factors affecting the transition towards LSRC is useful for policy-makers to examine whether delaying admission to a long-term care setting is the best approach for some individuals on the boundary of care. For example, this study showed that even with increased community care provision delivered through IHCPs, people with dementia remain more disposed to admission to LSRC than people without dementia. Therefore, providing people with dementia with more hours of formal care may not be enough to keep them out of LSRC. The form, type, structure, and intensity of those care hours may also be important (S.Walsh et al., 2020). Meeting the needs of people with dementia relative to those without dementia may be more difficult because of the absence of a person-centred approach among formal care providers (Trahan et al., 2014; S.Walsh et al., 2020). If personhood (Kitwood, 1997) is important for people with dementia, then person-centred provision becomes crucial. Getting providers to understand what person-centred care means to people with dementia is very important and not an easy task requiring significant investment in education and training.

Informal care was also found to be to a predictor for both placement decision-making and mortality among people with and without dementia, with study findings pointing to the importance of complementarity rather than substitutability between families and the state for keeping people out of residential care. Previous estimates by Family Carers Ireland suggest that in Ireland, informal carers across all sectors save the government approximately €10 billion each year (Family Carers Ireland, 2019). Therefore, should informal care be absent, or reduced by choice or through demography in the future, the state may have to invest much more to support dependent older people living at home than currently envisaged by policy-makers. A recent study by Teahan et al. (2021) examined the willingness-to-pay of Irish citizens to fund enhanced care for family caregivers of people with dementia in Ireland. The findings showed that the public is willing to contribute to additional taxation to support caregivers for people with dementia in Ireland. Citizens were found to particularly value the provision of caregiver services and supports such as: having access to regular breaks (through a mix of day care and long-break respite); the provision of monetary support (carer's allowance); and having access to carer support groups in order to strengthen social networks. Importantly, Teahan's (2021) study highlights various approaches that can be adopted to support family caregivers to continue caring for people with dementia. When it comes to resource allocation in Ireland, the authors caution that the contribution of caregivers need to be formally recognised by the government, as it is by no means certain that caregiving will continue in the coming years without significant additional public investment in caregiver supports.

Chapter 4 also showed that mortality was higher for IHCP recipients of an advanced age. This raises the issue of resource allocation at end-of-life, including the question of whether chronological age should be a factor in deciding on eligibility for IHCPs. The argument that additional resources, delivered through IHCPs, should be rationed for people aged 85+ may be attractive to policy-makers, on the basis that any additional investment might be better allocated to people in younger age categories who have better chances of survival, but there are other issues to consider. In the first instance, it is not methodologically sound to argue on the basis of one cross-sectional study that age should, or indeed should not, be used to ration scarce community-based resources. Moreover, we are only beginning to understand the importance of dementia in relation to death and dying in Ireland (Matthews et al., 2021). Nearly all deaths caused by dementia in Ireland were among older age groups, and the proportion of deaths in each age category increased with age. It may be that what this cohort need is better palliative care rather than conventional community-based care. This may simply require a change in focus in the type of care provided, from social care to end-of-life care. The European Union has declared it a priority to reform health and social care systems so that people have access to appropriate care, psychological and spiritual supports when dying (Matthews et al., 2021).

Importantly, Chapter 4 shows that physical dependency was also found to matter for mortality, suggesting a role for ongoing reablement and mobility monitoring for dependent older people across all stages of the continuum of care. Keeping older people mobile and agile for as long as possible conveys huge benefits, particularly on the boundary of care between home and LSRC (McNally et al., 2017). Previous research has shown that strength and balance training has been found to lower the risk of falls (National Institute for Health and Care Excellence, 2013). Enhancing the physical abilities of older people through exercise can help people to live more independently and autonomously (World Health Organization, 2015). The National Guidelines on Physical Activity for Ireland recommend that people aged 65 years and older should undertake 150 minutes of moderate intensity activity per week, with a focus on achieving aerobic activity, muscle strengthening, and balance (Department of Health and Children & Health Service Executive, 2009). This advice is supported by studies that have shown that such an amount of exercise can reduce mortality, morbidity, or functional dependence for older people compared to those who are physically inactive (Chou et al., 2014; Paterson and Warburton, 2010). It is important that people with dementia are included in any national programmes on physical exercise for older people.

Unfortunately, formal movement and exercise programmes are scarce in Ireland, especially for people with dementia, reflecting a disablement approach to ageing that impacts negatively on dependent older people living in all care settings (Kelly et al., 2017). McNally and colleagues (2017) suggest that HSCPs need to play a greater role in encouraging activity for older people through the provision of exercise prescriptions, making adaptations to home environments, facilitating group-based activities, and encouraging older people to share exercise goals with family or friends, etc. In Ireland, targeted intervention strategies that focus on movement, mobility, flexibility, and exercise are needed to impact on physical dependency and its consequences (Aspell et al., 2019). The findings from Chapter 4 of this thesis support the evidence that future models of home care should address physical dependency for older people with and without dementia.

Chapter 5 was concerned with resource implications of dementia in the acute care setting. Acute care is much more expensive than residential care but is rarely considered when it comes to BoC resource allocation decision-making, which has mainly been focused on the relationship between home care and LSRC. Preventing admission and/or accelerating discharge from acute care can have a significant impact on both budgets and health outcomes. To address the hospital issue, generalized linear modelling was used to estimate inpatient LOS and related costs of care for patients with dementia in Irish acute hospitals compared to similar patients without dementia. Both principal and secondary dementia diagnosis effects were estimated and valued. Heterogeneity in the impact of a secondary diagnosis of dementia on LOS was addressed by separately considering principal diagnosis disease categories identified using ICD-10-AM codes (National Centre for Classification in Health, 2000). This helped to identify those specific principal diagnosis disease categories that are more susceptible to increased LOS for people with dementia.

The findings from this study showed that patients with a principal diagnosis of dementia spent on average 17.5 days longer in hospital than similar patients with no principal diagnosis of dementia. LOS was 6.7 days longer for patients with a secondary diagnosis of dementia compared to similar patients with no secondary diagnosis of dementia. While a secondary diagnosis of dementia increased LOS for all principal diagnosis disease categories, the impact of a secondary diagnosis of dementia was lowest for patients with ‘diseases of the digestive system’ (1.6 days), while it was highest for patients with ‘factors influencing health status and contact with health services’ (24.7 days). The additional annual total cost of those presenting with a principal diagnosis of dementia in acute hospitals in 2019 was estimated to be €13.2 million. While the additional annual cost of care for patients in hospitals with a secondary diagnosis of dementia was €62.0 million.

This study highlights the economic impact of extended LOS for patients with dementia in Irish acute hospitals, even if it does not expand the argument into an opportunity cost estimation. Given the ageing population (Kane et al., 2015; O’Shea et al., 2017), the costs identified in this study are likely to grow significantly over the coming years in Ireland. At the very least, this research shows the need for greater attention to be paid to dementia within acute hospitals given the impact on LOS, costs and displacement in terms of crowding out appropriate admissions through people with dementia staying longer than they need to in a hospital bed. The findings from this study have, therefore, implications for the process of care within the hospital setting, especially the importance of identifying and addressing cognitive impairment across all patients in hospitals. Recognition of the problem is only useful, however, if staff have the experience, training, and resources to address the various challenges associated with the condition. That is not the case at the moment (Briggs et al., 2016; Ispos MORI, 2019; O'Shea et al., 2017). Change is required in the form of the delivery of more person-centred care by staff trained in the nuances and complexity of dementia care. The likely benefit would be a reduction in LOS for patients with principal and secondary diagnoses of dementia in acute care settings and an associated reduction in the cost of care.

However, improvements in the delivery of care will not fully address excessive LOS for people with dementia in acute hospitals. A shortage of alternative care options, both in the home and in LSRC, has been cited as a reason for extended LOS for people with dementia in the acute care setting (Connolly & O'Shea, 2015). In the Irish context, an integrated, adequately resourced community care system, including home care services, is required to reduce unnecessary hospital admissions and to facilitate timely discharge (World Health Organization, 2012, as cited in Keogh et al., 2018b). Ireland has been slow to formally commit to an Integrated Care Programme for Older Persons (ICPOP), which was established by the HSE in 2016, with the primary objective to support people at home instead of the acute hospital setting, where possible, through the provision of planned co-ordinated care (Integrated Care Programme for Older Persons Steering Group, 2017). According to Darker (2014), the benefits of integrated care won't be visible in Ireland until key areas are addressed, including the expansion of primary and community services and significant investment in social services such as reablement programmes and rehabilitation. Very importantly, Darker (2014) describes that part of the problem in Ireland relates to the integration of care and the relationship between home care services and supports and the acute care sector, thus emphasising the need to allocate resources that support the development of balanced service systems rather than favouring acute health care at the expense of prevention, primary, and community services. These are classic BoC problems in the delivery of services and supports for people with dementia.

While community care services for people with dementia remains underdeveloped, under-resourced and unevenly distributed in Ireland (Keogh et al., 2018a), so too does support for carers, even though caregiver stress and burden have been identified as predictors of prolonged LOS in acute hospitals (Lang et al., 2010; Toh et al., 2017). Previous research has shown that patients with dementia admitted from home sometimes remain in the acute care setting for longer as carers may sometimes encourage the hospital to keep the patient for longer (Hickey et al., 1997) and occasionally use admission as an opportunity to stop caring altogether. Therefore from a policy perspective, support for carers may also impact positively on LOS for people with dementia in acute care settings by relieving the caregiving burden and enabling caring to recommence on discharge (Teahan et al., 2021). The type of supports that carers need has recently been highlighted in a systematic review by Bressan et al. (2020). These include training and education to care for the person with dementia; the need to receive social, emotional, and psychological support to care for their loved one; access to information to improve knowledge about the disease and care services; and to find a balance between caring and meeting their own needs.

Government reforms in Ireland propose to recalibrate care towards greater support of people at home, where possible. Such a shift is reflected in the Health Service Capacity Review, which has considered social care for the first time ever when estimating future capacity and needs in acute care settings in Ireland. Thus, acknowledging the importance of achieving greater integration in the Irish health care system by moving care into the community setting, where appropriate, in order to relieve pressure off overburdened hospitals (PA consulting, 2018). However, accomplishing such a goal will require significant expansion of community care services given the current level of unmet need (Walsh et al., 2019). It remains to be seen whether this will happen to the required scale. Previous experience suggests that it will not, but there seems to be a new determination in government for the expansion of social care, and my work in this thesis suggests that the first stage of any reform should focus on the boundary of care across home, residential care, and acute care.

The new home care scheme proposed by the government will provide a statutory entitlement to home care for the first time ever in Ireland. It is not yet known what that change will actually require in terms of scale, infrastructure, budget, and cost sharing. This highlights the importance of addressing the funding issue in relation to long-term care in Ireland. The Citizens’ Assembly (2017) on ageing argued for a new social insurance model for long-term care in Ireland to meet some of the needs addressed in this thesis. Under this model, money would be collected from individuals while in employment over their lifetime in return for receiving an automatic entitlement to home-based care if needed in the future. This would result in a more transparent, protected, community-based funding model for Ireland (O’Shea et al., 2017). The various options for long-term care funding were last examined in Ireland back in 2002. Mercer (2002) was an advocate for the social insurance model, maintaining that this approach would give rise to additional resources and would establish a clear relationship between contribution and benefit. In anticipation of the new home care scheme, the government may need to re-examine funding models for long-term care in order to achieve social goals in relation to long-term care for people with dementia. Without adequate investment by government, current shortcomings of the home care system in Ireland, particularly on the margins of residential and acute care, are unlikely to be solved.

With regard to cross-cutting patterns of this Ph.D. research, the important role played by family carers was a recurring theme. It is evident that without family carers, the state would have to invest significantly more money to support dependent older people to remain living at home. Unfortunately, practical support for informal carers has been largely neglected in Irish public policy-making. Therefore, if the government wants to redirect care towards home, greater financial and social support is needed for carers. The upcoming new home care scheme is a clear opportunity to provide higher levels of support for this group. Despite having a relatively high hazard of institutionalization, the overall picture from this thesis is one of scarcity in regard to standard public community-based care provision for people with dementia living at home in Ireland. The evidence generated in this thesis confirms that community care services for people with dementia remain fragmented and under-resourced in Ireland (Bobersky, 2013; Keogh et al., 2018a). Furthermore, an inadequate supply of publicly funded home care in Ireland may have implications for admission to residential settings and discharge from hospital care, as discussed in Chapters 4 and 5 of the thesis (Walsh & Lyons, 2021).

Resource implications of dementia in the acute care setting are not commonly considered when it comes to BoC resource allocation decision-making. Concerningly, the findings from this thesis identified that LOS and subsequent costs were significantly higher for dementia patients in Irish hospitals. Therefore, preventing admission and/or accelerating discharge from acute care may accrue significant cost savings for the government. However, a current problem in the Irish context relates to a lack of integration and joined-up thinking between care delivery in the home and acute care settings. There is a need for more investment in community-based services, including dementia specific home care services, to develop equitable and balanced service systems (Darker, 2014). From a policy viewpoint, it is critical to examine interdependencies within the health care system, including the expansion of home supports to relieve the pressure off overburdened hospitals. Importantly, the results presented in this thesis allow for policy-makers to consider the costs (and consequences) of IHCPs in the broader context of the care continuum, including the hospital setting, whereby significant cost savings may be possible if home care services are increased. A significant expansion in the number of

IHCPs provided to older people living in the community setting would impact admission to, and discharge from, acute care facilities in the future.

Another cross-cutting pattern arising from this Ph.D. research is that greater attention needs to be paid to dementia as a condition, given its impact on both admission to LSRC and extended LOS in the acute care setting. At present, it is questionable whether home care workers and hospital staff have the experience, training, and resources necessary to address the various challenges associated with the condition. Ultimately, the needs of people with dementia are unique and complex (Røsvik & Rokstad, 2020), and adopting a person-centred approach to care among formal providers is crucial (Kitwood, 1997), requiring significant investment in education and training development. The focus of my research was predominantly on costs and cost drivers rather than outcomes, mainly because of the difficulty in generating data on consequences. More information is required on the latter, but the data on costs generated in this thesis will contribute to resource allocation decision-making for people with dementia living on the margins of home care, residential care, and acute care in Ireland.

6.3 Contribution to the literature

Chapter 3 adds to a growing field of international research on the costs of care for people with dementia and therefore contributes towards informing future health care service planning and provision for individuals with dementia living on the boundary between home care and residential care in Ireland. Importantly, in the Irish context, this study provides valuable insights into resource utilisation and costs of care for people with dementia on the margin of care who are receiving enhanced home supports in the form of IHCPs. Furthermore, this analysis facilitates the comparison between the cost of IHCPs and alternative placement in public and private residential care alternatives. Importantly, a comprehensive costing exercise was adopted in this study, which examined not only formal health care costs but also informal and private care costs, housing, and personal consumption costs. This research contributes new evidence on local unit cost data in the Irish context, where there is a paucity of unit cost data available.

Chapter 3 shows that even with enhanced community care provision, in the form of IHCPs, a significant amount of informal care is needed to keep people with dementia living at home rather than in residential care facilities. In Ireland, previous estimates suggest that informal carers of people with dementia account for just under half of the total cost of care (O’Shea et al., 2017). Without family carers, there would be a significant additional monetary burden placed on the state. Despite this, government support for family caregivers is weak, and informal care costs have been neglected in Irish public policy-making. Teahan et al. (2021) suggest that caring in Ireland is an unstated social obligation, which is not supported by government policy resulting in little or no protection against disadvantage experienced by those in caring roles. Current and successive governments in Ireland have taken the contribution of informal carers for granted, assuming they will continue to care in the future. But this is not necessarily the case as there are a number of factors that are likely to affect the supply of informal carers over the coming years, including, but not limited to, ageing demographics, greater female labour force participation, increased migration, and smaller families (Cahill, 2021). Therefore, if the government seeks to redistribute care to the community setting in Ireland over the coming years, realistic investment is required to support family carers to continue caring.

Chapter 3 also shows that private out-of-pocket care costs remained high even in the presence of IHCPs. This is an important finding as it signals the potential for inequities to develop as the market evolves in the future. According to Mercille and O’Neill (2021), private home care provision is growing rapidly in Ireland, and this is largely due to neoliberal government policies which have supported commercialisation of the home care market. In a country where an inadequate supply of publicly funded home care exists, this is likely to lead to more people seeking home support from private care providers, thus imposing significant costs on families. There is a danger that a shift towards privatisation of home care services will continue over the coming decades, without anyone noticing, in much the same way a shift towards privatisation occurred in the nursing home sector due to a scaling back of public funding (Mercille & O’Neill, 2021). Very importantly, this chapter highlights that irrespective of the additional supports received, some families incur high private out-of-pocket care costs. What happens to those that cannot afford to supplement public provision is an important question? There is a real danger of a two-tier social care system developing over the longer term.

Using sophisticated competing risks survival analysis, Chapter 4 provides important information on factors affecting the transition towards LSRC and mortality among people with and without dementia currently living at home with intensive formal care support. In this study the consideration of whether and how dementia affects placement and mortality is particularly important in a country like Ireland, where there is a significant increase expected in the number of people with dementia in the coming decade (Pierse et al., 2019). This research provides an improved understanding of the specific characteristics and circumstances of people who are most likely to benefit most from home-based care, including raising the question of whether seeking to delay admission to a long-term care setting is the best approach for some individuals on the boundary of care. When resources are scarce, difficult choices may sometimes have to be made in relation to the allocation of health and social care packages. The research in this paper sheds light on some of the factors that should be considered when making these decisions.

The data also allows for consideration of the role that family carers play in influencing admission to LSRC and mortality, thus again highlighting the significant reliance on informal carers to support dependent older people to remain living at home. The important role played by family carers is an enduring theme of my Ph.D. research. The new home care scheme must include clear benefits for family caregivers in Ireland. This might include financial compensation, the provision of more practical supports such as time off work, pension contributions, or the delivery of carer supports (Keogh & O'Shea, 2019; Teahan et al., 2021). It is evident that informal carers are an essential part of the 'care ecosystem' in Ireland (Keogh & O'Shea, 2020); as such, their contribution must be recognised over the coming years in order to ensure the sustainability of community-based care in Ireland.

Chapter 5 contains the first study in Ireland to robustly account for observed differences in patients when assessing inpatient LOS and related care costs for patients with dementia in Irish acute hospitals. Both principal and secondary diagnosis effects were estimated and valued. This paper builds on previous research (Briggs et al., 2016; Connolly & O'Shea, 2015) by controlling for the influence of case-mix on LOS. A major strength of this study was the relatively large number of observations in the control group, allowing me to perform CEM on a rich set of covariates, thereby reducing the problem of confounding. The inclusion of people with a comprehensive secondary diagnosis of dementia allowed differential analyses on the impact of dementia on the cost of care across a wide range of conditions. Importantly, this contributed new evidence on those specific principal diagnosis disease categories that are more susceptible to increased LOS for people with dementia. This research highlighted the significant costs associated with extended LOS for patients with dementia in the acute care setting. It is possible that dementia remains hidden in the acute care setting, and consequently, care for this cohort of people is not as efficient as it should be. Therefore, addressing specific dementia-related needs of people in hospital is likely to optimize resource use and decrease health care costs in acute care settings. Importantly, the findings from this study do have implications for the process of care within the hospital setting, especially the importance of identifying and addressing cognitive impairment across all patients in hospitals.

In the wider context of BoC, this thesis seeks to contribute to the Irish and international literature base by applying the BoC framework to the care of people with dementia, whereby only a limited number of studies exist. Furthermore, the analysis and findings of all three studies will add to the evidence base by providing important information on the costs and, where possible, consequences of placement decision-making for people with dementia living on the margin of care in Ireland. Importantly, the first study in this thesis considered cost shifting between the community and residential care settings. The comprehensive costing exercise facilitated the inclusion of not only formal health care costs but also informal care and private care costs, therefore providing important information on public-private mix elements for IHCP recipients living in the community setting. The second study used more sophisticated competing risks survival modelling to consider factors affecting placement in LSRC and mortality for recipients of IHCPs living at home. Very importantly, this data examined the role family carers play in influencing admission to LSRC and mortality, finding that both outcomes are impacted by the amount of informal care provision available. The final study in this thesis incorporated a BoC framework to analyse hospital LOS and care costs. This work discussed the potential for enhanced community-based service provision to reduce LOS. And highlighted the role that changes to care practice are likely to make to hospital production functions, including investment in education and training, resulting in reduced LOS for people with dementia.

Tucker et al. (2013) point out that the BoC approach offers the ability to incorporate a mix of existing local data, research findings, and experienced practitioner judgements into the decision-making process in a way that is transparent to participants and exposes its key assumptions to critical debate. The work presented in this thesis is immersed in ongoing policy debates in Ireland, which seek to shift the BoC towards home, where possible (Department of Health, 2019; Government of Ireland, 2018; Houses of the Oireachtas Committee on the Future of Healthcare, 2017; PA Consulting). The data used for the first two papers were generated through an HSE-Genio ‘real-world activity and practice’ initiative, which had its origins in the NDSIP, relating to the further development of integrated services for people with dementia to enable them to continue to live at home (Genio, 2016; Keogh et al., 2018a; Keogh et al., 2018b). IHCPs are a potential care alternative to residential care placement, and will also impact on admission to, and discharge from, acute care facilities. The provision of information on the costs and, where possible, consequences of placement decision-making will be particularly useful to inform the resource allocation process for people with dementia on the boundary of home care, residential care, and acute care in Ireland. Furthermore, the findings produced in this thesis are forward-looking and will help to shape the form and structure of new legislation on home care for people with dementia in the future.

6.4 Limitations of the research

Using a BoC framework, this thesis provided a thorough examination of costs and/or consequences of placement decision-making for people with dementia on the margins of home care, residential care, and acute care in Ireland, with the main emphasis on costs rather than outcomes. However, there are limitations to the research that must be acknowledged. Although specific limitations have been discussed in each of the papers, this section considers the limitations of the thesis more generally. Some of these shortcomings relate to the availability of appropriate data and to the various methodologies employed, meaning there are caveats for the interpretation of the results.

All three studies in this thesis were cross-sectional in nature; therefore, the results of each study should be viewed as associations rather than casual relationships. It is evident from the BoC literature that data is needed on the relative effectiveness of care in different settings, as policy-makers need information on both costs and outcomes to make resource allocation decisions. However, due to data limitations, the main focus of this thesis was predominantly on costs and cost drivers rather than outcomes. For example, in Chapter 3, while this study did compare the costs of community and residential care for IHCP recipients, it was not possible to measure the relative effectiveness of care in these settings. This is a study limitation, particularly when using the BoC framework, which seeks to determine the costs (and ideally outcomes) in different care settings.

In Chapter 4, the results may be susceptible to unobserved confounding. Predictors which may influence admission to LSRC or mortality, such as caregiver burden, income, quality of life, or comorbidities, were not included in the analysis, as data was not collected on these variables. In Chapter 5, a unique patient identifier was not available in the HIPE data set; therefore, it was not possible to analyse certain areas of interest, such as the number of hospitalizations per patient, nor to examine information on historic admissions that may have been informative in relation to the patients' health status. Therefore, the analysis was conducted at the discharge-level rather than the patient-level. For the purposes of this study, a generic unit cost for Ireland, representing the average cost across all nights in all Irish hospitals and in all types of inpatient cases, of €938 (Hospital In-Patient Enquiry, 2019) was used to calculate the costs attributable to LOS for patients with dementia. A more refined costing approach based on diagnosis-related groups (DRGs) may provide additional insight on cost differences between the groups (see future work Section 6.5). The absence of data on quality of life, for example, meant it was not possible to examine outcomes other than LOS and associated care costs in Chapter 5.

6.5 Future research

Based on the findings of this Ph.D. and taking stock of the limitations of this research, this section considers some possible future avenues for research. In relation to Chapter 3, which examined the costs of IHCPs for people with dementia, future research with more participants could valuably explore outcome measures such as quality of life for dementia-IHCP recipients or caregiver burden for those supporting people with dementia living in the community setting. For example, the results of this study suggest that even with increased public spending on IHCPs, significant informal care and, increasingly, private care are needed to keep people with dementia living at home rather than in residential care facilities. Therefore, evidence is needed on whether new investment in community-based care should focus on improving the quality of life of care recipients and/or may take some of the burden off family caregivers. With regard to private out-of-pocket expenditure on care, it would be useful to gain an understanding of what types of resources are being purchased in the community setting and by whom. The growth of private expenditure has the capacity to create unequal access to care and requires careful monitoring and analysis.

Future research on transition to LSRC and mortality could examine the impact of important variables such as prior resource utilisation of usual formal care in the community setting, caregiver work status, income, comorbidities, private care provision, quality of life, and caregiver burden. Previous research suggests that factors affecting institutionalization for people with dementia may be country-specific (Verbeek et al., 2015). As a result, more information is needed both in Ireland and across other countries on the specific characteristics of people who are likely to benefit most from community-based care as opposed to institutional care. Moreover, different countries are likely to have different thresholds in relation to the dependency cut-off point for admission to long-stay care. This is likely to be associated with localised budget constraints, including how much funders are willing to exceed per capita nursing home financial supports to keep people living at home. Contingent valuation exercises might be one way to explore the value citizens place on the benefits of living at home rather than in residential care settings. Strategies such as standard gamble or time trade-offs might also be useful in exploring the choice between home care and LSRC.

From a methodological point of view, future research could potentially seek to limit confounding using matching techniques such as CEM or propensity score balancing. Matching would identify non-dementia-IHCP recipients in the control group that are similar to dementia-IHCPs in the treated group, *ceteris paribus*, thereby allowing a more robust comparison between the groups. In Chapter 4 of this thesis, it was not possible to use matching techniques as the control group (non-dementia-IHCPs) was not sufficiently large.

In Chapter 5, in addition to studies such as ours that use routinely collected administrative data to examine inpatient LOS and related costs for people with dementia in the acute care setting, there may be benefits from carrying out smaller-scale studies to include in-person data collection on differences that cannot be observed in administrative data. Future research using cluster randomised trials on interventions such as dementia specific training and knowledge for staff would be useful to assess whether differences in LOS can be mitigated between dementia and non-dementia groups. Previous studies have shown that caregiver stress and burden have been identified as factors attributing to prolonged LOS in acute hospitals (Lang et al., 2010; Toh et al., 2017). Therefore, future work could examine if support for caregivers may reduce LOS for people with dementia in acute care settings by relieving burden, both ex-ante and ex-post, thereby allowing caring to recommence following discharge from hospital (Teahan et al., 2021).

Over the coming months, I plan to extend the work completed in Chapter 5 to the United States (US). Using secondary data from the National (Nationwide) In-patient Sample (NIS), which is the largest publicly available all-payer hospital inpatient care database, it will be possible to incorporate better cost data, based on DRGs, to analyse differences between groups with respect to LOS and inpatient care costs. I have recently obtained data for the years 2008 to 2011, but further analyses will expand the sample duration to 2017, thus significantly increasing the sample size. The application of my research question in Chapter 5 to another health care setting highlights the international potential of my Ph.D. work and, importantly, will enable cross-country comparison to determine if factors affecting LOS and care costs for people with dementia are country-specific. The abstract for this work is outlined in Appendix C of this thesis.

More generally, previous research has shown that an important reason for extended LOS for people with dementia in the acute care setting is the lack of alternative care options available, both in the home and in LSRC (Connolly & O’Shea, 2015). Furthermore, there is good evidence nationally, and internationally that personalised community-based services can reduce hospital admission for people with dementia (Cahill et al., 2012). In response to long recognised shortcomings of community-based care for older people (Keogh et al., 2018a), the Irish government plans to significantly expand home care services and supports in the coming decade (Department of the Taoiseach, 2020; Houses of the Oireachtas Committee on the Future of Healthcare, 2017). Policy-makers need empirical data on both costs and outcomes to examine whether expanding community-based home care services or developing alternative models of care will be effective in reducing future care demands for people with dementia. Personalised care is increasingly recognised as important for quality of life, but personalisation requires changing from the current generic model of care provision, incorporating much greater autonomy for people with dementia in decision-making about the type, duration, and intensity of services and supports available to them. This is a major area for future research in relation to BoC for people with dementia.

6.6 Concluding remarks

The expected increase in the number of people living with dementia will place significant cost pressures on the health care system. Therefore, from an economic standpoint, there is considerable incentive to make the best possible use of services and supports for people with dementia in Ireland (Tucker et al., 2015b). The cohort of people with dementia who are on the margin of admission to LSRC or admission to, and discharge from, acute care facilities are of particular importance. Keeping these people out of long-stay facilities, or even postponing admission, may yield significant cost savings for the Irish government, as well as yielding significant personal benefits associated with living at home in their own place and community. Reducing LOS in hospitals will also have positive effects on costs and outcomes for people with dementia. It is hardly surprising, therefore, to find that public policy in Ireland is now focused on shifting the BoC towards home and away from residential care and acute care as much as possible. Even with the inevitable changes that will follow this shift in emphasis, policy-makers will continue to face the complex task of identifying local needs, determining priorities, and allocating resources within enduring budget constraints. The papers included in this thesis are a contribution to the ongoing BoC debate for people with dementia and aid future decision-making in this complex field. The results of the three studies will be particularly useful for the Department of Health to address current and future challenges in relation to placement decision-making for people with dementia in Ireland.

6.7 Personal reflection on the work and the thesis journey

The Ph.D. was a well-rounded journey. My first year was a learning process in terms of getting to know how the Ph.D. works. The first few months consisted of undertaking a literature review and thinking about potential research questions to explore. I opted to do a Ph.D. by publication for a number of reasons. Firstly, to gain experience in writing journal articles. Secondly, to learn how the publishing process works, from journal formatting requirements to responding to reviewers' comments. And finally, to break the Ph.D. down into achievable goals in order to stay motivated throughout. Mid-way through the first year of my Ph.D., I obtained HSE-Genio data to conduct a cost analysis of IHCPs for people with dementia living on the boundary of care in Ireland, and it was during this period I began working towards a clear goal of publishing my first research paper. With regard to the cost analysis presented in Chapter 3, the paucity of unit cost data available in Ireland meant that l gained valuable experience in sourcing information on unit costs from a variety of different data sources. Additionally, I learned how to make relevant adjustments based on inflation and exchange rate indices. Gaining an in-depth knowledge about the calculation of unit costs is a skill that has benefited me greatly, having applied this knowledge numerous times thereafter, both in my Ph.D. research and in external collaborations with other researchers. The output from my work on the HSE-Genio data set contributed to two research reports for the HSE-Genio, which were subsequently published in 2018.

It was during the second year of my Ph.D. studies that I gained access to a larger HSE-Genio data set for Chapter 4 and began my journey of learning survival analysis techniques to analyse factors that may affect transition towards LOS and mortality for IHCP recipients living on the boundary of care in Ireland. The presence of competing risks in this study undoubtedly made the data analysis significantly more challenging as I did not have previous experience of using survival analysis competing risks techniques. In order to overcome this obstacle, I availed of training opportunities both online (via Stata) and at NUI Galway. In order to further my learning, I was the recipient of funding for a research trip, in the third year of my Ph.D., to visit Professor Peter Austin, who is a world-class research leader in survival analysis techniques based at the University of Toronto. On this trip, I gained practical experience in using competing risks techniques and learned how to overcome data issues, such as dealing with a violation of the Cox proportional hazards assumption. This trip greatly enhanced my methodological skills and was of fundamental importance to my learning of competing risks survival analysis techniques.

In semester two of 2020, I took up a three-month lecturing position to teach Principles of Macroeconomics at NUI Galway. During this role, I had the opportunity to learn organization, time-management, and leadership skills. Furthermore, this teaching role greatly improved my communication and presentation skills which gave me much more confidence when presenting my Ph.D. research at seminars and conferences. Teaching has always been a passion of mine, so I was delighted to have been provided with such an opportunity that I will always reminisce on fondly.

Since March of 2020, I have been working on my Ph.D. at home due to COVID-19. While I have missed the social interaction with fellow Ph.D. students and staff, I am in regular contact with my supervisor through zoom calls. However, in the third year of my Ph.D. studies, I did experience difficulties in obtaining my final data set as HIPE was dealing with staff shortages and much slower response times due to COVID-19. I overcame this obstacle and worked particularly hard over the past year or so to submit my final paper, which examined inpatient LOS and related costs for people with dementia in Ireland. However, I did receive a very welcome six-month extension from the university to compensate for the COVID-related disruption to my work. Despite time limitations when working on this paper, the data analysis conducted in Chapter 5 was a valuable learning experience that greatly enhanced my knowledge of various matching techniques such as propensity score matching, entropy balancing, and CEM.

As I approach the end of my Ph.D. studies, I now realise that four and a half years feels like a short amount of time. Personally, this journey has been very fulfilling and enjoyable, which is in no small part due to the help and support I have received throughout from my supervisors Prof. Eamon O’Shea and Dr. Stephen O’Neill, to whom I will always be grateful. This journey has taught me I am more resilient and determined than I thought I was. I have learned a lot throughout this period, and I have grown both personally and professionally. I feel the technical skills and practical experience I have gained over the past number of years while studying for a Ph.D. in Economics will better equip me to navigate the challenges and opportunities that await in my future career.

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Appendices

Appendix A: Supplemental material for Chapter 4: the Fine-Gray sub-distribution hazard model

A.1 Methods

In the presence of competing risks, the sub-distribution hazard model, developed by Fine and Gray (1999), can be used to analyse time to event outcomes. The sub-distribution hazard function is defined as:

$$h_k(t) = \lim_{\Delta t \to 0} \frac{\mathrm{Prob}\left(\mathrm{t} < \mathrm{T} \leq \mathrm{t} + \Delta\mathrm{t},\ \text{failure from cause k} \middle| \mathrm{T} > \mathrm{t} \cup (\mathrm{T} < \mathrm{t} \cap \mathrm{K} \neq \mathrm{k})\right)}{\Delta\mathrm{t}}$$

It represents the instantaneous risk of failure from a specified cause k in those subjects who have not yet experienced an event of type *k*. The risk set considers those who are event-free at time *t* but also the possibility that a competing event has occurred prior to time *t* (Austin et al., 2016). The sub-distribution hazard function has a direct relationship with the cumulative incidence function (CIF), which is an advantage over the cause-specific hazard function. The cumulative incidence function is defined as:

$$CIF_k(\mathrm{t}) = \mathrm{Prob}(\mathrm{T} \leq \mathrm{t}, \text{failure from cause k})$$

Where CIF_k(t) is the probability of failing from cause *k* before time *t* and before the occurrence of a different type of event (Cleves et al., 2010; Austin et al., 2016). The sub-distribution hazard model allows one to estimate the effect of covariates on the CIF for the event of interest (Austin & Fine, 2017). For the purpose of the analysis, a sub-distribution hazard model was initially used in order to examine the association between IHCPs and time to admission to LSRC, when mortality is defined as a competing risk. This facilitated the examination of the probability of admission to LSRC for those recipients who are currently event-free (Austin & Fine, 2017). Next, a sub-distribution hazard model was used to investigate the association between IHCPs and time to mortality while treating admission to LSRC as a competing event. This allows us to consider the probability of mortality in those recipients who are currently event-free (Austin & Fine, 2017). Following this, the hazard of admission to LSRC and mortality was regressed on a set of independent variables described in the main paper (Culliford et al., 2013; Ferraz &

Moreira-Filho, 2017; Feakins et al., 2018). The analyses were performed using Stata 16 (StataCorp, 2019).

A.2 Results

We first regressed the sub-distribution hazard of admission to LSRC on whether the individual was a non-dementia-IHCP recipient or a dementia-IHCP recipient while controlling for mortality as a competing risk. The estimated unadjusted sub-distribution hazard ratio (SHR) was 2.44 (Table A.1), suggesting that the probability of admission to LSRC was higher for dementia-IHCP recipients than for non-dementia-IHCP recipients (95% CI: 1.46 to 4.06; p<0.001). If a covariate increases the sub-distribution hazard function, it will also increase the incidence of the event (CIF); therefore, dementia-IHCP recipients had an increased incidence of admission to LSRC over the study period.

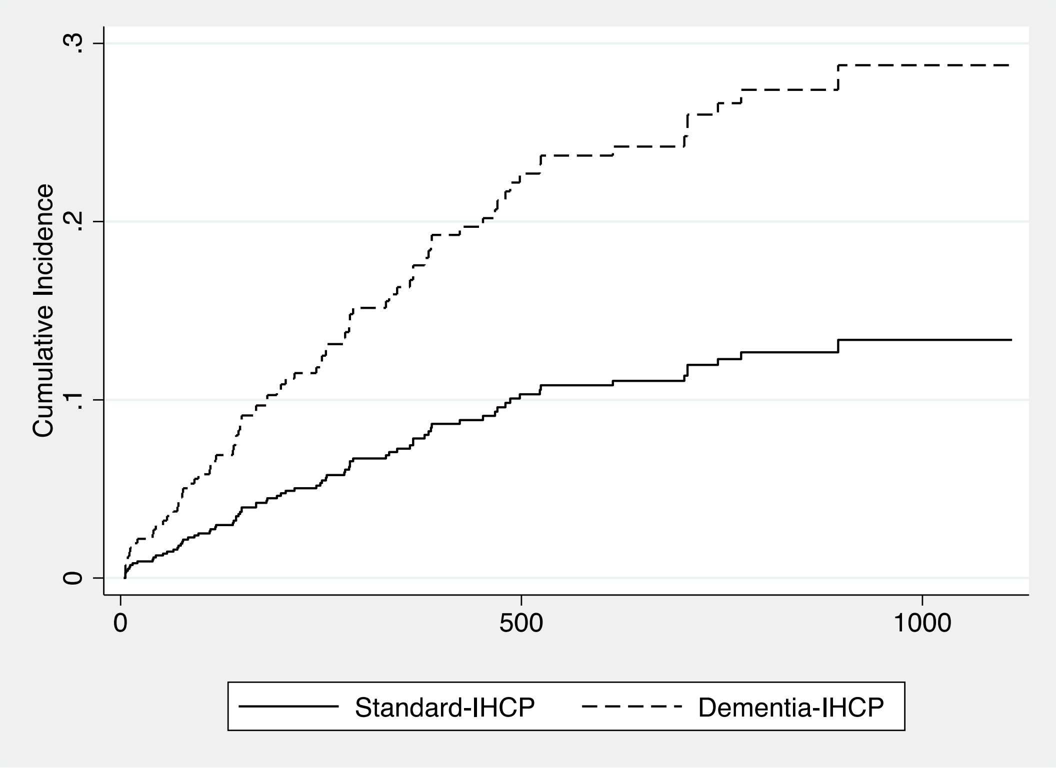
Following this, the model was modified to include a range of covariates to control for observable differences between the groups. The covariates can be interpreted as having an effect on the incidence of the event (Austin & Fine, 2017), positive (negative) coefficients (SHR > 1.0) increased (decreased) the CIF. Based on the SHRs presented in Table A.1, dementia-IHCP recipients still had significantly higher admission to LSRC compared to non-dementia-IHCP recipients even after controlling for differences in characteristics (SHR 2.36, 95% CI: 1.29 to 4.31; p<0.001). With regard to the level of care provided by the main informal caregiver, the results show that admission to LSRC was higher for individuals receiving between 0-8 hours (SHR 3.42, 95% CI: 1.70 to 6.89; p<0.001) and 8-12 hours (SHR 3.17, 95% CI: 1.48 to 6.78; p<0.001) of informal care per day, compared to those receiving more than 12 hours of informal care per day. None of the other covariates were found to have a statistically significant effect at the 5% level. At 500 days, the estimated cumulative incidence of admission to LSRC was approximately 23% for dementia-IHCP recipients compared to 10% for non-dementia-IHCP recipients (see Figure A.1).

Table A. 1: Sub-distribution hazard model regression coefficients (and 95% confidence intervals) for admission to long-stay residential care, accounting for competing risk of mortality

	Long-term care			***Long-term care, adjusted***		
Variable	**Coefficient**	**SHR (95% CIs)**	**P-value**	**Coefficient**	**SHR (95% CIs)**	**P-value**
Dementia-IHCP	0.892	2.44 (1.46, 4.06)	<0.001***	0.860	2.36 (1.29, 4.31)	<0.001***
Male				0.054	1.05 (0.66, 1.67)	0.81
Age at approval						
66-74 years				-0.094	0.90 (0.34, 2.39)	0.84
75-84 years				0.544	1.72 (0.70, 4.21)	0.23
85+ years				0.126	1.13 (0.43, 2.93)	0.79
Married				0.187	1.20 (0.56, 2.58)	0.62
Community				-0.033	0.96 (0.52, 1.77)	0.91
Living alone				0.096	1.10 (0.55, 2.18)	0.78
Barthel Index						
Medium dependency				0.467	1.59 (0.86, 2.94)	0.13
Low dependency and Independent				0.714	2.04 (0.91, 4.55)	0.08*
Main informal caregiver						
Other				0.735	2.08 (0.44, 9.75)	0.35
Spouse/Partner				0.755	2.12 (0.42, 10.63)	0.35
Level of care by carer						
8-12 hours per day				1.156	3.17 (1.48, 6.78)	<0.001***
0-8 hours per day				1.231	3.42 (1.70, 6.89)	<0.001***
IHCP hours per week				-0.006	0.99 (0.98, 1.00)	0.33

* p<.1; ***p<.01

Figure A. 1: Comparative CIFs for dementia-IHCPs and non-dementia-IHCPs for admission to long-stay residential care, accounting for competing risk of mortality and the effect of covariates



In the second model, the sub-distribution hazard of mortality was regressed on the main dependent variable of interest, which indicated whether an individual was a non-dementia-IHCP recipient or a dementia-IHCP recipient while controlling for admission into LSRC as a competing risk. The sub-distribution hazard of mortality was lower for dementia-IHCP recipients than it was for non-dementia-IHCP recipients (SHR 0.69, 95% CI: 0.49 to 0.96; $p<0.05$) (Table A.2). This suggests that dementia-IHCP recipients had a reduced incidence of mortality over the study period. However, after the model was extended to control for a range of covariates, this difference was no longer found to be statistically significant.

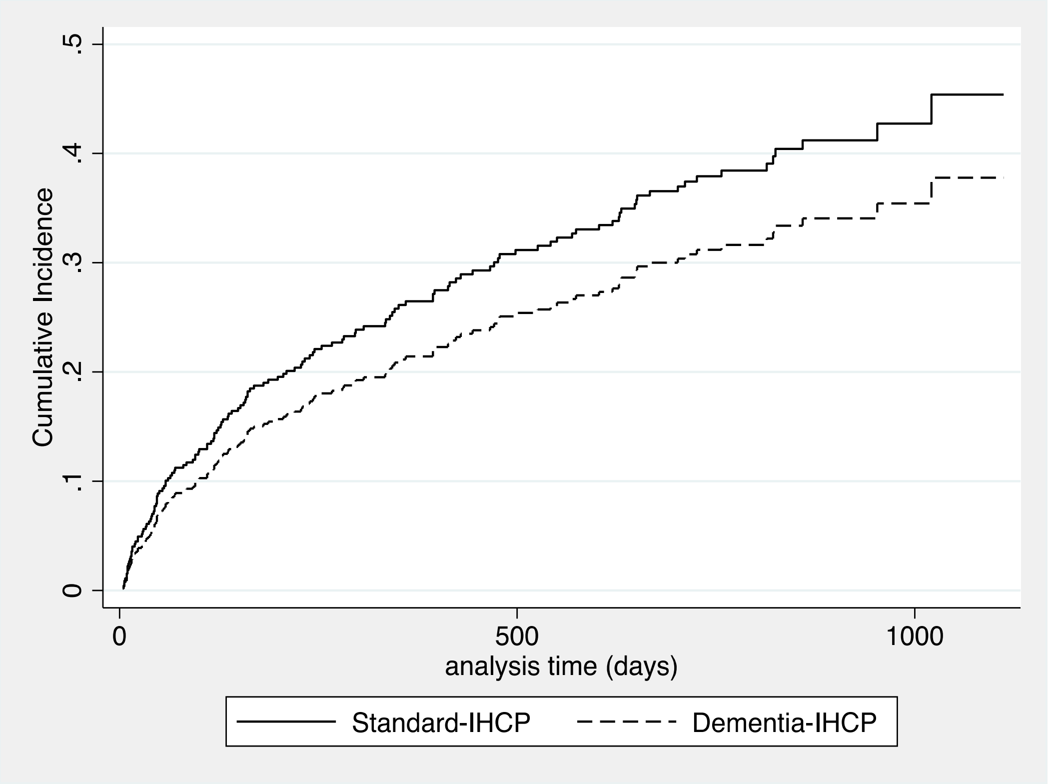
Table A.2 shows that the sub-distribution hazard of mortality was lower for individuals with a medium level of dependency (SHR 0.26, 95% CI: 0.11 to 0.61; $p<0.001$) and for those classified as having a low level of dependency/independent on the Barthel Index (SHR 0.30, 95% CI: 0.10 to 0.93; $p<0.05$) compared to those with a high/maximum level of dependency. With regard to informal care, mortality was lower for those receiving between 8-12 hours (SHR 0.42, 95% CI: 0.24 to 0.72; $p<0.001$) of informal care per day, compared to those receiving more than 12 hours of informal care per day. Finally, an additional hour of care provided as part of the IHCP was associated with higher mortality (SHR: 1.01, 95% CI: 1.00 to 1.02; $p<0.05$). This was possibly explained by the allocation of IHCP hours, whereby individuals who were more unwell would have received additional hours of care. None of the other covariates were found to have a statistically significant effect at the 5% level. At 500 days, the estimated cumulative incidence of mortality was approximately 25% for dementia-IHCP recipients compared to 30% for non-dementia-IHCP recipients (see Figure A.2).

Table A. 2: Sub-distribution hazard model regression coefficients (and 95% confidence intervals) for mortality, accounting for competing risk of admission to long-stay residential care

	Mortality			***Mortality, adjusted***		
Variable	**Coefficient**	**SHR (95% CIs)**	**P-value**	**Coefficient**	**SHR (95% CIs)**	**P-value**
Dementia-IHCP	-0.368	0.69 (0.49, 0.96)	0.02**	-0.242	0.78 (0.55, 1.10)	0.15
Male				0.078	1.08 (0.75, 1.54)	0.66
Age at approval						
66-74 years				0.623	1.86 (0.94, 3.67)	0.07*
75-84 years				0.135	1.14 (0.58, 2.25)	0.69
85+ years				0.666	1.94 (0.97, 3.87)	0.06*
Married				0.294	1.34 (0.73, 2.44)	0.33
Community				-0.288	0.74 (0.46, 1.19)	0.22
Living alone				0.034	1.03 (0.61, 1.72)	0.89
Barthel Index						
Medium dependency				-1.315	0.26 (0.11, 0.61)	<0.001***
Low dependency and Independent				-1.182	0.30 (0.10, 0.93)	0.03**
Main informal caregiver						
Other				-0.192	0.82 (0.27, 2.50)	0.73
Spouse/Partner				-0.624	0.53 (0.16, 1.70)	0.29
Level of care by carer						
8-12 hours per day				-0.857	0.42 (0.24, 0.72)	<0.001***
0-8 hours per day				-0.269	0.76 (0.51, 1.13)	0.18
IHCP hours per week				0.011	1.01 (1.00, 1.02)	0.02**

* p<.1; ** p<.05; ***p<.01

Figure A. 2: Comparative CIFs for dementia-IHCPs and non-dementia-IHCPs for mortality, accounting for competing risk of long-stay residential care and the effect of covariates



A.3 Stata commands

```
use "Dataset to end December 2017.dta", clear
destring Appliance, replace
replace Ceased_date = date("31-12-2017", "DMY") if Ceased_date== (.)
gen days_Everyone = Ceased_date - Commenced_date
replace days_Everyone=. if days_Everyone<0
tab days_Everyone
replace Ceased_date = date("31-12-2017", "DMY") if Ceased_date== date("12-01-2018", "DMY")
tab days_Everyone

tab Dementia_IHCP
tab Commenced_not_commenced Dementia_IHCP
drop if  Commenced_not_commenced==0
tab Commenced_not_commenced Dementia_IHCP

encode Status , gen (status)
recode status (7=3)
lab define stat 1 "Active" 2 "Admitted/Readmitted to hospital/respite" 3 "Ceased (Acute) " 4 "Ceased (Emigrated)" 5 "Ceased (LTC)" 6 "Ceased (RIP)" 8 "HSE provided alternative service (was active)"
lab values status stat

tab days_Everyone

tab Sex
encode Sex, gen (sex)
recode sex(1=.)
lab define se 2 "Female" 3 "Male"
lab values sex se
gen male= sex==3 if sex!=.

tab Age_at_approval
gen age_at_approval=.
replace age_at_approval =1 if Age_at_approval <= 65
replace age_at_approval =2 if Age_at_approval >=66 & Age_at_approval <= 74
replace age_at_approval =3 if Age_at_approval >=75 & Age_at_approval <= 84
replace age_at_approval =4 if Age_at_approval >=85
label define age 1 "65 years or under" 2 "66 - 74 years" 3 "75 - 84 years" 4 "85+ years"
lab values age_at_approval age

tab Marital_Status
encode Marital_Status, gen (marital_Status )
recode marital_Status (6=2) (3=.) (1=.)
lab define mar 2 "Divorced/Seperated" 4 "Married" 5 "Other" 7 "Single" 8 "Widowed"
lab values marital_Status mar
gen married=marital_Status==4 if marital_Status!=.

describe Referral_Source
tab Referral_Source
```

```
encode Referral_Source , gen ( referral_Source )
recode referral_Source (1=.)
lab define referral 2 "Acute hospital" 3 "Community" 4 "Community Hospital " 5 "National Rehabilitation Hospital" 6 "Nursing Home" 7 "Psychiatric Hospital"
lab values referral_Source referral
gen community = referral_Source==3 if referral_Source!=.

tab Living_Arrangements
encode Living_Arrangements , gen (living_Arrangements )
recode living_Arrangements (4=2) (7=5) (1=.) (3=.)
lab define living 2 "Alone" 5 "With other family" 6 "With other " 8 "With son/daughter" 9 "With spouse/partner"
lab values living_Arrangements living
gen livealone = living_Arrangements==2 if  living_Arrangements!=.

tab Barthel_Index
gen barthel_Index =.
replace barthel_Index =1 if Barthel_Index <= 10
replace barthel_Index =2 if Barthel_Index >=11 & Barthel_Index <= 15
replace barthel_Index =3 if Barthel_Index >=16 & Barthel_Index <= 20
lab define b 1 "High and Maximum dependency" 2 "Medium dependency" 3 "Low dependency and Independent"
lab values barthel_Index b

encode Main_Informal_Caregiver , gen (main_Informal_Caregiver )
tab main_Informal_Caregiver
tab main_Informal_Caregiver, nolab
recode main_Informal_Caregiver (1=.) (3=.) ( 2 4 5 8 9 10 11 =7)
tab main_Informal_Caregiver
tab main_Informal_Caregiver, nolab
lab define main 6 "None" 7 "Other" 12 "Spouse/partner"
lab values main_Informal_Caregiver main

encode Level_Care_By_Carer , gen (level_Care_By_Carer )
recode level_Care_By_Carer (1=.) (7=.) (3=2) (6=5)
lab define l 2 " > 12 hours of care daily" 4 "8-12 hours of care daily" 5 "0-8 hours of care daily "
lab values level_Care_By_Carer l

replace CHO = " CHO3" in 501
replace CHO = " CHO3" in 502
encode CHO , gen ( cHO )
tab cHO
recode cHO (1=4)(2=9)
lab values cHO c
tab cHO, generate (dummycHO)

tab Hours_per_week

gen CompleteCase = 1
```

```
replace CompleteCase=0 if status==.
replace CompleteCase=0 if days_Everyone ==.
replace CompleteCase=0 if Dementia_IHCP==.
replace CompleteCase=0 if male==.
replace CompleteCase=0 if married==.
replace CompleteCase=0 if Age_at_approval==.
replace CompleteCase=0 if age_at_approval==.
replace CompleteCase=0 if community==.
replace CompleteCase=0 if livealone==.
replace CompleteCase=0 if Barthel_Index==.
replace CompleteCase=0 if barthel_Index==.
replace CompleteCase=0 if main_Informal_Caregiver ==.
replace CompleteCase=0 if level_Care_By_Carer ==.
replace CompleteCase=0 if cHO==.
replace CompleteCase=0 if Hours_per_week ==.

drop if  CompleteCase==0
tab CompleteCase

tab days_Everyone
tab Dementia_IHCP
tab status Dementia_IHCP, column
tab male Dementia_IHCP, column
tabstat Age_at_approval if Dementia_IHCP==0, statistics (mean sd median iqr)
sum Age_at_approval if Dementia_IHCP==0, detail
tabstat Age_at_approval if Dementia_IHCP==1, statistics (mean sd median iqr)
sum Age_at_approval if Dementia_IHCP==1, detail
tab age_at_approval Dementia_IHCP, column
tab married Dementia_IHCP, column
tab community Dementia_IHCP, column
tab livealone Dementia_IHCP, column
tabstat Barthel_Index if Dementia_IHCP==0, statistics (mean sd median iqr)
sum Barthel_Index if Dementia_IHCP==0, detail
tabstat Barthel_Index if Dementia_IHCP==1, statistics (mean sd median iqr)
sum Barthel_Index if Dementia_IHCP==1, detail
tab barthel_Index Dementia_IHCP, column
tab main_Informal_Caregiver Dementia_IHCP, column
tab level_Care_By_Carer Dementia_IHCP, column
tabstat Hours_per_week if Dementia_IHCP==0, statistics (mean sd median iqr)
sum Hours_per_week if Dementia_IHCP==0, detail
tabstat Hours_per_week if Dementia_IHCP==1, statistics (mean sd median iqr)
sum Hours_per_week if Dementia_IHCP==1, detail

gen outcome_vers1 = status
recode outcome_vers1 (1=0) (2=.) (3=.) (4=.) (5=1) (6=2) (7=.) (8=.)


stset Ceased_date, failure(outcome_vers1 = 1) exit(time mdy(12,31,2017))
origin(Commenced_date)
sts graph, survival
```

```
sts graph, survival by(Dementia_IHCP)
sts list, survival by (Dementia_IHCP)
sts test Dementia_IHCP, logrank

stset Ceased_date, failure(outcome_vers1 = 2) exit(time mdy(12,31,2017))
origin(Commenced_date)
sts graph, survival
sts graph, survival by(Dementia_IHCP)
sts list, survival by (Dementia_IHCP)
sts test Dementia_IHCP, logrank

quietly stset Ceased_date, failure(outcome_vers1 = 1) exit(time mdy(12,31,2017))
origin(Commenced_date)
stcox Dementia_IHCP
estat phtest
stcurve, hazard kernel (gaussian) at1 (Dementia_IHCP=0) at2 (Dementia_IHCP=1)

stcox Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week
estat phtest
stcurve, hazard kernel (gaussian) at1 (Dementia_IHCP=0) at2 (Dementia_IHCP=1)

stcox Dementia_IHCP, tvc(Dementia_IHCP) texp(_t)
stcox Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week,
tvc(Dementia_IHCP) texp(_t)
stcox Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week,
tvc(i.male) texp (_t)
stcox Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week,
tvc(i.age_at_approval) texp(_t)
stcox Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week,
tvc(i.married) texp(_t)
stcox Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week,
tvc(i.community) texp(_t)
stcox Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week,
tvc(i.livealone) texp(_t)
stcox Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week,
tvc(i.barthel_Index)texp(_t)
stcox Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week,
tvc(i.main_Informal_Caregiver) texp(_t)
stcox Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week,
tvc(i.level_Care_By_Carer) texp(_t)
```

```
stcox Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week,
tvc(Hours_per_week) texp(_t)

stcox Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week, nohr
tvc(i.barthel_Index) texp(ln(_t))
stcox Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week,
tvc(i.barthel_Index) texp(ln(_t))
testparm i(2).barthel_Index dependency
testparm i(3).barthel_Index

quietly stset Ceased_date, failure(outcome_vers1 = 2) exit(time mdy(12,31,2017))
origin(Commenced_date)
stcox Dementia_IHCP
estat phtest
stcurve, hazard kernel (gaussian) at1 (Dementia_IHCP=0) at2 (Dementia_IHCP=1)

stcox Dementia_IHCP, nohr tvc(Dementia_IHCP) texp(ln(_t))
stcox Dementia_IHCP, tvc(Dementia_IHCP) texp(ln(_t))

stcox Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week
estat phtest // No violation here, however it does show violation below when tested
individually
stcurve, hazard kernel (gaussian) at1 (Dementia_IHCP=0) at2 (Dementia_IHCP=1)

stcox Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week,
tvc(Dementia_IHCP) texp(_t)
stcox Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week,
tvc(i.male) texp (_t)
stcox Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week,
tvc(i.age_at_approval) texp(_t)
stcox Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week,
tvc(i.married) texp(_t)
stcox Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week,
tvc(i.community) texp(_t)
stcox Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week,
tvc(i.livealone) texp(_t)
stcox Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week,
tvc(i.barthel_Index)texp(_t)
```

```
stcox Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week,
tvc(i.main_Informal_Caregiver) texp(_t)
stcox Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week,
tvc(i.level_Care_By_Carer) texp(_t)
stcox Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week,
tvc(Hours_per_week) texp(_t)

stcox Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week, nohr
tvc(Dementia_IHCP) texp(ln(_t))
stcox Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week,
tvc(Dementia_IHCP) texp(ln(_t))
testparm Dementia_IHCP

quietly stset Ceased_date, failure(outcome_vers1 = 1) exit(time mdy(12,31,2017))
origin(Commenced_date)
stcrreg  Dementia_IHCP, compete(outcome_vers1 = 2)
stcurve, cif at1(Dementia_IHCP=0) at2(Dementia_IHCP=1) title("CIF of LTC, stcrreg")
stcrreg  Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i. main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week,
compete(outcome_vers1 = 2)
stcurve, cif at1(Dementia_IHCP=0) at2(Dementia_IHCP=1) title("CIF of LTC, stcrreg with
covariates")

quietly stset Ceased_date, failure(outcome_vers1 = 2) exit(time mdy(12,31,2017))
origin(Commenced_date)
stcrreg  Dementia_IHCP, compete(outcome_vers1 = 1)
stcurve, cif at1(Dementia_IHCP=0) at2(Dementia_IHCP=1) title("CIF of RIP, stcrreg")
stcrreg  Dementia_IHCP i.male i.age_at_approval i.married i.community i.livealone
i.barthel_Index i.main_Informal_Caregiver i.level_Care_By_Carer Hours_per_week,
compete(outcome_vers1 = 1)
stcurve, cif at1(Dementia_IHCP=0) at2(Dementia_IHCP=1) title("CIF of RIP, stcrreg with
covariates")
```

Appendix B: Supplemental material for Chapter 5

B.1 Supplemental text

Two pregnancy related diagnosis categories were excluded from the analysis due to the age demographic being studied. A further three principal diagnosis categories (diseases of the eye and adnexa |H00-H59; diseases of the ear and mastoid process |H60-H95; and congenital malformations, deformations, and chromosomal abnormalities |Q00-Q99) were excluded from the analysis as n ≤ 30 in either or both groups.

Table B. 1: Descriptive statistics for inpatient discharges with and without a principal or secondary diagnosis of dementia[7]

Variable	**Principal diagnosis of dementia (n=803)**	**No principal diagnosis of dementia (n=177,491)**	**Secondary diagnosis of dementia (n=9,859)**	**No secondary diagnosis of dementia (n=178,704)**
Length of stay in hospital, median (interquartile range)	20 (6, 41)	5 (2,11)	9 (4, 21)	5 (2,11)
Gender, n (%)				
Male	371 (46.20)	92, 044 (51.86)	4,352 (44.14)	92,577 (51.80)
Female	432 (53.80)	85,447 (48.14)	5,507 (55.86)	86,127 (48.20)
Age 65-74, n (%)				
Yes	138 (17.19)	74,860 (42.18)	1,244 (12.62)	74,961 (41.95)
No	665 (82.81)	102,631 (57.82)	8,615 (87.38)	103,743 (58.05)
Age 75-84, n (%)				
Yes	422 (52.55)	68,824 (38.78)	4,467 (45.31)	69,349 (38.81)
No	381 (47.45)	108,667 (61.22)	5,392 (54.69)	109,355 (61.19)
Age 85+, n (%)				
Yes	243 (30.26)	33,807 (19.05)	4,148 (42.07)	34,394 (19.25)
No	560 (69.74)	143,684 (80.95)	5,711 (57.93)	144,310 (80.75)
Married, n (%)				
Yes	356 (44.33)	91,671 (51.65)	4,233 (42.94)	92,197 (51.59)
No	447 (55.67)	85,820 (48.35)	5,626 (57.06)	86,507 (48.41)
Medical card holder, n (%)				
Yes	676 (84.18)	137,465 (77.45)	8,143 (82.59)	138,462 (77.48)
No	127 (15.82)	40,026 (22.55)	1,716 (17.41)	40,242 (22.52)
Public patient status, n (%)				
Yes	738 (91.91)	149,098 (84.00)	8,734 (88.59)	150,186 (84.04)
No	65 (8.09)	28,393 (16.00)	1,125 (11.41)	28,518 (15.96)

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[7] Table B.1, presents key descriptive statistics for each group in Comparisons 1 and 2 before CEM.

Table B. 2: Balancing of observables for inpatient discharges with and without a principal diagnosis of dementia

Variable	**Principal diagnosis of dementia (n=803)**	**No principal diagnosis of dementia (n=177,491)**		**Principal diagnosis of dementia (n=743)**	**No principal diagnosis of dementia (n=67,745)**	
	Mean – before matching	**Mean – before matching**	**Std. diff.**	**Mean (balanced) – after matching**	**Mean (balanced) – after matching**	**Std. diff.**
Male	0.462	0.518	-0.113	0.453	0.453	0.000
Age 65-74	0.171	0.421	-0.506	0.161	0.161	0.000
Age 75-84	0.525	0.387	0.283	0.528	0.528	0.000
Age 85+	0.302	0.190	0.286	0.309	0.309	0.000
Married	0.443	0.516	-0.146	0.440	0.440	0.000
Medical card holder	0.841	0.774	0.161	0.853	0.853	0.000
Admission source: home	0.901	0.882	0.061	0.909	0.909	0.000
Admission source: long-stay accommodation	0.063	0.041	0.108	0.059	0.059	0.000
Admission source: other	0.034	0.076	-0.155	0.030	0.030	0.000
Public patient status	0.919	0.840	0.216	0.927	0.927	0.000
Emergency admission to hospital	0.960	0.842	0.322	0.969	0.969	0.000
Treated by consultant geriatrician (1=Yes, 0=No)	0.270	0.068	0.8	0.258	0.258	0.000
Time spent in intensive care environment (1=Yes, 0=No)	0.007	0.083	-0.274	0.006	0.006	0.000
Elixhauser comorbidities						
Congestive heart failure	0.017	0.064	-0.192	0.009	0.009	0.000
Cardiac arrhythmias	0.094	0.144	-0.141	0.086	0.086	0.000
Peripheral vascular disorders	0.006	0.014	-0.068	0.005	0.005	0.000
Hypertension, uncomplicated	0.054	0.106	-0.168	0.043	0.043	0.000
Other neurological disorders	0.077	0.031	0.259	0.060	0.060	0.000
Chronic pulmonary disease	0.028	0.057	-0.123	0.021	0.021	0.000
Diabetes, uncomplicated	0.134	0.118	0.05	0.123	0.123	0.000
Diabetes, complicated	0.068	0.098	-0.102	0.056	0.056	0.000
Hypothyroidism	0.017	0.004	0.184	0.009	0.009	0.000
Renal failure	0.057	0.088	-0.11	0.051	0.051	0.000
Solid tumour without metastasis	0.014	0.060	-0.192	0.013	0.013	0.000
Weight loss	0.029	0.015	0.114	0.018	0.018	0.000
Fluid and electrolyte disorder	0.094	0.106	-0.037	0.072	0.072	0.000
Psychoses	0.014	0.003	0.178	0.008	0.008	0.000
Depression	0.023	0.010	0.134	0.010	0.010	0.000
Other comorbidities	0.061	0.176	-0.302	0.048	0.048	0.000
Elixhauser comorbidity score	0.798	1.124	-0.265	0.640	0.640	0.000

Table B. 3: Balancing of observables for inpatient discharges with and without a secondary diagnosis of dementia

Variable	**Secondary diagnosis of dementia (n=9,859)**	**No secondary diagnosis of dementia (n=178,704)**		**Secondary diagnosis of dementia (n=8,242)**	**No secondary diagnosis of dementia (n=111,671)**	
	Mean – before matching	**Mean – before matching**	**Std. diff.**	**Mean (balanced) – after matching**	**Mean (balanced) – after matching**	**Std. diff.**
Male	0.441	0.518	-0.153	0.428	0.428	0.000
Age 65-74	0.126	0.419	-0.594	0.119	0.119	0.000
Age 75-84	0.453	0.388	0.133	0.455	0.455	0.000
Age 85+	0.420	0.192	0.579	0.425	0.425	0.000
Married	0.429	0.515	-0.173	0.421	0.421	0.000
Medical card holder	0.825	0.774	0.122	0.843	0.843	0.000
Admission source: home	0.719	0.881	-0.502	0.745	0.745	0.000
Admission source: long-stay accommodation	0.222	0.042	0.891	0.206	0.206	0.000
Admission source: other	0.058	0.075	-0.068	0.047	0.047	0.000
Public patient status	0.885	0.840	0.124	0.904	0.904	0.000
Emergency admission to hospital	0.953	0.843	0.302	0.962	0.962	0.000
Treated by consultant geriatrician (1=Yes, 0=No)	0.178	0.069	0.427	0.153	0.153	0.000
Time spent in intensive care environment (1=Yes, 0=No)	0.039	0.083	-0.159	0.022	0.022	0.000
Elixhauser comorbidities						
Congestive heart failure	0.068	0.064	0.015	0.045	0.045	0.000
Cardiac arrhythmias	0.168	0.144	0.067	0.134	0.134	0.000
Valvular disease	0.013	0.020	-0.05	0.006	0.006	0.000
Hypertension, uncomplicated	0.099	0.106	-0.023	0.073	0.073	0.000
Paralysis	0.026	0.018	0.066	0.014	0.014	0.000
Other neurological disorders	0.111	0.032	0.45	0.079	0.079	0.000
Chronic pulmonary disease	0.054	0.057	-0.011	0.038	0.038	0.000
Diabetes, uncomplicated	0.103	0.118	-0.044	0.094	0.094	0.000
Diabetes, complicated	0.107	0.099	0.03	0.079	0.079	0.000
Renal failure	0.098	0.088	0.035	0.074	0.074	0.000
Metastatic cancer	0.016	0.051	-0.16	0.008	0.008	0.000
Solid tumour without metastasis	0.026	0.060	-0.143	0.017	0.017	0.000
Weight loss	0.022	0.015	0.054	0.011	0.011	0.000
Fluid and electrolyte disorders	0.190	0.107	0.268	0.154	0.154	0.000
Deficiency anaemia	0.031	0.022	0.057	0.017	0.017	0.000
Alcohol abuse	0.013	0.022	-0.055	0.007	0.007	0.000
Other comorbidities	0.075	0.089	-0.049	0.047	0.047	0.000
Elixhauser comorbidity score	1.23	1.12	0.089	0.906	0.906	0.000

Table B. 4: Average additional length of stay (days) for inpatient discharges with a principal diagnosis of dementia (Comparison 1)[8]

	Unadjusted model		**Adjusted model**	
Variable	**Average marginal effect (95% CIs)**	**P-value**	**Average marginal effect (95% CIs)**	**P-value**
Principal Dementia	15.76 (12.75, 18,76)	<0.001***	13.58 (11.65, 15.51)	<0.001***
Male			0.84 (0.57, 1.11)	<0.001***
Age 75-84			1.07 (0.73, 1.41)	<0.001***
Age 85+			2.10 (1.70, 2.50)	<0.001***
Married			-0.43 (-0.70, -0.16)	<0.001***
Medical card holder			1.42 (1.09, 1.75)	<0.001***
Admission source: home			-1.62 (-2.75, -0.48)	<0.001***
Admission source: long-stay accommodation			-7.62 (-8.36, -6.88)	<0.001***
Public patient status			-1.93 (-2.49, -1.38)	<0.001***
Emergency admission to hospital			-5.00 (-6.47, -3.52)	<0.001***
Treated by consultant geriatrician (1=Yes, 0=No)			3.09 (2.71, 3.46)	<0.001***
Time spent in intensive care environment (1=Yes, 0=No)			1.61 (-0.84, 4.07)	0.20
Discharge destination: death			-3.23 (-4.02, -2.44)	<0.001***
Discharge destination: home			-10.45 (-10.79, -10.12)	<0.001***
Discharge destination: other source			-5.58 (-5.97, -5.20)	<0.001***
Elixhauser comorbidities				
Congestive heart failure			14.39 (9.94, 18.84)	<0.001***
Cardiac arrhythmias			11.93 (8.50, 15.36)	<0.001***
Peripheral vascular disorders			26.36 (18.83, 33.88)	<0.001***
Hypertension, uncomplicated			19.80 (15.50, 24.10)	<0.001***
Other neurological disorders			24.36 (19.90, 28.83)	<0.001***
Chronic pulmonary disease			14.89 (10.85, 18.93)	<0.001***
Diabetes, uncomplicated			10.08 (6.88, 13.29)	<0.001***
Diabetes, complicated			11.05 (7.58, 14.52)	<0.001***
Hypothyroidism			14.18 (10.06, 18.30)	<0.001***
Renal failure			13.03 (9.38, 16.69)	<0.001***
Solid tumour without metastasis			15.59 (11.29, 19.90)	<0.001***
Weight loss			13.57 (9.65, 17.49)	<0.001***
Fluid and electrolyte disorder			15.22 (11.48, 18.95)	<0.001***
Psychoses			12.29 (6.47, 18.10)	<0.001***
Depression			18.86 (13.99, 23.74)	<0.001***
Other comorbidities			16.61 (12.32, 20.90)	<0.001***
Elixhauser comorbidity score			-9.38 (-11.81, -6.95)	<0.001***

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[8] The base category for admission source is transferred from other source. The base category for age is 65-74 years. The base category for discharge destination is long-stay accommodation. The base category for Elixhauser comorbidities is those patients with no comorbidities. ***Denotes significant at 1% level; **Denotes significant at 5% level; *Denotes significant at 10% level.

Table B. 5: Average additional length of stay (days) for inpatient discharges with a secondary diagnosis of dementia (Comparison 2)[8]

	Unadjusted model		**Adjusted model**	
Variable	**Average marginal effect (95% CIs)**	**P-value**	**Average marginal effect (95% CIs)**	**P-value**
Secondary Dementia	4.98 (4.46, 5.49)	<0.001***	4.84 (4.41, 5.28)	<0.001***
Male			-0.21 (-0.43, 0.00)	0.05**
Age 75-84			0.05 (-0.27, 0.38)	0.75
Age 85+			0.85 (0.50, 1.20)	<0.001***
Married			-0.21 (-0.43, 0.00)	0.05**
Medical card holder			0.32 (0.03, 0.61)	0.03**
Admission source: home			-5.43 (-6.32, -4.54)	<0.001***
Admission source: long-stay accommodation			-10.77 (-11.32, -10.23)	<0.001***
Public patient status			-0.89 (-1.28, -0.50)	<0.001***
Emergency admission to hospital			-5.76 (-6.82, -4.69)	<0.001***
Treated by consultant geriatrician (1=Yes, 0=No)			4.58 (4.19, 4.98)	<0.001***
Time spent in intensive care environment (1=Yes, 0=No)			8.69 (7.33, 10.05)	<0.001***
Discharge destination: death			-2.27 (-2.67, -1.87)	<0.001***
Discharge destination: home			-9.67 (-9.95, -9.39)	<0.001***
Discharge destination: other source			-5.15 (-5.47, -4.82)	<0.001***
Elixhauser comorbidities				
Congestive heart failure			-0.78 (-5.47, 3.91)	0.75
Cardiac arrhythmias			-2.02 (-6.44, 2.39)	0.37
Valvular disease			-2.77 (-6.88, 1.34)	0.19
Hypertension, uncomplicated			-2.44 (-6.63, 1.74)	0.25
Paralysis			-0.65 (-5.44, 4.14)	0.79
Other neurological disorders			1.98 (-3.51, 7.47)	0.48
Chronic pulmonary disease			-2.04 (-6.33, 2.24)	0.35
Diabetes, uncomplicated			-4.50 (-8.13, -0.87)	0.02**
Diabetes, complicated			-2.35 (-6.58, 1.87)	0.28
Renal failure			-2.97 (-7.01, 1.05)	0.15
Metastatic cancer			-2.38 (-6.59, 1.82)	0.27
Solid tumour without metastasis			-1.89 (-6.22, 2.43)	0.39
Weight loss			-0.97 (-5.66, 3.71)	0.68
Fluid and electrolyte disorders			-1.36 (-5.96, 3.23)	0.56
Deficiency anaemia			-0.53 (-5.34, 4.27)	0.83
Alcohol abuse			-0.31 (-5.30, 4.67)	0.90
Other comorbidities			0.87 (-4.40, 6.16)	0.75
Elixhauser comorbidity score			4.49 (-0.41, 9.39)	0.07*

Appendix C: Abstract for future research on US data set

Title: Length of stay and mortality for patients with a secondary diagnosis of dementia in acute hospitals in the US.

***Objective*:**

To estimate the impact of a secondary diagnosis of dementia (by type) on inpatient length of stay (LOS) and mortality rates in acute hospitals in the US.

Data sources:

Secondary data from the National (Nationwide) In-patient Sample (NIS), the largest publicly available all-payer hospital inpatient care database, of admissions for patients with secondary diagnoses of dementia and a group of comparable admissions for patients without such a diagnosis between 2008 and 2011.

Study Design:

This observational study used administrative data collected on all hospital stays in the US, regardless of the expected payer for the hospital. We examined two groups of inpatient records for individuals aged over 35 years that are comparable in terms of observed confounders (age, gender, race, admission source, elective/non-elective, comorbidity status) after entropy balancing, one with and one without a secondary dementia diagnosis (identified using on ICD-9 codes). Individuals with a principal diagnosis of dementia and incomplete cases were excluded. Generalized linear models estimated differences in LOS and mortality between the groups. Further analyses will expand the sample duration to 2017, stratify by principal diagnosis type, and consider costs.

***Principal Findings*:**

After entropy balancing, patients with (N=801,158) and without (N=20,508,037) secondary diagnoses of dementia had similar characteristics. LOS for patients with a secondary diagnosis of dementia were on average 1.20 (95% CI: 1.19, 1.22; $p<0.001$) days longer than patients without, while mortality was 7.7 (95% CI: 6.8, 9.5; $p< 0.001$) percentage points higher.

Conclusions:

A secondary diagnosis of dementia extends LOS and increases mortality in acute hospitals, thereby placing significant additional costs on the health care system. Additional research is required on the health production function for people with a secondary diagnosis of dementia. in hospitals, including end-of-life care, as well as on alternative pathways to care outside of hospitals.