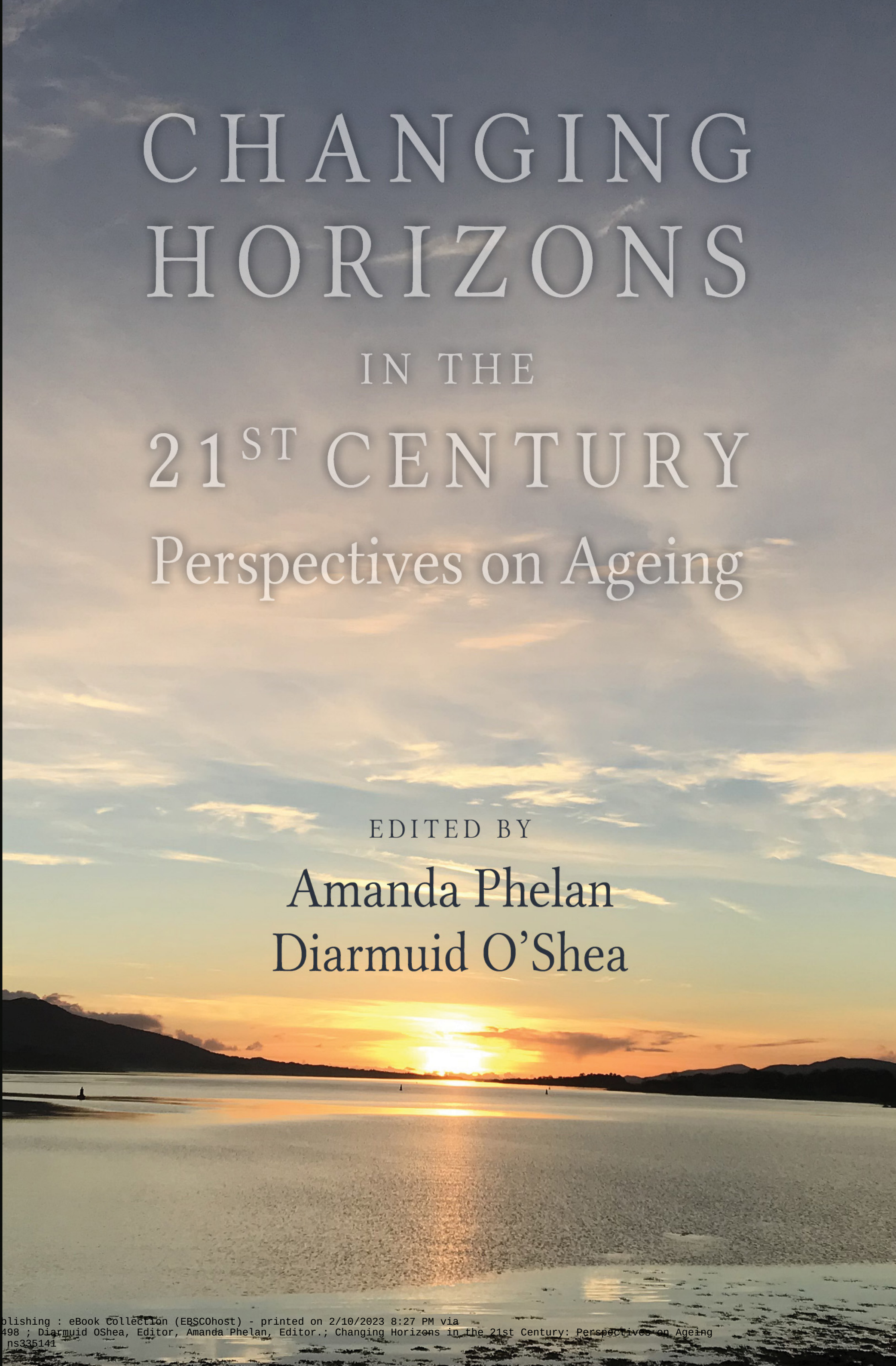

CHANGING HORIZONS IN THE 21ST CENTURY

Perspectives on Ageing

EDITED BY

Amanda Phelan
Diarmuid O'Shea

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With gratitude to our parents

James and Frances Phelan

and

Jerome and Margaret O’Shea

TABLE OF CONTENTS

Section 1: Context of Ageing

Section 2: The Lived Experience of Ageing

Section 3: Health Approaches to Older Person Care

Section 4: Emerging Horizons

LIST OF TABLES

LIST OF FIGURES

PREFACE

‘we thread the needles eyes – and all we do all must do together’
—W.B. Yeats

By 2050, the global population of older people is projected to more than double in size. Some countries are ageing more quickly than others. The World Health Organization (WHO) (2017) *Global Strategy on Ageing and Health and Global Strategy and Action Plan on Ageing and Health* advocates for major reform to health care systems to enable healthy ageing across the life course. How we value and support older people in the years ahead will determine the health and wellbeing of this fastest growing demographic worldwide. We need to recognise the important role older people have played and continue to play in our lives and society today. Central to this will be data production and analysis, public health initiatives, policy and multi-sector collaborations. This frames the backdrop against which this book was conceived, namely, to provide an update, account and insight into some of the work being done around the world that will enable and empower our societies become age-attuned, age-accommodating and age-friendly. In tandem with this, we must ensure that societies continue to demonstrate dignity, respect and compassion for older people.

Public health initiatives have contributed to delaying the onset of many diseases and actively treating others. This success has allowed life expectancy to increase. A baby born in 1900 could have been expected to live until they were 50, while a baby born today has a 50% chance of reaching the age of 100. Ageing is not an abstract concept; in today’s world we will all spend a longer time living and a shorter time dying. Growing up and growing old are important life transitions, and are not always experienced in an unproblematic way. Some of these concepts were addressed by Galen, writing over 2000 years ago, where he identified the importance of a healthy youth as a basis for robust old age–even then he noted the benefits of exercise and a healthy diet as a road to optimising the ‘healthspan’ (Burnstein and Finch, 2018).

Our modern world is evolving into a forward thinking and progressive society. However, we must also work towards becoming a just society. We must ensure that the online digital and i-cloud dominated tech-world is accessible and not simply the prevail of younger people. In many countries, there are dramatic transformations in everyday life. For example, banking and insurance transactions now require computer literacy while access to health and social care supports occurs only by conquering multiple complex medical and legal forms. Consequently, the practicalities and rapid change of day-to-day living may not be easy to negotiate. We must become better advocates for the requirements of all people as ageing occurs. We must learn to make our ‘modern world’ easier to live in and more considerate. So, in the forthcoming ‘e Tech’ dominated world we live in, we must be inclusive and responsive, promoting an intergenerational approach to enhancing health for all members of society. In particular, we must not over complicate access to social and health care supports, and we must simplify the processes that access care.

Every country has challenges that are unique to them, but in some, there are common experiences. We need to learn from and share these experiences with each other, so we do not have to ‘reinvent the wheel’. Among the challenges are the capacity of health and social care to support older people at home in the community and also, to facilitate their return home quickly and efficiently from the hospital and rehabilitation after illness, injury or surgery. This is a growing challenge both organisationally and financially that needs to be addressed around the world. As a society, deciding how we value, support and honour older people will be the legacy we leave when those in the future look back on our early twenty-first century work. What legacy will they see? We hope this book can contribute to making that legacy a positive one, by adding to your knowledge, in addition to providing you with the additional information that aids you in your advocacy and the work that you do.

Diarmuid O’Shea and Amanda Phelan

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This book began with a meeting to discuss how we could bring together foundational knowledge on ageing in the twenty-first century. While there are many contemporary aspects of ageing, we chose particular topics which could provide context, lived experience, health care directions and emerging horizons. The book would not be possible without the generous contributions of experts in the area of gerontology; for this we are truly grateful.

Ageing is one of the huge successes of the twenty-first century and we celebrate this. We also recognise the multiple people who enhance the daily lives of older people. These are the true ‘unsung’ and often unseen heroes. They are comprised of family, friends, neighbours and communities. Their contributions must never be underestimated or overlooked. In addition, we recognise the dedication of professionals and representative organisations who work with and advocate for older people. Without such commitment, older people’s quality of life would be more challenging and impoverished.

Finally, we recognise that without our own family and friends, this book would have been a more difficult journey. Thanks to Gary Murphy, Amy Lee, Aoife Murphy, Jack Murphy and Mary O’Shea for all their support and encouragement.

ABBREVIATIONS

2015 Act	Assisted Decision-Making Capacity Act, 2015
AAI	Active Ageing Index
ABAM-MF	L'Action Bénévole dans la lute contre la Maltraitance Matérielle et Financiére envers les aînés (Volunteering to Counter Material or Financial Mistreatment of Older Adults)
AChIs	Acetylcholinesterase Inhibitors
AD	Alzheimer's Dementia
ADAS-cog	Alzheimer's Disease Assessment Scale-cognitive subscale
ADC	AIDS dementia complex
ADL	Activities of Daily Living
AHD	Advanced Healthcare Directive
AMU	Acute Medical Unit
ANP	Advanced Nurse Practitioner
AP	Atlantic Philanthropies
BGS	British Geriatrics Society
BNI	Befriending Network Ireland
BP	Blood Pressure
BPSD	Behavioural and Psychological Symptoms of Dementia
cANP	candidate Advanced Nurse Practitioner
CAPI	Computerised Data Collection in the Home
CAS	Complex Adaptive System
CEU	Continuing Education Units
CGA	Comprehensive Geriatric Assessment
CHO	Community Healthcare Organisations
CPD	Continuous Professional development
CRT	Cognitive Rehabilitation therapy
CSO	Central Statistics Office
CSPD	Clinical and Strategy Programmes Division
CST	Cognitive Stimulation Therapy
DH	Day Hospital
DLB	Dementia of the Lewy body type
DOH	Department of Health
ECHR	European Convention on Human Rights

ED	Emergency Department
eFI	electronic Frailty Index
e-HR	electronic-Health Record
ELSA	English Longitudinal Study on Ageing
EOL	End of Life
EPA	Enduring Power of Attorney
ESRI	Economic and Social Research Institute
EU	European Union
FDA	Food and Drug Authority
FTD	Fronto-temporal Dementia
GP	General Practitioner
GRACE	Guided Care programme and the geriatric resource for assessment of elders
GREAT	Goal-oriented cognitive Rehabilitation in EArly sTage dementia
HaPAI	Healthy and Positive Ageing Initiative
HEI	Higher Education Institute
HRS	Health and Retirement Studies
HSE	Health Service Executive
IADL	Instrumental Activities of Daily Living
ICOPE	Integrated Care for Older People
ICPOP	Integrated Care Programme for Older People
ICPSR	Inter-University Consortium for Political and Social Research
ICT	Integrated Care Team
ICTs	Information and Communication Technologies
IHF	Irish Heart Foundation
IHI	Institute for Health Improvement
IMD	Index of Multiple Deprivation
ISDs	Integrated Service Developments
ISSDA	Irish Social Science Data Archive
LGBT	Lesbian, Gay, Bisexual, Transgender
LGBTQ	Lesbian, Gay, Bisexual, Transgender, Queer/Questioning
MDT	Multi-Disciplinary Team
MIPAA	Madrid International Plan of Action on Ageing
MMSE	Mini-Mental State Examination
MOA	Mistreatment of Older Adults
NCPOP	National Clinical Programme for Older People
NGO	Non-Government Organisation
NHS	National Health Service
NICE	National Institute of Clinical Excellence

NMDA	N-methyl-D-aspartate receptor antagonist
NPO	Non-Profit Organisations
ONMSD	Office of the Nursing Midwifery Services Director
PACE	Program of All-inclusive Care of the Elderly
PCT	Primary Community Care Team
PHI	Private Healthcare Insurance
PI	Principal Investigator
PRISMA	Program of Research to Integrate the Services for the Maintenance of Autonomy
QID	Quality Improvement Division
RABQ	Réseau de l’action bénévole du Québec
RANSAM	Random Sample
RCPI	Royal College of Physicians of Ireland
RCT	Randomised Control Trials
SCQ	Self-Completion Questionnaire
SEP	Socioeconomic Position
SGS	Specialist Geriatric Services
SGT	Specialist Geriatric Team
SGW	Specialist Geriatric Ward
SHA	Shared Housing Arrangements
SHARE	Study of Health, Ageing and Retirement in Europe
SIPA	Integrated Care System for Older Adults
TILDA	The Irish Longitudinal Study on Ageing
UCLA	University of California, Los Angeles
UDHR	Universal Declaration on Human Rights
UK	United Kingdom
UN	United Nations
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
US	United States
USA	United States of America
VaD	Vascular Dementia
WHO	World Health Organization
WMTY	What Matters To You

SECTION 1:

CONTEXT OF AGEING

CHAPTER ONE

SETTING THE CONTEXT

AMANDA PHELAN AND DIARMUID O'SHEA

Within the twenty-first century, we are witnessing an unprecedented demographic change in the ageing of the human race. Population composition is based on three variables: migration, fertility and mortality (United Nations, 2017). Changes in these variables have led to significant shifts in demographics, particularly related to ageing. The average life expectancy in the world has more than doubled since the 1900s (Roser, 2018). For example, in 1960 life expectancy was just 53 years, however by 2016, it had risen to 72 years (World Bank, 2018). Furthermore, this demographic trend is anticipated to continue, with the United Nations (UN) (2017) projecting a rise of those over 60 years from 962 million in 2017 to 3.1 billion in 2100 which also reflects a rising proportion of people over 60 years in the general population.

The concept of old age is a social construction, with many understandings linking this to the chronological age of 65 years and frequently to the age of retirement. This 'marker' can be traced to the influence of Otto von Bismarck who, fearful of the rising popularity of socialism in Prussia, introduced a rudimentary form of old age pension for those over 65 years. Other 'markers' are also used. For example, the World Health Organization (WHO) and the UN use 60 years as the gateway to old age. WHO (2002), however, recognises that using chronological representation is not always an accurate method of the ageing process. Moreover, as life expectancy increases, so too has the need to diversify understandings of old age. In 1974, a seminal publication by Neugarten argued for recognition that health status, economic status and other characteristics vary within old age and, using aggregate data on older populations in the United States, pointed to two sub categories: the young old (55 years to 74 years) and the old-old (75 years and over). Binstock (2002) contends that this has been erroneously translated into age categories, with adjusted young old (65-74 years) and older old as 75 years and over. This resonates with the concept of the third age (associated with the work of Neugarten) and fourth age, which is associated with the work of Laslett (1994). The age of 80-85 years is viewed as the general transition period from third to fourth age (Kydd et al., 2018). The third age is associated with active and successful ageing, autonomy and being able to pursue interests, while fourth age is associated with dependency and decline. In essence, this reflects a bio-medical understanding of ageing and concurs with Nature's (a highly influential academic journal) definition as stated below:

> 'Ageing is the process during which structural and functional changes accumulate in an organism as a result of the passage of time. The changes manifest as a decline from the organism's peak fertility and physiological functions until death.' (Nature 2019: webpage)

There continues to be much discussion as to what constitutes 'health' since the 1948 definition by the World Health Organization of 'physical, mental, and social wellbeing, and not merely the absence of disease and infirmity' (WHO, 1958). While clinical teams access and plan the care of individuals, public health focuses on populations or subgroups of the population and their health and wellbeing. While there are multiple aspects of ageing, age is a risk factor for declining health. A recent publication on integrated care for older people emphasises a comprehensive management of health decline, the management of geriatric syndrome and supporting caregivers (WHO, 2017a). However, ageing is much more than mere bodily decline. It can encompass stages of life change, such as those proposed by Erikson (1964), who identified seven developmental stages from birth to old age. Being 65 years and older was seen as a stage of maturity enabling the virtue of wisdom but also as a time of potential psychosocial crisis-ego versus despair. Ageing is also about celebrating age and its diversity and is also associated, in more recent times, with fostering successful ageing typified by avoiding disease and disability, high cognitive and physical function, and engagement with life (Rowe and Khan, 1997). Within all these diverse interpretations of ageing, this book offers a macro-overview of contemporary ageing in the twenty-first century. The book chapters each identify carefully selected and important aspects within context, the ageing experience, health and environment (physical and social).

Chapter two, by Turner and Kenny, looks at the contribution that longitudinal studies can make to collecting and documenting critical data on populations that can inform policy, health, wellbeing and planning. The *WHO Global Strategy on Ageing and Health* (2017b) speaks to fostering the functional ability of older people. We must align our health systems to the needs of the older populations that they will increasingly serve. You can only achieve these objectives if there is current relevant data and data that is nationally specific. The *WHO Global Strategy and Action Plan on Ageing* emphasises this. Census data and longitudinal studies afford some approaches that enable the collection and usefulness of such relevant data. One such study, The Irish Longitudinal Study on Ageing (TILDA), discussed in detail in chapter two, collects information on all aspects of health, economic and social circumstances from a cohort of Irish people aged 50+ years once every two years. The chapter outlines the values and methods of exploring the causes and consequences of biological ageing within the context of complex environmental influences. While outlining the challenges around the design and sustaining longitudinal studies of this nature, the chapter clearly emphasises the importance of collecting data in large samples in different countries, enabling national comparisons and, as an important follow on, how these data can inform policy and practice. The chapter also highlights the contribution that older people make in society today. It explores how health, social, economic and environmental domains contribute to age-related heterogeneity and highlights the value of engaging in healthy behaviours across the life course. Finally, Turner and Kenny remind us that Health and Retirement Studies (HRS) will play a very important role in building on our understanding of population-level strategies that will enable healthy ageing.

Chapter three examines the issue of intergenerational relations and their importance in an ageing society. Lowenstein and colleagues point to the application of generational intelligence to explore positive and negative aspects of communications and relationships between older and younger adults. The chapter commences with a consideration of intergenerational relations within families. Families operate in particular ways as systems, which interact with formal services such as health where ageing can be experienced positively or negatively. In an era of modernity, family structures have changed leading to a more complex experience and an altered system of family support, which demands a concurrent focus on attuning public policy and the state’s role. The authors advocate the use of generational intelligence to guide actions and provide steps to identify, recognise and move towards inter-generational accommodation and positive ‘othering’, within and between thinking and enabling present and lifetime centredness.

Chapter four presents an important consideration for ageing populations, that of decision-making capacity. Statistics demonstrate that as individuals age, the risk of cognitive challenges increases (van der Flier and Scheltens, 2005). In this context, it is important that the will, preference, values and beliefs of the older person are protected. Rickard-Clarke charts Ireland's legislative transformation to support older people's enjoyment of autonomy and human rights under various human rights instruments such as the European Convention on Human Rights (Council of Europe, 1950) and the United Nations Rights for Persons with Disabilities (2006). The chapter examines the implications of the previous legislation, the Lunacy Regulation Act (1871), pointing out its archaic and limiting impacts on people whose capacity is in question. Similar to legislative advances in other countries, the new Assisted Decision-Making Capacity Act, enacted in Ireland in 2015, marks a watershed in the protection of autonomy of individuals. The new legislation moves from a paternalistic, medical model based on a status approach to capacity to a rights-based approach which is underpinned by a functional approach to capacity. The chapter examines the guiding principles for the application of the act, the various intervention options if capacity is at issue or likely to be at issue as well as charting the protective legal instruments that can be put in place in advance of capacity challenges (Enduring Power of Attorney and Advance Healthcare Directives). Rickard Clarke concludes with the sage acknowledgement that such legislative transformations need a shift in culture from paternalism to defending each individual's right to self-determinism, regardless of age or decision-making capacity.

From Mary O'Rourke, in chapter five, we hear the voice of an older person regarding their expectations and experiences of life, health and social care. Her voice is central to articulating a 'new' vision for policymakers. Older people often report feeling invisible and unheard in society particularly in relation to health care services. Knowing what matters most to the person/patient enables us to set the compass of care in the right direction. More work needs to be done to reduce the stigma of age and the sense of invisibility that older people feel. This very personal account from O'Rourke captures why this voice is so important. Her account teaches and reminds us that age is a construct that should not represent years but love of life. We see the thoughts of one older person on ageing through personal and reflective accounts of journeying through life. In this way, we can appreciate the person and not the age, the rich and diverse life history and the need to see beyond the patient, the disability or the physical presentation. Only then can we facilitate human flourishing for everyone. She observes, 'My heart and mind remain that of a young woman.' A doyenne of the Irish political world at a time when female political representatives were few and far between, O'Rourke reflects on the remarkable contributions she has made and continues to make in her own personal life in shaping society and politics in Ireland today. She does this with an extremely personal and honest reflection on her life's journey to date, talking openly about love, loss and loneliness. Her perspective on ageing is a tour de force. The chapter emphasises the importance of interests, education and good self-care. Echoing, Lowenstein and colleagues' chapter, readers are advised on the greater acceptance of 'the mingling of ages' and of not needing to 'constantly rush, rush, rush'. Within O'Rourke's reflections, we can see how dealing with infirmities and frailties are individually experienced and her personal experience of the death of loved ones. In interpreting and representing the concept of 'What matters to you', we gain an insight and understanding of older people actively living in our societies today, which is the focus of this book. It reminds and inspires us all in the efforts we are making to improve care and support structures for good ageing experiences. Moreover, it highlights why we must continue to work towards a just society and explore ways of making our societies more age accommodating, age attuned and age friendly.

In chapter six, Moynihan and Loughran pick up on one of the themes of chapter five, that of loneliness. Loneliness is poorly understood and its impacts on quality of life and health are under-recognised by policymakers and the general public as a whole. Loneliness can affect anyone, of any age group, but its impacts and contributing factors may be most challenging for older people. The cycle of loneliness and the influence on health and quality of life in older age is made even more challenging by the lack of support and infrastructure in place. There is significant variation across the world in how loneliness is being tackled as a societal issue. The chapter begins to address some of the challenges and brings a focus on why tackling the issue of loneliness is so important. Moynihan and Loughran reiterate the need for a greater focus on research, policy and initiatives to combat loneliness and the positive impacts this will have on physical and mental health.

Browne (chapter seven) examines the concept of advocacy and its application to support older people, with particular reference to safeguarding. Similar to points made by Rickard Clarke, advocacy is underpinned by a human rights approach and is an integral resource to enable a good quality of life. The chapter begins by elucidating why advocacy may be needed for older people and how advocacy can be defined. Browne contends that advocacy's objective is to empower older people to have the information needed to make an informed decision based on their rights, acknowledging the right to take a risky decision or to be mistaken. Recognising the implicit and explicit potential for bias in advocacy in families and professionals, it is argued that independent advocacy is the desired standard and an advocate's role is within the framework of supported decision-making. For people who have decision-making capacity challenges, such as those with dementia, non-instructed advocacy takes cognisance of the individual's will preference, values and beliefs through accumulating knowledge of the person, their lives, choices and so forth. Browne concludes by arguing for the need for a new rights-based narrative to be imbued into our culture and an understanding of the context of each older person's life situation.

In chapter eight, Shelley and O'Shea discuss the need for a more holistic approach to health services, incorporating public policies, environments and communities which 'make the healthy choice the easier choice' for individuals, as well as reorienting health services towards prevention. Many health systems are designed to diagnose, care for and cure those with acute conditions and have not adapted to the longer-term systems and programmes required to prevent, manage and minimise the consequences of chronic conditions, multi-morbidity, frailty and functional decline. Allied to this, there is a belief that care in the community is less costly than care in the acute care setting. While those requiring acute hospital services should be cared for in an appropriate setting and only for as long as such care is required, high quality care in the community is unlikely to be deliverable at the low cost which is frequently implied in public discourse. Policy responses (informed by studies including longitudinal studies) are essential to manage the macroeconomic impact of the demographic transition. Shelley and O'Shea argue that these policies must include health promotion and disease prevention to reduce the population burden of non-communicable diseases and supports to maintain independence and community living.

In chapter nine, Phelan examines the concept of person-centred care. Similar to the focus of Rickard Clarke, O'Rourke and Browne, person-centred care is about creating therapeutic, helpful partnerships with people. The turn to person-centred care within healthcare is a relatively recent phenomenon and can be observed in many different countries. Person-centred care is underpinned by the recognition of the limitations of a paternalistic, bio-medical focused care system which creates hierarchies of power and is based on objective facts, while minimising the subjectivity of individual experience. In contrast, person-centred care views individuals as self-determined with leading roles in areas of decision-making, care planning and implementation, continuity in care and in transitions of care. The philosophical underpinnings, definitions, models of care and outcomes of person-centred care are presented and the evolution of systems to integrated healthcare which enables a scaffolding of coordinated care around the older person are examined. In using a person-centred approach, there is potential that the care experience is transformed from the ordinary to the extraordinary.

In chapter ten, Timmons and colleagues review the topic of dementia, one of the major challenges we will need to meet in the years ahead. Globally, dementia affects approximately 46 million people and, unsurprisingly, it has been identified by the WHO as a public health priority. Dementia impacts the lives of those who are affected, their families and friends. The current focus in health and social care is on supporting people to live well with dementia in their communities while we search to build on promising advances in potential pharmacological and non-pharmacological treatments. The chapter aims to provide a broad overview of dementia from diagnosis, treatment, respite and palliative care over the course of this chronic long-term condition. Separate from the personal cost to health and wellbeing, dementia exerts significant pressures on health, economic and social care systems. The economic burden of dementia currently ranks higher than stroke, heart disease and cancer combined, but healthcare funding allocations for dementia are significantly lower than each of these groups. Historically, there has been under-diagnosis of dementia, linked to stigma, poor awareness and indeed therapeutic nihilism. Improving awareness, while at the same time progressing with a diagnosis at a pace the person is comfortable with, is an important balancing act. In conjunction with this, how the diagnosis is disclosed–delivering the diagnosis while at the same time understanding the emotional impact of the disclosure on the person and their family–are all crucial concerns as all these factors will impact on how a person and their family engage with services. The chapter also discusses pharmacological and non-pharmacological methods of managing the cognitive and non-cognitive symptoms of dementia, often termed behavioural and psychological symptoms of dementia (BPSD) or more recently, responsive behaviours.

Health and social care design that seeks to strengthen continuity of care, reduces fragmentation and improves the overall experience and outcome for the older person is a core support to the aims of WHO. An ‘Integrated Care’ agenda needs broad base policies that underpin health and wellbeing in older populations and reflect changing needs, not just in health and social care, but in the broader multi-sectoral agenda. This, along with the fundamental components of integrated care and key elements of clinical care pathways that enable and support integration, such as a single transferrable record, home-based care, technology and case management, are highlighted from an Irish perspective by Kennelly and Harnett in chapter eleven. Designing services for people who have only one health challenge and are fully independent does not make sense in the context of an ageing population. Put simply, we should be designing flexible services for people who may have many complex morbidities and who may not be independent. In the discourse around healthcare, we all too often use ageist and inappropriate language. Examples such as 'bed blocker' and 'delayed discharge' are commonly used and imply a negative impression of older people. Such language distracts and sends out the wrong message entirely. It facilitates the shifting of focus and positions the older person using the health service as the 'problem' or as 'using the service inappropriately', rather than acknowledging where progress needs to be made. The construct of integrated care is shaped by a combination of perspectives held by users of various services, service managers, policymakers, academics, care professionals and carers. Consequently, there is great complexity associated with articulating what integrated care should deliver, who should benefit and what exactly those benefits are. However, systems of care which reflect a person-centred approach to integration are fundamentally key to service uptake and success. Kennelly and Harnett advocate that changes that support integrated care must cross the spectrum from local change practice right through to international health and social care practice.

Chapter twelve, by Lang and Hoey continues this theme. Healthcare systems need to adapt to meet the needs associated with the demographic changes that are occurring around the world. WHO has identified and promoted interdisciplinary collaboration as a strategy to strengthen and optimise health care systems and improve patient outcomes. This chapter describes the approaches taken by the National Clinical Programme for Older People (NCPOP) in Ireland to enhance the Irish Health services' capacity to improve wellbeing and healthcare for older people in Ireland. It must be emphasised that no single agency working on its own can achieve this. Transformation requires societal will and governmental policy support along with all voluntary and statutory agencies working together to do this. Getting to that cohesive think, plan and act stage is surprisingly difficult. How a society treats its most vulnerable, and among those vulnerable are frail older people, is a very good barometer of how we value what matters most in our society. In years to come, when we review our progress in improving health, wellbeing, social policy and care, we should be able to witness the impact of enhancing support for ageing.

Chapter twelve also focuses on how continuing education and professional development have important parts to play in improving care by implementing the most up-to-date evidence base while concurrently enhancing knowledge and skills. Within this context, the National Frailty Education Programme was developed. This innovative education programme has the capacity to be a key lever for change and support the introduction of new ways of working to improve health care outcomes for older people. Most health care for older people is provided in their community but acute deterioration in health will require referral to hospital. Communities and hospitals need to be resourced and prepared to meet this growing need. The chapter focuses on the role played by the National Clinical Programme for Older People in Ireland in addressing this challenge and meeting the growing need.

A major societal concern globally is that of safeguarding older people. Phelan, in chapter thirteen, discusses the topic of elder abuse. International studies have demonstrated that older people are abused in various ways: physical abuse, psychological abuse, financial abuse, sexual abuse and neglect. In more recent literature and scholarship of elder abuse, a rights based, public health approach has underpinned legislation, policy and practice responses within preventative and intervention programmes. The consequences of older people being abused are many and can impact physical and psychological health as well as mortality rates and premature admission to nursing homes. The chapter considers issues related to the maltreatment of older people, in the context of definition, theory, risk factors and interventions. The chapter concludes by pointing to the need for inter-agency and inter-disciplinary responses, which are flexible enough to respond to the complexities of the individual older person's experience of abuse. In addition, it is argued that further research, which involves older people in the co-design and generation of findings, has the potential to deepen understandings and offer enhanced interventions which acknowledge issues of diversity such as differences in the experiences of abuse due to geography, gender, culture, environment, sexuality and decision-making capacity.

Continuing on the theme of elder abuse, in chapter fourteen, Beaulieu and colleagues examine the management of field volunteers engaged in non-profit organisations (NPOs) dedicated to counter mistreatment of older adults (MOA). The discussion is drawn from a Canadian research study investigating the actions of NPOs engaged in countering the material and financial mistreatment of older adults. The chapter describes a multiple-case study which was conducted within five Canadian NPOs dedicated to addressing the mistreatment of older adults. Beaulieu et al.

investigate the perspective of salaried personnel and field volunteers on the management of volunteers at four stages: recruitment, orientation, support and supervision, as well as appreciation. Findings have potential relevance beyond the focus of maltreatment to fostering social capital within NPOs to areas of enhancing the volunteering experience and quality of service.

In chapter fifteen, Doron argues that there is a gap in current conceptualisation of age theory which is bridged through ageivism. Ageivism, which holds similar fundamental tenets as feminism and socialism, is defined as a call to action to emancipate older people from the oppression of ageism. This is achieved by the argument that ageism in society needs to be actively addressed; age, as a social construction, requires a transformation which includes attending to the ideological aspects of political identity, social justice and a rights based approach. Doron acknowledges that ageivism is conceptually in its infancy, but points to the potential influence of ‘grey power’ which has received scant attention to date. Doron concludes the chapter by acknowledging the potential of ageivism in contributing to a robust ideological basis for the integration of the science of ageing and the movement of older people.

Chapters sixteen and seventeen discuss environmental design and ageing. In chapter sixteen, van Hoof and colleagues examine how innovative environmental design in the home can provide tailored ageing in place spaces. Using the example of a Dutch social housing association, the authors describe the generation of new communities around the building structure itself rather than simply providing occupational therapeutic environments. The chapter points to the approach of individual self-management and community responsibility for care at home (termed communalisation). van Hoof and colleagues use philosophical explanations from both Martin Buber and Paul Ricoeur to support the development of these communities which focus on how environmental design can support caregiving and the ideals of mutuality in a tangible way. In particular, it is argued that social housing associations such as *Habion* have rejuvenated buildings with a specific focus on older people’s needs (applying Mazlow’s (1943) hierarchy of need), transcending mere physical accommodation to creating buildings that provide autonomy, a meaningful life with a sense of belonging and safety even when there is evolving health decline. Consequently, the aim is to promote ‘home’ through the application of place attachment theory. Thus, existing buildings are retrofitted, redesigned and co-designed with the potential of adaptation for declining health status to enable ageing in place, yet promote intergenerational living. Furthermore, each project is unique and is inductively and inclusively constructed around the bespoke needs of that particular community. As an example, the application of this model is illustrated in one case study example.

Chapter seventeen, also by van Hoof and colleagues, details how the macro-community environment can enhance the quality of life for older people. As population demographics change, the authors argue that accommodation within living spaces needs to facilitate ageing in place, in other words, to foster active ageing within integrated and inclusive communities, to be dynamic and adapt to the evolving needs as well as incorporating participation in planning from older people themselves. An important supporting element in advancing urban ageing spaces is robust public policy. In addition, the current and potential further use of technology is discussed with a focus on the development of smart homes to support independent living and assist in managing households and health monitoring. Using the Netherlands and Poland as case studies, the chapter details how ageing environments have been underpinned by the foci identified in the domains of age friendly cities (WHO, 2002). The chapter concludes by arguing the need for the development of public-private partnerships in the re-imagination of urban spaces to meet evolving needs and create sustainable, adaptive living environments which are age friendly.

Ylänne, in chapter eighteen, examines how the media portrays older people. There are a number of defined categories and representations of ageing that are used in the media. The chapter examines how older people are specifically positioned in newspapers, magazines, advertising and film. Ylänne points to the varying implicit stereotypes in different media types. Positive positioning is evident in film, advertising and magazines, while newspaper discourses tend to present old age in a negative stereotypical form. While these differences are apparent through the research studies, it is important to recognise their influence on public perceptions of ageing. In conclusion, we are cautioned to be critical of such representation, which is heavily dependent on issues of editorial decision, advertising focus or romanticised embellishment.

In conclusion, as demonstrated in chapters two to eighteen, scholarship on older people has greatly diversified in the twenty-first century. It is important that multiple insights are generated to understand the concept, context and the experience of ageing. In this way, we can ensure older age is a period of human flourishing, where rights are automatically recognised and defended and health and social care, environment, intergenerational relationships and supportive systems are continually fostered and revised according to the dynamics of changing landscapes of old age needs and experiences. As Betty Friedan (1994:4) observes:

> ‘Ageing is not lost youth but a new stage of opportunity and strength.’

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CHAPTER TWO

LESSONS FROM THE IRISH LONGITUDINAL STUDY ON AGEING

NIALL TURNER AND ROSE ANNE KENNY

Introduction

Ageing is one of the major demographic challenges of this century. Longer lives bring great opportunities, including the possibility of rethinking how our entire life course might unfold. But these opportunities are very dependent on people maintaining good health and quality of life into older age. Unfortunately, evidence suggests that many older people today experience poor health trajectories. Yet, the health issues that confront older people are often associated with chronic conditions that can be prevented or delayed by engaging in healthy behaviours across the life course. Other health conditions can be effectively managed, especially if they are detected and treated early. And for older adults with significant declines in capacity, supportive environments and integrated care systems can ensure that they live lives of dignity and continued personal growth. *Longitudinal studies* research representative cohorts of people above a given age, with comprehensive data collected at regular intervals, in domains which include not only health, but also social, economic and environmental, in order to determine factors which contribute to adult health and to age-related heterogeneity. The purpose of such research is to better understand the ageing process and the contribution that life course events and environmental factors make to this process. When such information is collected in large samples and in different countries, it enables cross-national comparability and informed recommendations for policy and practice. The societal and individual consequences of natural disasters or other events occurring during the course of study, such as the dramatic economic downturn in Ireland in 2007, also afford unique experimental opportunities.

In Ireland, there is regional variation in life expectancy at birth and at age 65. Among men the lowest life expectancy at birth is in the Mid-West – 76.3 years, the highest was reported in the Mid-East and Midland regions at 77.2 years. However, these regional findings were not maintained for life expectancy at 65 as the Dublin region has the highest life expectancy of 16.9 years, the Mid-West the lowest life expectancy of 16.1 years. For women, the shortest life expectancy at birth and at age 65 years was in Mid-West – 80.4 years and 18.7 years respectively. The longest life expectancy was in women in the West at 82.7 years at birth and 20.6 years at age 65 years (https://www.cso.ie/px/pxeirestat/Database/eirestat/Irish%20Life%20Tables/Irish%20Life%20Tables_statbank.asp?SP=Irish%20Life%20TablesandPlanguage=0). Cohort studies, such as The Irish Longitudinal Study on Ageing (TILDA), offer a vehicle to understand such variables.

Life Course and Ageing

A large body of research links disadvantaged socioeconomic position (SEP) during early childhood with poorer health in later life (Hayward and Gorman, 2004; Melchior et al., 2007; Power et al., 2007). It is debated whether the association between disadvantaged SEP in early life and poor health in later life reflect a direct physiological scarring effect of early childhood exposures or that disadvantaged SEP in early life is a robust marker of continuing socioeconomic disadvantage that erodes health over a span of years (i.e. accumulation). Recent work from TILDA suggests that social mobility (i.e., change in socioeconomic circumstances over the life course) can compensate for low SEP in childhood, at least with respect to musculo-skeletal development (McCrory et al., 2018).

A number of candidate processes and mechanisms provide intermediate frameworks linking SEP and healthy ageing, including telomeres (Robertson et al., 2012), epigenetics (Cunliffe, 2016) inflammation (Aiello and Kaplan, 2009) and allostatic load (Seeman et al., 2004; Seeman et al., 2004). TILDA's research supports allostatic load i.e. the lifetime accumulation of disruption to fundamental physiological regulatory systems, as the strongest candidate for the understanding of the mechanisms through which social adversity gets 'under the skin' and suggests that these processes are not immutable but rather are responsive to changes in social and economic circumstances and to the life course.

Longitudinal Studies and WHO Healthy Ageing Strategy

Given the World Health Organization's (WHO) conceptualisation of Healthy Ageing as being much more than the absence of disease, longitudinal research, such as the TILDA study affords the necessary support to compliment the comprehensive WHO guidance on how to foster the functional ability of older people to be and to do what they value (*WHO Global Strategy on Ageing and Health*, 2017). To achieve this the strategy calls for action to develop age-friendly environments; to align health systems to the needs of the older populations they will increasingly serve; and to develop sustainable and equitable systems of long-term care. Only in the context of nationally specific and current data can these objectives be achieved. Continuous multimodal observations allow policy to engage in flexible adaptation to demographic change and needs. Underscoring the vital role of longitudinal data collection, the WHO 'Global strategy and action plan on ageing' emphasises the importance of improved data, measurement, and research, and involvement of older people in all decisions that concern them. Longitudinal studies afford one of the best approaches to the collection of pertinent information. Many countries employ such data collection strategies and others are developing such processes. TILDA collects information on all aspects of health, economic and social circumstances from people aged 50+ years once every two years. In this chapter we will provide an overview of TILDA data measurements and research and the policy implications of the data.

Demography–Ireland

The 2016 Census recorded Ireland's population as 4,761,865. Of this population 2,985,781 live in urban areas. The population of Dublin city and suburbs accounts for 39.3% (1,173,179) of this total. The populations of the four cities of Cork, Limerick, Galway and Waterford were 208,669; 94,192; 79,934 and 53,504 respectively. The population of Irish towns of varying size accumulated to 1,376,303. The remaining 1,776,084 of the population are categorised as living in a rural environment. The average age of the population in 2016 was 37.4 years

Changes in Demography

According to the 2016 Census Ireland's population grew by 3.8% over 5 years. Overall, there was a rise of 1.3 years in the average age of the population to 37.4 years. Four of the 18 age bands used by Census 2011 and 2016 showed a decline-the 0-4 age group and the three bands covering those aged 20-34. In contrast the size of each age band covering the population aged 50 years and older grew in the same period. Accumulatively the size of the population 49 years and younger increased by 240 people whereas the >50 years population increased by 173,373 to 1,446,460. There are three main reasons for this difference in growth by age–reduced birth rates, net outward migration; and longer life span. Growth was greatest in men >85 years with a 24.8% increase in this category. The Central Statistics Office (CSO) projects that by 2046 life expectancy at birth will have increased to 85.1 years for men and 88.5 years for women. The impact of this increased life expectancy will dramatically change the demography of the Irish population (Figure 2.1). The proportion of the Irish population over the age of 60 years will more than double over the next 30 years (Figure 2.2) (CSO, 2013).

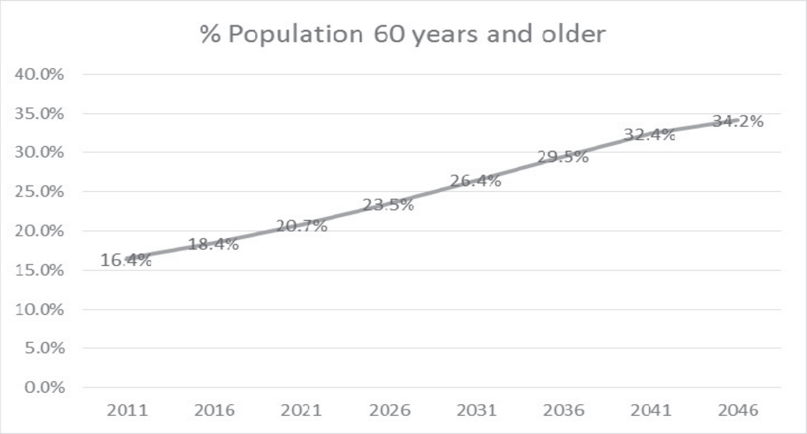


Figure 2.1: Projected per cent of Irish population 60 years and older 2011-2046

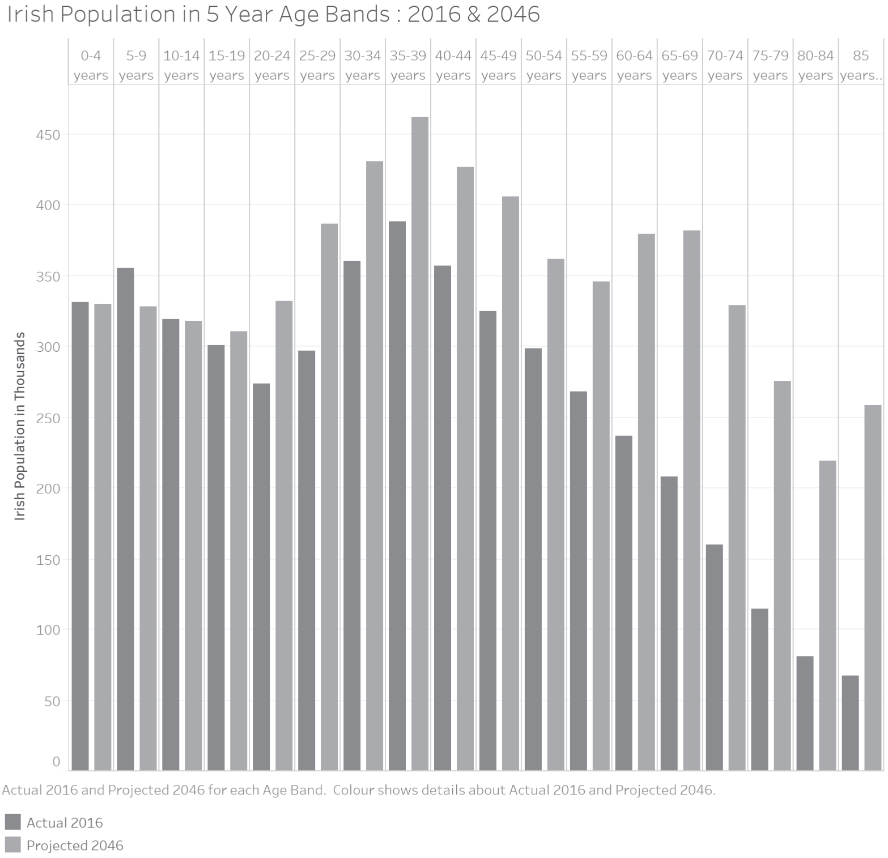


Figure 2.2: Size in thousands of 5-year age bands of Irish population from Irish Census data 2016 and CSO projection of 2046 population

TILDA-the History

Professor Rose Anne Kenny is the founding Principal Investigator for TILDA. Pilot work for the study commenced in 2006 and continued for a further 3 years, supported by a grant from Atlantic Philanthropies (AP)–a philanthropic organisation which has greatly contributed to the age-related research landscape in Ireland (Collins, 2017). This was the first time that large representative longitudinal data was collected from adults in Ireland and as such the study had many challenges. As a consequence, TILDA was responsible for the introduction of new research infrastructure to Ireland, which has since not only facilitated the TILDA study but greatly enhanced the Irish research landscape: for example, because there was no extant panel from which to select participants, a geo directory of addresses was used to randomly select household addresses. This created a unique new panel of participants. TILDA was the first to introduce computerised data collection in the home, (CAPI); this involved training of a new workforce of survey interviewers (circa 100) using face-to face-interviews coupled with computerised data capture and web-based download for centralised processing. For the first time in Ireland, blood samples were collected from a large representative sample in the home or at a health centre and transported to a central Dublin laboratory within 24-48 hours. These samples are available for biomarker and genetic analyses. New computerised systems were developed to link health centre data with other data sources.

A number of expert working groups were convened during the questionnaire and health assessment development, drawing on the expertise of gerontologists, psychologists, physiotherapists, ophthalmologists, nurses, geneticists, psychiatrists, sociologists, economists and biomedical engineers. During the pilot phase, validity and feasibility of all tests was carried out. Questions were drawn from existing international surveys on ageing–Study of Health and retirement in Europe (SHARE), the English Longitudinal Study on Ageing (ELSA) and the Health and Retirement Study (HRS). TILDA was designed to harmonise with international longitudinal studies on ageing and is part of the global ‘family’ of studies. Ensuring that the information in these studies are harmonised allows for cross-country comparisons, including lessons from policies adopted elsewhere (Shih et al., 2011). Additional new questions were developed specific to the Irish population, and in this case, each measure was piloted and validated.

TILDA was designed to provide an evidence base for addressing current and emerging issues associated with population ageing across health, economic and social systems. Before the establishment of this study, only minimal national information was available on the prevalence and incidence of disease, in addition to economic and social data, for the older population, thereby impacting policy development and programme planning. TILDA is a unique national resource which identifies trends in both health and health risks, providing an indication of threats. This includes prevalence of chronic disease, changes in health, and the accumulating burden of disease and disability at both individual and societal levels. In addition to analysing age-related changes in health, TILDA offers a rare glimpse into behaviours and developmental trends across the lifespan including the impacts of life events.

Ireland is an ideal location in which to conduct a longitudinal study on ageing. Firstly, the small geographical size permits the use of novel technologies for centralised health assessment, where objective measures of health can be undertaken to compliment self-reported health status (survey questions) and secondly, the older population is genetically homogenous and one of the youngest in Europe, offering exceptional opportunities to implement new and better prevention and treatment strategies that will improve the health of the population as it transitions into the oldest age group (85 years of age and over). Established in 2006, the study is now in wave 5 of data collection.

Sampling and Study Design

TILDA is a nationally representative prospective cohort study of the social, economic and health circumstances of 8,500 people aged over 50 in Ireland. The sampling and study design are described in (Whelan and Savva, 2013). Briefly, the sampling frame is based on the Irish Geodirectory, a comprehensive and up-to-date listing and mapping of all residential addresses in the Republic of Ireland, compiled by An Post (the Irish Postal Service) and Ordnance Survey Ireland. Participants were randomly selected using the RANSAM (random sample) sampling procedure so that each residential address in Ireland had an equal probability of selection. Community-dwelling adults aged 50 years and over and their spouses (of any age) who were non-demented and able to provide informed consent were eligible to participate.

There are three components to data collection (i) a computer-assisted personal interview (CAPI) administered by trained social interviewers in the participants' own homes (1.5 hours) which includes detailed questions on socio-demographics, health, wealth, lifestyle and social support; (ii) a self-completion questionnaire (SCQ) completed in the participants' own time designed for the collection of more sensitive information such as alcohol use and relationships, completed privately by the participant; and; (iii) a comprehensive 3-hour health assessment delivered by trained research nurses in a dedicated health centre or a modified version delivered in the participant's home. This assessment includes measures of the main domains that deteriorate with ageing, including cognition, cardiovascular function, mobility, vision, bone health, anthropometry and biomarkers (blood and hair samples). The health assessment is carried out every second wave to allow an appropriate time interval to detect subtle physical and cognitive changes.

Baseline interviews on 8,504 participants took place between October 2009 and February 2011; the response rate for eligible persons was 62%. The study represents 1 in 156 people aged over 50 in Ireland. Phase II (Wave 5 and Wave 6), commenced in 2018; replenishment of the sample aged 50-57 years will commence in 2020 (Wave 6).

The first four waves of the study (after pilot phase), were funded by the Irish Government, the Atlantic Philanthropies and Irish Life plc. Ethical approval for each wave of data collection was obtained from the Trinity College Dublin Faculty of Health Sciences Research Ethics Committee. Researchers can apply to access TILDA data through the Irish Social Science Data Archive (ISSDA) at [https://www.ucd.ie/issda/data/tilda/] and the Inter-University Consortium for Political and Social Research (ICPSR) at the University of Michigan [http://www.icpsr.umich.edu/icpsrweb/ICPSR/studies/34315]. Some variables have been removed or top-coded to maintain the anonymity of TILDA participants. The Gateway to Global Ageing offers a digital library of survey questions and identically defined variables, allowing comparison of TILDA data with population survey data on ageing obtained from several other countries [https://g2ageing.org/].

Key Findings and Publications

To date, TILDA has published extensively on a broad range of areas including cardiovascular health, mental health, cognitive function, frailty, healthcare utilisation, medications, retirement and social circumstances. In addition, normative values for cognitive, mobility, anthropometric and heel ultrasound tests have been published. A full list of TILDA publications, including those using baseline data from Wave 1, longitudinal data from subsequent waves and analysis of new measures introduced after Wave 1 are available at http://tilda.tcd.ie/publications/academic-papers/. A minimum of three topic reports are produced each year and these are complimented by limitless research reports which summarise research information for public understanding. These can be accessed from www.TILDA.ie.

To date, longitudinal data analyses have investigated determinants for changing health, including cognitive decline (Feeney et al., 2018; Donoghue et al., 2018; Feeney et al., 2016; Mosca and Wright, 2018; Robertson et al., 2016), physical decline and disability (O'Connell et al., 2018; Ryan et al., 2018; Donoghue et al., 2014; Donoghue et al., 2017;

McDowell et al., 2018; McDowell et al., 2018, Robertson et al., 2016; Briggs et al. 2018), and mood disturbances (Briggs et al., 2017, Freeman et al. 2016, Santini et al. 2016; Mosca and Barrett, 2016). Cognitive decline was associated with several risk factors including age-related cardiovascular changes (Feeney et al., 2016), perceptions of stress (Feeney et al., 2018), negative perceptions of ageing (Robertson et al., 2016), and retirement (Mosca and Wright, 2018). Data linkage using geocoded data has enabled us to examine the environmental influences of air pollution, seasonal and meteorological conditions, fluoridation and urban/rural location on health and cognitive decline in ageing. Findings include increased lung cancer in areas with high levels of radon exposure (Dempsey et al., 2018a), higher depressive symptoms in winter and in areas with higher rainfall (O'Hare et al., 2016) and improved oral health, but not bone density associated with water fluoridation (O'Sullivan and O'Connell, 2015). Living in an urban area was associated with better cognitive performance although this was moderated by disability (Cassarino et al., 2018). However, there was a U-shaped relationship between green spaces and obesity (Dempsey et al., 2018b). Linkage of TILDA to the national Primary Care Reimbursement Service prescribing database has shown that both inappropriate prescribing and prescribing omissions are common in older adults (Moriarty et al., 2017; Moriarty et al., 2015) and are associated with adverse outcomes (Richardson et al., 2015; Richardson et al., 2015; Moriarty et al., 2017).

Mental Health

The prevalence of depression is 10%, highest levels are among women, those less educated, those with long-term physical health conditions, and the youngest members of the cohort. The majority are not taking anti-depression medications (Regan et al., 2013). Depression increases the risk of cardiovascular disease by 80% following adjustment for cardiovascular risk factors. Depression is associated with orthostatic hypotension (Regan et al., 2013), lower systolic blood pressure (Briggs et al., 2017), negative ageing perceptions (Freeman et al., 2016), and alcohol misuse (Carvalho et al., 2018). Conversely, orthostatic hypotension predicts incident depression (Briggs et al., 2018). Anxiety increases the risk of cardiovascular disease but does not confer additive risk in participants with depression (Gallagher et al., 2012). Anxiety is more common among those who do not meet the physical activity guidelines (McDowell et al., 2018) and transferable between spouses through mutual influence (Stokes, 2017).

Healthcare Utilisation

Healthcare utilisation and the influencers of use has been studied using a number of approaches. Both self-assessed health status and the presence of chronic illness and/or disability are associated with an increase in General Practitioner (GP) visits. As illustrated in Table 2.1 one of the most influential factors for frequency of GP attendance is eligibility for free GP care (Hudson and Nolan, 2015). This finding was supported by subsequent research which found that the average number of GP visits increased from 3.03 per year when there was a cost to an average of 4.40 per year when they qualified for free GP care. Furthermore, the subset of the TILDA sample who lost free access to their GP between waves of data collection had a reduced attendance of on average 1.2 visits per year (Ma and Nolan, 2017). Further TILDA research identified that frailty is a significant independent predictor of utilisation of social and medical care services (Roe et al., 2017).

Table 2.1: Public healthcare eligibility and average number of GP visits (full TILDA sample)

Public healthcare eligibility	Definition	% of sample	Average number of GP visits
Medical card only	if full medical card or GP visit card, without PHI	36.4	5.8
Dual cover	=1 if full medical card or GP visit card, with PHI	16.1	5.1
PHI* only	if PHI only	36.6	2.6
No cover	if no medical card, GP Visit card or PHI	10.9	2.3

Source: Public healthcare eligibility and the utilisation of GP services by older people in Ireland. Hudson and Nolan, 2015)
**Private Healthcare Insurance*

Income

Many governments and international organisations have expressed concerns about the sustainability and adequacy of financial provision for old age (Department of Social and Family Affairs, 2002, 2010; OECD, 2013; European Commission, 2015). Adequate levels of income for retirement have been calculated by a number of studies and use a variety of approaches (Engen et al., 1999; Moore and Mitchell, 1997; Poterba, 2014, Scholz et al., 2006). One common method is calculating the fraction of pre-retirement income that is replaced by retirement income referred to as the retirement income replacement rate (Nivakoski, 2014). Research on the financial wellbeing of TILDA participants has determined that quality of life is associated with post-retirement income but not retirement income replacement rate. Furthermore, household income was influential to specific areas of quality of life – control, autonomy, self-realisation and pleasure (Mosca and Nivakoski, 2016).

Carers

For varying and complex reasons as a person ages the need for assistance with everyday tasks increases (Connolly et al., 2017). This was evident among TILDA participants with 11% of men and 14% of women reporting at least one limitation in daily activities. In those over 80 this increased to 27% of men and 39% of women having at least one everyday task difficulty (Kamiya et al., 2012).

Everyday tasks are typically referred to and categorised as activities of daily living (ADL) such as dressing, eating and/or toileting and instrumental activities of daily living (IADL) such as cooking, completing chores and/or managing medications. When the TILDA data was examined using these categories, 5% of the baseline sample had ADL difficulties only, 4% had IADL difficulties only, and 4% had both ADL and IADL difficulties. Specifically, among men in the oldest age group (age 80 and over) 9% had a difficulty with IADLs only, 7% in only ADLs, and 11% had difficulties in both categories. The rate was higher in women over 80 with 15% having difficulties with IADL's only, 7% with ADLs only, and 17% with difficulties in both categories.

The development of difficulties in completing daily activities has consequences not only for the individual but also their family, friends and the health and social services. Based on the data collected it was found that 89.5% of all carers are unpaid informal carers. Analyses shows that for TILDA respondents the source of assistance differs according to the category of daily activity difficulty. People with greater levels of dependency, i.e. with ADL difficulties, are more likely to have a spouse (50%) as a main caregiver followed by children (26%). With respect to IADL, the respondent's spouse is still the main helper (39%), however, the proportion of those who receive help from their children is higher than among those with ADL difficulties at 34%. Furthermore, for IADL difficulties 27% of people reported their primary assistance to be provided by ‘other relatives’ and ‘non-relatives’ compared to 22.7% where care is required for an ADL issue.

In total 1,017 carers were identified by TILDA respondents of whom 68% were female. Children of respondents accounted for 39.4% of carers followed by spouses at 26.8%. The time provided to meet respondent needs took an average of 67 hours per month for those with IADL difficulties compared to only 8 hours per month for those with ADL difficulties. Those with difficulties in both ADL and IADL receive on average 118 hours of informal help per month; if averaged over the week, this amounts to 30 hours per week and, therefore, represents an intense level of care inputs for this population group. Analysis revealed that only 13% (n=133) of carers were in receipt of carer’s allowance or carer’s benefit. These are available to carers providing care to individuals of all ages from the Department of Social Protection.

Contribution that Older People Make

A pervading theme which resonates at each wave of data collection from TILDA participants is the enormous contribution that adults aged 50 and over make to Irish society (McGarrigle et al., 2017). This is evident both in the amount of care provided to others and in financial and other transfers. Contrary to perceptions, the overwhelming direction of transfers of time and financial assistance is to children and grandchildren. For example, adults aged 54 years and over who have children are more likely to provide financial assistance to their children (48%) than receive financial help from them (3%). Furthermore, half of adults aged 54 to 64 years and 65 to 74 years provide regular childcare for their grandchildren for an average of 36 hours per month. This facilitates labour market participation of parents and flexibility of schedules for unanticipated events. For adults with living parents (14%), one quarter assisted their parent(s) with basic personal care while 43% provided help with other activities such as household chores, errands, shopping, and transportation. Half of older adults also provided financial help to their parent(s). Outside of supporting family, adults aged 50 years and older in Ireland are the backbone of our volunteer structure with more than half (53%) of older adults in Ireland having volunteered at some time during the previous year with 17% doing so at least once per week. Retired adults and those with higher levels of educational attainment are more likely to do so. Frequent volunteering is associated with better quality of life and fewer depressive symptoms.

Blood Pressure Behaviours

High blood pressure (hypertension) affects over 60% of people aged 50 years and over in Ireland. Remarkably, over half of these were unaware that they have the condition (Murphy et al., 2016). Furthermore, 40% of people who met guideline criteria for use of cholesterol lowering drugs were not prescribed appropriate medications (Galvin et al., 2014). The Department of Health and Health Service Executive (HSE) have used this information to target screening for cardiovascular risk and have introduced a remuneration scheme for assessment of 24-hour ambulatory blood pressure (BP) in general practice. Data from subsequent waves of TILDA will track the benefit of these new policy initiatives in risk reduction and appropriate target intervention for at risk groups.

One of the most novel outputs from TILDA is the haemodynamic response to a common and potent physiological stimulus–orthostatic change. Failure to stabilise orthostatic BP within 40 seconds of standing is a significant risk for a number of age-related adverse outcomes such as falls, in particular injurious falls, frailty and syncope (O'Connell et al., 2018; Finucane et al., 2014; Finucane et al., 2014). Furthermore, failure to stabilise orthostatic BP within 30s of stand predicts incident depression and cognitive decline (Briggs et al., 2018; Briggs et al., 2018; Briggs et al., 2017; Feeney et al., 2016). These findings have important implications for new American and UK blood pressure management guidelines. In these guidelines, predominantly based on the recent SPRINT trial (Bress et al., 2016; Williamson et al., 2016) more aggressive lowering of BP is recommended. When we applied the SPRINT criteria to the TILDA population, the adverse outcomes of orthostatic hypotension, syncope and falls were up to five times under-reported in the SPRINT trial. The TILDA researchers recommended, as a consequence, that the SPRINT trail outcomes cannot be generalised to the general population over 75 years (Sexton et al., 2017).

Orthostatic hypotension or a sustained drop in blood pressure after standing, increases with age affecting over 40% of Irish adults aged ≥80 years (Finucane et al., 2014). Adults who have supine hypertension combined with orthostatic hypotension, have poorer global cognition and executive function compared to those without orthostatic hypotension (Frewen et al., 2014). Betablocker medications were more likely to be the culprit for orthostatic hypotension than Ace inhibitors, Calcium channel blockers or Angiotension receptor inhibitors (Canney et al., 2016). Work to combine existing data with MRI, biomarker and epigenetic data is underway and will examine the longitudinal associations between these factors.

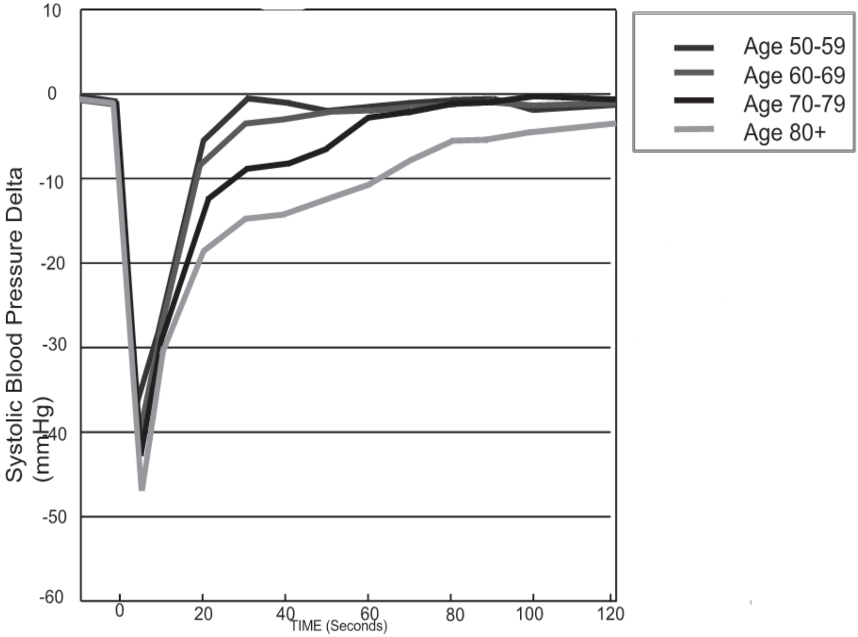
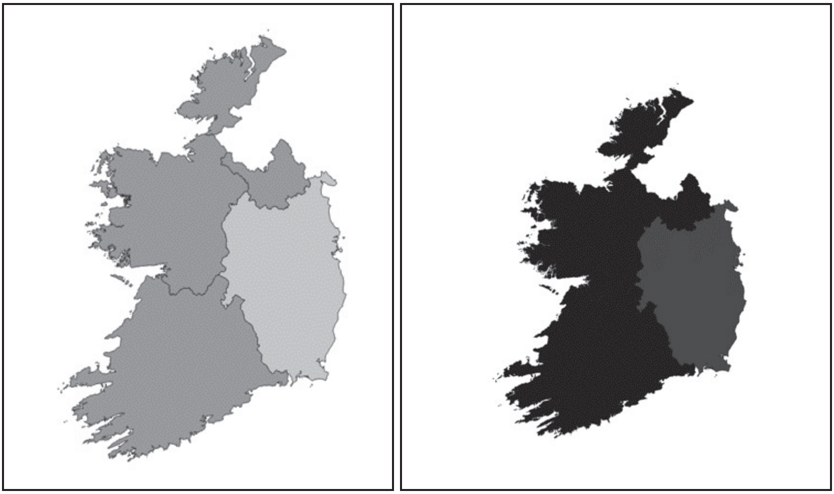
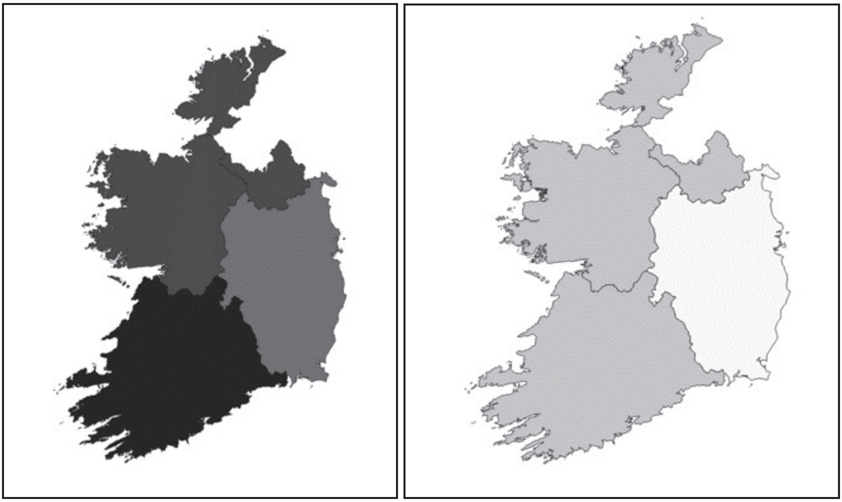


Figure 2.3: Age dependence of blood pressure stabilisation i.e. return to baseline level, after standing.



Autumn

Winter



Spring

Summer

Figure 2.4: Geographic and seasonal variation in the prevalence (% of population) of 25(OH)D deficiency (<30 nmol/L) in The Irish Longitudinal Study on Ageing (TILDA) population.

% <30nmol/L

☐	0 - 5
▨	5 - 10
▨	10 - 15
▨	15 - 20
■	20 - 25
■	25 - 30

Micronutrients

Research using the extensive TILDA biobank has examined the determinants and prevalence of vitamin D deficiency, and other micronutrients. The prevalence of vitamin D deficiency/insufficiency affects 40% of older Irish adults with fluctuating seasonal and geographical levels (See Figure 2.4) (Laird et al., 2018). Lower levels of vitamin D are associated with frailty and pre-frailty (O'Halloran et al., 2017). Other micronutrients such as folate and vitamin B12 are deficient or of low status in 15% and 12% respectively (Laird et al., 2018). We have also confirmed an association between low folate and cognitive impairment and determined that vitamin B12 is protective against cognitive deterioration. For lutein and zeaxanthin, both xanthophyll carotenoids obtained from orange/yellow and leafy green vegetables and fruits, there is a significant association with frailty (O'Halloran et al., 2016).

Objective and Self-Reported Health Status

TILDA has consistently reported a mismatch between what's found through objective health assessment and participant's health through subjective reporting, underscoring the importance of objective health measures. TILDA research has demonstrated large differences between subjective and objective reports for abnormal heart rhythm, high cholesterol, osteoporosis and high blood pressure.

Conclusion

The most significant findings from longitudinal studies are often realised after many years, as repeated measurements on the population allow for a much richer understanding of the causes and consequences of biological ageing within the context of the complex environmental influences. Furthermore, as TILDA is part of the HRS family of studies there will be expanding opportunities for international comparisons of findings which will deepen our understanding of population-level strategies that enable healthy ageing. Additionally, merging of data from harmonised studies will allow the sharing of 'big data' for scientific analysis by research groups across the world. We encourage researchers to exploit this rich archived data set at https://www.ucd.ie/issda/data/tilda/

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CHAPTER THREE

INTERGENERATIONAL RELATIONS AND THEIR IMPORTANCE FOR AN AGEING SOCIETY

ARIELA LOWENSTEIN, SIMON BIGGS
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Introduction

This chapter outlines three questions that, it is argued, are necessary in order to adequately address the challenge of population ageing. Firstly, how can we put ourselves in the place of someone of another generation? Secondly, what arises from the study of families that can be used to model harmonious intergenerational relations. And, finally how is it possible to critically interrogate contemporary debate to make it more generationally intelligent?

When compared to the end of the twentieth century, the first decade of the twenty-first century, has made the question of population ageing a commonplace of policy anxiety. The proportional growth of the number of older adults and the length of time that people are living is without historic precedent (WHO, 2000). Change in age structure is affecting both the developed and developing worlds (Aboderin, 2004). The question is one of societal adaptation as well as demography and may be expected to provoke challenges to existing norms of intergenerational behaviour (Antonucci et al., 2007). It is becoming clear that we do not currently, as national or global societies, have the cultural resources or the redundant cultural strength to draw on to negotiate this novel situation. We are, collectively, rather like mid-lifers who, according to Dan McAdams (1993), have to ‘figure it out on their own’. Traditional roles and responsibilities no longer seem to fit and the new demands lack the specificity and cultural embeddedness to supply a reliable guide to action.

The first question is necessary because, in life course terms, contemporary society so often eclipses the existential projects of the later, second half of adult life and replaces them with the priorities of the more youthful first (Biggs, 1999). This seems at first glance to make putting oneself into the shoes of the age-other an easy task. In effect, to the person in the first stage, the goals, hopes, desires and sense of past and future appear to be the same regardless of age. On closer inspection, however, the task becomes a considerable psychological and social challenge. It is not simply enough to become self-consciously aware of one's own and another's life course priorities. It is also important to achieve a rapport between them and find ways of negotiating a complementary relationship that can be sustained over time.

Generational Intelligence is a way of interrogating intergenerational relationships that exist at a number of levels (Biggs and Lowenstein, 2011). The term was first used by Biggs and Lowenstein (2009) as a means of identifying positive and negative aspects of communication between younger and older adults, so that individuals could be identified as exhibiting high or low levels of insight into the circumstances of persons felt to be of a different age. Here, we would like to explore this concept in a little more depth and draw out some of its implications for current trends in social policy.

The need to interrogate different degrees of Generational Intelligence is made more pressing because, as Kohli (2005:518) has argued: 'in the twenty-first century, the class conflict seems to be defunct and its place taken over by the generational conflict.' This assertion gains some support from Edmunds and Turner (2005) who has outlined generational tensions between baby boomers and younger generations within families and at work. Francophone writers such as Ricard Olazabal (2005) and Chauvel (2007) have criticized the boomer or generation lyric for social selfishness and disproportionate cultural and economic influence, to the disadvantage of succeeding generational groups. Moody (2008) has charted what he calls the 'boomer wars' as a recurrent polarisation of discourse in North American popular literature, while in United Kingdom (UK) politics, Willetts (2010) has blamed the boomer generation for using up resources belonging to other generational groups. While the Grattan Institute in Australia (Dailey and Wood, 2014) and the Intergenerational Foundation (2017) have promoted policies that promote competition between generational groups. This is in spite of evidence that indicates that, at least in the private sphere, generational transfers continue to travel downward, from older to younger generations (Irwin, 1998) and that family solidarity exists across systems that rely on family or state-based welfare support (Daatland and Lowenstein, 2005; Daatland, et al., 2010).

Intergenerational Relations Within Families

One of the main areas where there are existing models for intergenerational relations is within the family. This stems from several developments: The global demographic transition, with the extremely rapid rise in the coming years of the number of elders and very older persons (estimated for example for Europe at +37% and +54% respectively by 2030); Changing family structures and types, and changing attitudes and behavioural patterns of family members on age and ageing experiences and on family relationships. It will mean the need for changing attitudes and behaviours between three and more generations within families.

The family constitutes perhaps the most basic social institution, representing the very first group into which one enters at birth, and these ties remain primary over the life course (Wahl, et al., 2007). The need to understand family relationships and their diverse processes across time and place was noted by Bengtson et al. (2002), who indicated that we must look outside national borders to construct global conceptualisations of families and age.

The modern family is a family of relationships, having to assure for each of its members conditions for the construction of people's personal and social identity (Lowenstein and Katz, 2010). Thus, the study of intergenerational relationships in the older family has aroused great interest within the discipline of gerontology for several decades. The demographic transitions and the changes in family structures have prompted a rethinking of family relations.

One of the most common organising conceptual frameworks for understanding family relations in later life is the Intergenerational Solidarity Model (Bengtson and Dowd, 1981; Bengtson and Mangen, 1988; Bengtson and Roberts, 1991). Family solidarity has been considered an important component of family relations, particularly in successful coping and social integration in old age (McChesney and Bengtson, 1988). Intergenerational relationships are found to be one of the most important elements that influence quality of life in the family context (Silverstein and Bengtson, 1991; Lowenstein, 2007). Research in this tradition has tended to emphasise shared values across generations, normative obligations to provide care and enduring ties between parents and children.

The model conceptualises intergenerational family solidarity as a multi-dimensional phenomenon with six components, expressing the behavioural, emotional, cognitive and structural aspects of family relations (Bengtson and Schrader, 1982). These components reflect exchange relations and include structural solidarity, contact, affect, consensus, functional transfers/help and normative solidarity. The solidarity model has proven adaptable to innovations in methods and resilient to challenges to its dominance and universality. The paradigm was modified in the 1980s to become the ‘family solidarity-conflict’ model, which incorporates conflict and considers the possible negative effects of too much solidarity (Silverstein et al., 1996).

In 1998, Lüescher and Pillemer proposed that the experience of intergenerational relations in adulthood is characteristically ambivalent (Lüescher and Pillemer, 1998; Pillemer and Lüscher, 2004). Rather than operating on a basis of affection, assistance and solidarity, or being under threat of conflict or dissolution, the dynamics of intergenerational relations among adults revolve around sociological and psychological contradictions or dilemmas and their management in day-to-day family life. Indeed, scholars from a variety of orientations have argued in recent years that to understand the quality of parent-child relations, studies must begin to incorporate both positive and negative elements in a single study (Clarke et al., 1999; Bengtson et al., 2002; Connidis and McMullin, 2002; Lowenstein, 2007).

Population ageing has become a global phenomenon–almost all societies worldwide are affected by changes in their population structures, with a decreasing share of younger people and a growing proportion of older people living in them. This process of population ageing alters the age structures of nations and has caused the age pyramids to become rectangular-wise in most developed countries (Bengtson and Lowenstein, 2003).

This rapid increase in ageing populations globally, especially in the developed countries, as well as changing family structures impacts the dynamic between generations. However, population ageing is not necessarily apocalyptic for individuals, families, societies and their social systems–it means a changing balance between older and younger people in society. The challenge is then of finding new ways of communicating between generations, of supporting each other, of social inclusion and social integration, as well as dealing with the changing balance between families and state in care provision. Ageing can become a risk factor, or an opportunity for realising new possibilities.

Parallel to ageing of populations marked changes are in evidence regarding family structures. There is a collapse in fertility, changes in timing of family transitions, especially marriage, parenthood and grandparenthood that has resulted in two distinct family formats, based on timing of fertility: age-condensed and age-gapped family structures

(Bengtson et al., 1990); changes in family structures to beanpoles with an increased availability of extended intergenerational kin as family resources (Bengtson, 2000). However, increased participation of women (the traditional family caregivers) in the labour force impacts care for family elders. Additionally, changes in patterns of family formation and dissolution and ensuing diversification of families and households' systems leads to more complex and ‘atypical’ households' structures. Also, the growing number of elderly single households, an increase in the proportion of childless women and the increased mobility of adult children also have an effect. This diversity of family formats creates uncertainty in intergenerational relations and expectations and has specific effects on life course role transitions such as retirement and grandparenthood. In addition, there are broader societal and technological changes like internal and external migration. All the above contribute to a shrinking pool of family support (Wolf and Ballal, 2006)

Considering the above changes, intergenerational bonds among adult family members may be even more important today than in earlier decades because individuals live longer and thus can share more years and experiences with other generations (Bengtson et al., 2000; Connidis, 2001; Lowenstein, Katz and Gur-Yaish, 2007). Thus, when older persons might need care and support, the idea is that social relationships embody a reserve of potential support providers who can be drawn upon when needed. This idea is rooted in the sociological concept of social capital–the notion that obligations to others is a form of social equity that can be triggered into a manifested resource (Coleman, 1988). The concept of social capital, deriving from the work of Blau (2017), Bourdieu (1983) and Coleman (1988) is defined, in this context, as intergenerational family resources on which older people feel they should be able to depend for needed care and support.

In the new millennium, a child might have any number of parents, grandparents and great or even great-great grandparents. Technological developments should thus be sought to help health care and welfare organisations deliver services more efficiently and to foster independence among frail elders. As new generations of elders will be better educated and will have higher incomes, and as most families will be composed of four or five generations, care demands in the twenty-first century and the balance between informal and formal care will be different, tending more towards complementarity.

It is well established that in modern ageing societies, the quality of life in old age rests on the relationship between intergenerational family solidarity and the responses of the formal service systems. Families operate in the context of larger social structures that shape the role played by adult children in the support systems of older parents. In Western industrialised countries, intergenerational solidarity, including intimacy, contact, exchange of services, is maintained despite geographic separation (Litwak and Kulis, 1987; Litwak et al., 1993; Warnes, 1994; Lowenstein et al., 2003). Indeed, families and state institutions intersect to jointly produce portfolios of care and support for the elderly (Minkler and Estes, 1999; Lottman et al., 2013).

However, because of the changes noted above it has become increasingly important to understand the issue of family support to older people across societies. Comparisons across nations can inform social policy debates within each nation about how to best prepare for the demographic destiny of ageing societies. It is through the lens of the family that multifaceted developments can be explored, and perhaps anticipated, in housing, health, work, welfare, leisure, migration, finance, economy and especially the impact of growing communication technologies which are now embedded in everyday life and impacting health and elder care. This helps policymakers to identify upcoming issues and how the family landscape might change over the next few decades and consider what some of the implications for policy might be.

Despite the turbulences of recent decades, the family household has far from disappeared. However, a range of interrelated factors will be at play in changing the contours of family composition and functioning in the coming decades. Key among them will be population changes, fertility and mortality rates, immigration, which will be an important determinant of many a country's national family profile, but also economic and labour market prospects as well as the increase in communication technologies.

The Potential Benefits of Family Multigenerational Ties

As longevity extends yet further for men and women, anticipating changes in the number, size and composition of households is important for many issues of social concern. For example, the living arrangements of elders are a key determinant of their needs for socioeconomic, physical and emotional assistance.

When families find themselves increasingly with four and even five generations in their midst, the question arises whether multigenerational ties will play out to the advantage or disadvantage of the family in terms of its functions, adaptability and resilience in the face of socioeconomic and technological changes. There are in fact some very good reasons for believing that family multigenerational relations will become even more important in the twenty-first century. First, population ageing itself results in ‘longer years of shared lives’; second, the importance of grandparents and other kin in fulfilling family functions is expected to increase; third, as research spanning several decades has demonstrated, intergenerational solidarity remains remarkably strong and resilient over time. There will also be the bonus of diversity stemming from family multigenerational relations, because of changes in family structure involving divorce and widening networks of stepfamily relations; the increased longevity of kin; and the diversity of intergenerational types ranging from tightly-knit or at least sociable forms of interaction to looser, more distant or detached family network configurations.

One should also consider the specific roles of the state (welfare system), market and family in shaping the nature and intensity of relations between parents and their adult children. In a study on Sharing Lives (Szydlik, 2016), the general conclusion reached by the author is that, indeed, contemporary family generations do share their lives: the solidarity scenario is clearly predominant over two other potential scenarios of autonomy and conflict. Across Europe, parents and children manifest a dense net of lifelong ties, sustained contact (also in cases of living far from each other) and mutual support in times of need.

Deploying Generational Intelligence

This combination of complex generational relations, within families and in the wider public domain contributes to the contemporary importance of generational intelligence. If generational intelligence can be seen as unevenly distributed in terms of generations and age groups, then it follows that there could be certain steps to help move social actors from one state of awareness to another.

At an everyday level, generational intelligence can refer to the forms of information that are available to the active subject, in the sense of the ‘intelligence’ currently available in any one situation. Rather like the way that spies use the phrase to discriminate available and potentially available clues, generational intelligence refers to seeking out information or searching for data. In other words, we gather intelligence about generational relations as a guide to action. However, seeking out available information relies on that information being explicit and accessible.

A second way of using the term ‘intelligence’ addresses the degree to which a person is aware of and able to work with generational and related forms of information. It involves a critical approach to generational categories: working ‘intelligently’ with them. This emphasises the degree to which actors and groups behave as if they were immersed in their own group-specific form of generational consciousness as compared to more complex forms that include an openness to multiple generational perspectives. Generational intelligence in this sense denotes different degrees to which social actors behave reflexively with respect to generational identities and intergenerational relations. Just as with the deployment of a masquerade, a reflexive awareness of generation creates room for manoeuver. It creates a distance between immersion inside a generational identity and being able to step outside in order to take a position with respect the generational identities that are available options. It identifies the ground on which it is possible to take a stand.

Steps Toward Generational Intelligence

If generational intelligence is a matter of degree, particularly with respect to an awareness of self and others as members of a generational group, it also suggests certain processes that would need to occur, in order to establish higher degrees of generational sensitivity. It can, perhaps, be broken down into identifiable steps that are liable to increase the likelihood of generationally intelligent understanding and action (Biggs et al., 2011). By taking such steps immediate experience can follow pathways into more complex and reflective processes. It involves a process of separation and return which allows a critical reflective space to emerge. As this space is entered, it provokes recognition of the relationship between self and other, which leads to further action taking place beyond immersion. These steps might look like this:

Step One. This step is, as a first footfall, necessary to become aware that generational distinctiveness actually exists. This is a rather obvious point to make were it not for the tendency for certain policy statements and identity positions (Biggs et al., 2007) to deny or obscure it. Recognising distinctiveness would be necessary in order to locate oneself within generational space and to identify different contributory factors that are expressed through generational identity. The degree to which one's immediate experience is affected by cohort, family and life course position would need to be critically interrogated as part of this process. Socio-historical attitudes to family for example will influence a person's thoughts and feelings about themselves as a child, parent and grandparent, and progress through their own life course as one phase leads on to another from adolescence, through to midlife and on into old age. How these distinctions fold back into cohort identities would need to be disaggregated and understood. At this point self-awareness would be principally a personal reflective endeavour, an interior process where immersive awareness is separated out and made the subject of conscious reflection.

Step Two: This step would consist of understanding the relationship between generational positions. The purpose of this second step would be to identify the key generational actors in any one situation and see them through generational spectacles, thus making intergenerational relations explicit. Generational relations include the positions that each social actor may hold, but also the associations that each person brings with them about other generations, their internalised images of ageing that are organised generationally. As part of this process, it would be possible to see the age-other as a person with priorities, desires, fears and reflections that may or may not overlap with one's own, thus engaging with the difficult tasks of placing oneself in the position of that age-other.

Step Three: This step involves taking a value stance toward generational positions. Knowing that generational distinctiveness and difference exist is no guarantee of the quality of the relations that emerge. It is quite possible that participants in generational exchange take an antagonistic position, one based on harmony, on mixed feelings or on indifference. Each of these suggests a value position supported by certain power relations, and as generational intelligence's own value position is one of increasing the likelihood of harmonious accommodation between generations, being explicit about the position taken is important at this stage. Rather than assume that actions concerning generational relations are in themselves neutral or objective, the task would be to critically assess the relations that tacitly and explicitly underpin intergenerational behaviour. This is part of finding the ground on which we stand, which for critical gerontologists would require examination of generational power and how it might be negotiated.

Step Four: The fourth step concerns action in a manner that is generationally aware. Once a value stance has been taken with respect to generational power, then the ground on which action can take place is made much clearer. Generationally intelligent action would take place in the knowledge of one's own contribution and those of others. Action would work toward situations that move from immersion to actively negotiated accommodations, one to another, as it is in this way that sustainable generational relationships might emerge.

Taken together, these steps show a way of seeing through a generational lens, in order to draw out how social reality has been generationally inflected and sustainable negotiation around resources can take place. It is important, however, to engage in such a process without falling into the trap of saying what old age or other phases of adult ageing should be like. Rather, the objective would be to make a preliminary sketch of the processes that might have to take place to allow sustainable solutions to emerge, where sustainability refers to negotiations that take differing generational perspectives and requirements into account. The next section of this paper is used to examine recent trends in social policy and make some preliminary observations on their degree of generational intelligence.

Policy and Other Debates

Biggs (2018) has argued that decisions about generations can be analysed using three questions: to what degree does debate rely on negative or positive othering? Are debates relying on within or between age thinking? And, how far is planning present or lifetime centred?

Age-otherness And Positive Othering

An age-other, according to Biggs and Lowenstein (2011: xii) is:

> '…someone who is constructed as being of a different group to oneself, based on age. Age-otherness may include aspects of life course and family position and cohort identity. Whether an individual is seen as being "other" will be affected by the interaction of these elements of generational identity.'

The process of othering refers to seeing another person as different to the self and is most commonly associated with forms of age prejudice (Phillips et al., 2010). There is a way, however, that otherness based on age fulfils a positive function. This emerges through a recognition that in order to see the other more fully, it is necessary to separate self and other out in the mind's eye, in order to return with refreshed insight. The distinctive identities of others based on age and generation can then be identified and a more genuine form of relationship can potentially emerge. Rather than a process of rejection, this would:

> '…ultimately become a process of connection as the other person is approached as someone with his or her own characteristics, projects and idioms. Positive othering constitutes a willingness to consider distinctiveness based on adult age, even if these do not correspond with the dominant group's interests and world view' (Biggs, 2018:22).

Within- And Between-Age Thinking

Within- and between-age thinking is focused on where boundaries are drawn around debates and how priorities for action are identified. Within-age thinking is:

> 'Principally concerned with working out processes, projects and implications that are contained through a consideration of a single defined age or generational group' (Biggs, 2018:23).

Between-age thinking is concerned with 'The interaction between groups defined by age or generational difference' (Biggs, 2018:23).

The issues under consideration by within-age thinking exist in a closed system, as boundaries have been drawn around the debate that exclude the perspectives of other groups. Between-age thinking allows a more open system in which comparisons between generational priorities can be made.

Distinguishing between with- and between-age thinking allows insight into whether a debate is considering one generational position or the interaction between positions, or the relative weight given depending upon focus and context. The degree to which within- and between-age thinking takes place shapes the way social issues are addressed and responded to.

Present-Centredness And Lifetime-Centredness

Generational intelligence in this context involves an enhanced sensitivity to thinking about relationships marked by time. Lifetime thinking could be thought of as long term and strategic, while present-centred thinking is short term and tactical. Present-centred thinking would emphasise:

> 'The process of current relations and reflects an absorption in everyday experience. As such, it has a tendency to characterise the passage of time as a process that the social actor is not consciously aware of, giving life an ageless quality' (Biggs, 2018:24).

In one sense, present-centredness is tremendously important. It is the point of our current and immediate engagement with the world. Lifetime-centred thinking would emphasise 'Change within a life-course horizon, a long duration, beyond immediate experience, and incorporates a sense of past, present and future' (Biggs, 2018:25). Lifetime thinking is marked by a consciousness of distinctive periods of experience and engagement in context, both sequential and rhythmic. The importance of lifetime thinking lies in its ability to see interconnection and cumulative effects. While things may come and go, their consequences can stay with us and determine the futures we lead.

Concluding Comments

Social commentaries, especially those arising from the public sphere suggest a renewed aggression in intergenerational discourse, which if left unaddressed is likely to multiply as populations live longer, and the proportion of older adults increases. Looking at models arising from intergenerational relations within families and taking a generationally intelligent perspective may give us greater insight into how societies might adapt to a situation where generations are becoming approximately the same size. Positive othering, within- and between-age thinking and present- and lifetime-centredness, each in their different ways, begin to provide us with tools that may help in making sense of this historically novel situation.

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CHAPTER FOUR

UNDERSTANDING CAPACITY IN AGEING POPULATIONS: THE IRISH EXPERIENCE

PATRICIA T. RICKARD-CLARKE

Introduction and Context

The Assisted Decision-Making (Capacity) Act 2015 (2015 Act) was signed into law in December 2015 in Ireland.[1] It comprehensively reforms the law on decision-making capacity and when fully commenced will replace the very out-dated nineteenth century wards of court system based on the *Lunacy Regulations (Ireland) Act 1871*. The new legal framework gives effect to a number of international human rights conventions including the *European Convention of Human Rights* (1950), *The Hague Convention on the International Protection of Adults* (2000), which is incorporated in to the 2015 Act, and the *United Nations Convention on the Rights of Persons with Disabilities* (2006) (UNCRPD). The 2015 Act sets out a modern decision-making legislative framework to replace the Wards of Court system for those whose capacity is in question, may shortly be in question or who lack capacity.

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[1] Two commencement orders were made in 2016–the establishment of the Office of the Director of the Decision Support Service and the establishment of a multidisciplinary working group to make recommendations to the Director in relation to codes of practice for Advance Healthcare Directives. Both the HSE and the National Disability Authority have been working for the past 18 months on a number of other codes as provided for in S.103 of the 2015 Act. Full commencement of the 2015 Act is expected to be early 2020.

[2] In *Keogh, in re,* High Court unreported, 2002, Finnegan P. held that the requirement that the person is ‘‘of sound disposing mind and incapable of managing his person and property’’ is to be construed conjunctively rather than disjunctively.

Before considering some of the provisions of the 2015 Act, particularly how decision-making capacity is to be construed and supported, it is useful to look at some of the key drivers of the need for modern capacity legislation. In spite of clear constitutional provisions to respect the rights of all citizens, Ireland still lags very much behind in respecting individual rights particularly of those whose capacity may be at issue.

The population of Ireland in 2018 was 4.86 million, of whom 13.86% were over the age of 65 years with a total population of 5.284 million projected for 2028, of whom 19.5% will be over the age of 65 years. The total population is projected to reach 5.64 million by 2038 with more than one in five people expected to be aged 65 years or older by 2038 (Department of Health, 2018). With an increase in life expectancy, there is also a projected increase in the number living with dementia. Currently, 55,000 people in Ireland are living with dementia, that number is expected to double to 115,426 within twenty years and almost treble to 157,883 within thirty years (National Dementia Office and the Department of Health, 2018). While the National Dementia Strategy (Department of Health, 2014) recognises that population ageing has implications for the planning and provision of health services it also recognises that supporting people to maximise their independence and live as well as possible for as long as possible is an important societal aim. We all need support in our daily lives but as people age and particularly if a person is diagnosed with dementia, support with decision-making is critical to wellbeing.

In Ireland, the only legal mechanism to deal with decision-making has been the 19th century legislation entitled the *Lunacy Regulations (Ireland) Act 1871* (1871 Act) which provides that a person is taken into wardship by the court. Wardship presents capacity in the status context, that is, in an 'all-or-nothing' approach to capacity and based on disability. It is an across-the-board assessment of a person's capacity rather than in relation to a particular decision to be made at a particular time. The 1871 Act provides that a person must be declared to be 'of unsound mind and incapable of managing his person or property.' It does not take account of context, once a person has been admitted to wardship they lose all decision-making capacity in legal terms. As stated by the Supreme Court: 'An order making a person a ward of court has real consequences. It can deprive a person of the power to make many of the choices which are fundamental and integral to day-to-day life' (AM v HSE [2019] IESC 3). The 1871 Act predates the Constitution of Ireland, the European Convention of Human Rights and the UNCRPD, all of which have provisions which protect the dignity and rights of the person.

Legal Capacity, Mental Capacity and The Presumption of Capacity

(i) *Move from medical model to rights-based approach to capacity*

Prior to the adoption by the United Nations Assembly of the UNCRPD, it was recognised that there was the need for an ideological shift in disability policy away from a medical model of disability towards a social and rights-based model which aims to focus on capacity relative to what is being done and which encourages autonomy and empowerment.

The right to equal treatment before the law is enshrined in the Constitution of Ireland which provides:

> [A]ll citizens shall, as human persons, be held equal before the law. This shall not be held to mean that the State shall not in its enactments have due regard to differences of capacity….. (Bunreacht na hÉireann, 1937)

It also provides that the State will ‘vindicate the personal rights of the citizen...’ (Bunreacht na hÉireann, 1937). Both in legislation and at common law, Ireland has tended to ignore the legal rights of persons with disabilities (and indeed the rights of older people who may not lack capacity but who need support to exercise their legal capacity) as set out in the Constitution and which were affirmed in In *re a Ward of Court (No 2),* Hamilton C.J. stated:

> ‘The loss by an individual of his or her mental capacity does not result in any discrimination of his or her personal rights recognised by the Constitution, including the right to life, the right to bodily integrity, the right to privacy, including self-determination, and the right to refuse medical care and treatment. The ward is entitled to have all these rights respected, defended, vindicated and protected from unjust attack and they are in no way lessened or diminished by reason of her incapacity.’

The UNCRPD sets out how State Parties should respect and recognise those rights. Article 4 sets out the obligations that must be undertaken to ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. These include:

- the adoption of appropriate legislative, administrative and other measures for the implementation of rights;
- to take appropriate measures to include legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;

- to take into account the protection and promotion of human rights;
- to refrain from engaging in any act or practice that is inconsistent with the Convention and ensure that public authorities and institutions act in conformity with the Convention;
- to take all appropriate measures to eliminate discrimination on the basis of disability by any person, organisation or private enterprise.

The core Article of the UNCRPD, as far as decision-making capacity is concerned, is Article 12. Article 12(1) provides that State Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

Article 12(2) State Parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

Article 12(3) State Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

Article 12(4) State Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human right law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body.

(ii) *The interpretation of legal capacity:*

Even though legal capacity is a central concept of the UNCRPD, there is no definition of legal capacity in the Convention. However, the UN Committee on the UNCRPD (2013) in its first General Comment defined legal capacity as:

> Legal capacity and mental capacity are distinct concepts. Legal capacity is the ability to hold rights and duties (legal standing) and to exercise these rights and duties (legal agency). It is the key to accessing meaningful participation in society. Mental capacity refers to the decision-making skills of a person, which naturally vary from one person to another and may be different for a given person depending on many factors, including environmental and social factors. (Committee on UNCRPD, 2013: 4)

The UN Committee makes clear that ‘unsoundness of mind’ and other discriminatory labels are not legitimate reasons for the denial of legal capacity (both legal standing and legal agency) and that perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity. In recognition of this important distinction, Ireland has undertaken to amend existing laws which have denied persons with disabilities legal capacity in a number of areas. At the recent Committee Stage debate on the Disability (Miscellaneous Provisions) Bill 2016, the Minister for State confirmed that:

> 'Detailed work is ongoing to finalise amendments on a number of issues…these include amendments to address the use of the phrase 'unsound mind' in the Statute Book where those references potentially intrude upon the rights of the person deemed to be of "unsound mind." (Oireachtas Select Committee on Justice and Equality, 2019)

In the Irish context, there has been confusion about the concepts and distinction between legal capacity and mental capacity (or to use the more correct terminology 'decision-making capacity' as defined in the 2015 Act) mainly because of what has been our outmoded capacity legislation. In practice, mental capacity is often used as a basis for granting or denying legal capacity as many assessments of decision-making capacity include a medical determination about a person's impairment or disability. The fact that a person has an intellectual disability or dementia is not indicative of a lack of capacity to make some or all decisions. Most people with disabilities (even those with severe dementia) retain capacity or ability to make some decisions. What needs to be established is the ability of an individual to make a particular decision at a specific time in the context of the decision to be made.

(iii) *Presumption of Capacity*

While there is a presumption of capacity in Irish common law unless it is established that there is a lack of capacity, there has been no general definition either at common law or in statute until recently. The common law presumption has now been given statutory force. The 2015 Act provides that it shall be presumed that a person has capacity unless the contrary is shown in accordance with the provisions of the Act, that is, the criteria in Section 8(2) of the 2015 Act, which must be followed in order to rebut the statutory presumption. The burden of proof lies with the person asserting lack of capacity and the standard of proof is the balance of probabilities–the civil law test. This will require a huge cultural shift in current practice as there is still a strong tendency to make an assumption that a person who has a diagnosis of dementia, lacks the capacity to make decisions.

Assessment of Capacity Under the 2015 Act

(i) *Who is the Legislation For?*

The 2015 Act takes account of the different levels of capacity a person may have. It also recognises that those different levels may operate at the same time but in respect of different matters. Such a person is being defined in the legislation as a *relevant person* and means –

> (a) a person whose capacity is being called into question or may shortly be called into question in respect of one or more than one matter,
> (b) a person who lacks capacity in respect of one or more than one matter, or
> (c) a person whose capacity is being called into question or may shortly be called into question or who lacks capacity at the same time but in respect but in respect of different matters (Section 2, 2015 Act).

(ii) *Capacity is to be construed functionally*

The 2015 Act provides that a person's capacity is to be construed functionally and

> 'shall be assessed on the basis of his or her ability to understand, at the time that a decision is to be made, the nature and consequences of the decision to be made by him or her in the context of the available choices at that time.' (Section 3, 2015 Act)

The functional construction of capacity is therefore to be assessed on an issue and time specific basis which can be contrasted with the status approach as mainly used in the Wards of Court system. The status approach to capacity involves an across-the-board assessment of a person's capacity. It views capacity in all-or-nothing terms and typically involves concluding that a person lacks capacity based on the presence of a disability rather than on an assessment of their actual decision-making capability (Law Reform Commission, 2006).

Surprisingly, up until 2008 there was no direction as to how capacity should be assessed either at common law or in legislation. In *Fitzpatrick v K,* (No 2) [2008] IEHC, Ms Justice Laffoy considered what the test should be and confirmed it was the 'ability of a person to understand the nature, purpose and effect of the proffered treatment and the consequences of accepting or rejecting it in the context of the choices available.' Following this decision, the functional test was given effect in the national policies of both the Health Service Executive (2013) and the Irish Medical Council (2009; 2016). Despite the clear guide from the court and the guidelines contained in national policies, medical screening tools continue to be used (for example the Mini Mental State Exam (MMSE) (Folstein et al. 1975)) to determine a person's capacity to make a decision. In 2015 in *In re SCR* in addition to endorsing the functional test, Ms Justice Baker went further and confirmed that the test is a legal one and what is required is a legal assessment and not a medical assessment ([2015] IEHC 308).

(iii) *How is capacity to be assessed for the purposes of the Act*

As stated, the 2015 Act provides that there is a presumption of capacity unless the contrary is shown. Consequently, the onus is then on a person who asserts a lack of decision-making capacity to so prove based on specific statutory criteria. The 2015 Act provides that a person lacks capacity to make a decision if he or she is unable to understand information relevant to the decision, retain that information long enough to make a voluntary choice, use or weigh that information as part of the process of making the decision, or communicate his or her decision (by whatever assistance is required whether by talking, writing, using sign language, assistive technology, or any other means) or, if the implementation of the decision requires the assistance of a third party, to communicate by any means with that third party (Section 3, 2015 Act).

The 2015 Act provides that 'a person is not to be regarded as unable to **understand the information** relevant to a decision if he or she is able to understand an explanation of it given to him or her in a way that is appropriate to his or her circumstances'. The legislation therefore puts the onus on the assessor/intervener to assist the person whose capacity is at issue, in every manner possible to maximise his or her decision-making ability. The emphasis in the legislation is on supporting the person to make the decision by giving him or her all the relevant information before actually carrying out an assessment. An intervener may be called upon to explain the support and assistance they have given to a relevant person.

In relation to the **information relevant to a decision**, the legislation provides that this shall be construed as including 'information about the reasonably foreseeable consequences of:

(a) each of the available choices at the time the decision is made, or
(b) failing to make a decision.' (Section 3(7), 2015 Act)

The question as to whether it was appropriate to put forward options or set out choices to a person whose decision-making capacity is being assessed was considered by the courts in England. Barker J stated that in assessing capacity it is inappropriate to start with a 'blank canvas.''

> The person under evaluation must be presented with detailed options so that their capacity to weigh up those options can be fairly assessed. I find that the local authority has not identified a complete package of support that would or might be available should KK return home, and that this has undermined the experts' assessment of her capacity. The statute requires that, before a person can be treated as lacking capacity to make a decision, it must be shown that all practicable steps have been taken to help her to do so.' (CC and KK v STCC [2012] EWCOP)

The fact that a person is able to **retain the information** relevant to a decision for a short period only does not prevent him or her from being regarded as having the capacity to make the decision. People who have short-term memory problems can be prompted so, even if they retain the information for a short period of time but have the ability to weigh the information then they are to be regarded as being able to make the decision. This is particularly important for older people who have a diagnosis of dementia.

The functional construction of capacity is emphasised a number of times in the 2015 Act by requirements such as:

> 'The fact that a person lacks capacity in respect of a decision on a particular matter at a particular time does not prevent him or her from being regarded as having capacity to make decisions on the same matter at another time and [t]he fact that a person lacks capacity in respect of a decision on a particular matter does not prevent him or her from being regarded as having capacity to make decisions on other matters.'(Section 3(5) (6), 2015 Act)

Capacity assessment should therefore only be done at the highest level of functioning and the question of who assesses a person's capacity will depend on the particular decision to be made. Thus where a legal transaction is involved, executing an enduring power of attorney, it will be a matter for a solicitor to be satisfied that the client has the capacity to give instructions and has the capacity 'to understand the nature and effect of the instrument he actually purported to execute.' (Re SCR [2015] IEHC 308). Where the decision relates to consent to medical treatment, it will be matter for the treating healthcare profession to be satisfied that the patient understands the treatment choices and has the capacity to consent to the particular treatment.

Guiding Principles

The 2015 Act sets out a number of Guiding Principles (only some are commented upon) and provides that the principles 'shall apply for the purpose of an intervention in respect of a relevant person, and the intervener shall give effect to those principles.'

The first principle restates the presumption of capacity. The right of autonomy and self-determination is given effect to in the principle that a relevant person 'shall not be considered as unable to make a decision…merely by reason of making, having made, or being likely to make, an unwise decision' (Section 8(4), 2015 Act). It is necessary to establish if the person has the ability to make the decision rather than predetermine the possible outcome of a decision he or she might make or to decide whether it is a wise or an unwise decision. As was pointed out in KK, it is important to acknowledge the difference between unwise decisions and decisions based on a lack of understanding of risks or inability to weigh up the information about a decision (CC and KK v STCC [2012] EWCOP). This will be particularly challenging where there is an over emphasis on the avoidance of risk (which cannot be measured) and not either allowing positive risk-taking or respecting the right of a person to make the decision.

A further principle in the 2015 Act provides 'there shall be no intervention in respect of a relevant person unless it is necessary to do so having regard to the individual circumstances of the relevant person'. This indicates that there is an onus on the intervener to make enquiries about the individual circumstances and to understand why a decision is necessary in those circumstances. Even if a person lacks capacity, it may not be necessary to intervene unless it is necessary. Any intervention must be made in a manner that minimises (i) the restriction of the relevant person's rights, and (ii) the restriction of the relevant person's freedom of action, and have due regard to the need to respect the right of the relevant person to his or her dignity, bodily integrity, privacy and autonomy (Section 8 (5) and (6), 2015 Act). The right to freedom of action was very much an issue for Mr Justice Hogan in AC v CUH when he considered the case of Ms C who had refused to be admitted to a nursing home. He stated, the power to detain:

> 'claimed by the hospital amounts to a paternalistic entitlement to act in the best interests of patients whose capacity is impaired and, in effect to restrain their personal liberty and freedom of movement and, if necessary, to do so at the expense of close family members'. (AC v Cork University Hospital and Ors [2018] IECA 217)

The common law principle of ‘best interests’ which is generally regarded as paternalistic and restrictive has been replaced in the 2015 Act by a principle which puts the voice of the person centre stage. It sets out the obligations that an intervener must comply with either before concluding that the person lacks the capacity to make the decision or even if the person lacks capacity. These include permitting, encouraging and facilitating, in so far as practicable, the relevant person to participate, ‘or to improve his or her ability to participate, as fully as possible in the intervention.*’* The intervener, must give effect, in so far as practicable*,* ‘to the past and present **will and preferences** of the relevant person, in so far as the will and preferences are reasonably ascertainable,’ and take into account ‘the **beliefs and values** of the relevant person (in particular those expressed in writing), in so far as those beliefs and values are reasonably ascertainable’. The intervener must ‘act at all times in good faith and for the benefit of the relevant person’.

Decision-Making Intervention Options

In order to comply with the UNCRPD’s requirement that, ‘at all times, including crisis situations, the individual autonomy and capacity of persons with disabilities to make decisions must be respected’ (Committee on CRPD, 2013:5), the 2015 Act provides for a number of supported decision-making interventions which must take account of the ‘will and preferences’ of the person whose decision-making capacity is at issue. The type of intervention will depend on the level of capacity and different options may be used at the same time in respect of different decisions based on the functional construction of capacity that a person may have capacity to make some decisions but lack capacity to make others.

(i) *Assisted Decision-Making (Section 9, 2015 Act)*

At the first level a relevant person (the appointer) who considers his or her capacity to be in question or may shortly be in question may appoint another person to be known as a Decision-Making Assistant and who must be over the age of 18 years, to assist in making decisions in relation to person welfare and property and affairs or both. The appointment of the Decision-Making Assistant will be made in a **decision-making assistance agreement** which may be revoked or varied at any time. The functions of the Decision-Making Assistant are to assist the appointer to obtain information, to explain information relevant to a decision/s, ascertain the will and preference of the appointer and assist the appointer to communicate them, assist the appointer to make and express their decision and endeavour to ensure that the appointer’s decisions are implemented. A decision made by the appointer with the assistance of a decision-making assistant is deemed to be taken by the appointer for all purposes.

(ii) *Co-Decision Making (Section 16, 2015 Act)*

A person with greater capacity needs has the option of making decisions jointly with a trusted family member or friend. A relevant person (appointer) who considers his or her capacity to be in question or may shortly be in question may appoint a ‘suitable’ person who has attained the age of 18 years, to jointly make one or more than one decision on the appointer’s personal welfare or property and affairs or both. The appointment of a co-decision-maker shall be made in writing and in a **co-decision-making agreement**. The functions of the Co-Decision-Maker are to advise the appointer by explaining information and considerations relating to a relevant decision, ascertain the will and preferences of the appointer on the matter the subject of, or to be the subject of a decision and assist the appointer in communicating their will and preferences, assist the appointer in obtaining information, discuss with the appointer the known alternatives and likely outcomes of a decision, make a decision jointly with the appointer and make reasonable efforts to ensure that the appointer’s decision is implemented.

A co-decision-making agreement will not enter into force until it has been registered and there are detailed requirements for registration. The appointer must state that he or she understands the implications of entering into the agreement, wishes to enter into the co-decision-making agreement, is aware that he or she may, with the consent of the co-decision-maker vary the co-decision-making agreement and is aware that the co-decision-making agreement may be revoked. A statement is also required from the co-decision-maker that he or she understands the implications of entering into the co-decision-making agreement, understands and undertakes to act in accordance with his or her functions as specified in the co-decision-making agreement, understands and undertakes to act in accordance with the guiding principles. A statement is also required as to why the less intrusive measure of a decision-making assistance agreement was not chosen.

(iii) *Decision-Making Representative (Section 36, 2015 Act)*

For a person who is unable to exercise his or her decision-making capacity and is not capable of availing of either the decision-making assistance or co-decision-making options (or who has not included the relevant decision in an Enduring Power of Attorney or an Advance

Healthcare Directive), an application may be made to the court and the court will make one or both of the following orders:

- An order making the decision or decisions concerned on behalf of the relevant person where it is satisfied that the matter is urgent or that it is otherwise expedient for it to do so.
- An order appointing a suitable person who has attained the age of 18 years to be a decision-making representative for the relevant person for the purposes of making one or more than one decision on behalf of the relevant person in relation to his or her personal welfare or property and affairs or both.

In making an order, the court must have regard to the terms of any advance healthcare directive or enduring power of attorney made by the relevant person and shall ensure that the terms of the order are not inconsistent with the directive or the enduring power of attorney and where a decision-making representative is appointed, ensure that his or her functions are not inconsistent with the powers exercisable by any designated healthcare representative or the attorney (see below). When considering the suitability of a person to be a decision-making representative, the court must have regard to the known will and preferences of the relevant person, the desirability of preserving existing relationships with the family, the compatibility of the proposed representative, whether he or she will be able to perform the functions and any conflict of interest (Section 38(5), 2015 Act).

In each of decision-making processes outlined the emphasis is on the right of the person to make the decision. Even in the third category, where it is recognised that the person is unable to make a decision even with support, the legislation provides that insofar as it is possible, the will and preferences of the relevant person must be ascertained.

Planning Ahead

The best approach to obtaining the ‘will and preferences’ of a relevant person is if the person, when he or she has capacity, sets out in writing those wishes and preferences, by either creating an Enduring Power of Attorney or making an Advance Healthcare Directive (Council of Europe, 2009; 2014). Thinking and planning ahead enables a person to give thought as to who is the most suitable person/s to nominate to make decisions on their behalf in the event that they do not have the capacity to make decisions personally. It enables a person to consider what authority (general authority or limited to specific decisions) they wish to give the attorney or designated healthcare representative.

(i) *Enduring Powers of Attorney* (EPA) *(Part 7, 2015 Act).*

Since the Powers of Attorney Act, 1996, it has been possible to create an EPA and give authority to another (attorney) to make decisions on their behalf in the event of subsequent lack of capacity. The 2015 Act reforms and updates a number of aspects with regard to EPAs. The procedural requirements both at execution and registration stage have been extended and there will now be reporting and accountability requirements once the EPA has been registered, to ensure appropriate safeguards are in place to prevent abuse. As in the 1996 Act, an EPA created under the 2015 Act will not come into effect until it is registered. To comply with the functional construction of capacity an EPA may now be registered in respect of one or more than one decision. There will also be a Register of EPAs and access to the Register will be available to a body or class of persons who have a legitimate interest to such access.

(ii) *Advance Healthcare Directive (AHD) (Part 8, 2015 Act)*

Advance healthcare directives have been legally recognised in Ireland but until the enactment of the 2015 Act, there has been no statutory provision for them. This had led to uncertainty as to the legal status of such directives but has also resulted in directives not being respected. There is now a statutory framework in the 2015 Act, the purpose of which is to 'enable persons to be treated according to their **will and preferences**, and to provide healthcare professionals with information about persons in relation to their treatment choices'.

An AHD refers to treatment decisions, that is, a refusal of treatment which if valid and applicable is legally binding. A relevant person is entitled to refuse treatment for any reason notwithstanding that the refusal – 'appears to be an unwise decision, appears not to be based on sound medical principles, or may result in his or her death' (Section 83, 2015 Act). A request for treatment is not legally binding (it may not be clinically indicated as necessary or feasible) however, the 2015 Act provides that it must be taken into consideration during any decision-making process if it is relevant to the medical condition for which the directive-maker may require treatment. When a request for specific treatment is not complied, with the healthcare professional must record the reasons for not complying with the request.

A person who has reached the age of 18 years and who has capacity may make an AHD. A refusal of treatment set out in an AHD must be complied with if 3 conditions are met:

(a) at the time the AHD is to be followed the person who made the AHD lacks capacity to give consent to the treatment;
(b) the treatment to be refused must be clearly identified in the directive;
(c) the circumstances in which the treatment refusal is intended to apply are clearly identified in the directive.

An AHD is not applicable to life-sustaining treatment unless it is substantiated by a statement by the directive maker to the effect that the directive is to apply to that treatment even if his or life is at risk. This is an additional safeguard to ensure that the directive maker understands the seriousness of the nature of such a directive. An AHD will not be applicable to basic care which includes (but not limited to), warmth, shelter, oral nutrition and oral hydration and hygiene measures but basic care does not include artificial nutrition or artificial hydration (which would come within the definition of treatment – as both are interventions). In the 2015 Act, Section 82 provides that 'treatment' means an intervention that is or may be done for a therapeutic, preventative, diagnostic, palliative or other purpose related to the physical or mental health of the person and includes life-sustaining treatment. Certain personal information about the directive-maker must be contained in the AHD and certain formalities must be followed in order to make a valid AHD (Section 84, 2015 Act). There will also be a **Register** of AHDs.

Currently very few Irish people plan ahead, this means that the person's will and preferences are not known and decisions may be made that they would not agree with if they had the capacity to do so. Stress is caused to family members, some of whom are of the view that they have the right to make decisions on behalf of family members which is not the case, unless they have been given legal authority to make the decision in an EPA or AHD (see Sage Advocacy, 2018). The lack of advance planning has implications for society at large because clear arrangements are not in place for those who lack capacity. This leads at times to abusive practices (National Safeguarding Office, 2017).

Conclusion

The Assisted Decision-Making (Capacity) Act 2015 sets out a clear legal framework as to the principles that must be followed to respect the dignity and rights of older and vulnerable people taking into account the State's domestic and international human rights obligations. However, it should not be underestimated the huge cultural shift required by society as a whole to move away from customs and practices of the nineteenth century which are simply not acceptable today.

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SECTION 2:

THE LIVED EXPERIENCE OF AGEING

CHAPTER FIVE

AGEING: THE LIVED EXPERIENCE

MARY O'ROURKE

Introduction

I suppose any words on this subject (ageing) should begin at the beginning, so to speak. I am 81 years of age, born in Athlone, County Westmeath, Ireland in 1937, and now living back in Athlone and reflecting on a life lived through those 81 years. When I was younger, growing up in Athlone, older people were your parents and your parents' friends; younger people were you, your brothers and sisters and all your friends. Somehow, at that time, you put older people in a different bracket – they were there to be obeyed or to give suggestions and you followed them, whereas young people in those days seemed to be free to roam as they pleased, to make friends and to enjoy life. It all seems different now, but I'm just offering my reflections back on that time.

Somehow, it all seemed easier. Now when you look around and observe, children are corralled more, they are driven to sleepovers; they're driven to games; it's all done in a very structured way, whereas in my time growing up play was informal. You could be out all hours just playing and with no reference back home. It seemed more free, less supervised, but maybe that's looking back through rose-tinted spectacles. I don't know, but that was my idea of childhood. I was the youngest of four children. Brian was seven years older, Paddy was six years older, my sister Ann was four years older, and then I was the tag-on-Mary, after four years. I was always conscious of being the youngest in the family and I was always determined that I would not stay younger; in my childish mind I always felt that one day I would be the same as the others, the same age, and have the freedoms and exploits they appeared to enjoy. But I never caught up; they were always years ahead of me in everything, but I guess that's life.

Education

Now, I was sent away to boarding school when I was twelve, and by the way I think boarding school is a horrific place to send a child and why anyone should do so I don't know. Thankfully, the habit has disappeared. But anyway, my sister was there in that boarding school, Loreto in Bray, four years ahead of me, and she was in her second last year when I arrived. I want to make it very clear that I *hated* boarding school. I was always either cold, hungry or desperately lonely for my parents, for my family, for my friends back in Athlone and for the town of Athlone. In those days, you went to boarding school in September and you got out for Halloween, and I never came home then, I stayed with my Auntie May in Dublin. Then, after the Christmas break, you came back and you didn't come home until Easter. Likewise, after Easter, you didn't come home until summer. So those few years of my life were filled with loneliness and wishing I was anywhere else but there.

But to talk like this is wrong, and as I go on in life, I realise that I had a wonderful education in Loreto Convent in Bray. Those nuns at that time were marvellous teachers. I had a teacher of Latin, a Mother Benedicta Corless, and she was just brilliant. In the modern world she'd be the CEO of an upmarket technological company. Be that as it may, she was my teacher of Latin and she instilled in me a love of the Latin language – a love of the words and how they are made and the effect they have on all the other languages. I went on to do Honours Latin, the only student in the class to do so, and got my honours in the subject in Leaving Cert. I also had a wonderful nun as an English teacher. She was just brilliant, and my love of words now and my facility in quoting poetry or whatever are due solely to that wonderful grounding in Loreto Convent in Bray all those years ago.

Now, all this is by way of groundwork, and yet I was growing up, obviously, during those years. My father and mother had moved to purchase the 'Hodson Bay' in Athlone, which was a small Queen Anne house three miles from the town, and they turned it into what would now be called a boutique hotel – twelve bedrooms catering for people who wished to visit the Midlands and enjoy the beauty of Lough Ree and the nearby golf club.

After boarding school, I went to University College Dublin where I commenced my Bachelor in Arts degree. I remember my father asking me, 'Now what would you really like to be?' and I said, 'I would love to be a journalist writing for newspapers.' At that time there were very few, if any, women journalists in the world, or certainly in Ireland, so my father in a very matter-of-fact way said, ‘Well, let’s start with a good degree in English, wouldn’t that be a grounding? You could go on and do law or anything else.’ And the idea of law certainly enthused me.

Anyway, I went off to University College Dublin, which was then in the old Earlsfort Terrace, and there I did my first year in a myriad of subjects as one always did, and I think that is still the case. I took English and Latin and History and Social Studies and I went my merry way through first year. I didn’t study very much; it seemed to me that a lot of what we were doing was Leaving Cert stuff. Anyway, I did my first year exams and came home, and worked in the Hodson Bay Hotel. I was paid for my work; my father always believed a labourer was worthy of his/her hire, and so I washed dishes – there were no dish washing machines at that time in the hotel – I made beds, and as I got older I served in the public bar. I enjoyed every minute of it because you were meeting people of all ages and all types, and it seemed to me this was a wonderful life. My results came in at the end of first year and I remember Professor Lorna Reynolds, the English professor, contacted my father. It appears I had a very high first year English mark. She suggested to him that I should do this Group IV English which was specialising from *Beowulf* and early English, through Chaucer and right down through the whole pantheons of English literature. My father and mother agreed it seemed a good idea and so I went back to second year to do my two years, leading to a Bachelor of Arts in English. Now I enjoyed my college work, but I remember clearly I did not do much study or work apart from that. Then, I developed a trait which has stuck with me throughout my life. I only ever started to work when I was faced with a deadline, be it of an exam or a written timeline or whatever. I work best under huge pressure, and so it has proved to be in all my life’s endeavours. I don’t know if it’s the correct way to do it, but it suits my temperament and I developed that habit when I was studying for the final exam of my English degree in University College Dublin.

Returning to Athlone

I finished the Bachelor’s degree when I was 20 and because my sister who had trained in hotel management had got married, my father and mother asked me if I would come home for a year and help them to run the hotel. I was delighted to do so, because by then I had put my eye on one Enda O’Rourke in Athlone whom I had met when I was just 18 years old, out playing tennis at the Hodson Bay Hotel. So, I struck up a very strong romantic friendship with Enda. He was really my first serious boyfriend apart from innocent flirtations with some of the students in the literary society in Dublin, who were mainly of the earnest type, talking through what we were studying and wondering together what life held for us. Anyway, to cut to the chase, I stayed at home working in the Hodson Bay Hotel, and also doing the books and accounts for my brother Paddy who ran the Athlone Transport Company, which was a road haulage business. So I was paid for both jobs and worked during the day, and at night I flew off with Enda in his little old black Prefect Anglia car. It was bliss and I was in those very early stages of my twenties, in love and happy. The whole world stretched before me, and I was so young that I never dreamt of getting older. I remember one day in the hotel chatting to somebody who was in their mid-seventies, and I thought, ‘Oh to be in the mid-seventies is the end of the world’ – in my own mind of course – ‘You must be really ready to die.’ Little did I know that some years later I would be going through exactly that phase myself. Anyway, I’m putting it all in a kaleidoscope fashion. I married and had no children at first; Enda and I had problems with fertility. We went through all that and then I had my son Feargal and thought there was no trouble in having another, but of course that’s where the trouble began.

When I was 29 years old, I went to Maynooth College to do a Higher Diploma in Education. I loved that second foray into university life. Four of us went from Athlone on Monday, Tuesday, Wednesday and Thursday nights and then we studied together. Coming home each evening in the car was like an ongoing tutorial, which meant there was very little need for work when we got home – for academic work I mean; there was loads of work awaiting me where Enda had kept the fort, along with a young girl who I employed to watch Feargal and play with him in the afternoon until Enda came home from work. Now this is all very much put together in sort of an essay, but it is just to give an overview of my life. When I got my Higher Diploma – all four of us qualified – I started doing part-time teaching in Athlone, just two hours a day because I wanted to be at home with my son Feargal and later on my second son Aengus. During those years I was 30, 31, 32, 33 years old, with no concept whatsoever of ever really growing old. Many of the students I taught were 15, 16, 17 years old and to me we all appeared the one age and of the one mind.

Political Engagement

Life went on. I continued to teach and started to get involved in the local political party of Fianna Fáil, where my father was the TD until his untimely death at age 65 in 1970. I vividly remember when he died everyone saying how awful it was that he died so young in life. And he *was* young. In today's terms to die at 65 years, in the whole of your health, would be very young, but of course to me he was my father and he was the age of 65 years. I took his death extremely hard, and began to realise around that time, I think, that life was going on and that I myself was getting older.

In the 1970s, I had my first electoral success, in that I was elected to the Athlone Town Council and from then my horizons altered. I was quite determined that politics would be the life for me. I continued to teach, I served my time in the town council, and then was elected to Westmeath County Council. Then, in the early 1980s, I made my first foray into national politics. I went for and was elected to the Culture and Education Panel in Seanad Éireann (Upper House in Irish Government) in 1981. The following year, in November of 1982, I went forward and got elected to the constituency of Longford-Westmeath as one of its four Teachta Dála (Member of the Irish Parliament). I remember being so elated, on such a high that I had achieved this and I thought the sunny plains beckoned, and I was going to enjoy this wonderful political life.

Well I did enjoy it, and despite the hillocks and the valleys and all that went on in between, I always felt the honour of being elected by the voters in Longford-Westmeath, and the honour of being elected by them to speak and act for them in the parliament of my country. Now I know that sounds very high-blown, but that was the way I felt all through those years.

Enda was at home doing his daily job and being 'Dada' to the two children while I was away, and happily relinquishing the role when I would be back and we would be Mama and Dada in a regular family again. Over the years, we had the bliss of having a wonderful housekeeper who came for two hours per day to relieve me of some heavy housework and I always think so kindly of her. Her name was Mrs Pearl Samuels and the children when they were young used to call her 'Mrs S.'. I often think how she really made a difference to the texture of my life, and I think fondly of the many working households all over the country where the two parents are working and a Mrs S. took the place of Mum while she was out working.

Now I have to come to the bit where I'm getting older, but I must add a caveat: my life as a politician meant that somehow whilst I was dealing in my weekly clinic with many older people, I still never felt that I myself was getting older. My fifties and sixties slipped by, and I literally never felt them passing away. I was so busy, so over-busy; my life was so crowded with life, with love, with family, with work, that the days, the weeks, the months, the years passed by in a blur and I never realised that I was myself ageing.

Life after Enda

But of course, age I did. Enda passed away in 2001 and now this was when I really felt life hitting me with a bang and my age coming up. Suddenly, I was Mary O'Rourke, widow. I expect my whole life had been buttressed so soundly and so lovingly by Enda that that is why, in addition to everything else – the turmoil, the tumult, and all that went on–I failed to see the years advancing. Enda was two years older than me, but like my father he too died suddenly and far too early. Now I was truly alone. My two children were both away, Feargal finished college and married in Dublin, and Aengus was in college and doing a steady line with a lovely young woman whom he had met in the Institution of Technology in Athlone. And, when I closed the door every night, when I came home, I was Mary O'Rourke, on her own. I coped with the loneliness. After all, I was a Minister still, very very busy with my life in Dublin and coming home to my domestic political life in Athlone each weekend. But I so missed Enda. I missed him morning, noon and night. I went to bed alone, I got up alone, then life took over each day and still there was this aching, empty void. Where there had been two, there was now one. I lost my seat in the General Election in 2002 and wept bitterly at what I thought was the unfairness of it. Of course. it wasn't unfair, it was democracy having its way. I was fortunate that Bertie Ahern, the then Taoiseach (Prime Minister), appointed me to be leader of An Seanad Éireann and I went back to my first political home. I was very happy there for five years, and when the General Election of 2007 came along, I was ready and bolstered up for another tilt at the windmill of politics. I entered the fray again and was fortunate to be elected with my highest vote in the constituency.

Now I was acutely aware that I was going on my last lap, so to speak. I was 70 years of age and I began to feel I was 70 years of age. My last political job was when I was invited by Bertie Ahern to be chair of the committee set up to construct the wording for the referendum on the rights of children. It was the most painstaking and yet delightful job I had in government. Combined with my early five years as Minister for Education, I was dealing with young people again. I concluded that work just as the economic tsunami hit the world and then hit Ireland, and the political tsunami hit Fianna Fáil (Irish political party) in February of 2011. I was heavily defeated, and I knew defeat was coming.

I could not rail against it. I'd had a wonderful innings, a marvellous political life, and I was in a strange way glad that it happened the way it did and I could draw my breath and sit back, or so I thought. I was now 74, and did I sit back? No, I didn't. I decided I was going to embark on a writing career and I wrote my autobiography, *Just Mary,* which became an outright bestseller, much to my surprise and utter delight.

Did I begin to feel I was ageing? Yes, I did, in my body but not in my heart or mind. That is the funny thing about ageing; no matter what age I became, and I am now 81 years old, my heart and mind remain that of a young woman. I know that my body has caught up with me, and an earlier ankle injury, from when I broke my ankle in 2001, is now beginning to affect me, on and off, quite seriously. But it has not at all dimmed my wish to keep going in the world, to stride onwards each day and to achieve more and more. It is most definitely odd. I am old, I am 81 years-plus, but I am not old in my mind or in my heart. I cannot explain it any better than that. I have embraced a world of writing. I have had a second bestseller, *Letters Of My Life,* which to my mind is really an outpouring of my life and well worth reading if I may say so! I write a weekly column for the local *Advertiser* newspaper, which is available in the Midland and Western counties. I write articles for newspapers, and I talk a lot. I have been so lucky over the years to be invited to be a guest speaker at literary festivals, or to talk to Leaving Cert classes in school, or to talk to various groups of women.

Now, do I feel old? I have six grandchildren, and two wonderful sons who despite having had a jumbled-up childhood are modern men who look after their families, who do their jobs and who also, in their own way, look after me, their mother. I am so pleased that Aengus, my second son, has embraced the political life. He became a member of the County Council and he has been Mayor of Athlone and is looking forward to further political forays in the years to come.

I can only assume that because my life has remained active and hurried and full, that somehow I have escaped the worst vagaries of ageing. Yes, I have, as I referred to earlier, my health difficulties, but they are mostly of a physical kind, dating from my ankle injury. My heart, my lungs and all the major things in my body appear pretty sound and I am thankful for that, and I sleep well. Yes, of course I am lonely; yes of course there are difficult periods, and during those times I have recourse to my other love in life which is reading. I am lucky enough to have been invited by Pat Kenny (national radio show) to be on his ongoing book review team which meets once a month, and I find such joy in that, in travelling to Dublin, reading my book, doing my homework as I call it, and giving my opinion of it on the airwaves. And still the old habit persists; I find myself leaving the book until the last few days before I am due in Dublin and then I read it swiftly and with enjoyment and make my notes therefrom.

So I know when I go about my daily activities, that I am older. Thankfully, in Ireland there is still a certain courtesy towards older people; I notice that in my daily dealings with people in businesses or on the streets of Athlone. But no one ever mentions to me the age I am. The only person who mentions it is myself, to myself. In the world today there is most definitely a greater acceptance of the mingling of ages; there is a greater acceptance that there are no boundaries, that if one wants to keep working at whatever is your following or your bent, you can do so and nobody says 'Oh she can't do that, sure look at the age she is.' No, that hasn't arisen in my case. Anything that has arisen is because of the infirmity of my ankle, which leaves me from time to time to be slower in physical movement. I think that's a very good thing, because I have noticed I was always in life a hurtler and a dasher. I dashed at everything. I was always in a hurry and I was trying to do four jobs instead of one. Now, that has slowed down. Age has slowed that down, and I'm able to take a bit longer to rest between jobs or missions or whatever it is, and I no longer feel the need to constantly rush, rush, rush. If this is a perspective on ageing, well I have that.

I am also very conscious because of my age to eat reasonably well. I am often asked out to family lunches or to lunches with friends, but I mostly cook for myself. I eat a lot of fish which I love, and I always eat a lot of fruit. I have never got over, shame on me, my distaste for vegetables, but I compensate with salads and my forever culinary standby, tomatoes.

When I think back to my youth, I would have thought that anyone aged 81 years was sure to die the next day. Do I think of death coming up close? Of course it is coming closer, the older one gets. An odd time yes, I get a flicker, particularly when I go to bed and start to think over my day, of how happy I have been, I say to myself 'This can't continue Mary, you can't continue in this happy-ever-after land.' And then I say 'Well, I'll meet that when it comes' – not *if* it comes, because of course it will come.

I have set myself the aim of reaching 90 years. How realistic that is I do not know, but that is my bourn, my end-of-life achievement so to speak!! I'm glad that I've reached the age I have, that I have my email and can converse with the world, that I'm an avid TV watcher – I love documentaries and films – that I have retained a huge love of talking which is marvellous, and of reading which is equally marvellous. I love my family; when I have them with me or around me, my sons and their wives and my grandchildren, I am so happy to have reached the age I have. Yes of course I often think of Enda; I often dream of Enda and wish he was here to savour the beautiful grandchildren. He would love them, indulge them, spoil them, adore them as I do and there would be two of us to do that.

There is great emphasis now in modern reading about loneliness. I actually think there's a huge difference between being lonely and being alone. I'm quite happy from time to time to be alone with my own thoughts, with my books and with my memories, and if that means I am lonely then so be it, but to me it's not a bad place to be as I reflect from time to time on my life.

Conclusion

Now I know that my experience of ageing will not perhaps be a satisfactory template for study purposes. But I can say that from my years of my political work with older people, a few quite outstanding matters remain with me. Firstly, the main determination of many older people is to retain their independence, i.e. hopefully in their own home or abode where they can have their familiar things around them and be able to live life more or less as it always was. Now this is not always suitable or available, but many older people feel that with home help of a limited nature perhaps, they could get by in their own accommodation and retain their independence.

Secondly, among all the older people I have met and dealt with (including myself) the outstanding characteristic which will carry them through difficult times health-wise and mind-wise is a spirit of optimism and a spirit of hope. Now I don't know how that can be worked into any study or any observations on older people, but to me both from my own experience and from my experience of dealing with older people, that characteristic of optimism aligned to independence as I have detailed above, are the outstanding characteristics which will carry many older people into even older age.

I hope this little account has been of some value to the group who invited me to write it. I don't know if it has in any way reflected my perspectives on ageing. Be that as it may, I am the age I am, and I have lived all those years, so all I could do in this essay was to put it down starkly as it went year by year, and hope that out of it can come some gleaning of a perspective on ageing in Ireland. I've had two great losses in my life, my darling lovely Enda and young Brian Lenihan, Brian Junior, my nephew. Each in their own way meant a huge amount to me and there isn't a day I don't feel keenly about either or both of them. However, life continues and life was and is the Great Adventure. How that adventure will end is another matter entirely. Of course, I think of it from time to time but I don’t dwell on it. When it comes, it no doubt will be another adventure also. Let’s hope so. I keep in mind always the Chinese proverb: ‘Keep the bough green and soon the singing birds will come.’

CHAPTER SIX

LONELINESS AND AGEING: A NON-GOVERNMENTAL ORGANISATION PERSPECTIVE

SEÁN MOYNIHAN AND GRÁINNE LOUGHRAN

> 'I am a retired public servant and have no immediate family, I do have great friends, but they are busy with their own lives, their own grandchildren or other family events. Every day I go to a different coffee shop or little restaurant just to hear other people's voices. My home phone rings about once a month when I chat with an elderly relative and my mobile only rings when I'm getting a delivery or a courier is coming to the house. I'm healthy, independently comfortable and have no financial worries, but I'm lonely...If I walked to the pharmacy this morning and told them I had any ailment, they'd have some lotion or potion for me, but if I told them I was lonely, they'd probably laugh at me.'' (Submission to The Loneliness Taskforce, 2018)

There can be little doubt that general perceptions and stereotypes associated with getting older are largely negative. A study by Arnold-Cathalifaud et al. in 2008 concluded that while no single stereotype of old age exists, it is generally perceived as a stage in which the positive characteristics of life, such as health, are lost (Arnold-Cathalifaud et al., 2008). When we think about getting older, many of us consider the physical changes and challenges that may come, the financial implications on ourselves and our families, and potentially our future care needs. However, it is only in recent years that we have begun to seriously consider the emotional health of older people in Ireland and to realise that stereotypes of ageing such as loneliness should not go unchallenged, and to understand the impact that loneliness can have on physical health and quality of life.

Loneliness has many different definitions, but broadly it can be defined as the feeling that one is lacking in social connections to the extent that they are wanted or needed (Varney, 2013). A report by Age UK (United Kingdom), *All the Lonely People: Loneliness in Later Life* (2018:2), defines loneliness as:

> '…a negative feeling people experience when the relationships they have do not match up to those they would like to have.'

Although they are often used interchangeably, social isolation has a different definition. Social isolation relates to the absence of social interactions, social support structures and engagement with broader community activities or structures (Varney, 2013). In other words, social isolation can be said to describe objectively the state of being alone or in other ways disconnected from wider society; loneliness is the subjective feeling of being alone.

In Ireland, studies on the prevalence of loneliness differ in their estimates. The 2016 National Indicator Report by the Healthy and Positive Ageing Initiative (HaPAI) indicated that 7.1% of people aged 50+ often feel lonely. On the other hand, a 2004 report by The National Council for Ageing and Older People measured social, family and romantic loneliness. It found that just under 50% of older people identified themselves as moderately romantically lonely, 10% were moderately socially lonely, and 7.2% were moderately lonely in the family category (Treacy et al., 2004). Meanwhile, it has also been argued that 10% of older people suffer from chronic loneliness. (Harvey and Walsh, 2016)

The vast difference in these numbers, as well as the different methods of categorisation of loneliness, highlights the challenges involved in measuring and quantifying loneliness. Different measures include the University of California Los Angeles (UCLA) scale (Hughes et al., 2004) and the De Jong Gierveld scale (De Jong Gierveld and Tilburg, 2010), while the *Campaign to End Loneliness* (2019) in the UK has developed its own scale. Different scales take different approaches; the UCLA three-point scale asks negatively skewed questions, such as how often you feel you lack companionship; how often you feel left out; and how often you feel isolated from others. The *Campaign to End Loneliness* measure asks respondents to give ratings on how content the person is with their friends and relationships; does the person have enough people they feel comfortable asking for help at any time; and on whether their relationships are as satisfying as they would want them to be. Part of the reason that loneliness is difficult to measure is the lack of willingness to associate and engage with the idea to begin with, and indeed an evidence review by Age UK highlighted that people may be less willing to identify as being lonely due to the stigma attached to loneliness in today's society (Davidson and Rossall, 2015).

These differing approaches and the stigma already associated with loneliness highlight the importance in the phrasing of questions for quantitative surveys, and how vital it is to probe the issue in ways other than direct questioning. Although loneliness and social isolation are not the same issue, they are inextricably linked, and high rates of objective isolation can be an indicator of loneliness. For instance, although the HaPAI survey highlighted that 7.1% of people aged 50+ self-identify as lonely, The Irish Longitudinal Study on Ageing (TILDA) found in 2018 that just 13% of older men claim to have positive supportive friendships, and 40% of people fell in the moderately to most isolated categories.

We, in Ireland, are some years behind our neighbour, the UK, and particularly England and Scotland, in research and taking action on loneliness. As many will know, the Jo Cox Commission on Loneliness was set up to take action and resulted in the remit of the Ministry of Sport and Civil Society being increased to include a remit on loneliness. The *Campaign to End Loneliness* has published a number of research materials and reports which consider the figures on loneliness in England: there are 1.2 million chronically lonely older people in England and 9 million lonely people. The report assumes that the proportion of people 'often lonely' remains at the 10-year average (of 7.5%) observed between 2006/07 and 2016/17 (All the Lonely People, 2018).

There is a growing awareness of loneliness and how it affects people throughout the lifespan. Evidence suggests that loneliness levels fluctuate throughout the lifespan, with peaks in late adolescence and young adulthood, and in mature adulthood and older age (Qualter, 2015). It has also been reported that loneliness is higher in teenage years, lower during family formation and working years, and rises again in older age (Harvey and Walsh, 2016). With an increasing reliance on digital communications, technology and social media as a means of providing social interaction, the changing nature of our communities and the transition from rural to urban lifestyles, it may be some time before we realise the full impact of our changing way of life on our emotional wellbeing and on the wellbeing of younger generations as they age. Already, research has shown that social media use is linked to increased feelings of social isolation in young adults, showing that those who click into their social media profiles more than 58 times per week were three times more likely to feel socially isolated than those who logged in less than nine times (Primack et al., 2017**).**

Ireland's ageing population also brings potentially huge challenges in this area. As of the 2016 Census, there were approximately 876,423 people aged over 60 living in Ireland, representing 18.36% of the overall population. By 2031, it is estimated that this will grow to 1.31 million under the M2F2 population projection model (CSO, 2018). Although today we can say that loneliness is a public health crisis, in the coming years it has the potential to become a public health epidemic.

ALONE

ALONE is a national Irish organisation established in 1977. Our organisation's vision is for every older person to have the opportunity to age happily and securely at home. We work with all older people, including those who are lonely, isolated, homeless, living in poverty, or are facing other difficulties. We support them through these challenges to help them find long-term solutions.

In our experience at ALONE, there is still a stigma surrounding loneliness. There are many among the 1,500 older people to whom ALONE provides befriending and support services who would not associate themselves with the words 'lonely' or 'isolated'. Loneliness is still seen as a source of shame for many, an admittance of personal social failure rather than a recognition of changing circumstances in our lives and communities.

There are significant grassroots organisations in Ireland who have formed and grown to meet emerging needs around loneliness in their communities. Through Befriending Network Ireland, ALONE supports more than 50 organisations who provide befriending and other supports on varying levels. Often these organisations struggle with a lack of resources and funding. Solutions for loneliness however are coming from this sector, the community and voluntary sector, to meet their own community's needs, and it is vital that these efforts are recognised and supported.

Who is Affected by Loneliness?

Loneliness can affect anyone, of any age group. Groups most at risk of loneliness include members of the Lesbian Gay Bisexual and Transgender (LGBT) community, individuals living with dementia or cognitive impairment, those with a physical disability, mobility issues, or intellectual disability, carers, and individuals from ethnic minorities (Harvey and Walsh, 2016). Factors that can contribute to loneliness for older people include living alone, advancing age, widowhood, low levels of education or income, poor health, and infrequent contact with family (Harvey and Walshe, 2016). Risk factors for loneliness identified by Age UK also included demographic/social group, environment (urban/rural), having a caring responsibility, having a dementia diagnosis, living on a low income, poor mobility, and hearing/sight loss (Campaigntoendloneliness.org**).** A study in Belfast has also found that loneliness was higher for divorced or separated people, lower for married and lowest for single people (Boyle, 2010). As we can see, the risk factors associated with loneliness are many and diverse; however, there may be many more risk factors which have not been identified here.

There is evidence to suggest that men and women experience loneliness differently. Loneliness in men is more often associated with the quality of their relationship with a spouse or partner, whereas for women, the presence or absence of social networks is particularly important (Bernard and Perry, 2013). Loneliness is often most associated with older people who do not have significant family ties. However, while this can be a contributing factor, it is not always the case. It is also important to note that loneliness in older people should not be seen as a failure on the part of the older person themselves or their family. For example, Joan, aged 84, who receives ALONE's befriending service says:

> 'I just thought I was getting depressed and I didn't want that. Although I have five daughters that devote all their time to me at the weekends, they're all working during the week and then they have to come home and deal with their families and I don't like to put pressure on them, but I'm somebody that loves company.' (ALONE, 2018: 3)

While loneliness can affect any age group, the relationship between loneliness and age is not clear. Harvey and Walsh (2016) cite that studies by the National Council for Ageing and Older People and a 2001 Economic and Social Research Institute (ERSI) study found that loneliness was most evident among those who were 80 years and older, single or widowed women living alone, with lower education, lower socio-economic status, in rented accommodation, few transport connections and were more likely to be rural. They note that in contrast, a TILDA report found no significant correlation between advancing age and loneliness, suggesting that the relationship between old age and loneliness may not be straightforward. However, older people may be more likely to exhibit multiple risk factors for loneliness and social isolation, such as declining health, the death of a partner, or mobility and transport difficulties.

Although there may not be a direct correlation between advancing age and loneliness, the circumstances and challenges older people face which lead to loneliness can be more insurmountable, resulting in long-term solutions being more difficult to find. The complexity and number of issues which can prompt loneliness for older people may also lead to the experience of loneliness becoming chronic. This may become even more complex should loneliness begin to impact on one's physical or mental health.

Health Impacts

The various links between loneliness and physical health are continually being established. This is a two-way cycle; loneliness can have negative impacts on physical health, but declining health can also result in increased feelings of loneliness. The impact of loneliness on physical health has been compared to that of smoking or obesity, but still it fails to receive the necessary recognition as a serious public health issue.

Specifically relating to older people, the English Longitudinal Study of Ageing has shown that older people who experience high levels of loneliness are at increased risk of becoming physically frail (Gale et al., 2017). Loneliness in older people has also been found to affect cardiovascular health (Cacioppo et al., 2002). Lonely people suffer disproportionately with cognitive decline and hypertension and are more likely to be admitted to residential or nursing care (Russell et al. 1997). Perhaps most drastically, older people who are lonely are twice as likely to die within six years as those who are not lonely (Luo et al., 2012).

The reverse has also been shown through measures of increased levels of social engagement, which have been shown to impact *positively* on other forms of health. Research carried out on a sample of more than 1,100 older people without dementia showed that after controls for sex, education, race, depression, and chronic conditions were removed, more social activity was associated with less cognitive decline. The rate of cognitive decline was reduced by an average of 70% in older people who were frequently socially active, compared to persons who were infrequently socially active (Bennett et al., 2012). Work by the Alzheimer Society of Ireland has highlighted how social isolation can contribute to increased risk of dementia, and a lack of social integration can contribute to cognitive decline as we age (Hartigan et al., 2019).

More generally, loneliness and social isolation have been linked to other negative health outcomes. Loneliness has been shown to increase the risk of heart disease and impede recovery rates from stroke. A recent study in the journal *Cancer* concluded that women who were socially isolated had a 40% increased chance of recurring breast cancer and 60% higher risk of dying from it (Alcaraz et al., 2018).

Loneliness can also have a severe impact on mental health, the results of which many of us may be more aware of. It has been associated with psychological conditions such as anxiety, depression, substance abuse, lower social skills, a more critical view of self, and perfectionism (Zysberg, 2012). At ALONE, we have seen the impact that loneliness can have on mental health. When Christy, aged 72, retired, loneliness led to a period of low mood.

> 'I had a bit of a breakdown and I took to the armchair, he says. The doctor said to me, "Christy, there's millions of men like you all over the world. You worked all your life and now you don't know what to do with yourself. But we'll sort you out…" The loneliness ate me up. I was waking up at night thinking my life was over and I was going to be on my own for the rest of my life. Everybody has bad patches in their life. I often went to a football match, and you can be surrounded by thousands of people and be the loneliest man in the world. It's a terrible disease.' (ALONE, 2018: 1)

Christy now volunteers with charities and is still involved in his local running club, but he still found the evenings lonely until he got in touch with ALONE.

> 'It's the evening times are quiet. But the volunteer visit stops the loneliness of being on your own.'

Christy's story highlights the importance of continued social engagement after retirement. Christy says he now 'works hard' to keep himself busy and avoid a return to loneliness. However, as well as loneliness impacting health, declining health can also be a predictor for loneliness and social isolation. The report by the Institute of Public Health highlighted work by Burnholt and Scharf (2014:320) which found that:

> 'increasing numbers of chronic conditions can be considered as a precipitating event, which leads to a decrease in achieved levels of social interaction.'

Work by Dykstra et al. in 2005 also found that declining health can be a predictor of increased loneliness, but that loneliness can abate if the individual's heath improves or if they can make new social ties.

This was the case for Betty, aged 84. Betty began to feel lonely after the death of her husband, but it was in the aftermath of a hip operation that she began to feel this most strongly.

> 'I came home the first chance I could get but after the second day, I thought, oh my god, I couldn't manage it. The house was getting in on me. I normally do things, I'd be out every day, and I couldn't walk very well and it got very depressing, she says. It's very hard to explain it. I think everyone suffers differently.' The nurse asked did I need a carer, I said of course not, I can care for myself. I said no, I just have to try and start getting out to walk. Then she said, will I get in touch with ALONE for you?' (ALONE, 2018: 2)

In Betty's case, as Dykstra et al., (2005) highlighted, her loneliness lessened by making new social ties. This began with a volunteer visit once a week and Betty comments:

> 'ALONE got a girl coming to me and I started coming out of myself when she came. To me, that was like my own daughter. Soon I was giving the orders again.' (ALONE, 2018: 2)

Now, Betty gives knitting lessons at her local health centre. She continues to receive a volunteer visitor, but she is linked in with her community and has had the opportunity to create new relationships. Her loneliness has abated.

The Challenge of Infrastructure

The vicious cycle of loneliness and the impact on health and quality of life in older age is made even more challenging by the lack of support and infrastructure in place. Currently, the range of supports available varies hugely by location. Although illnesses and declining health alone may result in additional feelings of loneliness, these are compounded by insufficient infrastructure to support and enable people to remain active and engaged in society. Such infrastructure includes access to public transport, seating and toilet facilities, as well as services which promote engagement.

For instance, according to the HaPAI survey, nearly two-thirds (64%) of older people surveyed were dissatisfied with the availability of accessible toilet facilities. This can severely hinder access to urban and town centres for older people. Almost a third reported difficulties in accessing public transport (65% of these were severely limited by longstanding illness or health issues). This rose to 68% among those living in rural areas.

More generally however, a lack of transport has been shown to impact access to services and social outlets. The HaPAI survey shows that almost

10% of older adults have great difficulty accessing social services including shops, pubs, restaurants, and venues where they can meet friends. Nearly 11% of older adults could not get to venues where social activities are taking place. Overall, 25% of people surveyed have difficulty socialising, doing essential tasks, and/or getting to health or social care appointments due to a lack of transport (Healthy and Positive Ageing Initiative, 2016).

This is particularly true of older people living in rural areas. For example, 25% of older people living in rural areas report some or great difficulty accessing public transport while a further 30% report that public transport is not available to them. Non-drivers are particularly affected: 23% of rural non-drivers have difficulty socialising (most or all of the time) because of a lack of transport compared to 12% of urban non-drivers.

Irish, United Kingdom and European Approaches

Approaches to loneliness vary across different countries. Currently, policy approaches to loneliness in Ireland are limited. The National Positive Ageing Strategy in Ireland makes several references to ageing and loneliness. While the strategy does not identify measures to specifically address loneliness in older people, among the national goals are:

> ‘Remove barriers to participation and provide more opportunities for the continued involvement of people as they age in all aspects of cultural, economic and social life in their communities according to their needs, preferences and capacities.’ ‘Support people as they age to maintain, improve or manage their physical and mental health and wellbeing.’ (Department of Health, 2013:19)

Several of the key actions associated with these goals, including access to lifelong learning, promoting development of activities in communities, and provision of accessible transport systems in urban and rural areas, could result in higher levels of social integration and reduced feelings of loneliness for older people in Ireland. However, the Department of Health Strategy, which was launched in 2013, has proven slow to implement and it may yet be some years before full implementation is achieved.

There was no mention of loneliness in Healthy Ireland–a framework for improved health and wellbeing 2013-2025. Despite the impact loneliness can have on health and wellbeing, the number of people affected by it and the increasing awareness brought to it by high profile campaigns such as in the UK, loneliness is not yet seen as a policy priority in Ireland. To date, most initiatives and programmes to combat loneliness have been developed within the community and voluntary sector. However, in some countries, loneliness is beginning to be taken seriously as a public health priority. In the Netherlands, the Government is investing €26 million to combat loneliness among older people. According to reports, the package of measures includes an annual home visit for all over 75-year-olds to check whether they are lonely, a 24-hour phone service that can be used by older people feeling lonely, and mapping of areas ‘at risk’ where higher numbers of older people live for further development of local amenities (DutchNews.nl, 2019). In Australia, $46.1 million dollars was dedicated to the national Community Visitors Scheme which combats loneliness and isolation among older people, until 2021 (The Hon Ken Wyatt AM, Member of Parliament, Minister for Aged Care Minister for Indigenous Health 2018). In Ireland, in 2018, Dr. Keith Swanick established the Loneliness Taskforce in collaboration with ALONE to coordinate a response to the growing issue of loneliness in Ireland across all demographics. The Loneliness Taskforce includes members from the education, mon-government organisations (NGO), sporting, nursing, psychology, business and academic sectors. The taskforce sought submissions from the general public, Oireachtas and Northern Ireland Assembly Members, Local Authorities, MEPs, charities, Public Participation Networks and volunteer networks across the country, both North and South. In total, 310 submissions were received, with almost 1,000 ideas for how to combat loneliness. The submissions we received highlighted how loneliness is affecting young people, older people, people with disabilities, carers, recent immigrants and returning migrants, and a broad range of other groups. One person described their experience of loneliness as ‘a feeling of emptiness that is hard to describe, kinda like you ran out of petrol in the car.’ (Loneliness Taskforce, 2018:2). Another man told the story of how his long-time neighbour, who had little day-to-day interaction with him, approached him to ask if he would be their emergency contact.

The Taskforce came up with five recommendations for how to combat loneliness in Ireland. These recommendations are: annual funding of €3 million towards combating loneliness; the allocation of responsibility to combat loneliness to a specific Minister and Government department; a public campaign; support for initiatives and organisations which alleviate loneliness as their primary function and an action plan for volunteering; and Ireland specific research on loneliness. Although the taskforce recommended initial annual funding of €3 million per year, as we see from the funding spent solely on loneliness among older people in the Netherlands, it is likely that this will not be sufficient. The full costings of initiatives to alleviate loneliness have not yet been established in an Irish context. Over the coming months and years, we at ALONE and the Taskforce are committed to working towards the implementation of these recommendations in order to ensure that loneliness is taken seriously as a public health issue and that all necessary resources are put in place to address it.

Solutions to Loneliness

The million-dollar question remains: how do we prevent and find solutions to loneliness? Although a lack of access to transport, services and facilities are aggravating factors, implementing improvements in these areas alone would not result in loneliness being eliminated altogether. Currently, no catch-all solution for loneliness has been identified, but this is not to say that a huge number of effective interventions are not being carried out on a local level across Ireland and the world, by ALONE and other organisations. A 2016 literature review study by Gardiner et al. identified six categories of loneliness intervention: social facilitation interventions, psychological therapies, health and social care provision, animal interventions, befriending interventions, and leisure/skill development. While the authors highlighted that findings on the benefits of various interventions have often been contradictory and unable to provide conclusive evidence, they noted that the majority of interventions analysed reported some success in reducing social isolation and loneliness. Adaptability, community participation and activities involving productive engagement were common features of successful interventions in loneliness (Gardiner et al., 2016).

The Campaign to End Loneliness in the UK in their report *Promising Approaches to Reducing Loneliness and Isolation in Later Life,* (Jopling, 2015:9) saw ‘the biggest challenges, and the greatest innovations’, taking place in reaching lonely individuals, understanding the nature of an individual’s loneliness and developing a personalised response, and supporting lonely individuals to access appropriate services. Jopling notes that these ‘foundation services’ are the first step towards combating loneliness and should also be considered (Jopling, 2015:9).

Implementing foundation services such as accessible and reliable public transport options, as referenced previously is essential, but also technology and internet access are vital to combating loneliness. Technology-based interventions such as video conferencing, computer training and internet access have been shown to have positive effects on social isolation. However, for these initiatives to work, older adults need to have access to household internet, which only 68% have (Positive Ageing in Age Friendly Cities and Counties, 2018). Technological solutions may also be particularly beneficial for those with long-term health conditions or mobility impairments, enabling the creation and maintenance of relationships from within the home. At ALONE, we have been working to combat loneliness in older people for more than 40 years. We provide a visitation befriending and support service, where volunteers visit an older person every week to provide companionship. ALONE matches older people with volunteers who share things in common with them and who often go on to form long-term friendships. For those who may not easily be able to attend events outside the home, visitation and befriending services can offer vital social support. ALONE also provide a telephone befriending service, where volunteers call older people, some daily, some weekly, to provide social contact and information. Telephone befriending is a beneficial and cost-effective way to address loneliness. Research into telephone befriending has found that it helped older people 'to gain confidence, re-engage with the community and become socially active again' (Cattan et al., 2011:198), as well as providing a sense of security and autonomy.

We are also dedicated to ensuring the provision of quality befriending services nationwide. ALONE hosts Befriending Network Ireland (BNI), a national network of befriending services. The network was created in recognition of the need for increased collaboration between befriending services and for the centralisation of information and resources. ALONE provides training, information and resources to BNI members to promote consistent and quality services nationwide. Today, BNI has more than 50 members. However, these groups typically struggle in areas such as creating awareness of their service, recruiting volunteers, and maintaining adequate funding and resources.

Services can also work together to combat loneliness and provide individuals with multiple solutions. For instance, ALONE works to link in with organisations such as Siel Bleu, which provide exercise classes for older people. Mary, aged 79, became lonely after husband passed away and has been receiving ALONE's Befriending and Support service for some years.

> 'Helen comes to me every Wednesday, she takes me shopping and brings me back home and we can have a cup of tea. Sometimes we even go for a bit of lunch. I'd be lost without her.' (Fitzgerald, 2019:NP)

In recent months, we have linked Mary in with Siel Bleu's exercise classes. Not only does this support Mary with her physical health, but it has also helped her to create new connections.

> 'Michelle's (Siel Bleu Physical Trainer) a great girl, she's helped me an awful lot with the exercise and mostly, we have a great laugh, it cheers me up because I can get very low as I'm on my own, except for my dog and my cat. Everyone here (in the class) is lovely as well, they're very welcoming and we get on great.' (Fitzgerald 2019: NP)

Conclusion

Although ALONE is dedicated to combating loneliness among older people, we recognise that we can't do this alone. Reducing loneliness requires support and collaboration between government departments, the HSE, groups and health professionals which work with older people. Loneliness is little understood and its impacts on quality of life and health are under-recognised by policymakers and the general public as a whole. Loneliness can affect anyone, of any age group, but its impacts and contributing factors may be most challenging for older people. While there are many contributing factors to loneliness, it can affect older people regardless of location, gender, relationship status or family attachments.

In Ireland, there is a severe lack of research, and a corresponding lack of policy response, to combat loneliness, particularly in comparison to our neighbours in the UK. There is also conflicting information regarding the data associated with older people who struggle with loneliness. This is potentially due to the stigma which is still attached to admitting that one is lonely in today's society. However, this is particularly concerning due to the impact that loneliness can have on physical and mental health, which is also amplified by the lack of foundation services such as public transport and technology. Smaller and local groups are recognising and working to meet the needs of older people within their communities and it is vital that they are supported. While this is extremely welcome, it highlights the inconsistent levels of access to services across the country.

Today, loneliness is a huge problem among older people. With an ageing population and uncertainty regarding the impacts of our changing lifestyles, this might become significantly more in the coming years. We need to recognise loneliness for the crisis it is and provide supports to older people to manage and cope with loneliness and its effects to ensure the best quality of life possible for our ageing populations.

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CHAPTER SEVEN

GIVING VOICE TO VULNERABLE OLDER PERSONS – THE ROLE, POTENTIAL AND LIMITATIONS OF ADVOCACY

MICHAEL BROWNE

Introduction

The discussion on advocacy and older people is located here within the broader context of a growing emphasis on the rights of older persons (European Union Agency for Fundamental Rights, 2018), increased longevity[1] and challenges to ageism in all its forms which are gradually emerging. In recent advocacy discourse, the principle of enabling people to assert their will and preferences has replaced the notion of representing people's 'best interests'. This is accompanied by a growing emphasis on the concept of supported decision-making in ensuring that each individual's voice is heard in all decisions affecting their wellbeing, health, place of residence and finances.

Areas in which advocacy has been to the fore include the promotion of the rights and voice of people with disabilities and users of mental health services and, more recently, users of healthcare services generally. There is a general consensus internationally that vulnerable older persons need to be protected both legally and in the manner in which social and healthcare services are delivered (European Union/Madrid Declaration, 2002: Article 17). It has become increasingly recognised that many older people need advocacy support in order to assert their legal and human rights (Browne, 2018).

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[1] For example, by 2030, in Ireland the number of people aged 65 and over is expected to grow from its present one in eight to one in six (Wren *et al.* 2017).

Why some Older People may need Advocacy

Older populations are widely diverse in terms of assets, disposable income, access to goods and services (including the legal protection system) and health status. Many people live out their lives relatively autonomously with good health and physical and cognitive functioning while others will require care and support to varying degrees. Despite the provision of appropriate medical treatment for many of the diseases associated with old age, a minority of older people remain incapacitated to some degree and require varying levels of long-term care and support, often over lengthy periods of time. The availability of an advocacy service has potential to contribute to ensuring that this care and support is of the best quality possible for each individual. Vulnerable older people may need the support of an advocate for a number of inter-related reasons.

> 'They may be victims of abuse and neglect or have their human rights ignored or denied' (Council of Europe, 2014: 2).

Those living in long-term nursing home care are widely regarded as being among the most vulnerable in our society by reason of the special supports and continuing care assistance they need – 'therefore, particular attention should always be paid to their requirements, and to fostering quality in the care they receive' (National Council on Ageing and Older People, 2000: 37).

Some older people may have to engage for the first time with care services and supports at a stage of their lives when they are particularly vulnerable, e.g. where they have become cognitively impaired as a result of dementia or stroke. This is where advocacy can play a crucial role and can enable such people to express their will and preferences in negotiating the health and social care system.

Defining and Understanding Advocacy

There are multiple definitions and types of advocacy. Two definitions are quoted here which succinctly sum up what advocacy is about:

> (i) The process of pleading the cause and/or acting on behalf of another person (or persons) to secure services they require and/or rights to which they and their advocate believe them to be entitled. Advocates owe those they represent a duty of loyalty, confidentiality, and a commitment to be zealous in the promotion of their cause (Kerr and Kerr, 2003: 11).

> (ii) Advocacy is a means of empowering people by supporting them to assert their views and claim their entitlements and where necessary representing and negotiating on their behalf. Advocacy can often be undertaken by people themselves, by their friends and relations, or by persons who have had similar experiences. Delivering a professional advocacy service means providing a trained person who, on the basis of an understanding of a client's needs and wishes, will advise and support that client to make a decision or claim an entitlement and who will, if appropriate, go on to negotiate or make a case for him/her
>
> (Citizens Information Board, 2007: 7).

The literature identifies different models of advocacy (Weafer, 2003)– at an individual level, self-advocacy (incorporating group/collective advocacy), citizen advocacy, peer advocacy, patient advocacy, family advocacy, professional advocacy, representative advocacy and at a policy level, system advocacy (lobbying).

Advocacy has also been described in terms of the approach used (Dunning, 2005: 11), such as casework advocacy and personal advocacy; instructed or non-instructed advocacy; condition (such as dementia) advocacy; and issue/complaints advocacy (Dunning, 2005). Another variation within the domain of advocacy is whether the focus is on the individual or the group, e.g., people with an intellectual disability.

While there are different advocacy models and approaches, the underlying principle of advocacy is to facilitate and support people in speaking for themselves and in articulating their own needs. In practice, advocacy often entails the use of a number of approaches working together with supports being provided at various points along a continuum.

Within this kaleidoscopic range of 'advocacies', it is essential to be aware that people may need to draw on different types of advocacy for different needs and it may be necessary to integrate different types simultaneously to provide effective support (Dunning, 2005: 11).

Systemic Advocacy

The provision of necessary levels of health and social care services, housing and income in the context of an ageing society and limited public resources represents an ongoing social and economic challenge. Systemic advocacy or 'lobbying', aimed at influencing decisions made by the government or public bodies has an important role in helping to address larger systemic issues that affect older people's choice and access to supports and services. This type of advocacy is important because it:

> '…pla*ys* a central role in adjusting the power relations between service users and service providers, and is a vital element in challenging inequality and oppression' (Kinlen, 2013: 7; Oliver, 2008).

The experiences of individuals and groups engaging with the health and social care delivery system as mediated through advocates can provide a rich data source to inform policy development. Advocacy in this sense is not just about achieving improvement for individuals but is also aimed at bringing about political, legislative or economic change on behalf of a collective interest. Advocacy can be regarded as an essential function in a democracy by representing the viewpoints of minorities and disempowered groups, and by critically monitoring and pushing for changes in public policies (Kinlen, 2013).

The Values and Principles Underpinning Advocacy

Advocacy work generally is underpinned by a core set of values and principles, both among practitioners and within the projects and organisations that employ them. In relation to older persons, these can be stated as follows (Sage Advocacy, 2015; Age Concern, 2013; Scottish Independent Advocacy Alliance, 2009).

- Empowerment of the person where possible
- Promoting the wellbeing of individual older persons, based on an understanding of their personal and social context
- Promoting and respecting their autonomy and independence
- Involving individuals in all decisions that affect them directly or indirectly
- Recognising that what is going on in one part of an individual's life can affect other areas of his/her life
- Working in partnership with families and friendship networks, where an individual so wishes
- A holistic perspective of influences in a person's life – needs, risks and positive aspects
- Capacity-building
- The avoidance of harm

Empowerment of People as a Key Underlying Principle of Advocacy

Empowerment refers to a process where, through the provision of information and support, people are enabled to assert their rights, make choices and decisions and contribute to wider policymaking in the areas that affect their lives (Reed, 2004: 55). Provision of basic information on an individual's rights and entitlements can in itself be hugely empowering. An advocate can build up a client's confidence simply by listening to and supporting the person in expressing an opinion or working through options for him/herself. The aim of the advocate should be to assist people to be as autonomous as possible while acknowledging a person's right to be mistaken, to change his/her mind, to take risks and to seek outcomes that may appear not to be the best options in the situation.

Building on the concept of empowerment, it is now established best advocacy practice that self-advocacy should always be the goal. This can prove extremely difficult in the case of persons whose decision-making capacity may be diminished or in the case where people simply want someone to represent them, e.g. in making a complaint and seeking redress.

Independent Advocacy

It is important to recognise that many of those who provide social and healthcare services to people – nurses, doctors, social workers – see advocacy as part of their role. The principles and values of advocacy resonate closely with those espoused by these professions and the relationship between the client/patient and advocate is an important component of the role of many professionals (Browne, 2018). Legal advocacy is obviously provided by lawyers to their clients as required.

Given that vulnerable adults may experience barriers in having their voice heard by professionals (and also by family members), it is crucially important for people to have access to an independent advocacy service to support them and enable them to speak for themselves, or, where appropriate, to have an advocate speak on their behalf. The independent advocate can be particularly valuable in creating a bridge between the service providers/professionals and service users/patients.

Non-Instructed Advocacy: Acting as a Safeguard

A non-instructed advocacy approach may be appropriate when a person has complex communication needs or has a long-term illness or disability that prevents them from forming or clearly stating their wishes and desires (Scottish Independent Advocacy, Alliance 2009: 4). Following Henderson (2006), Non-instructed advocacy has been defined as:

> ‘Taking affirmative action with or on behalf of a person who is unable to give a clear indication of their views or wishes in a specific situation. The non-instructed advocate seeks to uphold the person’s rights; ensure fair and equal treatment and access to services; and make certain that decisions are taken with due consideration for their unique preferences and perspectives’ (Scottish Independent Advocacy Alliance 2009: 5).

If people lack capacity or have such profound communication difficulties that they cannot tell an advocate what they want in life, they are additionally marginalised and therefore have a greater need for independent advocacy. The role of the advocate in such a situation involves gathering as much information as possible about the person and their past and present wishes (if appropriate). This may be from family, friends, care staff and other people involved in that person’s life. It is important to acknowledge that a person’s capacity can vary from day to day depending on their condition and/or the issue with which they are dealing.

Linking Advocacy with Older People’s Quality of Life

How quality of life is understood and defined is fundamental in determining how advocacy is understood, especially in the context of people with cognitive impairment and dementia. Perceptions about quality of life can vary considerably between different groups of people. For example, health service professionals’ views about quality of life and dementia may differ quite considerably from an individual’s own views.

Quality of life domains include physical health, psychological and emotional wellbeing, level of independence, social relationships and relationship to the environment in which people live (Cahill and Diaz, 2010). In some cases, dependency in old age is created and sustained by weak social relationships and impoverished social conditions – thus,

> ‘…it is not disability that creates dependency, rather it is the failure of social structures and processes to facilitate autonomy and independence…’ (National Council on Ageing and Older People, 2007: 176).

Deliberately and proactively connecting people with impaired capacity with family, friends and community can enhance their quality of life individually and collectively.

Advocacy and Human Rights

Advocacy clearly does not operate in a vacuum and is both grounded in and reflects a rights-based approach. The human rights approach places the individual centre stage in all decisions affecting him/her. A rights-based approach is particularly relevant for vulnerable adults in that it views people as subjects rather than objects and as equal citizens and stakeholders in society and challenges the:

> '…social impulse to rank people in terms of their usefulness and to screen out those with significant differences' (Quinn and Degener, 2002: 10).

Contemporary international conceptions of human rights can be traced to the foundation of the United Nations. The Charter of the United Nations recognises the existence of human rights and calls for their promotion and respect. Article 1(3) of the Charter includes as one of the purposes of the United Nations to promote and encourage:

> '…respect for human rights and for fundamental freedoms for all without distinction as to race, sex, language, or religion' (United Nations, 1945: Article 1(3)).

The Universal Declaration of Human Rights (UDHR), widely regarded as a milestone document in the history of human rights, sets out, for the first time, fundamental human rights to be universally protected.[2]

The European Convention on Human Rights (ECHR) (*Convention for the Protection of Human Rights and Fundamental Freedoms*) built on the Universal Declaration to provide an international treaty to protect human rights and fundamental freedoms in Europe.[3] The European Social Charter (Council of Europe, 1996) is a Council of Europe treaty guaranteeing basic social and economic rights which concern all individuals. The right to protection against poverty and social exclusion and the right to housing are particularly significant.

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[2] The Universal Declaration of Human Rights was given expression in 1976 in the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights.

[3] The Convention entered into force on 3 September 1953 and the text of the Convention was subsequently amended in 1971, 1994, 1998 and 2010.

What are Human Rights?

Human rights are rights held by individuals simply because they are part of the human species. They are essentially the rights one has as a human being and are shared equally by everyone regardless of sex, race, nationality, and economic background. They are universal in content (Ishay, 2008: 3). The following three core components of human rights have been identified (Donnelly, 2003: 10):

(a) Human rights are *equal* rights–one either is or is not a human being, and therefore has the same rights as everyone else (or none at all);
(b) Human rights are *inalienable* rights–one cannot stop being human, no matter how badly one behaves or how barbarously one is treated;
(c) Human rights are *universal* rights–in the sense that we consider all members of the species *Homo sapiens* 'human beings' and thus holders of human rights.

Human Rights Principles

The underlying principles of a rights-based approach have been summarised (Quinn and Degener, 2002) as:

- The inestimable dignity of each and every human being
- The concept of autonomy or self-determination that demands that the person be placed at the centre of all decisions affecting him/her
- The inherent equality of all regardless of difference
- The ethic of solidarity that requires society to sustain the freedom of the person with appropriate social supports

Rights-based advocacy discourages *en bloc* compartmentalisation of identities (*viz.* older persons, people with disabilities) and focuses instead on the complexity and multiplicity of identifiers. People are understood primarily in terms of the challenges and opportunities faced at each stage of the lifecycle rather than as members of 'identity-groups'. In relation to persons with disabilities, a rights approach means:

> 'abandoning the tendency to perceive people with disabilities as problems and viewing them instead in terms of their rights' (Quinn and Degener 2002: 9).

Seven components of a rights-based paradigm have been identified (Browne and Millar, 2016) which are centrally relevant to advocacy work–citizenship and social inclusion, recognition, autonomy and self-determination, personal agency, voice, and equality–these are summarised in Table 7.1 below.

Table 7.1: Components of a rights-based advocacy

Citizenship and social inclusion	The right of individuals to share to the full in the social heritage and to live the life of a civilised being according to the standards currently prevailing in society (Marshall, 1950; Council of Europe, 2014).
Recognition	The esteem that one feels based on the respect that is afforded by others. It is based on the notion of each person being able to observe and feel that s/he has a recognised identity, experiences a sense of belonging and is given due regard by others accordingly (Honneth, 1995; Honneth, 2003).
Autonomy and self-determination	Being able to determine one's own life course, including at the end of life. It assumes that physical and functional independence is not a prerequisite to retaining autonomy (UN 2007; Council of Europe, 2014).
Personal agency	Participation and inclusion in critical decisions that affect one's life (Carlson and Kittay, 2010; Koh 2004). Supporting people to maximise decision-making capacity is a basic component of the United Nations Convention on the Rights of Persons with Disabilities (UN, 2007).
Voice	The right of each individual to express his/her views freely in all matters affecting him/her. This includes having control over one's accommodation, daily routines, activities, and general life direction (UN, 2007; Council of Europe, 2014).
Equality	All citizens being equally enabled to maximise their potential. While people may differ profoundly in capacity, character and intelligence, they are equally entitled, as human beings, to consideration and respect and society should provide appropriate supports (Tawney, 1964).

Advocacy and Supported Decision-making

Put simply, the goal of advocacy for people with reduced decision-making capacity, e.g. those with dementia, people with intellectual disability or other cognitive impairment, is to support them as individuals in achieving what they wish and in having access to what they value. A basic premise underlying supported decision-making is that everyone should be presumed to have the capability to make decisions.

> 'Legal capacity means the capacity to have rights and the power to exercise those rights. Practically, legal capacity is the law's recognition of the

> validity of a person’s choices’ (Centre for Disability Law and Policy, 2013: 2).

In Ireland, the Assisted Decision-making (Capacity) Act (2015) legislates for supported decision-making to assist people with reduced capacity and sets out key guiding principles.

Providing advocacy support for people with dementia is often a complex process which presents significant challenges in terms of people’s right to be protected and ensuring that their voice is heard. There are five key considerations for advocates working with people with dementia:

(i) Whether a person has the capacity to give instructions or not, the advocate’s role is to ensure that his/her voice is heard;
(ii) There is a need to explore alternative ways of facilitating agency by people with cognitive impairment – these should include an emphasis on collaborative processes (Carlson and Kittay, 2010);
(iii) There is a crucial and important distinction between decisional autonomy and the ability of a person on his/her own to execute those decisions;
(iv) The focus on providing support to people with dementia as individuals must fully take into account that people are (or certainly have been) part of a wider community including family, friendship networks/neighbourhoods and service provider professionals;
(v) People with cognitive impairment in residential care settings may be vulnerable, not only because of their individual needs, but also because historically the system of service provision has tended to be based on a dependency model rather than on an approach that maximises choice, supported decision-making and independence.

Independent advocates have a potentially significant role to play in supported decision-making in that it is crucially important that support is provided at the appropriate level – in other words, adequate but the least restrictive in terms enabling individuals to maintain independence and autonomy to the greatest extent possible.

Advocacy and Rights Safeguarding

The safeguarding and protection of vulnerable people is a key aim of advocacy. In this regard, helping to identify and address any forms of elder abuse is a central consideration in advocacy work. The Council of Europe urges Member States to provide for appropriate and effective safeguards to prevent abuse in all areas that relate to decision-making and the exercise of legal capacity of older persons, including possible restrictions which may be required for protection purposes (Council of Europe, 2014).

There are several forms of abuse (Government of Ireland, 2002) – physical abuse (including deprivation of liberty); sexual abuse (including sexual acts to which the older adult has not consented); psychological and emotional abuse; financial or material abuse (Fealy et al., 2012*)*; neglect and acts of omission (including failure to provide access to appropriate health and social care); discriminatory abuse (including ageism). In 2017 there were 10,118 safeguarding concerns managed by the Health Service Executive (HSE) Safeguarding and Protection Teams in Ireland, representing a 28% increase in alleged concerns reported from 2016. HSE figures also indicate that the rate almost triples for males and doubles for females in the over 80 age category (HSE, 2018).

The reality is that some people, due to circumstances, age, isolation, disability or cognitive impairment are not able to defend their rights and interests. For example, they may not be aware that abuse is taking place or may not know or have access to a means of dealing with violations to their human rights. In addition, in many cases where abuse or violation of rights occurs, such people are under the control of the perpetrator of the abuse and fear retaliation. In other cases, people may not have the capacity to voice their concerns.

The Council of Europe Statement on the Rights of Older Persons (Council of Europe, 2014) includes a number of stipulations in respect of protecting older persons irrespective of whether this abuse occurs at home, within an institution or elsewhere.

> ‘Older persons who have suffered from abuse should receive appropriate help and support… older persons are entitled to an effective remedy before a national authority and, where appropriate, to receive adequate redress for the harm suffered in reasonable time’ (Council of Europe, 2014: Article 20).

Advocacy and Older Persons in Residential Care Facilities

There are four key considerations which need to be taken into account in advocacy work with people whose ordinary place of residence is a nursing home. Firstly, some people may be there against their will which is in effect a deprivation of their liberty. Secondly, people in nursing homes should be enabled and supported in remaining active and valued members of the broader community in accordance with their individual wishes. Thirdly, the majority of older persons in residential care settings are vulnerable for reasons of dependency and reduced capacity to self-care which means that they frequently need assistance with maintaining and developing an appropriate social support infrastructure to enable them to assert their rights. Fourthly, older people resident in nursing homes may be vulnerable because historically the system of service provision has tended not to maximise individual choice and independence.

Advocacy Standards

It is clear from the literature that there are a number of potential benefits to be gained by developing standards for advocacy services and many organisations in Ireland and internationally have developed such standards (Sage Advocacy, 2015). Advocacy Standards should ideally include the provision of a benchmark by which to gauge the effectiveness of performance; clarity around the expectations of what the service can provide; transparency through accountability, which, in turn, serves to maintain the integrity of the service, and above all, protect and safeguard vulnerable people from a poor service (Browne, 2018).

Conclusion

The protection of older person's rights is at the very core of advocacy – the right to liberty; the right not to be subjected to abuse in any form; the right to health and social care commensurate with need; the right to choose; and the right to make decisions about all personal matters. However, the reality is that potential of advocacy is significantly constrained by social and political priorities, resource availability, organisational contexts, the service delivery infrastructure and, very importantly, the legal status of independent advocacy.

The key question for advocates is how to support the will and preferences of the individual and enable his/her voice to be heard. This can be particularly challenging where the individual's desired outcomes are difficult to ascertain clearly.

Advocacy is clearly not a stand-alone intervention and advocacy alone is clearly not the answer. It requires rights-based structures, context and frameworks, a commonly agreed and understood language about *independent* advocacy, an open dialogue about where it best fits in a continuum of services and supports and an *inter-agency* approach (Browne, 2018). There is a clear need for legal recognition in Ireland of the practice of independent advocacy which is currently provided for under a number of pieces of proposed legislation being considered by government.

Advocacy can potentially play a critical role in safeguarding vulnerable persons and in identifying and addressing system issues that undermine people’s legal and human rights. However, in order for advocacy to be effective, there is a need to develop a new narrative which would reflect and create a stronger context for the development of a rights-based health, social care and community supports infrastructure for vulnerable older persons and within which advocacy can play a central role. This requires a strong and proactive emphasis on older people’s legal and human rights irrespective of their decision-making capacity. Advocacy (individual, group and systemic) has the potential to create a transformative narrative which would fundamentally question current culturally engrained patterns that may have become broadly established over time and not questioned in any meaningful way, e.g. ways of dealing with older people with reduced decision-making capacity, including a discourse around ‘best interests’ as distinct from enabling people to assert their will and preferences. This would have as its key component supporting independent and autonomous decision-making by all people based on their legal capacity, their right to assert their will and preferences and to be safeguarded against abuse in all its forms. The challenge for providers of independent advocacy to older people who require support is to ensure an effective balance between addressing the needs of individuals, as they express them, and addressing the underlying issues which give rise to such needs.

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CHAPTER EIGHT

IMPACTING THE EXPERIENCE OF AGEING WELL: A POPULATION HEALTH PERSPECTIVE

EMER SHELLEY AND DIARMUID O'SHEA

Introduction: The Rationale for a Population Perspective

There are compelling reasons for governments to adopt a population health approach to planning to meet the health needs of older people. These include the increasing life expectancy beyond middle age which continues across most of the world, and the high burden of disease and disability in older people (Mathers et al., 2015; Prince et al., 2015). Primary prevention in younger people will improve health as successive cohorts age. However, much of the potential to reduce disease burden will be realised through more effective primary, secondary, and tertiary prevention targeting older age groups. These initiatives prevent or delay the onset of chronic conditions, detect and treat them at an early stage, or provide treatment, rehabilitation and risk reduction measures for those presenting with symptomatic disease.

The evidence is mixed on whether the increased life expectancy is associated with a lengthening of life spent with disability. There is evidence in some high-income countries that total lifetime days of disability have decreased (a 'compression of morbidity') in successive cohorts (Chatterji et al., 2015). There is also some evidence of a decrease in incidence rates of dementia in high-income countries (Prince et al., 2016). However, caution is required from a policy and planning perspective in that any benefits from lower incidence are likely to be more than counterbalanced by the increase in the numbers of older people.

To add to uncertainty about projecting the burden of disease in populations, upcoming cohorts have different exposure to risk factors as well as higher prevalence of chronic disease compared to previous generations (Chatterji et al., 2015). In the United States, the Behavioral Risk Factor Surveillance System found that despite 85% of adults reporting their health as good or better than that in 2015, nearly 30% were obese, 23% had some form of arthritis and 11% reported poor mental health in the previous month (Pickens et al., 2018). Of those aged 45 or older, 16% had diagnosed diabetes, one in ten had coronary heart disease and 5% had a history of stroke. The English Longitudinal Study of Ageing (ELSA) reported a similar prevalence of obesity (31% in men and 34% in women aged ≥55 in 2016/2017) and of diabetes (15% and 13% respectively) (Lassale et al., 2018). This burden of morbidity is unprecedented in human history and may result in a levelling off or a reduction in life expectancy.

Many chronic conditions are associated with lifestyle, resulting in a high prevalence of multi-morbidity. The prevalence of two or more chronic conditions in the ELSA cohort aged ≥ 50 increased from 32% in 2002/2003 to 43% in 2012/2013 (Dhalwani et al., 2016). In a cohort of similar age and using the same definition of two or more but including a wider range of conditions, the Irish Longitudinal Study on Ageing (TILDA) found a 72% prevalence of multi-morbidity in 2012 (Ryan et al., 2018). Both ELSA and TILDA found an association between inactivity and the development of multi-morbidity. The causal relationships are unclear because low levels of physical activity may increase risk of illness or the presence of chronic condition(s) may impact on capacity to undertake physical activity, increasing the likelihood of developing additional morbidity.

The association between ageing and limitations in activities of daily living has been examined in cohort studies. At least one such limitation was reported by 17% of men and women aged 60 to 64 in Wave 8 of ELSA, increasing to a quarter of those aged 70–74 and approximately 55% of those aged 80 or older (Lassale et al., 2018). There were large differences in reported limitations depending on wealth, ranging from 12% in the highest of five groups to 37% of men and 35% of women in the lowest.

The high prevalence of chronic health conditions is associated with regular use of medication (Richardson et al., 2012). TILDA found that 69% of those aged ≥ 50 years reported such use, with one in five reporting regularly taking five or more medications, thereby meeting the definition used for polypharmacy. For those aged 65 years or older, potentially inappropriate prescribing was identified in 57% of those surveyed, with potential prescribing omissions in 42% (Moriarty et al., 2016). Those with one potential inappropriate or two omitted prescriptions had higher use of emergency departments and general practitioner services than those with no such findings. In addition, those with multiple potential omissions had increased risk of functional decline and lower quality of life. Person-centred assessment and prescribing of behavioural change or medication is therefore part of the suite of interventions to maintain function into old age.

While much of the research has focused on those with non-communicable diseases or declining function, intervention to maintain health requires attention to the characteristics of those who do not have such conditions or acquire them at a later age than their peers. A review of longitudinal studies of behavioural risk factors in mid-life (40 to 64 years) and the absence or delay in non-communicable chronic conditions, including dementia and the onset of disability or frailty, found an association between physical activity in middle age and healthy ageing (Lafortune et al., 2016). Not surprisingly, smoking was a predictor of poor outcomes but the evidence about alcohol consumption was described as ‘mixed’. There was consistent evidence that healthy eating habits, similar to the Mediterranean diet, were associated with better outcomes and modest reductions in weight were associated with important health benefits.

The review of studies which started in mid-life added to the weight of evidence about the adverse outcomes of those with poor health behaviours and the converse, better outcomes in those on the healthier end of the distribution (Lafortune et al., 2016). There was less evidence about the impact of leisure or cognitive activities, or of social networks in mid-life on health outcomes at an older age. In addition, few studies focused on disadvantaged groups.

The studies with the longest follow-up started when life expectancy was lower and there were high death rates and lower prevalence of smoking and diet-related diseases. The dearth of evidence from earlier studies about the benefits of leisure activities or social networks should therefore not be interpreted as meaning they are not important. There is more recent evidence that while developing chronic health conditions and disabilities impacts negatively on quality of life, social integration and supportive friendships moderate this effect (McGarrigle and Ward, 2018). In TILDA this effect was found particularly in men, though women were twice as likely to report such positive friendships (16% and 31% respectively). There is evidence that the psychological, social and behavioural components of cultural engagement impact positively on risk of frailty, for example through cognitive stimulation, reducing stress and loneliness, and involving physical activity (Trivedy Rogers and Fancourt, 2019). Older adults in ELSA who engaged in cultural activities every few months or more had a reduced risk of becoming frail and a slower progression of frailty over time, supporting the case for community interventions to support healthy ageing.

In addition to the benefits for health and wellbeing, there are strong economic arguments for supporting healthier lifestyles and social integration of older people (Bloom et al., 2015). Policy responses are essential to manage the macroeconomic impact of the demographic transition, with fewer people of working age and a greater number in older age groups who are retired and likely to require health and social services as they age. Such policies include health promotion and disease prevention to reduce the population burden of non-communicable diseases and supports to maintain independence and community living despite the onset of disability.

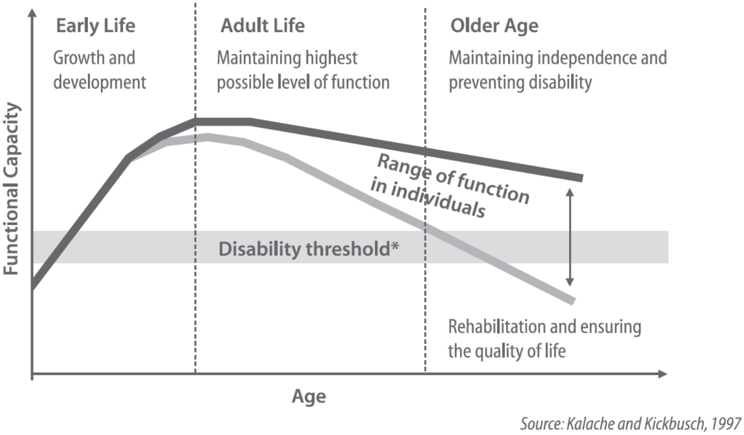
In its Global Strategy and Action Plan on Ageing and Health, the World Health Organisation (WHO) emphasised to Member States the importance of recognising healthy ageing as a public health priority and to commit to a sustainable, evidence-informed response (WHO, 2017). The potential for the demographic transition to impact on societies and economies is evidenced by advice on planning for age-friendly environments published by the European Commission in association with WHO Europe, while the Organisation for Economic Cooperation and Development has published a comprehensive report on the implications of inequality in resources and health in older age, and on measures to reduce the divergence between groups in society (WHO Regional Office for Europe and The European Commission, 2017; Organisation for Economic Co-operation and Development, 2017).

Concepts Underlying Policies for Healthy Ageing

Public health focuses on populations or subgroups of the population, just as clinical teams assess and plan the care of individual patients. In this instance the focus is on the experience of ageing. However, many interventions to support the health and social needs of older people are likely to also impact on other segments of the population. This may be a direct impact, as when accessible and safe environments improve the experience of adults with young children and those with a disability at any age, or may indirectly benefit family members and others who assist and care for older people.

There has been much discussion as to what constitutes ‘health’ since WHO’s definition in 1948 of ‘physical, mental, and social wellbeing, and not merely the absence of disease and infirmity’ (World Health Organisation, 1958). With the transition to lifestyle-related non-communicable diseases as the main cause of morbidity globally, it was recognised that health education alone would not be insufficient to prevent or delay their onset. The Ottawa Charter for Health Promotion laid the foundations for more holistic approaches, incorporating public policies, environments and communities which ‘make the healthy choice the easier choice’ for individuals, as well as health services which were reoriented towards prevention (WHO, 1986).

WHO’s *Active Ageing Policy Framework* set out a life course approach to improving and supporting healthy life expectancy and autonomy, independence and quality of life (Figure 8.1).



Source: Kalache and Kickbusch, 1997

Figure 8.1: Life course perspective on ageing (World Health Organisation, 2002:14)

The evidence base underpinning the Framework was summarised as follows:

> ‘Functional capacity (such as ventilatory capacity, muscular strength, and cardiovascular output) increases in childhood and peaks in early adulthood, eventually followed by a decline. The rate of decline, however, is largely determined by factors related to adult lifestyle – such as smoking, alcohol consumption, levels of physical activity and diet – as well as external and environmental factors. The gradient of decline may become so steep as to result in premature disability. However, the acceleration in decline can be influenced and may be reversible at any age through individual and public policy measures.’

The Active Ageing Policy Framework identified the determinants which continue to be relevant: gender and culture having an overarching impact on personal and behavioural factors, as well as the social, economic and physical environment, and health and social services.

Further evolution of these concepts was required to address the recognition that many older adults have one or more chronic conditions that, when well controlled, have little influence on their wellbeing (WHO, 2015). Healthy ageing, defined as ‘the process of developing and maintaining the functional ability that enables wellbeing in older age’, is the basis for WHO’s current recommendations to governments. Functional ability enables individuals ‘to meet their basic needs; to learn, grow and make decisions; to be mobile; to build and maintain relationships; and to contribute to society’, and is made up of intrinsic capacity, relevant environmental characteristics and the interaction between them (Beard et al., 2016).

Theoretically, interventions to maximise health and wellbeing in older age should begin preconception and *in utero* and continue into youth and middle age. Many interventions to maintain health target the young and those in middle age, so WHO strategies for healthy ageing focus on what can be done for people in the second half of their lives (WHO, 2017). The *Policy Framework for Healthy Ageing* is built on the theories outlined above, including actions across multiple sectors, enabling people to remain a resource to their families, communities and economies. It illustrates the changing needs for supportive environments and health services in the transition of population groups from ‘high and stable’ through ‘declining capacity’ to ‘significant loss of capacity’, mirroring the well-researched stages in individuals from fit and well, to pre-frail and frail (Figure 8.2).

A concept developed in relation to reducing risk of cardiovascular disease can be applied to the distribution across the levels of capacity in older age groups. The ‘prevention paradox’ identified that in order to reduce future morbidity it is necessary to intervene across the whole distribution of the population and not just in those with the highest level of risk (Rose et al., 2008). The individuals in this last group are likely to benefit the most. However, the greatest gain from a population perspective will be in the much larger number of people at lower risk who may each benefit to just a small extent but when combined for the group results in a large improvement in health. Translating this to the spectrum of functional capacity, it is essential to provide personalised services and supports to those who are frail, at the right-hand end of the distribution, but to maximise the impact, there should also be interventions which aim to maintain and improve health and capacity in those with declining capacity and in the majority of older people who have good functional capacity.

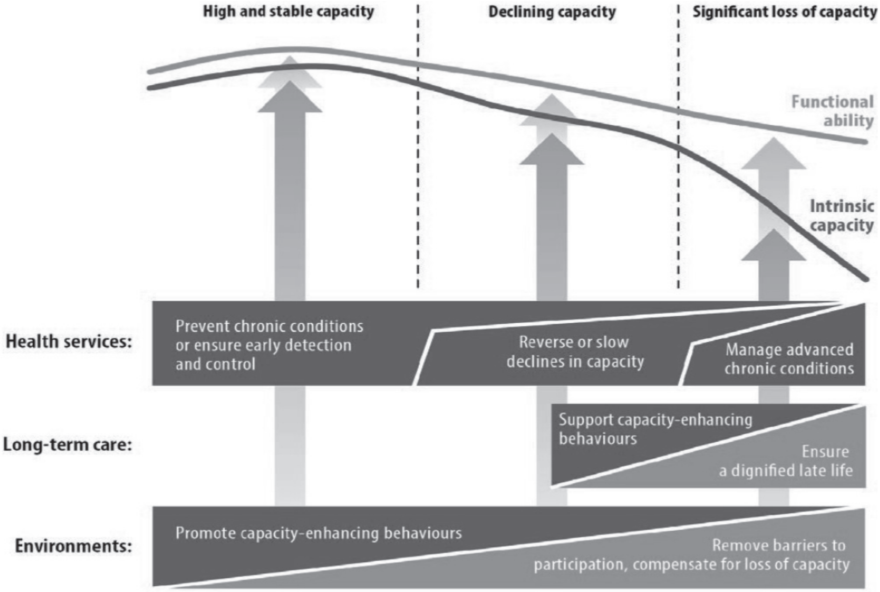


Figure 8.2: Public health framework for healthy ageing: opportunities for public health action across the life course (WHO, 2015)

National policies should therefore target the population from middle age onwards and also take into account and seek to influence the ‘environment’ in which people age, which includes the home, community and potential for social interaction and relationships, but also the built environment, societal attitudes and values along with health and social policies and services (WHO, 2015). A large proportion of the diversity in capacity in older age is the result of the cumulative impact of advantage or disadvantage throughout life. So, in planning to cater for the range of physical and mental capacities in older age groups, interventions should include attention to the inequity which results in higher levels of morbidity and mortality in those with lowest levels of education and access to resources (Institute of Health Equity et al., 2013).

Policy for Healthy Ageing

The WHO *Global Strategy and Action Plan,* adopted at the World Health Assembly in May 2016, emphasises the importance of population approaches to maintaining health and function, as well as personalised support through health and social services (WHO, 2017). The five strategic objectives of the Plan are intended to do the preparatory work at global and national levels for a Decade of Healthy Ageing from 2020 to 2030:

1. Commitment to action on Healthy Ageing in every country
2. Developing age-friendly environments
3. Aligning health systems to the needs of older people
4. Developing sustainable and equitable systems for long-term care
5. Improving measurement, monitoring and research on Healthy Ageing

At national level the most important first step to maximise the health and wellbeing of older people is acknowledgment by government of the demographic transition, followed by policy formation, planning and implementation. The rationale for policy development and a population approach which was outlined above include changes in life expectancy and morbidity, and the factors associated with the maintenance of health and wellbeing in older people, as well as demographic trends and economic implications. In addition to the moral imperative to provide appropriate support for all citizens and to care for the vulnerable, by signing up to the United Nations *Political declaration and Madrid international plan of action on ageing* governments agreed for the first time to link policies on ageing beyond the health arena to frameworks for social and economic development (Second World Assembly on Ageing, 2002). Importantly, this included acceptance that older people are covered by agreements on human rights at the United Nations conferences and summits.

It is acknowledged that public health responses to ageing have been inadequate in most countries. Beard, a leader for the development of policy and strategy in WHO, considered that:

> ‘to date, policy related to older age in many countries has often prioritized cost containment over the investment needed to enable the human and social resource that is inherent in older populations. Moreover, policy can appear disjointed, reflecting a political polarization that portrays older people as either vulnerable and needing support, or robust and needing to contribute. Although each characterization may have legitimacy, they are simply the ends of a continuum of diversity, and broader policy responses

> are needed to encompass this heterogeneity in a coherent way' (Beard et al., 2016:S165).

WHO is clear that doing more of what is already being done or doing it better will not meet the current and future needs of ageing populations (WHO, 2015). Many health systems are designed to diagnose, care and cure those with acute conditions and have not adapted to the longer-term systems and programmes required to prevent or manage and minimise the consequences of chronic conditions, multi-morbidity and functional decline. Deficiencies are exacerbated by structural and professional silos. Systemic change is necessary and can only be brought about by the creation and adoption of comprehensive policies, actively supported by governments, political parties and civil society.

Advocacy and media coverage of aspects of ageing are addressed in chapters seven and eighteen. Discussion in the public domain frequently seeks to improve supports so that people remain in their homes and communities for as long as possible and can access services in a timely manner. While this is useful, an overriding priority is for government to publish comprehensive policies to address the needs of ageing cohorts. Structures to oversee implementation and identifying timelines and performance indicators are essential to ensure that plans stay on track.

Delivering day-to-day services and care can take such a high proportion of personal and organisational resources that there is little reserve or energy for ongoing advocacy. Yet this is essential if the needs of older people are to receive the required investment despite being in competition with the many other demands on governments. Alliances of non-governmental, patient, caregiver and professional organisations need to mount sustained campaigns to achieve policy development and implementation.

When advocating for action on healthy ageing, it is important to cover the key messages in the *WHO Report on Healthy Ageing*: the heterogeneity of the older population and their needs, the importance of health promotion and disease prevention, the potential for older people to contribute to society and to the economy, as well as highlighting the costs of inaction and the needs for suitable housing, transport, access to services and long-term care (WHO, 2015). Local statistics and case studies can strengthen the case for government action. Such discourse will impact on the public, increasing the likelihood that government will respond and commit to policy development and implementation.

There are examples in many fields of courageous and energetic leaders succeeding in achieving action by government. Despite signing up to the declarations of international agencies such as WHO, it is unlikely that national and regional policies to support healthy ageing will be implemented effectively unless the case is made repeatedly for as long as it takes to achieve the desired outcome i.e. government commitment, political support, implementation structures, resources, and performance indicators, with regular monitoring and reporting on progress.

Population Health Planning

Other chapters of this book address components of national policy on healthy ageing, ranging from economic considerations to the need to create age friendly environments and technological supports, advocacy and promoting positive attitudes towards ageing and older people, as well as providing access to health and social care to meet their needs. Implementation of policy requires planning at national, regional and local levels in order to deliver health promotion and the necessary interventions to prevent disease and disability, and care for communities and individuals.

It is acknowledged that the evidence base on effective interventions is thin (WHO, 2015). Being realistic, it is likely to remain inadequate. Just as people are heterogeneous in their physical and cognitive functions, and in their attitudes and behaviours, so too are societies and services. Health and social systems cannot start from scratch to address the diverse needs of older people but must build on the structures already in place. Lessons can be learned from the successes and failures in other settings but may require substantial adaptation when being implemented in a different care system. Thus, translation from international policy and the available evidence requires national, regional and local contextualisation and ongoing review in order to deliver real and meaningful change.

Population health planning involves a detailed study of the target population, beginning with a demographic analysis. Much of the public discourse centres on the percentages of the population in the young, working and older age groups, on the basis of probability that age separates those who are less likely to be contributing economically from those who are likely to be in employment and less likely to require state support. These groupings form the basis for calculating dependency ratios which are important for projecting the funds required to meet the need for social protection and the capacity of those in working age groups to generate that national income. However, the number of people and not the percentage of the population is more relevant for planning, to estimate and project the need for services.

Population projections are derived from the current number, age and location of the population, as estimated at the census of population. Using recent trends in fertility, migration and mortality, assumptions about likely future trends in those parameters are used to estimate the size and structure of the population in the coming decades. While being mindful that the accuracy of the projections depends on the extent to which future demographic trends are reasonably consistent with the underlying assumptions, such projections provide the best basis for predicting need for publicly funded services.

While population projections provide the basis for planning, understanding the factors underlying past and recent demographic trends enables stakeholders to make the case for the necessary actions and resources. These may relate to historic events or trends in migration, as well as trends in mortality and morbidity. For example, the First and Second World Wars impacted on the size and structure of affected populations both immediately and for generations thereafter because of lower marriage and fertility rates. There was a ‘baby boom’ in several countries soon after the Second World War, and decades later that contributes to the increase in older age groups.

Past as well as current migration also impacts on the size, age and sex structure of populations. Returning emigrants or increases in immigration may explain higher current and future need for services, as may internal migration from rural to urban areas, or from city slums to suburbs. Migration may also impact on those who do not move, with reduced opportunities for marriage, less family support and social isolation, especially in rural areas.

Demographic analysis also involves attention to the density of the population. It is challenging to provide health and social services in areas with low density, especially if the population is dispersed and not clustered in villages or towns. There is a belief that care in the community is less costly than care in acute care setting. While only those requiring acute hospital services should be cared for in that setting and only for as long as such care is required, high quality care in the community is unlikely to be deliverable at the low cost which is frequently implied in discussion of these issues. Telemedicine and air transport may enable access to acute and complex care in sparsely populated areas. However, services such as early supported discharge or multidisciplinary care for those who are frail are challenging to deliver in a domestic setting and may require alternative models such as community hospitals for convalescence, assessment, therapy, rehabilitation and reablement.

Given the strong evidence of the excess morbidity and lower healthy life expectancy among those in the lowest socioeconomic groups as described in chapter two, an essential aspect of population analysis is identification of the geographic locations with concentrations of disadvantaged groups. Service providers are usually aware of them but planning to meet their special needs requires mapping and quantifying the population in these areas.

There are challenges in identifying the parameters to include in the definition of deprivation and different countries use different indices to characterise this at area level. The United Kingdom's strong history of research and use of indicators of deprivation is exemplified in reports from ELSA which use the Index of Multiple Deprivation (IMD) derived from seven dimensions measured at the small-area level: income; employment; health and disability; education, skills and training; barriers to housing and services; living environment; and crime (Matthews et al., 2018). Other countries use indices which are less complex and in the absence of government-provided area level information, indicators of relative deprivation may be used such as census data on employment status and level of education attained.

There are caveats about the use of area-level data to identify those in greatest need of support. Not everyone in an area with a concentration of those with limited resources suffers from relative deprivation and vice versa, there are people at high risk due to life circumstances who live outside such areas. In addition, people who become ill or disabled frequently suffer loss of income and become more disadvantaged. Nevertheless, population analysis will identify the numbers and trends in older age groups, and recognition of areas of deprivation adds to the evidence-base for planning interventions and services.

Use of Health Services

Policymakers, planners, service providers and the public are aware that the use of health services by adults increases as people get older. For the purposes of planning, funding and managing services it is necessary to quantify and analyse trends in service use by age group.

Data on acute hospital activity by age group is reported by many countries. For example, in Scotland in 2017/2018 one person in three of those aged 75 or older was admitted to hospital at least once, compared to one in twelve of those aged 25 to 44 (Anderson et al., 2018). The impact of the ageing population on acute hospital activity is illustrated in Ireland by the increasing percentage of bed days for those 65 and over from 48% in 2008 to 53% in 2017 (Statistics and Analytics Unit, 2018). In 2017 there were more inpatient bed days in women aged 85+ years than for any other group, male or female. In men, inpatient bed days were highest for those in their 70s, reflecting their lower life expectancy. The majority of admissions of older people were as an emergency which impacts on capacity for elective admissions. There was a 7% reduction in surgical inpatients during the previous decade, but surgical day cases increased by 67%.

TILDA reported a trend for increasing use of services according to whether participants were classified as robust, pre-frail or frail which was evident for frequency of visit to general practitioners (mean of 2.6, 4.3 and 6.7 visits in the previous year) (Roe et al., 2018) This trend was evident also for outpatient, emergency and inpatient acute hospital services.

Demand for healthcare, based on current level of service, and the cost implications may be estimated for the short and medium term by utilising data on service use by age group, demographic projections and estimates of disease prevalence (Smyth et al., 2017). For example, it was calculated that 1.4% higher funding would be required from 2016 to 2017 for publicly funded health services in Ireland based only on the impact of demographic changes. The increase would be higher, 1.7%, for inpatient and day case treatment in the acute sector. While there are caveats attached to such estimates, for example, that they are dependent of the quality of the data and the accuracy of the projections, and they do not include unmet need, they nevertheless provide information which can be used to make the case for the additional resources to meet the needs of the population, including those in older age groups.

Health Behaviours and Preventive Health Care

While there are financial costs and potential negative effects on quality of life associated with the higher use of health services by older people, there are also greater opportunities for prevention and anticipatory care including:

- Administration of vaccines or other interventions to reduce risk of future illness, including pneumococcal vaccine, annual immunisation against influenza, and assessing and managing risk factors in those at high risk of a cardiovascular event or diabetes.
- Screening for conditions which are not symptomatic where there is evidence that early detection improves outcome; examples include checking blood pressure and pulse (for atrial fibrillation), assessing risk of osteoporosis and referral for measurement of bone density if indicated, as well as encouraging participation in population-based screening programmes e.g. for bowel or breast cancer .

- Asking about common problems which may be overlooked when the person presents with another condition; these include depression, anxiety, alcohol misuse, history of falls or fractures.

There are strong health, quality of life and economic arguments for targeting health improvement initiatives to older people who are well even if they have one or more chronic conditions, and to those who are pre-frail.

Maintenance of health may be supported by interventions at community level but there is also scope for personalised advice. For people who have high and stable levels of capacity, an overall aim is to build resilience through capacity-enhancing behaviours, strengthening personal skills and relationships (World Health Organisation, 2015). For those with declining capacity, the aims are to identify and treat the underlining causes of declines in capacity, and to maintain muscle mass and bone density through exercise and nutrition. Those who have been more seriously affected may also benefit from interventions to recover some of the lost capacity but also require support to compensate for resulting disabilities and the impact on activities of daily living.

Older people may be more amenable to act on advice from a health professional, as they can understand the potential for more immediate gain compared to those who are younger (WHO, 2015). Health messages should however be given in ways which are relevant to the audience or the individual and require consideration of health literacy. Linked to literacy in general, health literacy:

> ‘entails people’s knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements and take decisions in everyday life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course’ (World Health Organisation, 2013:4).

For older people, information is important to encourage adherence to prescribed medications and to advise on the appropriate action if an adverse reaction is suspected.

Whether the issue is health maintenance or optimising management of chronic conditions, there has been a transition from ‘doctor knows best’ to shared responsibility. This means that the health sector works with and supports community and patient empowerment. This model of care was proposed by the Wanless report, based on the philosophy of ‘No decision about me without me’ (Wanless et al., 2004; Coulter and Collins, 2011). Batalden (2018) considered that with the current burden of chronic morbidity and disability, patient coproduction is essential to get maximum value from inputs to healthcare. While written from a perspective of quality improvement in the delivery of healthcare, all policymaking, planning and interventions to maintain and improve population health will be improved by fully engaging with older people across the spectrum of capacity, diversity, resources and education.

Conclusion

Population approaches complement one-to-one services to support health and wellbeing in older citizens. International organisations such as WHO encourage governments to develop and implement policies which recognise the spectrum of functional capacity of older people. Benefits from population-level initiatives to maintain health will be maximised by targeting the majority who are robust as well as those who are pre-frail. Those who are frail require personalised services and supports.

To be effective, national policies for ageing populations must be accompanied by plans for implementation and the necessary funding must be forthcoming. Intersectoral action is necessary, recognizing that needs encompass shelter, heat and nutrition, access to transport and age-friendly environments – physical but also social and cultural – which support interaction and a sense of purpose and meaning. Where policies are weak, those with a special interest in the wellbeing of older people can collaborate to advocate for action by government.

A population approach is essential to project need and to plan services. The lower healthy life expectancy and shorter life span of those who are poor is acknowledged as the biggest health inequity in the developed world, brought about by lower access to the means to maintain health across the lifespan. Planning should include identification of areas with higher levels of deprivation, followed by allocation of additional resources.

Ageing of populations and the increasing burden of chronic conditions are impacting on the costs and capacity of health and social services. Reorientation towards prevention is therefore essential to maximise quality of life for older people as well as to maintain the viability of services and the capacity of societies to pay for them. The best outcomes for all stakeholders will be achieved through sharing responsibility for healthy ageing between publicly funded and non-governmental agencies, and through engaging to provide appropriate, clear information to community groups and individuals.

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SECTION 3:

HEALTH APPROACHES TO OLDER PERSON CARE

CHAPTER NINE

PERSON CENTRED CARE: PRINCIPLES AND PRACTICE

AMANDA PHELAN

Introduction

The term person-centred care has become common within health and social care practice, policy and delivery as well as being a fundamental aspect of health and social care regulatory principles and public expectations of healthcare experience. Person-centred care has a broad global community of practice, but there remains diversity within understandings which may be attributable to the needs of different populations and the structure and delivery of various healthcare systems (Harding et al., 2015). This chapter provides an overview of the topic of person centred care, with reference to older people, and explores the more recent extension into an integrated health system constructed around person-centred co-ordinated care.

A Shift in Focus

Person centred care marks a reorientation of care focus from the narrow objectivity of disease centred, reductionalist bio-medicine to appreciating the person as a unique, self-determined human being. Influencing factors inherent in sustaining traditional bio-medical models include the time and resource pressure experienced by healthcare professionals leading patients to feel their voice is being marginalized (Chochinov et al., 2015). Other issues relate to paternalistic approaches, organisational needs, inflexible schedules and processes (Fazio et al., 2018), traditional training foci and the socialization of healthcare professionals, which prioritizes disease signs and symptoms, their treatment, professional disciplinary knowledge and task based approaches to care delivery. The reorientation to person centred care marks a democratic power sharing relationship between the ‘professional’ and the patient. This relationship is underpinned by facilitating personhood, building trust, establishing partnerships and promoting humanistic principles (Harding et al., 2015) within the co-production of care (SCIE, 2015). Moreover, a transformation to person centred care has tangible value in terms of individuals' physical and mental health, health service sustainability and wider social outcomes such as reducing health disparities (Ballard et al., 2018).

Person Centred Care

The dominant principles of person centred care can be traced to the work of Carl Rogers (1961), a psychologist, who argues that client-centred care demanded a particular practice orientation to the person. This focused on having a position of unconditional positive regard towards the client, being empathetic, accepting and genuine. Rogers (1961) proposed that each individual (a) possesses considerable qualities, (b) can draw strength from available resources, and (c) can find a way to remedy difficulties (Rogers, 1961). Following on from this, Tom Kitwood, also a psychologist, emphasised the environment within which older people with dementia were cared for. Kitwood (1997) observed that the social environment could be malignant in the context of human flourishing; relationships could be either supportive or damaging to the person living with dementia. In contrast to exclusive neurological-focused perspectives on dementia, Kitwood proposed that dementia involved the interaction of neurological impairment with psychosocial influences, with relationships and environment being key factors (Fazio et al., 2018). For Kitwood (1997), the idea of respecting and promoting personhood was central to enabling the positive wellbeing of older people. Consequently, personhood is constructed as a unique and moral and ethical status which requires deep respect. Personhood is defined by Kitwood as:

> '… a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust.' (Kitwood 1997: 8)

For people living with dementia, personhood can be challenged by the environmental and social (non) engagement contexts they experience as the disease process advances. The progression of dementia can be constructed as a social death before a physical death if the bio-medical model is core to care delivery (Alzheimer's Society, 2013). Consequently, society, including health and social care systems, perceives the person as the 'disease', skewing the true meaning of personhood (Kitwood, 1997).

Furthermore, Dewing (2008) notes that correlating particular attributes to personhood, such as cognition, can mean those without these attributes do not meet the criteria of being a person. For example, the commonly used term ‘loss of self’ is equated to a declining cognitive and functional ability rather than each individual holding the innate quality of personhood. Accordingly, debunking this fallacy is imperative and research points to the need for revised communication approaches which can enhance connections with the older person living with dementia focusing on how things are done (engagement) rather than what is done (tasks) (Kitwood, 1997; Fazio et al., 2018). Despite the recognition of a more humanistic approach to care delivery, there have been some concerns focused on the utility of personhood in relation to conceptualising dementia care. For example, a recent paper by Higgs and Gilleard (2016) argued that personhood has multiple meanings within moral philosophy and metaphysics and Kitwood’s (1997) constructions are consequently limited in contributing to the construction of person centred models and care standards. Rather, the authors argue, that the focus should be on supporting capabilities and reducing the impact of incapacity (Higgs and Gilleard, 2016).

When we shift our social positioning of people (of any age), the result can be a tacit change in our attitudes, perspectives and behaviours, which enables marginalisation and different standards of care experience (Fu-Chan Tsai, 2009). Harding et al. (2015) notes that the conceptual development of person centred care points to fundamental canons such as individuals being self-determined with leading roles in areas of decision-making, care planning and implementation, continuity in care and in transitions of care. Consequently, the person is valued as an individual and care delivery is flexible, engaged and facilitated through supportive communication. In this regard, there are similarities with Wolfensberger’s (1983) social valorisation theory, which enables people to be recognised as having socially valued roles in society. Thus, in reconstructing care towards a person centred focus, it becomes evident that the person is not ‘lost’ as meaningful connections are visibly manifested and embodied autonomy is possible even in the advanced stages of dementia (Watson, 2019).

Person-centred care has extended beyond the population of older people living with dementia and is considered an important foundation in many care systems, regardless of age (Phelan et al., 2018). Person-centred care recognises the multiple dimensions of ‘being’. McCormack (2004) proposes that individuals are enmeshed in four dimensions of being, namely, being in a social world (understanding people’s subjective narratives), being in relation (the individual’s relationships with others and relational processes), being in place (an individual’s environment and interactions) and being with self (recognising that how one is related to impacts on self-conceptualisation). Consequently, for McCormack and McCance (2017), person centredness is defined as:

> '…an approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons (personhood), individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development.' (McCormack and McCance, 2017:20)

Delivering person centred care also acknowledges the healthcare professional as a person, who recognises their own values and experiences and engages in person-to-person therapeutic alliances (Harding et al., 2015). Moreover, person centred care involves more than the dyadic relationship between the older person and the healthcare professional. For success, it demands sustained organisational support and a focus on a cultural transformation to support and promote a care ethos centralising the person.

Person centred care can be measured (Brooker and Surr, 2005; Edvardsson et al., 2013; de Silva, 2014; Grealish et al., 2017) and has demonstrated improvements in areas such as quality of life, sleep patterns, a reduction of agitation (Epp, 2003), better health outcomes (Ekman et al., 2012), positive care experiences (Olsson et al., 2013), increased patient satisfaction, a greater experience of efficacy (Pirhonen et al., 2017), enhanced service delivery (Delaney, 2018) and staff retention (Brownie and Nancarrow, 2013). However, although person centred care can have positive impacts (Harding et al. 2015; WHO 2013), there may be challenges in its translation to practice (Santana, 2017). These can relate to a lack of familiarity and understanding with the discrete aspects of person centred care's philosophy (Colomer and DeVries 2016; Oppert 2018), a lack of translation to and implementation in practice (Donnelly and MacEntee, 2016), or an emphasis on efficiency, leading to task and routine focus and a lack of supportive organisational culture (Sharp et al., 2018). For instance, one Swedish study pointed to barriers to person centred care manifested through a continued entrenchment of traditional practices and structures, a persistence in or return to more bio-medically focused care and issues related to developing person centred care interventions (Moore et al., 2016). Equally, the notion of partnership is fundamental in person centred care and is premised on the wish or ability of the person to be involved in their own care, yet, research demonstrates that this is not always desired or possible (Eldh et al., 2006). Moreover, as discussed earlier, within the knowledge base on person centred care, there is more work needed to standardise definitions and challenges remain in comparing interventions across studies (Harding et al., 2015). Thus, additional research is needed (Van Royen et al., 2010) to demonstrate universal understandings and outcome evaluation.

Models of Person Centred Care

Several frameworks have been developed to articulate the operationalisation of person centred care. However, there are central concepts inherent in the models which include the provision of relationship-based care that promotes personhood, individualising care in order to support meaningful engagement and ensuring those who deliver care are equipped with appropriate knowledge and skills (Levy-Storms, 2013; Harding et al., 2015). More recent frameworks or models incorporate an organisational systems level approach, which acknowledges that person centred care transcends the direct interface with the older person to incorporate the multi-dimensional conditions of its possibility. Common person centred care models/frameworks are demonstrated in Table 9.1 together with the main concepts.

Table 9.1: Person centred care models/frameworks, authors and related concepts

Model/ framework	**Authors**	**Concepts**
Person centred Care	Kitwood (1997)	**Love:** The overarching component of care. Individuals need to experience unconditional acceptance and genuine positive regard in their lives. **Attachment:** Each person needs to have meaningful attachments through close links with family and friends. **Inclusion:** Individuals need to be included and feel part of a community. **Identity:** Every person has their own identity and individualism, so stereotyping older people denies this. **Comfort:** An individual needs to feel at ease and experience wellbeing in his/her environment. **Occupation:** Individuals need to be facilitated to engage in things that interest them.

VIPS	Brooker (2007)	**V**=Values people–Values and promotes the rights of the person **I**=Individual's needs–Provides individualised care according to needs **P**=Perspective of service user–Understands care from the perspective of the person with dementia **S**=Supportive social psychology–Social environment enables the person to remain in relationships.
Senses Framework	Nolan et al. (2010)	Based on relationship-centred care and focuses on the older person, staff and relatives. **Sense of security:** To feel secure in the environment and have timely attention to needs with adequate support networks. **Sense of belonging:** To feel involved and valued and to enjoy mutuality in relationships and confidence in others. **Sense of continuity:** To be recognised as having individuality and that this individuality is respected and promoted within a continuity of competent care delivery. **Sense of purpose:** To have personal goals and to experience meaningful activities, pursuing goals and desires. **Sense of achievement:** To be able to follow goals and make a valued contribution. To feel satisfied with contributions. **Sense of significance:** To feel that you are valued, appreciated and that you matter.
Person centred Practice Framework	McCormack and McCance (2010, 2017)	**Macro-context:** Health and social care policy, strategic frameworks, workforce development, strategic leadership. **Pre-requisites:** Professionally competent, developed interpersonal skills, commitment to the job, clarity in beliefs and values, knowing self. **The care environment:** Appropriate skill mix, shared decision-making systems, effective staff relationships, supportive organisational systems, power sharing, potential for innovation and risk taking, the physical environment. **Person centred processes:** Working with the patient's beliefs and values, engaging authentically, sharing decision making, being sympathetically present, providing holistic care. **Person centred outcomes:** Good care experience, involvement in care, feeling of wellbeing, existence of a healthful culture.

Gothenburg Model	(GCPCC nd)	**Partnership:** Mutual respect, recognition of person and family's experiences, recognition of the healthcare professional's knowledge and skills. **Patient narrative/story:** The subjective knowledge of the person combined with objective findings from assessment and examination. Involves a health plan formulation with goals and strategies. Relatives can be jointly involved. **Documentation:** To record in documentation the care plan including the patient narrative and health plan. Documentation is a live, dynamic process which is accessible to the person and follows the care journey.

Building on the work of Kitwood's (1997) model discussed earlier, Brooker (2007) developed the VIPS framework as a building block for person centred care environments, again illustrating the fundamental ways personhood can be promoted. While the VIPS framework guides how care is delivered, this can be measured by observing and mapping the positive and malignant social psychology aspects of care through the process of dementia care mapping (Brooker and Surr, 2005).

In 2006, Nolan and colleagues developed the senses framework which advocates enriched environments which not only focus on care delivered to the older person but emphasises relationships between all individuals in the care environment, including staff and family. Relationship-centred care is experienced in having all six senses needs met and creating 'the right environment for everyone to grow' (Nolan et al., 2006:124).

In 2010, McCormack and McCance developed the person centred care practice framework. Person centred care is enabled when there is an alignment of all components of the model. For example, healthcare staff need to have the appropriate prerequisites to work with older people; the care environment and care processes need to support human flourishing, partnership and individualism while it is also a requirement to demonstrate evidence that person centred outcomes are experienced by those receiving care. In a further iteration of the model in 2017, a macro context component was added which pointed to the need to have supporting policy and strategies to create enabling person centred environments.

In the Gothenburg model, there are three conditions for person centred care. Firstly, a recognition of the person as an active, authentic and knowing partner in care who has a right to self-determination. The partnership emphasises the knowledge and skills of practitioners and care is mediated through mutual negotiation. Recent findings based on a review of the Gothenburg model point to the need to build on the informal and formal elements of partnership to progress care participation (Wolf et al., 2017). The patient narrative is viewed as the creation of care, which may include relatives' involvement. This uncovers the meaning and subjective interpretation of the illness in daily life. Through such understanding, person centred goals can be articulated, increasing opportunities to enhance human flourishing. The final component of the Gothenburg model relates to documentation, which evidences the mutually developed narrative based care plan, which is accessible to the older person if desired.

Person Centred Coordinated Care

As older people transition from setting to setting, there is a need for consistency, continuity and integration in the experience of person centred care. Recent research has extended person centred care to the broader care co-ordination context which has been intrinsically linked to universal health insurance (WHO, 2015). Health is not experienced in a uni-discipinary or a uni-setting way, particularly by older people, who may experience complex co-morbidities which require multifaceted healthcare management traversing multiple settings and disciplines. Health systems can struggle to meet the demands of delivering person centred care across settings (NICE, 2006; Royal College of Nursing, 2008; Lewis et al., 2010; WHO 2016). In addition, health systems which have traditionally focused on siloed, fragmented disease management approaches have been increasingly ineffective in the management of a rising ageing demographic who are at greater risk of frailty and chronic diseases which require enhanced supportive systems (Damery et al., 2016; Mittinty et al., 2018). Compounding this is the fact that health has many contextual and environmental influences which demand a wider consideration in the context of the individual's social determinants of health. For example, issues such as genetics, income, employment, educational level, housing status, social isolation, family and community support and access to various services all impact on health status, yet care has generally focused on treating diseases/conditions in an isolated, reductionist way. Such fragmentation in healthcare delivery has led to a higher rate of acute hospitalisations and increased stress on the older person (Calver et al., 2006) and is manifested by challenges in accessing providers, a lack of coordination when transitioning care and gaps in care integration (Higgins et al., 2015). A reorganisation of sustainable health systems is needed to provide integrated care which prioritises person centredness as well as public and patient involvement (Phanareth et al., 2017). Consequently, the core focus for person centred co-ordinated care is on the provision of 'systematic, responsive and supportive care' (Ehrlich et al., 2009: 622). This realignment requires targeting organisational, functional, service and clinical levels of service delivery (Lewis et al., 2010).

From a health system's perspective, person centred care demands three elements, namely integration (national/structural) a compassionate service (local) and personalisation (individual level) (Glasby, 2017). In essence, this means person centred coordinated care has a dual outcome agenda. It needs to focus on care provision across the boundaries of health and social care services, including within various teams as well as fostering service provider-person relationships to maximise authentic partnerships in care (Koch, 2013). Person centred coordinated care can lead to better patient outcomes, enhanced patient and family satisfaction with healthcare services, greater levels of collaboration, improved quality, less overlaps and less gaps in care provision (Huber et al. 2014; Borycki et al., 2015; Higgins et al., 2015; Di Pollina et al., 2017). However, the implementation of person-centred coordinated care is not without some challenges. Ehrlich et al. (2009), for example, suggested that positive outcomes should not be assumed as there may be a danger that costs increase through identifying unmet need and that systems need to be reformed to facilitate person centred coordinated care. In addition, budgeting within different healthcare sectors may mean eligibility of care in one environment, but not necessarily another. For example, in Ireland, there is a financial eligibility (means tested) supported through legislation, to nursing home care (Nursing Home Support Scheme), yet this is not necessarily the case in community-based care, where budgets are more precarious.

Narratives of Person-Centred Co-ordinated Care

In tandem with the ethos of involving people in care delivery, some studies have been undertaken to identify how care should be experienced from the narratives of patients and their caregivers/family. Person centred care inherently values the voice of the individual receiving care, yet, in some serious case reviews it has been identified as relatively silent to the detriment of patients (Francis, 2013). In more recent times, patient experience surveys have been seen as core to developing and improving service provision and are a key driver for local, regional and national healthcare reform (see HIQA et al., 2018, Raleigh et al., 2015, for example).

In the United Kingdom, National Voices, a coalition of charities focused on service development towards person centred coordinated care, advanced a narrative for what people wanted in their care experience:

> I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me. (National Voices, 2013: np)

This narrative is supported by six domains and 38 'I' statements articulating the experience of person centred coordinated care as presented in Table 9.2.

Table 9.2: Domains and 'I' statements for patient narratives of person centred co-ordinated care (National Voices 2016).

Domain	'I' statements
My goals and outcomes	• All my needs as a person are assessed and taken into account • My carer/family have their needs recognised and are given support to care for me • I am supported to understand my choices and to set and achieve my goals • Taken together, my care and support help me to live the life I want to the best of my ability
Care Planning	• I work with my team to agree a care and support plan. • I know what is in my care and support plan. • I know what to do if things change or go wrong. • I have as much control of planning my care and support as I want. • I can decide the kind of support I need and how to receive it. • My care plan is clearly entered on my record. • I have regular reviews of my care and treatment, and of my care and support plan. • I have regular, comprehensive reviews of my medicines. • When something is planned, it happens. • I can plan ahead and stay in control in emergencies. • I have systems in place to get help at an early stage to avoid a crisis.
Communication	• I tell my story once • I am listened to understand about what works for me, in my life • I am always kept informed about what the next steps will be.

	• The professionals involved in my care talk to each other. We work as a team. • I always know who is coordinating my care. • I have one first point of contact. They understand both me and my condition(s). I can go to them with questions at any time.
Information	• I have the information and the support to use it that helps me manage my condition(s). • I see my health and care records at any time. I can decide who to share them with. I can correct any mistakes in the information. • Information is given to me at the right times. It is appropriate to my condition and circumstances. It is provided in a way I can understand. • I am told about other services that are available to someone in my circumstances, including support organisations. • I am not left alone to make sense of information. I can meet/phone/email a professional when I need to ask more questions or discuss the options.
Decision-making including budgets	• I am as involved in discussions and decisions about my care, support and treatment as I want to be. • My family or carer is also involved in these decisions as much as I want them to be. • I have help to make informed choices if I need and want it. • I know the amount of money available to me for care and support needs, and I can determine how this is used (whether it's my own money, direct payment or 'personal budget' from the council or NHS). • I am able to get skilled advice to understand costs and make the best use of my budget. • I can access the money quickly without over-complicated procedures
Transitions	• When I use a new service, my care plan is known in advance and respected. • When I move between services or settings, there is a plan in place for what happens next. • I know in advance where I am going, what I will be provided with, and who will be my main point of professional contact. • I am given information about any medicines I take with me – their purpose, how to take them, potential side effects. • If I still need contact with previous services/professionals, this is made possible. • If I move across geographical boundaries, I do not lose me entitlements to care and support.

A similar process occurred in Ireland, but the data were generated through focus group and survey methodologies with patients, caregivers and relevant lobby groups. The project used the CAHPS Patient Narrative Elicitation Protocol (Agency for Healthcare Research and Quality, 2016; 2017) which recognises the importance of personal storytelling in healthcare staff's understandings of care experience. Person centred coordinated care (Phelan et al., 2018) was defined as:

> …care that provides me with access to and continuity in the services I need when and where I need them. It is underpinned by a comprehensive assessment of my life and my world combined with the information and support I need. It demonstrates respect for my preferences, building care around me and those involved in my care. (Phelan, 2018:vi)

In addition, under three domains, 18 'I' statements were generated representing the experience of person centred co-ordinated (Table 9.3).

Table 9.3: Domains and 'I' statements for patient narratives in Ireland (Phelan et al., 2018)

Domain	'I' statements
My healthcare experiences	• Staff communicate with me in a way that I understand. • I have up-to-date information on my health condition(s), treatments, and available support services. • Staff help me to understand the choices and services available to me now and for my future care. • Healthcare staff listen to me so that they understand my world and what is important to me. • I am treated with empathy, respect and dignity in all dealings with healthcare staff. • In partnership with healthcare staff, I make choices based on what I prefer and my goals. • If I choose, my information can be shared securely with relevant healthcare staff. • I do not have to repeat myself each time I meet new healthcare staff involved in my care. • I can contact the relevant healthcare staff to ask questions that are important to me and I get timely responses to my questions. • Decisions about my care include me as much as I want and involve my carers if I choose.

Healthcare I am confident in.	• Healthcare staff have the skills, knowledge and expertise to plan my care with me. • My care is of a high quality and is delivered safely and efficiently. • Healthcare staff are accountable for care that they give to me. • I know I can get appropriate care when and where I need it. • I know healthcare staff will coordinate my care to include my complete health status and my world.
My journey through healthcare	• My care includes issues that my health influences, such as finances, housing, employment, ability to travel and access to transport. • I have services delivered by the most suitable healthcare staff in the correct setting and when I need them. • I can have one person who will oversee and follow up on all my care.

Person centred coordinated care is therefore focused on what people want within the totality of their care experience. Central to these narratives is the desire to be involved, have understandable and comprehensive communication with service providers, hold decision-making authority, experience continuity of care as well as service providers having an appreciation of the context and life world the person lives in. To experience this, there is a need for policy and legislative reorientation, sustained engagement between service users and service providers, revised systems of care aligned to integrated care and comprehensive systems of evaluation (Lloyd et al., 2017). Only by re-orientating health systems to scaffold care around the person can person centred coordinated care be realised.

Conclusion

While person centred care has emerged in recent years as a fundamental element of care quality, research demonstrates that much work is required to further both empirical understandings and practice implementation. Proponents of person centred care point to both the fragmentation of care and the limitations of the biomedical, reductionist approach to health care and argue that care should be co-created, acknowledging individualism. For older people, as major consumers of healthcare, it is imperative that systems work with the individual’s wishes, preferences, values and beliefs. This means an authentic engagement, where the focus is on human flourishing rather than task completion and quantitative-based performance indicators. Care is about mutuality, partnerships and negotiation rather than fragmentation and paternalism. Of particular importance for older people is ensuring continuity and integration of care. As populations age, the risk of co-morbidity rises and the complexity of care is intensified. This requires a move from siloed care experiences to a more macro joining up of the healthcare experience across disciplines and settings so that managing health is not a battleground but a cohesive experience which interconnects, limiting gaps in care, enhancing care quality, optimal outcomes and wellbeing, increasing consumer satisfaction as well as maximising the health system's efficiency.

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CHAPTER TEN

AGEING AND DEMENTIA

SUZANNE TIMMONS, SIOBHÁN FOX AND EMMA O'SHEA

Introduction

Dementia is one of the most significant diseases affecting older people, and has been identified by the World Health Organisation as a public health priority. Dementia massively impacts the lives not only of the individuals who are affected, but also their family members. While there are currently no curative treatments, there have been promising recent advances in pharmacological and non-pharmacological therapies which can greatly improve the quality of life of people with dementia. This chapter will provide a broad overview of dementia from diagnosis, to treatment of cognitive and non-cognitive symptoms, to respite and palliative care.

Dementia–from Syndrome to Subtype

Dementia is an umbrella term for a range of progressive conditions affecting the brain that result in structural and/or chemical changes, involving dysfunction and death of neurons (Zeilig, 2015). This leads to a clinical syndrome of cognitive decline (affecting learning and memory, language, executive function, complex attention, perceptual-motor, and social cognition), that over time is sufficiently severe to interfere with social or occupational functioning, and hence independence (Chertkow et al., 2013).

Most dementias involve abnormal accumulation of proteins in the brain (such as amyloid, tau, and alpha-synuclein), but ischaemia and inflammation also play key roles. By definition, dementia is a progressive condition, whereby symptoms gradually worsen over time, ultimately causing severe functional impairment and death (Campbell et al., 2016), but this progression varies from person to person. The median survival from diagnosis is 3–9 years (Winblad et al., 2016).

It is estimated that there are several hundred sub-types of dementia (Stephan and Brayne, 2008: Boyd, 2013: Zeilig, 2015: Dementia UK, 2018), with the most common sub-type, Alzheimer's Disease (AD), accounting for over 60% of all diagnosed cases of dementia (Boyd, 2013; Dening and Sandilyan, 2015; Waldemar et al., 2007). Other common types include Vascular Dementia (VaD), which is due primarily to cerebral ischaemia, and Mixed Primary Neurodegenerative Dementia-Vascular Dementia where any other dementia is compounded by co-morbid cerebral ischaemia, with both these types of dementia being to some degree preventable, or deferrable, by vascular risk factor modification. Another common sub-type, Dementia with Lewy Bodies (DLB; due to alpha-synuclein accumulation), includes Parkinson's Disease Dementia and Lewy Body Dementia, the former occurring after several years of Parkinson's Disease and the latter presenting with or rapidly progressing to dementia. The other notable protein-accumulation dementia is Frontotemporal Dementia (FTD; due to tau accumulation), associated with prominent behavioural and/or language difficulties. This is relatively rare in older people but accounts for 12% of Young Onset Dementia i.e. dementia developing before the age of 65 (Young Dementia, UK 2018).

Alcohol-related dementia deserves a special mention as an entirely preventable dementia, caused by a combination of direct neurotoxicity, thiamine deficiency (causing Korsakoff's syndrome [Stephan and Brayne, 2008]) and other linked morbidities (such as lifestyle-related cerebrovascular disease; poor cognitive reserve; trauma and seizure-related neurotoxicity). Infectious causes of dementia are rare, but include Creutzfeldt-Jakob disease and AIDS dementia complex (ADC).

Prevalence and Financial Impact of Dementia

Globally, dementia affects approximately 46 million people (Global Burden of Disease, 2016) making it a major healthcare concern and global issue. These figures are expected to rise significantly in the coming years in developed countries, as a result of increased longevity and ageing populations, with even more dramatic increases in dementia prevalence in developing countries, particularly China and India (Prince et al., 2015). Current projections indicate that by 2050 there will be over 131.5 million people living with dementia worldwide (Prince et al., 2015). In Ireland, there are currently around 55,266 people living with dementia and this is expected to rise to 95,863 by 2031 and 157,883 people by 2046 (Pierce et al., 2014).

Dementia exerts significant pressures on health, economic and social care systems. Worldwide, dementia costs over €784 billion (Michalowsky et al., 2017). In the United States, the cost of dementia care in 2010 was $109 billion, estimated to rise to $1.2–$1.6 trillion by 2040 (Bynum, 2014). In the UK, projections of cost are over £50 billion annually by 2040 (Comas-Herrera et al., 2007; Hawkins 2015). The economic burden of dementia currently ranks higher than stroke, heart disease and cancer combined (Prince et al., 2015). However, healthcare allocations for dementia care have been substantially lower than each of these individual disease groups (Trepel, 2010). Direct medical care costs account for roughly 20% of global dementia costs, while direct social care and informal care each account for roughly 40% of costs (Prince et al., 2015). In Ireland, dementia is estimated to cost over €1.69 billion annually, or €41,470 per person with dementia, with half this cost met by the Health Service through health and social care, and the other half borne by family and friends providing informal care (Connolly et al., 2014; Pierce et al. 2014).

Apart from the obvious goal of preventing dementia entirely, or modifying the disease progression with novel therapies, the costs associated with dementia care could be relatively readily reduced by preventing, or at least deferring, incident dementia, through better risk factor modification. It is estimated that deferring the age of onset of dementia by 5 years could reduce the total number of cases by up to 50% over 50 years (Jorm et al., 2005). Another potential means of reducing dementia care costs is earlier diagnosis and treatment, assuming that earlier treatment will reduce later costs. Some interesting modelling analyses have been performed, including one by Getsios et al. (2012) who performed a discrete event simulation of AD progression based on donepezil Randomised Control Trials (RCTs) and follow-up registry data. They concluded that timely treatment, compared to no treatment or delayed treatment, reduced residential care requirements and hence cost. Other modelling studies have shown similar benefits of early diagnosis, but the recent National Institute for Clinical Excellence (NICE) Guideline (2018) cautions against over-relying on modelling studies rather than clinical trial evidence.

Finally, a large proportion of the government (and hence societal)-borne cost relates to residential care; it is logical that providing acceptable, alternative care in the community could reduce this cost. A pilot project of intensive home care in Ireland has demonstrated that it is feasible to support people with dementia with a high level of complex needs at home;

with the likelihood of admission to long-term care being reduced (Keogh et al., 2018).

Cognitive Reserve and Prevention

A key concept to understand in relation to both general brain health and dementia is ‘cognitive reserve’. Broadly, cognitive reserve describes the mind’s resistance to damage of the brain. The idea is that some people can tolerate more changes to their brain than others while still maintaining function.

The study of cognitive reserve can be traced back to the late 1980s when incongruities between cognitive symptoms and underlying disease pathologies were first noted. In a study by Katzman et al. (1988), which reported findings from a post-mortem of 137 older people, a discrepancy between the extent of AD neuropathology, and the degree of clinical manifestation of the disease was found. The authors suggested two explanations; that these people had incipient AD but avoided the loss of large numbers of neurons, or they started with larger brains and more neurons thus having a greater ‘reserve’. The same research team published the results of post-mortem examinations of ten women’s brains and found that they showed clear histopathological signs of dementia, despite the absence of clinical cognitive signs in life (Katzman et al., 1989).

Some authors differentiate the terms brain reserve and cognitive reserve. Brain reserve can be defined as the brain’s resilience to cope with increasing damage while still functioning adequately. Actual differences in the brain itself may increase tolerance of pathology. The theory is that people with higher brain reserve have more neurons/synapses to lose, and protective anatomic changes on the basis of experience. This concept is supported by studies which indicate a lower prevalence or incidence of dementia in people with larger brains (Katzman et al., 1988: Schofield et al., 1997). Brain reserve is often described as a passive model, in that it suggests that the brain can simply tolerate more pathology before it reaches a critical threshold for clinical symptoms to appear (Stern, 2012).

Cognitive reserve also refers to resilience to damage, however the emphasis is on the way the brain uses its damaged resources. It could be defined as an active mechanism which facilitates the flexible use of available brain reserve through efficient information processing and task performance strategies (Dubois et al., 2012). Individuals with high cognitive reserve would be more successful at coping with the same amount of brain damage compared to those with low cognitive reserve.

This has clinical implications in that a diagnosis of dementia is not perfectly linked to underlying neuropathology; people with high reserve go undiagnosed until damage is severe, then once dementia manifests, those with a higher cognitive reserve experience a more rapid decline (Scarmeas et al., 2006; Helzner et al. 2007).

There is now much evidence supporting the theory that various life experiences impart a reserve against AD pathology (Valenzuela and Sachdev, 2006). Epidemiological studies have shown that many person-specific variables enhance reserve, such as education, occupation, leisure activities, and intellectual ability (Stern et al., 1994; Scarmeas et al., 2001; Valenzuela and Sachdev, 2006). A systematic review which summarised the available epidemiological research calculated that higher cognitive reserve decreases the risk of developing dementia by 45% (Valenzuela and Sachdev, 2006). Research into cognitive reserve suggests that contributions to reserve come from multiple sources, and that reserve is not a fixed entity but can change across the lifespan depending on exposures and behaviours, even in late life (Bunting-Perry, 2006). This is encouraging as it supports the possibility of intervening even later in life in order to impart reserve, slow age-related cognitive decline, and prolong healthy ageing (Stern, 2012).

Two of the most significant lifestyle factors for reducing dementia risk are physical activity and stimulating cognitive activity, with both associated with significant reductions in the risk of dementia in longitudinal studies (Cheng, 2016). In addition, physical activity, specifically aerobic exercise, is associated with less age-related grey and white matter loss and with less neurotoxic factors (increased brain reserve). Cognitive training for executive functions, on the other hand, is associated with improved prefrontal network efficiency, which support brain functioning in the face of cognitive decline (increased cognitive reserve [Cheng, 2016]).

There is a wealth of epidemiological evidence, as well as neuroimaging and post mortem studies, which support the theory of cognitive reserve (Alexander et al., 1997; Bennett et al. 2003; Scarmeas et al., 2003). However, intervention studies are needed to firmly establish causal links between life experiences, individual characteristics, and cognitive reserve. These studies are underway, but in the meantime recommending that people engage in mental enrichment and physical activity should certainly cause no harm and likely will have numerous positive effects.

Diagnosis of Dementia –'Timely' and 'Good'

Prima facie, good dementia care requires a diagnosis of dementia, yet historically there has been under-diagnosis of dementia, linked to stigma, poor awareness of dementia as an illness (as opposed to part of normal ageing) and therapeutic nihilism. It is possible to improve diagnostic rates, as occurred in the UK due to a combination of national targets, financial incentivisation, and awareness raising, where it is estimated that 70% of people with dementia in England and Scotland are now diagnosed with dementia. A key step in improving diagnostic rates is improving overall public perceptions about dementia and the value of a diagnosis, and most national dementia strategies include elements of dementia awareness raising, tackling stigma, and focusing on the ability to live well post-diagnosis. There is a focus in most dementia strategies on 'timely' diagnosis, but there can sometimes be a tension between targets for a 'rapid diagnosis', i.e. avoiding long waiting times for first assessment or for specialist imaging, and the need to progress at a pace set by the person, who may need time to adjust to the possibility of a forthcoming diagnosis of dementia (Minghella, 2013).

As well as timeliness, a crucial element of a good diagnosis experience is the disclosure process, noting that most people, whether they have cognitive problems or not, would want the disclosure of the diagnosis to them if they had dementia (van den Dungen et al., 2014). In good disclosure, the goal of 'imparting information' must be balanced with the demonstrated need to address the emotional impact of the disclosure on the person (Paterson and Pond, 2009; Riva et al., 2014; Dooley et al., 2015). Thus, there is a need for flexibility in disclosure, planning, and early post-diagnostic support, allowing the person to decide when they are ready for more information or engagement with services.

The gold-standard diagnostic model since the 1970s has been the memory clinic, with these evolving from a mainly research to a clinical focus and from a medical-only to a multidisciplinary model. Memory clinics can efficiently and accurately diagnose people with even early, subtle cognitive impairment, and those with a high patient volume and broad multidisciplinary team input appear to be most cost-effective (Revez et al., 2018). This early diagnosis will become increasingly important as therapies evolve from symptom control only to disease-modifying and perhaps curative. Concurrently, in order to meet current and predicted demand, and in keeping with the goal to provide local healthcare at the lowest effective level of complexity, there is an increasing move internationally towards community-based diagnostic models.

There is a large body of literature exploring ways to facilitate dementia diagnosis in primary care, often based on increasing general practitioners' (GPs) confidence and skills in diagnosing dementia. In a systematic review of educational interventions conducted by Perry et al., (2010), the authors concluded that only educational interventions for GPs that require active participation show evidence of improving dementia detection, and that ideally education would be combined with adequate reimbursement or other incentives at the organisational level. Five cluster-RCTs of educational interventions have shown mixed results, with the earlier two positive, but the latter three negative (Downs et al., 2006; Perry et al., 2008; Rondeau et al., 2008; Donath et al., 2010; Iliffe et al., 2015; van den Dungen et al., 2016). A variety of computer-based aids (e.g. computer-assisted learning packages, computer decision-support systems, and computer-based audit and feedback tools) have been developed and tested (Turner et al., 2003; Millard et al., 2008, Waldorff et al., 2009; Boise et al., 2010), but robust evidence on their efficacy is lacking to date.

Canada and the UK have demonstrated the feasibility of formal memory services embedded in primary care, with a lead GP with a special interest in dementia and telephone or direct support from a specialist service (Callahan et al., 2006; Chodosh et al., 2006; Austrom et al., 2006; Cherry et al., 2009; Reuben et al., 2010; Callahan et al., 2011). Another model is the outreach memory service model, such as the much-cited Gnosall model (Greaves et al., 2015) where a member of the primary care team performs the initial assessment and links closely with the outreach specialist team, providing an important single-point-of-contact support to the person throughout the diagnostic process. Other community-based service models include out-reach 'memory nurses' (i.e. dementia nurse specialists) in GP practices (Dodd et al., 2014); and existing community mental health teams.

Managing the Cognitive Symptoms of Dementia

Cognitive symptoms refer to problems incurred with memory, cognition, perceptual or language skills. These symptoms worsen over time and can be distressing for the person with dementia and/or their families.

Pharmacological approaches

There are two main classes of medications to improve cognition in dementia, namely (AChIs) and the N-methyl-D-aspartate (NMDA) receptor antagonist memantine. For AChIs, the number of people with AD needed to treat is 10, for a 4-point improvement in ADAS-cog (Alzheimer's Disease Assessment Scale-Cognitive Subscale) (Lanctot et al., 2003; O'Brien and Burns, 2011). AChIs are licensed for AD and DLB, and although the evidence for benefit in pure VaD is weak, as many people have overlap of VaD and AD, clinicians often prescribe AChIs' for possible VaD.

Memantine is licensed for moderate to severe AD, and is useful if AChIs are not tolerated, and also in combination with an AChI in moderate and more so in severe dementia, being superior to monotherapy with either agent (Schmidt et al., 2015). It is important to note that no medication has shown benefit or is licensed for FTD. In Europe, no medications are currently approved for preclinical AD, prodromal AD, or mild cognitive impairment.

Several other symptomatic medications have been trialled in recent years, such as Dimebon (latrepirdine), an antihistamine which is a weak inhibitor of cholinesterase activity. One study showed benefit over placebo but this has not been replicated and a Cochrane review concluded that there was no beneficial effect on cognition in AD (Doody et al., 2008; Chau et al., 2015). Noradrenaline reuptake inhibition, GABAergic neurotransmission modulation, thiamine derivatives and insulin/insulin analogues are all currently under trial.

In addition to symptomatic treatments, there are many ongoing trials of disease modification. In AD, these include beta and gamma secretase inhibitors to reduce beta-amyloid production (the pro-fibrillar type of amyloid), and immunotherapy to prevent the accumulation of beta-amyloid in the brain or promote its clearance. Similarly, microtubule stabilisers, tau aggregation inhibitors and protein kinase inhibitors target hyperphosphorylated tau aggregration (see Lancet Commission for a full review of medications under trial).

Non-pharmacological approaches

Building on the concept of cognitive reserve discussed earlier, various cognition-based approaches have been introduced, however there is some confusion between them, and the terms cognitive 'stimulation', 'rehabilitation', and 'training' (latter not discussed here) have often been used interchangeably. Clare and Woods (2004: 387-394) provide useful definitions to delineate these interventions:

> *'Cognitive stimulation is engagement in a range of activities and discussions (usually in a group) aimed at general enhancement of cognitive and social functioning.'*

> *'Cognitive rehabilitation is an individualised approach where personally relevant goals are identified and the therapist works with the person and his or her family to devise strategies to address these. The emphasis is on improving performance in everyday life rather than on cognitive tests, building on the person's strengths and developing ways of compensating for impairments.'*

Cognitive Stimulation Therapy: Cognitive stimulation therapy (CST) may involve a wide range of activities that aim to stimulate thinking and memory generally, including discussion of past and present events and topics of interest, word games, puzzles, music, and practical activities such as baking or indoor gardening (Woods et al., 2012). Typically, this is carried out by a trained person with a small group of four or five people with dementia for around 45 minutes, at least twice a week. CST groups can take place in different settings including residential homes, hospitals or day centres. With appropriate training, CST can be administered by anyone working with people with dementia, such as care workers, Psychologists, Occupational Therapists or nurses. Family caregivers have also been trained to provide CST to their relative on a one-to-one basis (Onder et al., 2005).

As mentioned previously, 'cognitive stimulation' is used inconsistently in the literature, however it is helpful to recognise the main attributes of an intervention which may be described as CST, namely that it: (a) targets cognitive and/or social function, (b) has a social element—usually in a group or with a family carer, (c) includes cognitive activities which do not primarily consist of practice on specific cognitive modalities and (d) may be described as reality orientation sessions or classes (Spector et al., 2010).

CST is an evidence-based treatment. The most recent NICE guideline (NICE, 2018) recommend the use of group cognitive stimulation for people with mild to moderate dementia. Their recommendation is based on the results of 22 intervention and randomised-controlled studies published between 1979 and 2017, which overall support the effectiveness of CST as an intervention for people with dementia.

A Cochrane review and meta-analysis of 15 RCTs, involving 718 participants, found that cognitive stimulation has a significant beneficial effect on cognition of people with mild-moderate dementia (Woods et al., 2012). Studies which provided follow-up data showed that these effects were maintained for one to three months after the end of treatment (Woods et al., 2012). CST has been shown to be as effective as several dementia drugs in improving cognition (Spector et al., 2010), and has also been shown to be more cost effective when compared with usual care with regards to benefits in cognition and quality-of-life (Knapp et al., 2005, D’Amico, 2015). CST has proven effective for various dementia subtypes, including AD, VaD, and mixed types (Piras et al., 2017; Capotosto et al., 2017).

CST also improves self-reported quality-of-life and wellbeing for the person with dementia (Woods et al., 2006; Spector et al., 2003; Woods et al., 2012), and these improvements are independent of improvements in cognition. Qualitative research with people attending CST has shown that positive effects observed on formal memory tests are also noticed by people with dementia and their carers in day-to-day life, and that they enjoyed taking part in CST (Spector et al., 2011).

Cognitive Rehabilitation Therapy: In contrast to CST, cognitive rehabilitation therapy (CRT) is an individualised approach which directly tackles those difficulties considered most relevant by the person with dementia and their family. Goals for rehabilitation are selected collaboratively, and interventions designed to meet these goals are devised and implemented by the therapist in the person’s everyday setting. The emphasis in CRT is on improving performance in everyday life rather than on cognitive tests, building on the person's strengths and developing ways of compensating for impairments (Clare and Woods, 2004).

The evidence base for CRT is not currently as strong as that for CST. The NICE guideline recommendation is to ‘consider’ CRT (National Institute for Health and Care Excellence, 2018). A single-blind RCT of goal-oriented CRT for people with early-stage AD (Clare et al., 2010) found that CRT was superior to the control condition in relation to a number of outcomes in the short term (patient-reported improvement in goal performance and satisfaction immediately after intervention) and in the medium term (greater satisfaction with memory performance 6 months after the intervention). There was also evidence that caregivers of participants in the CRT group had improved social relationships following the intervention relative to the control condition. Finally, a subset of participants showed changes in task-related brain activation on functional Magnetic Resonance Imaging following CRT (van Paasschen et al., 2013).

Two large RCTs have been completed more recently. A multi-centre randomized, parallel-group trial, with a two-year follow-up, was conducted in France across 40 sites (Amieva et al., 2015). The trial compared people with AD receiving standardised programmes of cognitive training (group sessions), reminiscence therapy (group sessions), individualised CRT programme (individual sessions), and usual care (control group). Of the interventions, only CRT had any effect on outcome measures; this group had significantly lower functional disability and a six-month delay in institutionalisation at two years were evidenced. However, no effect on rate of survival without severe dementia at two years was observed.

The GREAT study (Goal-oriented cognitive Rehabilitation in EArly - sTage dementia) was a multi-centre, single-blind RCT conducted in eight sites across England and Wales (Clare et al., 2017). Sessions were delivered in the homes of 209 people with dementia, and outcomes were compared to 218 control participants receiving usual care. At 3-month follow-up there were statistically significant large positive effects for participant-rated goal attainment, corroborated by carer ratings, and these effects were maintained throughout 9-month follow-up.

Both CST and CRT are effective, acceptable, and cost-effective interventions to improve cognitive function and quality-of-life in people with dementia. The introduction and expansion of such programmes within the healthcare system would greatly complement and improve available treatment strategies.

Managing the Non-Cognitive Symptoms of Dementia

Non-cognitive symptoms such as psychosis, agitation or restlessness, aggression, apathy, anxiety and depression are common in people with dementia (Dyer et al., 2018; Alzheimer's Society, 2011). In some instances, either associated with these non-cognitive symptoms, or in response to external stimuli, people with dementia may exhibit ‘behaviours that challenge’, often as expressions of unmet needs. These behaviours include: walking about; pacing; hoarding; repetitive vocalizations; inappropriate sexual behaviour; resisting care etc. Together, non-cognitive symptoms and responsive behaviours are often termed Behavioural and Psychological Symptoms of Dementia, or BPSD (Lawlor, 2002; Kales et al., 2015). Non-cognitive symptoms are extremely common in dementia, affecting nearly all people with dementia over the course of their illness (Savva et al., 2009). Their presence can result in significant distress to the individual and/or their family members and/or carer, and results in increased rates of admission to long-term care facilities (Brodaty et al., 2014).

All existing guidelines for the management of non-cognitive symptoms state that non-pharmacological interventions should be used initially, unless the person has severe distress, or there is a risk of harm to the person with dementia or others (for example, NICE, 2018). However, the evidence to support non-pharmacological interventions for non-cognitive symptoms is generally weak. In a 2016 systematic review of systematic reviews (38 systematic reviews and 142 primary studies), evidence is presented for sensory stimulation interventions (acupressure, aromatherapy, massage/touch therapy, light therapy, Snoezelen®, and sensory garden), cognitive/emotion-oriented interventions (cognitive stimulation, music/dance therapy, dance therapy, transcutaneous electrical nerve stimulation, reminiscence therapy, validation therapy, simulated presence therapy), behaviour management techniques, and other miscellaneous therapies (exercise therapy, animal-assisted therapy, special care unit and dining room environment-based interventions) for behavioural disturbances (Abraha et al., 2017). Of these, music therapy was effective in reducing agitation and anxiety. Home-based behavioural management techniques, caregiver-based interventions, or staff training in communication skills, person centred care or dementia care mapping, with supervision during implementation, were found to be effective for severe agitation.

Despite the consistency of guidelines to the contrary, the current management of non-cognitive symptoms frequently involves the use of psychotropic medications. Defined as substances that affect brain chemicals associated with mood and behaviour, psychotropic medications include antipsychotics, antidepressants, anticonvulsants, benzodiazepines and z type drugs. The use of many of these medications is ‘off label’ when used for non-cognitive symptoms (European Medicines Agency, 2016).

Some psychotropic medications have shown modest efficacy in the treatment of some non-cognitive symptoms. It is estimated that, at best, only 20% of people experiencing non-cognitive symptoms derive benefit from an antipsychotic (Banerjee, 2009). However, there is increasing recognition of the adverse side effects associated with their use (Mittal et al., 2011; Tampi et al., 2016). Psychotropic medications can cause confusion, drowsiness, extra-pyramidal symptoms, increased risk of falls, lethargy, peripheral oedema, arrhythmias, respiratory depression (Lawlor, 2002; Feldman et al., 2009; Henry et al., 2011; El-Saifi et al., 2016; Dyer et al., 2018). Furthermore, in terms of the burden of polypharmacy and inappropriate prescribing, psychotropic medications constitute a significant proportion of culprit medications, and psychotropic polypharmacy (concurrent use of multiple psychotropic agents) increases the risk of adverse events (Mojtabai and Olfson, 2010).

In April 2005, the Food and Drug Authority (FDA) published an independent, pooled analysis of 17 RCTs, which reported a 1.7 times increased risk of all-cause mortality associated with atypical antipsychotics, leading to a ‘black box warning’. Based on randomised controlled trial data, Banerjee, (2009) estimated that about 1 in 100 people with dementia treated with an antipsychotic would die due to the medication and about 1 in 60 would have a stroke. Maust et al., (2015), using data from a large

Veterans Affairs registry (90,000 people, mainly men), estimated the numbers needed to cause a death for several different antipsychotic medications (adjusted for comorbidities), ranging from 1 in 26 with haloperidol to 1 in 50 with quetiapine, also demonstrating a clear dose-risk effect of antipsychotics. Although observational data is open to bias from other confounding factors which might overestimate the actual risk, equally it may be more reflective of real life use of antipsychotics, i.e. being prescribed to people who would not necessarily be included in an RCT, and being continued for 6 months, not 6-12 weeks.

Regardless of the exact risk, it is clear that antipsychotics should be used with caution for non-cognitive symptoms, at the lowest dose possible, and for the shortest time possible. In Ireland, 29% of people with dementia being admitted to hospital are receiving an antipsychotic, and an additional 12% received a new prescription for an antipsychotic during the admission (Gallagher et al., 2016). The forthcoming National Clinical Guideline for the Appropriate Prescribing of Psychotropic Medication for non-cognitive symptoms in People with Dementia, for healthcare professionals in Ireland, may help to reduce inappropriate prescribing, as has been found in other countries. In the UK, there was an overall reduction in antipsychotic drug prescription in dementia from 22.1% in 2005 to 11.4% in 2015 (Donegan et al., 2017) and in the United States, there was a 33% reduction in antipsychotic prescribing in residential care from 2012 to 2017 following a national initiative (Gurwitz et al., 2017).

Respite Care in Dementia

Respite care is the temporary provision of care for a person with dementia, at home or in an institution, by people other than the primary carer (Maayan et al., 2014). Settings for respite care include temporary residential care, day care and in-home care. Respite is commonly used, with the intention of facilitating ‘ageing-in-place’, however there has not been a great deal of research into its effectiveness, especially in comparison to other interventions.

A Cochrane review uncovered just four RCTs, all of a low methodological quality and short time frame and found no evidence for the effectiveness of respite for the person with dementia, or the carer, on any outcome (Maayan et al., 2014). More recently, a systematic review on the effectiveness of respite care in supporting informal carers of people with dementia was published, based on 17 included eligible papers (Vandepitte et al., 2016). Overall, the use of day care was seen to result in a decrease in ‘burden’ and similar stress-related caregiver factors, especially when caregiver support is included in the day care programme.

Day care programmes may also decrease non-cognitive symptoms, but they also accelerate time to nursing home admission. This is likely not a direct effect, but a reflection of the type of situations in which day care is used–often too late, when a crisis point is reached and the carer can no longer cope. When looking at temporary residential admission, the results, based on four included studies, were mixed. The authors tentatively concluded that temporary residential respite has less favourable effects on caregivers and recipients than does day care. Finally, only one study investigated an in-home respite care programme, even though this type of respite is often preferred by carers (Zarit et al., 1999; Ashworth and Baker, 2000). However, this study did have promising results in terms of reduced carer morbidity and mortality and the effectiveness of in-home programmes is also corroborated with qualitative evidence (Parahoo et al., 2002; van Exel et al., 2006).

Clearly, the empirical evidence base for the effectiveness of respite is weak, in part because randomisation to a respite condition is not always feasible or even ethical. One inherent problem with attempting to synthesise the quantitative evidence is the heterogeneous nature of respite services, in terms of where they are delivered, who delivers them, what constitutes the respite intervention, its duration and frequency, etc. Further, the care users and their personal situations and care needs are equally diverse.

Owing to these problems, the qualitative literature greatly complements these quantitative syntheses. Recently, O’Shea et al., (2017a) conducted a qualitative systematic review of key stakeholders’ experiences of respite services. The review included 23 eligible papers, representing the views of 13 people with dementia, 690 carers, and 186 healthcare workers/volunteers/policymakers etc. Key areas for development of respite services for people with dementia were identified, namely: the need for flexible and responsive ‘person centred care’ (i.e. care that meets the needs of people with dementia in a personalised and holistic manner, and in a way that supports their personhood), meaningful activity for people with dementia, enhanced client-service communication, informational support, and communication and partnership development. The authors concluded that future services should be truly person centred, preferably community based, and respond to the needs of individual dyads.

Another major impediment to research into respite is the heterogeneous conceptualisations and descriptions of what respite is, who it is for, what it entails, and what it should achieve for the service user(s) (Evans 2013, a, b; O'Shea et al., 2017b). O'Shea et al., (2017b) clarified the term 'respite' in an evolutionary concept analysis. Respite is understood as both a service (i.e. provides a physical break from caring) and an outcome (i.e. a mental break for the carer). However, the term 'respite' as it is currently understood acknowledges the experience of the carer only (i.e. their need for a physical break from caring), and thus is fundamentally discordant to the person centred care paradigm. Paradoxically, carers note that they can only achieve a respite experience if they perceive that services are focused on providing responsive, person centred care, and so in this sense mutual benefit is a key antecedent for 'respite' for carers. The authors suggest 'restorative care as a potential alternative nomenclature to respite care, to highlight the importance of providing mutual, personalised health and social care services that enhance care relationships rather than diminish them (O'Shea et al., 2017b).

Palliative Care in Dementia

In recent years, guidelines and policy documents of many different countries have recognised the important role of palliative care for people with dementia (UK Department of Health, 2009; Irish Department of Health, 2014; National Institute for Health and Care Excellence, 2018). This includes improving care in advanced disease and at the end-of-life (EOL) and planning for the future. Currently the majority of people with dementia die in an acute hospital or in a long-term care facility, rather than in their own home or with hospice involvement (Houttekier et al., 2010), even though most people with dementia wish to remain at home for as long as possible, including at EOL (van der Steen et al., 2017; Poole et al., 2018).

While this topic is gathering increasing attention, there were some frequently reported impediments to research and service provision in this area. One complicating factor is that the view of the people with dementia and their families might differ regarding EOL care preferences (Iliffe et al., 2014). A recent review identified challenges to the implementation of palliative care specifically for people with dementia, including: how generalist and specialist services should work together; the timely identification of patients for referral; the need for a 'culture change' amongst healthcare professionals; and generally the lack of training and funding available (van der Steen et al., 2017).

Improving the palliative and EOL care of people with dementia requires a multidisciplinary and holistic approach. For EOL care, a promising model has been proposed of a community or a mobile team specialising in dementia palliative care (van der Steen et al., 2017). In this way continuity of care, including place of care, can be maintained, with the addition of specialist expertise. Another notable programme is the COMPASSION intervention, which facilitates integrated EOL care in advanced dementia; it includes training and support to enable this to occur (Jones et al., 2016). There is mounting evidence for the benefit of palliative care for this population. For example, people with dementia who use community-based palliative care services have reduced emergency department admissions in their last year of life (Rosenwax et al., 2015).

A major gap in current research is that most of the little research that has been published on this topic is on the EOL phase specifically, although most palliative care guidelines for chronic illnesses state that it is applicable throughout the course of the illness. The Model for Dementia Palliative Care Project is currently underway in Ireland, to develop a service-delivery model for dementia palliative care that will align with overall post-diagnostic support pathways.

Conclusion

As the world's population ages, more and more people will be living with dementia. The quality of life of those affected, and their experiences of healthcare, will be greatly improved if governments take account of the most recent research as summarised herein, and commit to providing suitable diagnostic and post-diagnostic services, suitable therapies to address distressing symptoms, and respite and palliative care services.

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CHAPTER ELEVEN

INTEGRATING CARE FOR OLDER PEOPLE – THE WHAT AND THE HOW

SIOBHÁN KENNELLY AND P.J. HARNETT

> ‘I can plan my care with people who work together to understand me and my carer(s), allowing me control, and bringing together services to achieve the outcomes important to me.’ (National Voices, 2013: NP)

Introduction

Rapid population ageing coupled with an increasing proportion of older people living with frailty as a long-term condition, and other co-morbidities, create major challenges for health systems which have been historically developed to provide episodic and curative healthcare (Briggs et al., 2018). The World Health Organisation (WHO), *World Report on Ageing and Health and Global Strategy and Action Plan on Ageing and Health* advocate for major reform to healthcare systems to enable healthy ageing. Within this discussion there has been an increasing focus on ‘integrated care’ a form of health and social care system design which seeks to strengthen continuity, reduce fragmentation and improve overall experience of healthcare in those with long term conditions (de Carvalho et al., 2017). Given its population-based approach, integrated care has taken on a particular relevance and focus in service design and planning for older people in both national and international health policy discussions. This chapter will identify those aspects of planning and system design that reflect integration at micro, meso and macro policy levels, their components as they are reflected in older persons’ care and some examples that reflect implementation of an ‘integrated model’ to date in international healthcare systems. Finally, it will look at the experience of implementation of an integrated care model within an Irish context and the early lessons learned from same.

What is ‘Integrated Care’?

WHO (2016) points out that there is no unifying definition or common conceptual understanding of integrated care which results from its polymorphous nature. Instead the construct of integrated care is shaped by a combination of perspectives held by service mangers, policymakers, academics, care professionals and service users/carers. A conceptual exploration of integrated care identified over 170 different taxonomies in use (Kodner, 2009). They include the values, context, types and levels of integration under consideration. This acknowledges that the perspectives held are critically informed by the context in which integration is being described. There is complexity associated with articulating what integrated care should deliver, who should benefit and what those benefits are.

WHO defines integrated care as ‘services that are managed and delivered so that people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease management, rehabilitation and palliative care services coordinated across the different levels and sites of care within and beyond the health sector, and according to their needs throughout the life course’ (WHO, 2016: web).

Increasingly the need for these services to reflect those outcomes that are important to older people themselves has been recognised by WHO (WHO, 2017). The ICOPE (Integrated Care Older People) guidelines emphasise the key requirement of any integrated care approach for an older population to adopt a proactive approach to the early detection of and management of functional decline (described as loss of intrinsic capacity), approaches that address areas of high needs (geriatric syndromes such as falls and incontinence) and a specific focus on caregiver support (WHO, 2017). Services should therefore reflect a joined-up approach that targets and prevents functional decline in older people rather than encouraging siloed entities supporting the management of individual health conditions (WHO, 2017; Briggs et al., 2018). The delivery of those services in the community (i.e. closer to the person’s home) that will proactively address frailty have become the increasing focus and ‘integrated care’ has in some areas become a proxy term for community and primary care delivery systems (Briggs et al., 2018; Sheaff, 2018; Valentijn, 2016)

Within the expanding literature around integrated care is the recognition that changes that support integration must be supported through changes that take place at micro (local change practice and innovation), meso (hybrid of regional and national supports in infrastructure, policy and health and social care operating environment) and macro (national and international health and social care policy environment) levels if they are

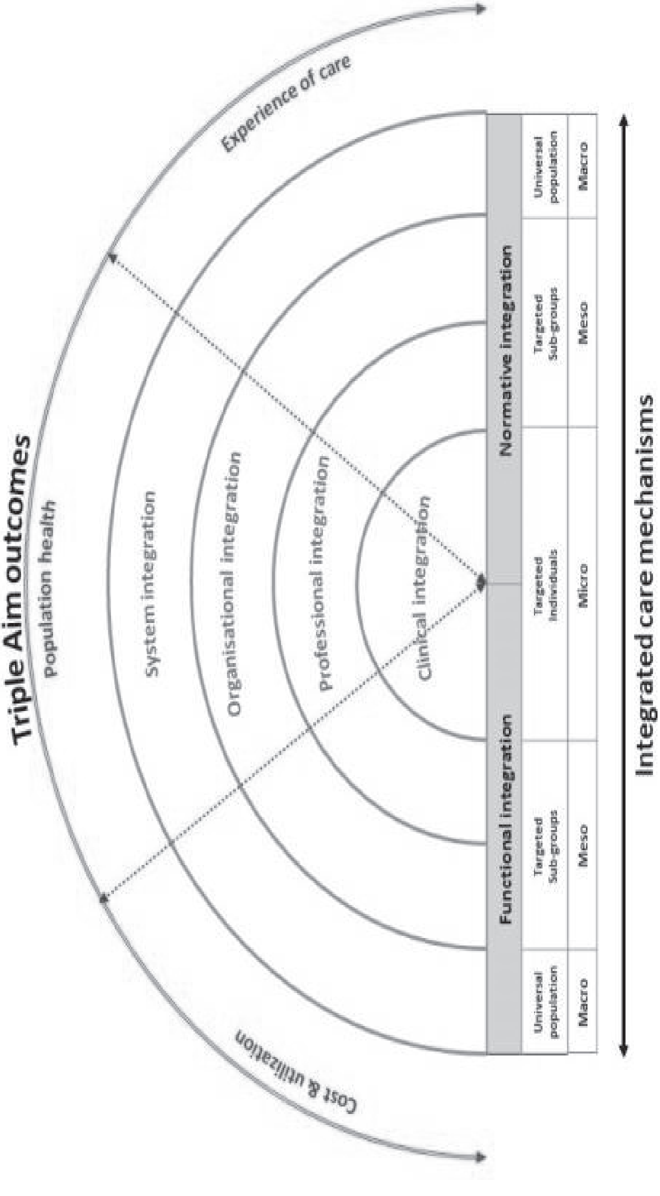


Figure 11.1: The revised RMIC, value-based integrated care (Valentijn, 2015:160)

to be sustained and scalable (Rainbow Model Of Integrated Care, Figure 11.1) (Valentijn et al., 2013; Valentijn, 2017). Designing and delivering integrated care systems for older people therefore is a multifaceted collaborative process between providers, users and carers. It involves changing the way health and social care is planned and delivered whilst ultimately focusing on the patient experience, outcomes, and quality of care.

Addressing Frailty as a Long Term Condition through Integrated Care

> ‘Frailty is the manifestation of ageing that is associated with poor outcomes’ (iHub, 2018: NP).

The language and construct of frailty and its proactive identification, the development of restorative models of care that reverse functional decline and the use of inter-sectoral approaches that address key areas such as technology, reduce social isolation and promote self-management become key targets of a comprehensive approach to frailty management in an integrated care system (Hendry et al., 2018). Such systems will also focus on a healthcare agenda that seeks to reduce medication burden, acute hospital use and poorer health outcomes in older populations. The integrated care agenda nationally and internationally points to the need then for broad-based policies that underpin health and wellbeing in older populations and that reflect changing needs for example not just in health and social care but in broader agendas such as housing and transport (Wodchis et al., 2015).

While there is recognition that outcomes attributable to integrated care are difficult to demonstrate, the evidence for key building blocks of integrated care (e.g. frailty attuned pathways) indicate improved outcomes for older people with complex care needs. There is growing consensus on ‘what works’, with a consistent body of evidence based around common elements such as:

1. Use of multidisciplinary teams collaboratively working with a common assessment and shared care plan.
2. A case management/care coordinator approach that assertively targets a vulnerable population and provides ease of access and care coordination.
3. Bespoke care pathways that are age attuned and facilitate rapid holistic assessment (CGA), community intervention and/or early supported

discharge especially at times of transition and crisis (Briggs et al., 2018; Wodchis et al., 2015).

The need for these elements to be able to work across care settings, professional care boundaries (especially within MDT) and reflect those outcomes that prioritise the patient's experience of care has been highlighted by a number of authors (Harvey et al., 2018; Sheaff, 2018; Kaehne, 2018). Encompassing these approaches Hendry et al. (2018), have proposed that the following components are key elements of clinical care pathways that enable care integration for older people with frailty (Table 11.1).

Table 11.1: Key components of clinical care pathways enabling care integration for older people with frailty (Hendry et al., 2018)

- Single point of entry – generally in primary care
- Use of simple frailty specific screening tools in all care settings
- Comprehensive assessment and individualised care plans – including for caregivers
- Tailored interventions by an interdisciplinary team (both in hospital and community)
- Case management and continuum of support across the continuum of providers
- Effective management of transitions between care teams and settings
- Shared electronic information tools and technology-enabled care solutions
- Clear policies and procedures for service eligibility and care processes

Single Point of Entry – Generally in Primary Care

Given that frailty prevalence across populations can vary considerably (O'Caoimh et al., 2018a), the deployment of frailty tools within primary care that can readily identify frailty in a user-friendly time-efficient way has become a key area of interest. In many countries the ability to use case records underpinned by identifiable 'frailty risks' within primary care data has become an area of increasing interest (Roe et al., 2017). For example, The Irish Longitudinal Study on Ageing (TILDA) identified high levels of frailty prevalence in older people accessing public health nurse services (TILDA, 2016). The introduction and validation of an electronic frailty index (eFI) in the UK (Clegg et al., 2016) heralds an important opportunity in the routine identification of 'high-risk' vulnerable older patients with frailty (using an established deficits model with high predictive value in terms of risk of hospitalisation, service use and long-term institutionalisation), who will benefit from interventions at primary care level (Clegg et al, 2016; Lansbury et al., 2017).

Comprehensive Assessment and Care Planning-Delivery in Ambulatory and Community Care Settings for Older People

The delivery of CGA (comprehensive geriatric assessment) underpins the care delivery model to address frailty in older populations (Ellis et al., 2011; Briggs et al., 2017; NCPOP, 2016). Therefore, the ability to deliver seamless CGA across care settings becomes key in the discussion of its implementation within an integrated care framework. Facilitating CGA therefore in acute hospitals, day hospitals and community settings while minimising duplication and ensuring the distillation of the resulting care plan into a single transferable care record will be central to the development of integrated services and a key test of their implementation (O'Caoimh et al., 2018b; iHub, 2018). This has resulted in an increasing focus on the work of multidisciplinary teams in day centres and community hospitals. The British Geriatrics Society (BGS) has identified the primary focus of community geriatrics services as ‘reducing admissions to hospital and as far as possible preventing readmissions by ensuring that the older person receives adequate care within the community, whether at home or in residential care’ (BGS, 2014). Six core components of a good community service for frailty are.

- Effective recognition, diagnosis and referral for frailty
- Person-centred ethos and practice
- Integration across multiple settings
- Expertise of staff
- Practice underpinned by CGA and care planning
- Use of tools to assist case finding (BGS, 2015).

Specific recommendations under the BGS Fit for Frailty Model is that community geriatric services deploy recurrent care planning cycles that reflect a proactive approach to the care of the person with frailty embedded in CGA and care planning discussions with the older person and/or carers. Such integration is seen as a key element of supporting care at times of transition and when crisis occurs. In the Scottish context significant emphasis has been placed on anticipatory care planning (NHS, 2017), reflecting a desire to have plans in place that will reflect discussions around management of periods of decline and/or end of life in primary care. There is however a significant level of complexity associated with their introduction and implementation which services need to be cognisant of if they are to be adopted at scale (Sharp et al., 2018).

Many of these components have shared or overlapping features; for example a case management approach will frequently encompass a single point of contact along with effective management at times of change e.g. acute hospital admission or decline in function that requires increased multidisciplinary support, social care provision or possible move to long-term care.

Case Management

Case Management is a complex intervention that involves organising and coordinating care for the individual. It forms a key cornerstone of a new way of working that enables and supports the delivery of secondary care in the community appropriate to the needs of older adults with complex needs and long-term conditions such as frailty (Hopper, 2018). The flexibility and adaptability of case management models is a key strength as approaches can be tailored to suit a diverse range of settings and locations. Emerging evidence suggests that case management approaches may have a key role to play in achieving improvements in clinical care and in system- and patient-oriented outcomes for older people. The potential benefits of this approach seem to be most significant for individuals ‘at risk’ of hospitalisation and for those living with multiple health problems. The role of Case Manager is central to the success of a case management programme. It must be clearly defined. The person fulfilling the role must have the necessary skills and competencies to carry out their role effectively, including; interpersonal skills, advocacy and negotiation skills, systems knowledge, needs assessment capability, problem-solving skills, medication management (prescribing ability if possible) and clinical governance. They must also receive the required training and support to enable them to understand how to get the best from the case management programme (Lewis et al., 2017).

Case management involves collaborative and multidisciplinary approaches to organising and coordinating care for the individual. It typically comprises of case finding, needs assessment, care planning, care coordination and case closure. Its strength lies in its flexibility and adaptability to a variety of health care settings, but the absence of a clear definition and the existence of numerous overlapping case management models make evaluation and model comparison very difficult. Within older person’s care however, a number of innovative approaches, such as the development of ‘community virtual ward’ are critically enabled by a case management approach (Lewis et al., 2017). These innovations speak to a core agenda within integration and are fundamental to our understanding of ‘what works’.

Even the most well-designed case management programme, however, will falter if the environment in which it is implemented does not support integrated care provision. Radical system redesign may be required in order to deliver the benefits of case management approaches to the broader health and social care system. Case management, therefore, works best when it is part of a wider programme of integrated care and it should be embedded as a tool with a more integrative structure in order to realise potential benefits. The services responsible for providing case management must be flexible and have the organisational and structural capability to be responsive to individual client needs. Finally, case managers report that conflicting organisational goals and high volumes of administrative work can hamper their ability to provide person centred case management to their clients (Hopper, 2018).

Home-Based Care

Interventions supporting the care of older people in their homes are positively associated with reductions in mortality and transition into long-term care for older people (Lewin et al., 2013). There is considerable heterogeneity in the individual components, specific interventions and target populations that will benefit from home-based care and their cost effectiveness, but the evidence base is evolving (Lewin et al., 2013). Recent studies have indicated high levels of frailty in those in receipt of home supports (Kelly et al., 2017; Roe et al., 2016) and authors emphasise the opportunities to be harnessed in identifying users of these services for targeted interventions maintaining independence such as physical exercise or connected health programmes (Lewin et al., 2013). Earlier reviews focused on the ‘health visitor’ role within the home care setting (primarily community nursing) with recent work focusing on social care models and dividends that may be attributable to interdisciplinary care models (Lewin et al., 2013). Evolving models of home care ‘reablement’ (focusing on time-limited interventions that involve active participation of the older person in interventions in the home to maximise independence and reduce loss of function associated with traditional home care models) require further validation but will be central to the discussion on sustainability (iHub, 2018).

Supported Self-Management

Supported self-management refers to those interventions that enable the older person to develop and take ownership of guided and evidence-based health behaviour strategies that will prevent frailty or its progression. This can come within a number of remits of integrated care with strongest evidence thus far for interventions such as physical exercise (class based with home-based practice) (Apostolo et al., 2018), increased focus on lifestyle factors that will increase frailty (smoking, obesity and modifying alcohol intake), and immunisation uptake (iHub, 2018). Self-management programmes also promote carer resilience through the development of peer and carer networks that increase knowledge and information sharing around chronic conditions e.g. dementia where a number of models exist (Joling et al., 2016; Boots et al., 2018). Within an integrated frailty prevention agenda these programmes will take centre stage at a population level in maximising health promotion opportunities that will pay short- and long-term health dividends for ageing populations and will become an increased focus of policies at meso and macro levels (EU Advantage, 2018).

Technology-Enabled Care

Integrated care relies heavily on important technology-based components of integration. These include common e-HR (electronic health records), tools for predictive risk assessment and case finding, decision-support systems, inter-professional/institutional communication (‘Doc-2-Doc’), long-term conditions self-management, telemedicine (remote patient management; ‘Doc-2-Patient’) and health and wellbeing applications (Buse, 2015). In Ireland, technology is a critical element of delivering integrated care within healthcare reform as part of the transformation of healthcare in meeting the challenge of delivering sustainable high-quality care for the entire population. The e-Health Strategy (HSE, 2016) recognises that information and knowledge is a core asset of our health systems in order to provide high quality, comprehensive information in a timely manner. More critically, the ability to record and share key information on patients’ and service users’ interaction across organisations and care settings is a key component of integrated care. The development of an e-health strategy seeks to recognise that the current system of health and social care delivery in Ireland is unsustainable without significant reform. A national e-HR will consist of core operational solutions (with functions such as e-Prescribing and Case Management), along with the ability to aggregate data from these systems into a comprehensive national record.

Ensuring the Voice of The Older Person is Central to Integrated Service Planning

Increasingly the voices of older people themselves regarding their expectations of health and social care systems should become central to articulating a new ‘vision’ for policymakers (Kaehne, 2018). For most patients, as Kaehne emphasises, the organisational and professional boundaries are of little relevance but what is of concern for them is access to a patient journey through a system that is seamless and centred on their own needs. Central to many of the issues highlighted by older people across healthcare systems is the need for a more person centred approach to managing their problems and their needs, the need for continuity of care and access to care in settings other than ‘acute hospitals’ and in particular at times of care transition (HSE, 2015). These outcomes should become more central to the policy agenda for change as health systems look at the broader agendas in older persons’ health care (Akpan et al., 2017). At a micro level these key ‘desired’ outcomes were reflected as (1) one care assessment – every older person should have access to comprehensive assessment, (2) one goal – optimising functional ability and (3) one care plan – which should be shared across all providers (Briggs et al., 2018). What most systems, however, seem to struggle with most is not the identification of the components of integrated care for ageing populations (the what) but rather the implementation of joined-up care reflecting those components (the how) (Harnett, 2018).

Removing Barriers to Integrated Care – Challenges in Implementation

> ‘Attempts to make the ship more watertight need to be firmly centred on the older person, pay close attention to implementation and embrace approaches that promote collaborative working between all the stakeholders involved.’ (Harvey et al., 2018:290)

A number of authors point to the widespread development of good models of practice that reflect integration at a local (micro) level (BGS/RCGP UK, 2016; Briggs et al., 2018; Goodwin, 2015; HSE ICPOP, 2018). These examples for the most part reflect strong local championing of health and social care innovations for older people that span a continuum of care with support from local managerial and operational structures. This has been typical of the development of many ‘models of care’. What is clear however through much of the literature is that the broader policy environment that enables systematising of practice to provide the critical ‘meso’ and ‘macro’ support that will sustain these initiatives and enable scalability for the desired ‘whole system change’ lags behind much of the work taken at a local level (HSE-ICPOP, 2018). At a national level in Ireland, there has been formal recognition at government level through an all-party agreement on healthcare delivery (Sláinte Care) that positions integrated care and its implementation as a central tenet of healthcare policy over the next 10 years (DoH, 2018). However, although an enabling policy environment is a fundamental building block to care integration it cannot in itself deliver the critical changes needed to ensure implementation.

A number of national and international health policy advisory bodies have emphasised some key formal policy and governance parameters that must form part of the health policy provision if integration is to be truly supported and enabled. These include:

- Organisational governance that reflects and enables integration. Within the literature there is an emphasis on steering away from significant organisational structural reforms in favour of governance that reflects shared policy, engagement on older persons’ issues and agreed progressive and incremental shift towards integration.
- Information sharing that improves flow and information exchange. This information can help identify older people’s needs, plan care over time, monitor responses to treatment and assess health outcomes. Information systems can also facilitate collaboration between different healthcare workers and between healthcare teams and their patients, who may be located in a range of settings or geographic locations.
- Healthcare workers with specific skillsets and competencies in the care of older people with a critical mass of specialist geriatric expertise are needed for more difficult and complex cases. Given the key requirement for multidisciplinary teams, policy advisers emphasise the need for undergraduate, postgraduate curricula and health workforce policies to reflect these areas that reflect interdisciplinary working.
- Financial governance systems or bundle payment systems that enable funding across the care continuum (de Carvalho et al., 2017)

The recent European Joint Action on Frailty (EU ADVANTAGE) advised that the strategic and implementation capacity of integrated care for older people has to have therefore key systemic critical enablers including:

1. Strong political support
2. Legislative frameworks
3. Financial incentives
4. Leadership and support to change the professional culture
5. Screening and risk prediction tools to select frail older people for interventions
6. Person centred and holistic approaches

It also identifies that age attuned pathways that reflect close integration between primary care and hospital services are critical in the management of established frailty and multimorbidity requiring a more intensive approach. (EU Advantage, 2018).

Shared Vision, Cultural Values and the Importance of a Fundamental Change Agenda in Supporting Implementation of Integration

International experience indicates there is no 'one model' of integrated care which provides an 'off the peg' model of care and suggests there is no single best 'approach' to integrated care. The role and influence of context (political ideology, professional groups and organisational complexity) have been recognised for some time, (Mc Cormack et al., 2002). In particular, applying improvement methods such as Lean Six Sigma works in specific local contexts (labs, radiology) but is not a good fit with systemic change (Radnor et al., 2012). In order to operationalise systemic improvement, (the how of integrated care) Ovretveit (2011) suggested there is need to create the conditions for improvement. This not only includes necessary incentives and enablers (finance, technology and evaluation) but crucially, adopting the appropriate change methodology when working with high autonomy professional networks.

In tandem with this, Valentijn et al., (2013) recognise that it takes time to build social capital and foster trust in order to see demonstrable changes in outcomes. They suggest that normative forces (cultural/professional/political dimensions) impact on implementation and suggest that integrated care is:

> 'an "art form" founded on a colourful pallet of values and perceptions arising from several political, organisational, professional and clinical fields.' (Valentijn et al., 2013:3)

The features of a complex adaptive system (CAS) where the participants/agents within a complex social system are both independent and interdependent are key to understanding the methodologies needed to bring about key change in cultural practice that will support integration. Managers, healthcare workers, policymakers and others depend on one another to function effectively but can choose to operate independently. In light of that, the behaviour of agents within a CAS is heavily influenced by social rules, (Halpern, 2015; Begun et al., 2003) with consequent change methodologies in CAS more responsive to nudges rather than programmatic management. Therefore, a dominant property of a CAS is one of emergence, rather than design. This recognises that any change/improvement effort are embedded in complex social systems, where individuals are highly autonomous and whose views are influenced by powerful, shared professional narrative.

The importance of attending to the interests of providers as well as recipients of services is reflected in the Institute for Health Improvement (IHI) which advocates developing a quadruple aim that address staff meaning, purpose and motivation.

Finally, further insights into achieving behavioural change in health systems at a systemic level are described by Burd and Hallsworth (2016). They leverage lessons from behavioural insights to effect change at scale in the health policy arena, albeit with discrete behavioural change, (e.g. reducing harmful behaviours such as smoking or increasing donor card uptake). The United Kingdom’s (UK) Behavioural Insights Team (Halpern, 2015) has worked with public sector policymakers and practitioners over the last five years to develop the EAST framework, which is an accessible way of applying behavioural science to real-world issues. When taken together, these ideas are a departure from industrial models of efficiency, effectiveness and control and have important implications for the implementation methodology associated with the design and implementation of integrated care models (Evans et al., 2016; Leviton, 2011; Benson, 2005; Booth et al., 2013).

Examples of Successful Practice in Integration-International

As highlighted earlier the evidence base that reflects discrete care pathway components that enable integrated care delivery are still evolving. However international experience points towards key areas that reflect care developments which ‘focus on frailty’ and for which strongest evidence is likely to emerge. A systematic review of integrated and coordinated care networks for older people (Veras et al., 2014) identified five key models in the US and Canada: The Integrated Care System for

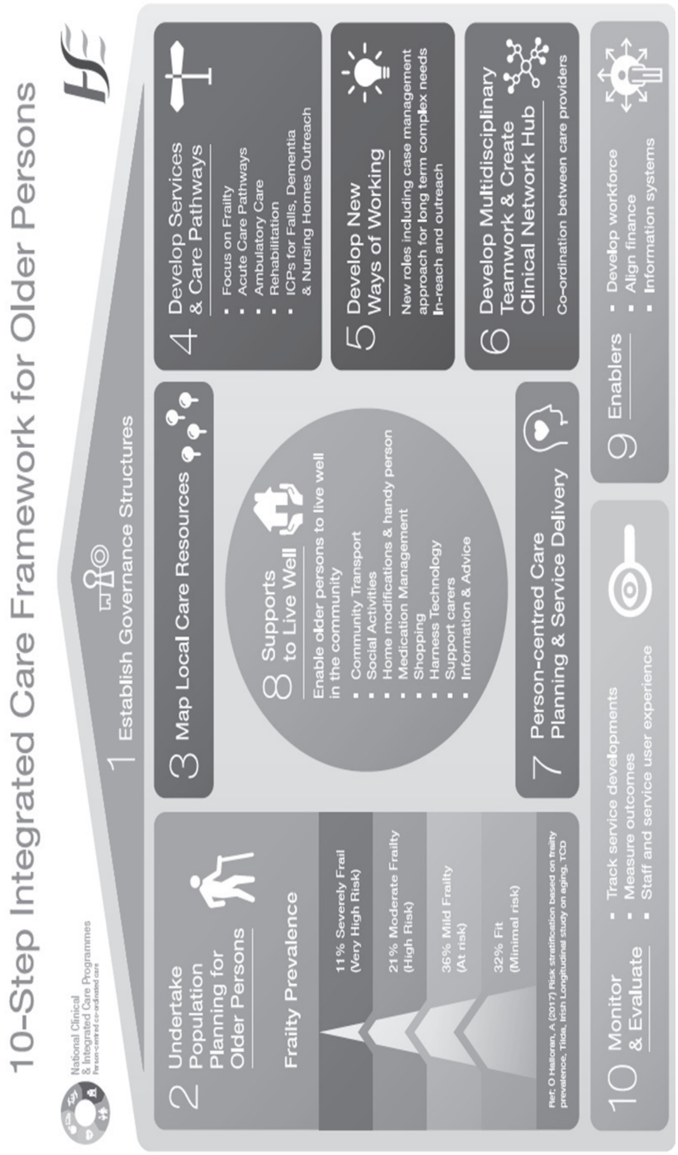
Older Adults (SIPA), the Program for All Inclusive Care for the Elderly (PACE), the Program of Research to Integrate Services for the Maintenance of Autonomy (PRISMA); the Guided Care Program and the Geriatric Resource for Assessment and Care of Elders (GRACE). The review found that the Integrated Service Developments (ISDs) were developed to improve care continuity, thereby increasing the efficiency of the services offered, especially for older adults and those with disability. The main elements that the programmes sought to address were those areas of 'high contact' with older people in health and social care services within the networks including acute hospital services, Emergency Departments, ambulatory models offering specialist services and social activities in day centres, home care and long-term care. Shared care records facilitated electronically enabled patient record access to the programmes. There was one entry point for users to enter the system, accompanied by a triage of risk, be that risk of frailty or risk of repeated hospitalisation. This was followed by a comprehensive functional or geriatric assessment around which a care plan was developed. The models used a case management approach to coordinate between institutional and community services. A specific focus on developing team expertise in the care of the older adult was deployed by some of the programmes (SIPA, PACE and Guided Care) reinforcing and sustaining the benefits of the integrated service delivery models. The SIPA and PRISMA systems showed significant network integration and care coordination with the patient. The authors concluded that patient care managed from entry into the system until end of life and integrated at all levels optimised care outcomes and experience for older people and their carers. There was evidence to show that interventions in these networks were targeting the individuals with highest need in terms of frailty and vulnerability and outcomes that reflected improved functional outcomes and less institutionalisation over time. Critically they identified that increased spending on community service provision was necessary in order to realise cost savings in acute hospital and institutional care over a longer term (Veras et al, 2014).

In a UK and European context there have been a number of examples of integration of older person's care at micro level which provide valuable learning in implementation and adaptation (RCGP /BGS UK, 2016; Wodchis et al, 2015). In reflecting care innovations for older people that promote healthy ageing, extension of primary and community care settings and community input in acute care settings, the sense of what integration looks like in reality becomes key in identifying what is different about it.

Experience of Implementing Integrated Care in Ireland- The Integrated Care Programme for Older People (ICPOP)

The Integrated Care Programme for Older People was launched in 2016 under the auspices of the Health Service Executive, Ireland. Its primary remit was to engage nationally and locally with healthcare providers and managers in facilitating the development of age-attuned pathways across services with relatively modest investment. The emphasis was therefore on harnessing a change agenda and reflecting the collaborative nature of local stakeholders in the development of services for older people within their areas using a population-based approach. This inherently contrasted with previous service developments which were based on a more traditional ‘top-down’ approach to service development in many areas. An integrative literature review was conducted to inform the ICPOP change methodology. A further literature review undertaken using a rapid review approach, synthesised the evidence on ‘what worked best’ in integrating care for older persons. The results of both literature reviews were captured in the ICPOP 10 Step Framework Integrated Care Framework in an iterative process (Harnett, 2018; HSE, 2017). This was undertaken in consultation with members of the National Working Group, Older Persons by the authors. This group (8 members) had specialist expertise in both older persons and healthcare improvement. The framework was iteratively developed and represents a schematic conceptualisation of the key ingredients of integrating care.

The ICPOP 10 Step Integrated Care Framework, Older Persons (Figure 11.2) contains ten key design elements. This represents a roadmap for local leaders who can develop components incrementally by building on what is already in place. This is supported by national enablers (workforce, finance, evaluation, ICT) that are beyond local capacity. The framework includes key integration ingredients such as new ways of working (case management) and bespoke older person pathways (ambulatory or inpatient). The inclusion of supports to live well address the WHO initiative on Age Friendly City and Counties and facilitates co-production. Underpinning this is a governance structure linking national and local decision-making. This is in keeping with Nicholson et al., (2016) who suggest that adopting design principles for governance in complex adaptive systems, combined with simple rules (to guide behaviour) offers a more promising way forward. Using this approach, within the Irish context, several ICPOP sites have demonstrated ‘early wins’ in terms of feasibility of care pathway implementation even with relatively small



10-Step Integrated Care Framework for Older Persons

National Clinical & Integrated Care Programmes
Person-centred co-ordinated care

1 Establish Governance Structures

2 Undertake Population Planning for Older Persons

Frailty Prevalence

- 11% Severely Frail (Very High Risk)
- 21% Moderate Frailty (High Risk)
- 36% Mild Frailty (At risk)
- 32% Fit (Minimal risk)

Ref; O Halloran, A (2017) Risk stratification based on frailty prevalence, Tilda, Irish Longitudinal study on aging, TCD

3 Map Local Care Resources

4 Develop Services & Care Pathways

- Focus on Frailty
- Acute Care Pathways
- Ambulatory Care
- Rehabilitation
- ICPs for Falls, Dementia & Nursing Homes Outreach

5 Develop New Ways of Working

New roles including case management approach for long term complex needs In-reach and outreach

6 Develop Multidisciplinary Teamwork & Create Clinical Network Hub

Co-ordination between care providers

7 Person-centred Care Planning & Service Delivery

8 Supports to Live Well

Enable older persons to live well in the community

- Community Transport
- Social Activities
- Home modifications & handy person
- Medication Management
- Shopping
- Harness Technology
- Support carers
- Information & Advice

9 Enablers

- Develop workforce
- Align finance
- Information systems

10 Monitor & Evaluate

- Track service developments
- Measure outcomes
- Staff and service user experience

Figure 11.2: ICPOP 10 Step Integrated Framework for Older Persons (HSE, 2017)

investments. Early examples in the South East (www.WICOP.ie), North-West and elsewhere across sites have identified strongly the utility of the 10-step framework in establishing these pathways (Harnett, 2018). A distillation of key learning from early adopter sites and from the programmatic approach used in ICPOP to inform further developments has been published (HSE, 2018).

Conclusion

Increasingly as health systems identify the opportunities that integration offers through enhancing care outcomes and sustainability, the learning from innovator sites will inform national and international policy systems in promoting those key systemic enablers that will allow for spread and scale (Kings Fund, 2018; HSE, 2018). However, the recognition of a fundamental holistic approach to implementation (including embracing the change and cultural agenda needed to support it) will determine the success or otherwise of this important step-change in older persons' care. Such approaches will need to fundamentally address the person's experience of care and be centred on addressing the needs of the individual. If integration is to become a reality, significant focus on its implementation will be required across multiple sectors with a focus on evaluation that reflects lived experience, meaningful outcomes and added value.

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CHAPTER TWELVE

HEALTHCARE DIRECTIONS IN AGEING: IRELAND AS A CASE STUDY

DEIRDRE LANG AND CARMEL HOEY

Introduction

> 'It must be remembered that longevity is an indicator of social and economic progress; a great triumph of civilisation and specifically of science and public policy, over the many causes of premature death which truncated lives in earlier times. Therefore, we must recognise that this unique phenomenon is one of the greatest achievements of the 21st century.' (Walker 2002:758)

Population ageing is occurring rapidly. Between 2015 and 2030, the number of people in the world aged 60 years or over is projected to grow by 56% and, by 2050 the global population of older persons is projected to more than double its current size (United Nations, 2015). In Ireland, the old population (i.e. those aged 65 years and over) is projected to increase by between 58 and 63 per cent from 2015 to 2030. The older old population (i.e. those aged 80 years of age and over) is set to rise even more dramatically, by between 85 per cent and 94 per cent in this time period (Wren et al., 2017).

An ageing population is one of the success stories of modern society. However, it also poses a real and significant challenge to individuals and families, and for social, economic, and healthcare systems. While many people remain well, engaged and active into later life, increasing age brings an increasing chance of long-term medical conditions, frailty, dementia, disability, dependence and/or social isolation (Oliver et al., 2014). Recent research undertaken by The Irish Longitudinal Study on Ageing (TILDA, 2016) reported that while 31% of the Irish older population aged 65 and over are robust, 45% are pre-frail and 24% are frail. The prevalence of frailty varies significantly from 17% to 29% across Community Healthcare Organisations (CHO).

There is clear evidence that those showing signs of frailty are at a particular risk of adverse outcomes such as death and institutionalisation and that they benefit from specific and effective interventions (HSE, 2012 and 2016). The Irish healthcare system, therefore, needs to adapt to meet the demands associated with these demographic changes. This chapter describes the directions taken by the National Clinical Programme for Older People to continue to enhance the Irish health service's capacity to improve the wellbeing and healthcare of older people in Ireland.

The National Clinical Programme for Older People

The National Clinical Programme for Older People (NCPOP) is a joint initiative between the Directorate of Clinical Strategy and Programmes Division (CSPD) of the Health Services Executive (HSE) and the Royal College of Physicians of Ireland (RCPI). The overall aim of the programme is to improve the quality and efficiency of care for older people with complex healthcare needs. It brings clinical leadership to the heart of the decision-making process by working in partnership with services, with the ultimate aim of improving quality, access and value of healthcare (HSE, 2012). The NCPOP recognises that to achieve its aims will require a change in culture and a transformational approach to the care of older people. This change requires a paradigm shift; a move from a position of cognitive bias and labelling of older people as frail to understanding frailty as a long-term condition. It requires the development of a system that provides timely identification and proactive preventative care, where the person is placed at the centre of the decision-making processes, in a system that provides community-based, coordinated services across a number of agencies (British Geriatric Society, 2014).

Frailty as a Long-Term Condition

Frailty is theoretically defined as a clinically recognisable state of increased vulnerability resulting from age-associated decline in reserve and function across multiple physiological systems (Qian-Li Xue, 2011). A lack of consensus regarding the operational definition of frailty makes it difficult to identify and manage in clinical practice (Rodríguez-Mañas et al., 2013). Conceptualising frailty as a continuum from not frail, to pre-frail, to frail is considered a valid way to identify subgroups of older adults at risk of adverse outcomes such as falls, worsening disability, prolonged hospitalisation and death (Clegg et al., 2011).

The clinical condition of frailty is one of the most-challenging consequences of population ageing (Clegg et al., 2013). It develops as a consequence of age-related decline in multiple body systems and results in a vulnerability to sudden changes in health status. These changes can be triggered by minor stress or by events such as an infection or a fall at home. Frailty is a graded abnormal health state which ranges from the majority who are mildly frail and need supported self-management, to those who are moderately frail and would benefit from interventions, such as case finding/case management, to those who have advanced frailty where anticipatory care planning and end-of-life care may be appropriate interventions (NHS, 2014).

The Role of Healthcare and the Impact of Frailty

The impact and potential serious adverse outcomes is a central problem associated with frailty. For people living with frailty, even a relatively minor event, such as an infection, can result in a dramatic change in their health state: from independent to dependent; mobile to immobile; postural stability to falling; lucid to delirious (Clegg et al 2013). Further to this, frailty has been shown to be a strong and independent predictor of emergency department visits and hospitalisations, hospital readmissions and in-hospital mortality (McNallan et al., 2013; Pugh et al., 2014; Bagshaw et al., 2013). These admissions create rising demands on acute hospital beds and result in enormous costs to Ireland's health service, while also being stressful to patients and their families.

The recognition of frailty is therefore important and should form part of any interaction between an older person and a healthcare professional. An individual's degree of frailty is not static, in fact, it may improve or deteriorate, and is influenced by factors which include the care received when an individual presents to a healthcare professional (British Geriatric Society, 2014). The organisation of care in hospital can also exacerbate the effect of frailty. For example, it has been estimated that each ward move, while in hospital, will increase the length of stay for a person aged over 75 years by two days (HSJ/Serco, 2014).

This increase in length of stay further compounds the problems with hospitalisation in this age group; with many experiencing a significant deterioration in their base-line functional level on discharge from hospital. The most predictable effects of deconditioning are seen in diminished muscle mass, decreases of muscle strength and marked loss of leg strength that seriously limit mobility. The decline in muscle mass and strength has been linked to falls, functional decline, increased frailty and immobility (Liu et al., 2018).

Studies suggest that, in general, healthcare professionals have a poor understanding of frailty (HSE, 2016; HSE, 2016; Gwyther et al., 2018). In light of this, the NCPOP developed the National Frailty Education Programme to provide healthcare professionals with the knowledge and skills required to provide effective care to older people living with this long-term condition. By increasing awareness and understanding, we can improve the detection, prevention, management and therefore outcomes for these older adults (Clegg, 2013).

Unlocking Knowledge–a National Frailty Education Programme

The National Frailty Education Programme is a collaboration between the National Acute and Emergency Medicine Programmes; Clinical Programmes and Strategy Division, Health Service Executive, in partnership with TILDA. The programme's philosophy is based on the belief that education increases knowledge and enhances healthcare professionals' skills in the clinical area. It promotes and encourages evidence-based practice by ensuring knowledge is current. It aims to promote excellence and encourage innovation and creativity in the management of the older person living with frailty.

Evidence suggests that participation in education programmes can have a positive effect on attitudes towards ageing and older people (Coffey et al., 2017). Positive attitudes are considered a prerequisite for high-quality health services in a variety of different settings (Neville et al., 2014). The NCPOP believe this education programme has the ability to be a key lever for change and for introducing new ways of working to improve health outcomes for older people. Empowering healthcare professionals with up-to-date knowledge and skills will ensure that when an older person needs health or social care, the care they receive will be better planned, better coordinated, easier to access and truly person centred.

This one-day programme provides an overview of the 'Fundamentals of Frailty' and includes modules on Frailty, Delirium, Continence, Falls, Polypharmacy, Cognition and Comprehensive Geriatric Assessment. It has received Nursing and Midwifery Board of Ireland post registration Category 1 approval with 6.5 Continuing Education Units (CEU's). For health and social care professionals, continuous professional development (CPD) credits are awarded on the basis that one hour of learning is equal to one CPD point (Health and Social Care Professionals Council) or as per their governing body. Pharmacists attending this programme seek approval for their CPD learning through the Irish Institute of Pharmacy. Doctors apply for CPD via the Royal College of Physicians in Ireland. Quality assurance and oversight of the programme content sits with the NCPOP Frailty Advisory Sub-group. Future iterations of the programme will include the development of an e-Learning platform and a scaffold approach to learning. This will support access to and the sustainability of the programme, as it will reduce the burden of releasing staff to attend for a full day.

The World Health Organisation (WHO, 2010) has identified and promoted interdisciplinary collaboration as a strategy to strengthen and optimise healthcare systems and improve patient outcomes. While health professionals have traditionally been educated in professional silos, the NCPOP recognise that all healthcare professional working with older people will need to have frailty as a focus and core part of their continuing education and professional development. The National Frailty Education Programme utilises an inter-professional approach to its delivery and roll out. It advocates that the programme is delivered in an integrated manner across hospitals and their corresponding CHOs. The evaluation to date suggests that his approach has enhanced knowledge and understanding of frailty among healthcare professionals and has informed the coordination and development of age-attuned care pathways between acute and community services. Key to its evolving success is the leadership being shown at local level by the frailty facilitators, the multi-disciplinary (MDT) networks and local lead Geriatricians. A critical component is the establishment of local governance groups, where senior decision-makers ensure the sustainability of the programme, by promoting and supporting its delivery and by agreeing new ways of working. Where an Integrated Care Team (ICT) exists, this work is undertaken under the auspices of the Integrated Care for Older People (ICPOP) local forum (See chapter by Kennelly and Harnett)

Providing Direction

The NCPOP Specialist Geriatric Services Model of Care Part 1: Acute Service Provision sits within the overall context of the development of comprehensive, integrated and patient focused services for older people. It is one of a series of initiatives to provide a continuum of healthcare services for older people. It defines the care pathways and services required to meet the needs of the frail older person presenting to hospital.

It recognises that for regular users of acute hospital services, plans that interface with community services are essential to meet their needs, improving access to home supports and other resources to enable them to stay well and remain at home if possible (HSE, 2012). The following table describes the recommendations of the model at each stage of the patient pathway. This pathway interfaces with the work of the Integrated Care Programme for Older People (ICPOP) as described by Kennelly and Harnett.

The Model of Care has set out a number of recommendations (Table 12.1) for the establishment of a Specialist Geriatric Service and successful delivery of measurable outcomes for frail older people. The recommendations follow the end-to-end pathway/patient journey through acute care and discharge home or other (HSE, 2012).

Table 12.1: Acute model of care: Specialist geriatric services-programme recommendations

Pathway stage	**Recommendation**
Identifying complexly ill/at risk older people in ED/AMU Section 4.5.3.1 (Page 22)	Each Emergency Department (ED)/Acute Medicine Unit (AMU) in conjunction with the Specialist Geriatric Service (SGS) will have in place an agreed process for identifying/ triaging the frail/at risk older patient.
Role of SGS in ED/AMU Section 4.5.3.2 (Page 23)	The SGS will link with the ED and AMU when an at risk/complexly ill older adult is identified requiring referral to SGS, including for Comprehensive Geriatric Assessment (CGA) or admission to a specialist geriatric ward.
Referral to SGT Section 4.5.4 (Page 26)	Each SGS will have defined and agreed criteria with their ED, AMU and Community that determines whether a patient should be referred to the Specialist Geriatric Team (SGT). Once referred, decisions about the appropriate SGS to meet the patient’s needs will be made by a senior professional to a specified timeframe.
Comprehensive Geriatric Assessment Section 4.5.5 (Page 27)	All identified older at risk/complexly ill patients to have a timely CGA performed and documented in their permanent health record that is accessible to both the primary and secondary care teams.
Specialist Geriatric Ward Section 4.5.6 (Page 28)	Each hospital receiving acutely ill older adults must have a dedicated Specialist Geriatric Ward with appropriate staffing levels and a designated Multidisciplinary Team (MDT)

Rehabilitation Section 4.5.7 (Page 29)	Each hospital has access to on-site and off-site rehabilitation beds
Discharge Planning Section 4.5.8 (Page 29)	A systematic approach to discharge planning will be facilitated by admission of the frail older person into an SGW with an SGT. Each hospital to have an SGT, with clear responsibility and processes for CGA, integrated discharge planning, and communication with the patient and professionals in other care settings.
SGS Outpatient and Rapid Access Clinic Section 4.5.9 (Page 30)	Each SGS will provide an outpatient service which encompasses subspecialty clinics with rapid access slots for urgent referrals.
Day Hospital on the acute site Section 4.5.10 (Page 30)	The Day Hospital (DH) will be the setting for acute ambulatory services. It will also function as the coordination, information and training hub for services for older patients, supporting integration between hospital and community-based services. In addition, it will act as a resource for others involved with the care of older people.
Outreach to long-term care residential facilities Section 4.5.11 (Page 31)	Each SGS will provide an Outreach service, prioritising patients in long-term care referred by the GP or Medical Officer. The Outreach service will also liaise with psychiatry for older persons and support training and education of community-based staff.
Working with Community Based Services Section 4.5.12 (Page 32)	The establishment of SGTs in acute hospitals will facilitate communication with GPs and PCTs. A single access point will be established to support referral. Outcome of hospital assessment and care will be communicated in a timely manner to the referral source.

The NCPOP recognises that frailty is a new and emerging science and continues to develop evidenced-based, supplementary resources to enhance and support the Model of Care. In the meantime, clinical patient care pathways that support the specialist geriatric service model of care have been developed in collaboration with other clinical programmes, to assist healthcare professionals to assess and treat older patients appropriately. These include the implementation of an ‘Early Identification and Initial Management of Delirium in the Emergency Department/Acute Medical Assessment Unit’ pathway and the development of a suite of tools to assist the management of delirium on an acute medical or surgical ward. These documents will support the early identification and management of delirium and thus improve outcomes for patients who experience this medical emergency.

The NCPOP recognises that transitions for older people with multiple chronic conditions between care settings are particularly critical and vulnerable periods for them. Transitions are frequently characterised by serious breakdowns in communication both within and between services, which create gaps in care and can lead to poorer outcomes for the older person. Transitions between residential and acute care settings have been identified in the literature as periods of particular vulnerability, when communication deficits can occur (Griffith, et al., 2014). The NCPOP in collaboration with the Office of the Nursing and Midwifery Services Director commissioned a body of research to develop and validate a national transfer document for use when an older person is being transferred between residential and acute care facilities. The final document will be ready for publication by December 2019.

Towards the Gold Standard–Comprehensive Geriatric Assessment

Comprehensive Geriatric Assessment (CGA) is the gold standard of care for an older adult living with frailty. Rubenstein et al. (1991:8S) defines CGA as a:

> 'multi-dimensional, interdisciplinary diagnostic process to determine the medical, psychological and functional capabilities of a frail older person, in order to develop a coordinated and integrated plan for treatment and long-term follow-up.'

Substantial evidence shows that in hospital, those who receive in-patient CGA on specialist geriatric wards are more likely to return home, are less likely to have cognitive or functional decline and have lower mortality rates than those who are admitted to general wards (Ellis et al., 2011). CGA is based on the premise that a full evaluation of a frail older person, by a team of healthcare professionals, may identify a variety of treatable health problems, resulting in a coordinated plan and delivery of care leading to a better health outcome. When an older person is identified as being at risk of frailty, whether in an acute hospital, day hospital, community or residential care, they should be considered for a CGA. The content of the assessment may vary depending on different settings of care.

To support the implementation of CGA in Ireland, the NCPOP developed a Specialist Geriatric Team Guidance for Comprehensive Geriatric Assessment (HSE, 2016). It advocates that, where indicated, CGA should be initiated as soon as possible after admission to hospital, by a skilled, senior member of the multidisciplinary team, and used to identify reversible medical problems, target rehabilitation goals and plan all the components of discharge and post-discharge support needs. It is grounded on evidence-based practice and multidisciplinary expert opinion and is primarily intended for use by medical, nursing and health and social care professionals working across many settings, but it should also prove useful for education. The main focus of the guidance document is the assessment of older people across the integrated services in the specialist geriatric ward acute hospital, emergency departments, outpatient clinics and day hospitals. It does recognise, however, that all older people should have equal access to specialist geriatric expertise regardless of the setting.

Augmenting the Nursing Workforce

Coffey et al., (2015:33) identified:

> ‘the growing older population has consequences for the nursing profession and for nurse education. An increasing demand for nurses to work with older people over a wide range of services including hospitals, residential care, health and community services is inevitable.’

This increasing demand is set against a background of a shortage of skilled healthcare professionals globally (Engstrom et al., 2011) but more importantly a lack of interest or desire from these professionals to work within the gerontological context.

Gerontological nursing has been described as the ‘Cinderella’ of the services (Government of Ireland 1998) and has consistently been found to be the least popular career option among nurses and other healthcare professionals (Boswell et al., 2012; Higashi et al., 2012). Negative views about working with older people appear to stem from little or no clinical experience with older people, a perception of less desirable working environments and the lack of opportunity for career advancement (Kydd et al., 2013). With the rapidly growing older adult population and the dynamic healthcare services of today, the attitude of nurses towards working with older people is an important variable to consider when planning for future care and services. In addition, nurse education and curricula need to be responsive to the diverse and holistic needs of older people and changing care environments. It is imperative that the future of gerontological nurse education is designed to equip nurses with the knowledge skills and competences necessary to meet those needs.

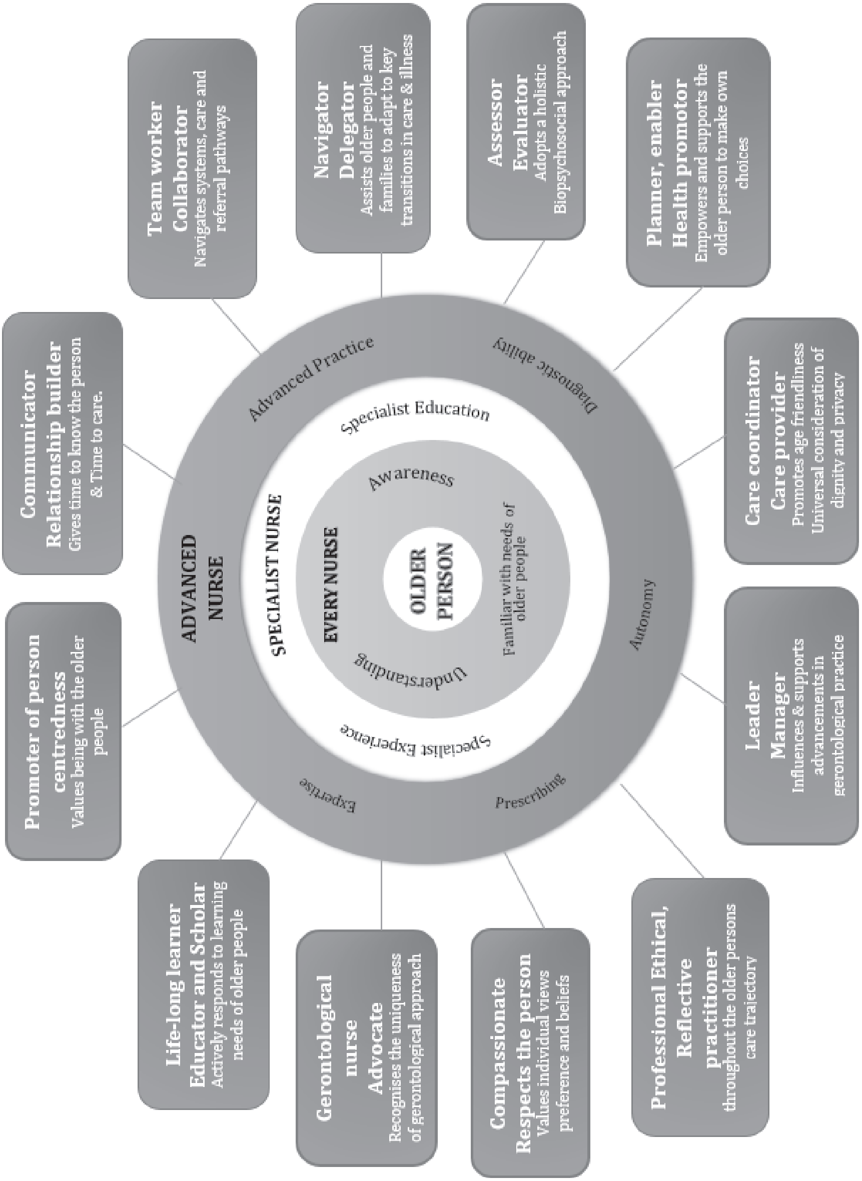

Figure 12.1: Educational framework for gerontological nursing

In 2016, the NCPOP in collaboration with the Office Nursing Midwifery Services Directorate (ONMSD) commissioned a body of research to determine the knowledge, skills and competences required to produce a nursing workforce that can provide quality person centred care to older people across the spectrum of healthcare. The findings of this research will inform the development of a strategic vision for gerontological nursing in Ireland. The educational framework provides direction for nursing to build capacity in generalist, specialist and advanced practice roles and to support an integrated delivery of care for older people. It will enable the nursing profession to respond to the challenges and opportunities that arise from the changing demographic and new ways of working. The educational framework will enable nurses to acquire and maintain the necessary knowledge, skills and competences, at the appropriate level to deliver care to older people, throughout the Irish Health Service. A national Higher Education Institute (HEI) Working Group has been established across the island of Ireland and HEIs are mapping their undergraduate and post-graduate nurse education programmes to the framework (See Figure 12.1). A similar body of work is underway with the Health and Social Care Professionals/Pharmacy subgroup of the NCPOP, who are scoping the development of a competency framework for all healthcare professionals working with older people.

In 2017, the Minister for Health approved a Draft Policy on Graduate, Specialist and Advanced Nursing Practice in Ireland. The purpose of the draft policy is to help provide a solution to a number of critical challenges facing the health service. It recommends the development of a critical mass of advanced nurse practitioners in the areas of most service need. The key driver for the draft policy is the creation of a more responsive, integrated and person centred health and social care service, as outlined in Strategic Priority 3 of the Department of Health (DOH, 2016) Statement of Strategy 2016-2019). Linked to this priority, is the development of advanced practice roles to support the implementation of the National Clinical and Integrated Care Programmes by the Health Service Executive.

In 2017, older persons services recruited an inaugural group of candidate Advanced Nurse Practitioners (cANPs), with an additional cohort of cANPs in recruitment for 2018. The NCPOP has supported the development of these cANP roles to enable alignment with programme objectives. This has included the establishment of a cANP network and the development of a competency framework to support consultant geriatricians in their supervisory roles. It must be noted that the involvement of geriatricians nationally has been key to progression of these roles locally across hospitals and CHOs.

The output of each gerontological advanced practice service must demonstrate an impact on one or more of the following service challenges: access to services; reducing waiting lists; facilitating early discharge; and avoiding unnecessary hospital attendance by keeping patients at home through pathways of integrated care. The NCPOP looks forward to supporting and watching this key service emerge.

Setting the Compass of Care in the Right Direction for Older People

Care, compassion, trust and learning are core tenets of healthcare values in Ireland. The public expect healthcare that is competent, compassionate and caring (DOH, 2016b). Recent studies in Ireland found that older people feel invisible and regard health services to be lacking in dignity, respect, and compassion (HSE and Age Friendly Ireland, 2015; 2016). This finding is similar to the Mid-Staffordshire Enquiry, which noted older people were viewed as a nuisance, rather than adults who should be partners in their care (Francis, 2013).

On admission and throughout the acute hospital stay, the main focus of the healthcare professional is the medical model of care, which revolves around the physical status of the patient (Francis, 2013). The emphasis appears to centre on ‘What’s the matter with you’. While a focus on rapid treatment, high turnover and shorter lengths of hospital stay is not wrong, problems arise when these goals are prioritised at the expense of values such as compassion (Patterson et al., 2011). When values are regarded as an optional extra, the primacy of care is lost. The system must find a way to allow both paradigms of care to flourish and co-exist (Doyle et al., 2010; Dewar, 2011). Until we synthesise and value both elements of care and deliver them in equal measure, on a consistent basis, we will not meet the needs of frail older people, their families or the community. While the presenting health issue is a concern to the patient, their experience of hospital care is measured by the level of dignity, compassion, and respect with which they are treated (HSE and Age Friendly Ireland, 2015; 2016).

‘What Matters to You’ (WMTY) is therefore one of the most important questions healthcare professionals can ask their patients because knowing what matters to the patient sets the compass of care in the right direction. WMTY is an initiative that supports person-centeredness as it assists in capturing issues that are important to the individual and when known by staff can improve patient experiences. The NCPOP, in collaboration with the Quality Improvement Division (QID) and the Irish Hospice Foundation (IHF), partnered with two acute hospitals in Ireland, as part of a pilot project to inform the national rollout of WMTY. The programme encorporated the ‘Hello my name is’ work of Dr. Kate Grainger as an integral part of its work.

The result of the six-month pilot project suggested that the WMTY initiative was seen as a positive initiative by staff on the wards. Staff reported that the information captured was helpful to patient care, as it enabled conversations, building rapport and establishing relationships. One interviewee stated WMTY enhanced person-centered care, as knowing the patient as a person resulted in more flexibility around meal times and visiting times on her ward (Lang, 2017). This finding is supported in the literature, where the quality of care is reported to be based upon relational dynamics, which can positively impact upon the patient’s experience of healthcare (Patterson et al., 2011).

Interviews with patients suggest they think it is a positive initiative, especially for older people with cognitive and communication issues. The learning diaries maintained on the ward captured a number of situations where WMTY was key to the provision of better outcomes for patients. These included reduced agitation and better relationships between staff and patients. However, comments such as ‘I’m old so what can you expect’ and the concerns patients raised at their interviews around the burden of waiting, suggest that there is a lot more to do to reduce the stigma of age and the sense of invisibility older patients feel (Lang, 2017).

The learning from the pilot has been adapted into a suite of tools to assist other services to adopt the iniative into practice and the NCPOP and the QID continue to support International What Matters to You day on 6th June every year.

Conclusion

The ageing of our population represents one of the most significant demographic and social developments that Irish society has encountered. There is no doubt that this will pose challenges but it will also bring great opportunities.

The overall aim of the NCPOP is to improve and standardise the quality of care for older people in Ireland. While most healthcare for older people is provided in the community, acute deterioration in health may result in referral to an acute hospital. The Acute Model of Care defines the care pathways and services required to meet the needs of the frail older person presenting to hospital. Frailty, is a concept not understood well outside of the realm of gerontology. The national education programme was developed to provide healthcare professionals with an understanding of frailty as a long-term condition. It has the potential to improve the care people receive in hospital, reduce unnecessary hospital admissions, lengths of stay and re-admissions.

CGA is fundamental to the assessment, planning and intervention required to meet the health and social care needs of the older person that is frail or at risk of frailty. The SGT Guidance Document supports healthcare professionals to work closely together to ensure an integrated assessment and response to the older person's individual needs. Adequately resourced, this can be available to an older person in the community or in the hospital.

The attitudes of nurses to working with older people has significant implications for our rapidly growing older population. It is imperative that nurses are equipped with the knowledge, skills and competence to meet the diverse and holistic needs of this demographic. The Strategic Vision and Educational Framework for Gerontological Nursing and the development of a critical mass of Advanced Nurse Pracitioners (ANP) are key drivers in the creation of a more responsive workforce.

Finally, to ensure that services are provided in a person-centered fashion, the NCPOP in collaboration with QID and IHF developed a suite of tools to support compassionate, relational care. WMTY is one of the most important questions a healthcare professional can ask their patients. It sets the compass of care in the right direction and provides information about the person that can inform the plan of care.

The NCPOP in Ireland is commited to the development of an age-atuned health service and to improving patient outcomes for older people. The initiatives described in this chapter provide a foundation towards enhancing older peoples experience of ageing well and healthcare in Ireland and achieving the overarching aim of the NCPOP that every older person has access to the right care and support at the lowest level of complexity. It is an example of a true buidling block to future improvements and developments in Older Persons services in Health and Wellbeing.

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CHAPTER THIRTEEN

ELDER ABUSE: A MULTI-DIMENSIONAL CHALLENGE

AMANDA PHELAN

Introduction

Elder abuse represents one component of the spectrum of family violence, together with intimate partner violence (domestic violence) and child protection. Although we can identify elder abuse in various historical records, such as within the Bible, literature, or folklore (Phelan, 2013), its formal identification occurred in 1975, when medical doctors published on the physical abuse of older women (Baker, 1975; Burston, 1975). Since that time, understandings of elder abuse have grown and this has had an impact in generating specific policy, legislation and practice responses to this social challenge. Yet, within the broader context of family violence, elder abuse is under-researched (Phelan, 2013). Elder abuse is a global phenomenon and as the twenty-first century heralds a triumph in human longevity, it is imperative that this success is accompanied by a concurrent focus on enhancing quality of life, particularly related to ensuring older people's right to experience a safe and self-determined life. This chapter commences by contextualizing elder abuse within a human rights lens and follows on by presenting current perspectives on the topic.

Rights Based Approaches

Human rights have a fundamental importance in elder abuse as they assert the equality, security and treatment that all human beings are entitled to regardless of age. While the concept of human rights can be traced back to records relating to the Code of Hammurabi (circa 1780 BC) and the Cyrus Cylinder (580 BC), three generations can be broadly identified in the evolution of contemporary understandings. Firstly, the

Code of Hammurabi delineated 282 Babylonian laws which were seen to provide protection to the weak, justice to widows and orphans and provide scope to right wrongdoing (Prince, 1904). When Cyrus the Great of Persia conquered Babylon in 539 BC, he freed the slaves, declared a right to choose a religion and created racial equality. These directives were prescribed in a clay-baked cylinder (Cyrus Cylinder) written in the Akkadian language. This was a landmark in the development of human rights (Curtis, 2013) and subsequently, these principles spread to Greece and Rome. These rudimental rights could vary for different classes of people (upper classes, poor, slaves), however, so rights were conditional. The second generation of human rights marked a further evolution in perspectives and included specific charters such as the Magna Carta (England 1215), Petition of Right (England 1628), United States Declaration of Independence (1776), Constitution of the United States (1787) and Bill of Rights (USA 1791), Declaration of the Rights of Man and Citizen (France 1789) and the First Geneva Convention (1864 – sixteen countries and some American states who focused on just treatment of wounded soldiers in combat). The third generation, which represents current understandings, emanated from the early work of the United Nations (UN), established post World War II in 1945. Observing the atrocities of the war, fifty countries came together to work to prevent future conflict and promote peace. In 1948, the UN published the Universal Declaration of Human Rights which contained thirty fundamental human rights and has been translated into over 500 languages. This Declaration states:

> 'Whereas disregard and contempt for human rights have resulted in barbarous acts which have outraged the conscience of mankind, and the advent of a world in which human beings shall enjoy freedom of speech and belief and freedom from fear and want has been proclaimed as the highest aspiration of the common people...All human beings are born free and equal in dignity and rights.' (UN, 1948: NP)

This Declaration was very significant; it demanded equal protective standards for all human beings, crossing many national borders and stated that an individual had a fundamental right to equality and non–discrimination, a right to life, a right to liberty and a right to respect regardless of issues such as age, socio-economic status, religion, race or gender. Since then, other hybrid rights-based covenants, conventions and charters have been articulated as detailed in Table 13.1 below:

Table 13.1. Covenants, conventions and charters further reinforcing human rights

- International Covenant on Civil and Political Rights (1976)
- International Covenant on Economic, Social and Cultural Rights (effective 1976)
- United Nations Convention on the Rights of the Child (1989)
- United Nations Convention on the Rights of Persons with Disabilities, European Convention on Human Rights (1950) and Protocols.
- European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (1987)
- American Convention on Human Rights (1967) and its Protocols (1988 and 1990)
- Inter-American Convention to Prevent and Punish Torture (1985)
- African Charter on Human and Peoples' Rights, adopted (1981)
- African Charter on the Rights and Welfare of the Child (1990)
- International Convention on the Elimination of All Forms of Discrimination Against Women (1979)
- International Convention on the Elimination of All Forms of Racial Discrimination (1969)
- International Convention for the Protection of All Persons from Enforced Disappearance (signed 2006)

Many countries have enshrined the principles of the UN Declaration into legislation and the constituent articles are often used to benchmark the treatment of individuals by other people, communities or states. While there is no specific declaration or convention for older people, the UN has recognised the potential of creating a bespoke human rights instrument to reinforce rights which are currently perceived as invisible for older people. Such a convention would have the capacity to enable governments to defend the rights of older people with the input of a Special Rapporteur (INPEA et al., ND). To this end, a UN Open Ended Working Group commenced discussions in 2010 with its 9th meeting in July 2018. It remains to be seen if this will culminate in a formal declaration or convention which has the potential to enhance the lives of older people and further protect against abuse.

The impact of human rights is apparent in policy related to safeguarding adults. For instance, in safeguarding policy in Northern Ireland and the Republic of Ireland, there is a recognition of the need to have a rights-based, empowerment approach that is underpinned by consent, collaboration and person centredness (DHSSPS and DoJ., 2015; Social Care Division, 2014). Such an approach is an important dimension in addressing elder abuse and ensuring the right to a safe environment.

Elder Abuse

Defining elder abuse has been problematic. As an increasing knowledge base is generated and concepts evolve, there is a concurrent need to ensure definitions match understandings. For example, definitions can be impacted by their levels of specificity, cultural nuances, gender differences and professional perspectives. Definitions of elder abuse can also be hampered by a lack of conceptual development and a lack of clarity on areas such as intentionality, potential impact and actual impact (Goergen and Beaulieu, 2013). Using a definition developed by Action on Elder Abuse (1995), a United Kingdom-based charitable organisation, the World Health Organisation (WHO, 2002) and the United Nations (ND) describe elder abuse as:

> ‘ …a single or repeated act or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person.’

While this definition is useful, it is limited in terms of the person who perpetrates the abuse (who must be in a position of trust) and that also stipulates that the abuse must result in harm or distress to the older person (which does not necessarily occur). Thus, the act in itself is not independently classed as abuse unless it meets these defined criteria. Other definitions can have a wider scope. Many services for elder abuse are delivered within general adult protective services (USA, Ireland, United Kingdom) where definitions focus on adults who may be at risk of abuse, rather than just older people. For example, in Ireland (Social Care Division, 2014: 8), the abuse of vulnerable adults is defined as:

> ‘…any act, or failure to act, which results in a breach of a vulnerable person’s human rights, civil liberties, physical and mental integrity, dignity or general wellbeing, whether intended or through negligence, including sexual relationships or financial transactions to which the person does not or cannot validly consent, or which are deliberately exploitative.’

Definitions of elder abuse are also noted to be generated in a ‘status’ way. This means that they may lack the flexibility to accommodate change that occurs over time in terms of risks or other impacting circumstances (Wallace and Crabb, 2017). Another area of debate is the status of ‘vulnerability’ (Goergen and Beaulieu, 2013). For instance, in Northern Ireland, policy makes a distinction in terms of impact and consequences of constructing the adult as vulnerable. The policy states that an adult at risk of harm is where risk may be increased due to personal or life circumstances. An adult in need of protection is considered as one whose risk may be increased due to personal or life circumstances, and who is unable to protect themselves or where the action or omitted action of another person places them or is likely to place them in harm (DHSSPS and DoJ, 2015). While such clarification demonstrates important subtleties in meaning and advances understandings, as research, practice and legislation evolve in the future, so will formal definitions.

Elder abuse has differing modes of perpetration. Similar to other forms of family violence, elder abuse can be perpetrated through physical abuse, psychological abuse, financial/material abuse, sexual abuse and neglect. Possible manifestations and potential indicators are detailed in Table 13.2.

Table 13.2: Types of abuse, possible manifestations and potential indicators of elder abuse (Phelan 2010)

TYPE OF ABUSE	POSSIBLE MANIFESTATIONS	POTENTIAL INDICATORS
Physical abuse	Hitting, slapping, pushing, kicking, spitting, medication misuse, restraint, force feeding or inappropriate sanctions.	Bruising, cuts, lacerations, scratches, sprains, hair loss, missing teeth fractures, slap marks, kick marks, eye injuries, burns.
Psychological abuse	Humiliation, intimidation, threats of abandonment, ridicule, causing fear/anxiety, bullying, blaming, controlling, coercion, harassment, verbal abuse, lack of acknowledgement, isolation/withholding social contact, denial of basic rights, over protective.	Demoralisation, depression, withdrawal, apathy, feelings of hopelessness, insomnia, appetite change, unexplained paranoia, agitation, tearfulness, excessive fears, confusion, ambivalence towards the perpetrator.
Neglect **Passive neglect represents acts of omission by lack of knowledge. Active neglect represents deliberate acts of omission.**	Ignoring physical, medical needs, failure to provide access to appropriate services (health, social, educational) of life and/or aids for activities of daily living (such as medication, heating).	Dehydration, malnutrition, inappropriate clothing, poor hygiene, unkempt appearance, over/under medication, unattended medical needs, exposure to risk/danger, absence of aids (Zimmer frame, reading glasses), pressure sores.

Financial abuse	Sudden reduction in financial funds, Removal of material property. Coerced signing over of property/funds/material goods or change of will.	Sudden/unexplained inability to pay bills or to buy necessities, uncharacteristic withdrawal of funds, diverted funds for another's use, damage to property, disappearance of property, absence of required aids or medication, refusal to spend money, disparity of assets and living conditions, extraordinary interest by others in older person's assets, dramatic financial decisions.
Sexual abuse	Rape, sexual assault or acts the older person has not consented to or has not the ability to consent too or was compelled to consent.	Trauma around the genitals, breasts, rectum or mouth.
Discriminatory abuse	Towards older people, individual/ group.	Ageism, sexism, racism.

Neglect can be perpetrated through omission/passive neglect, where, for example a caregiver may not have the appropriate skills/knowledge to provide care leading to a negative outcome; neglect by commission/active neglect is where the caregiver is aware of the required caregiving activities, but chooses not to meet the requirements. A similar category is cited by the National Institute on Ageing in the United States (2016) who recognise abandonment as a distinct form of elder abuse. This is where the older person is left alone with no provision for their needs.

Self-neglect is considered under the rubric of elder abuse in some jurisdictions but not in others, yet it represents a substantial client group in Adult Protective Services in the Unites States (Teaster et al., 2006; Administration for Community Living, 2018). Self-neglect is defined as a failure of the older person:

> '…to provide himself/herself with adequate food, water, clothing, shelter, personal hygiene, medication, (when indicated), and safety precautions.' (US DHHS 2014: online)

Both neglect and self-neglect are chronic manifestations of elder abuse but can have profound consequences in terms of diminished physical and psychological health, higher mortality rates and greater health service use (Dong et al., 2009; Dong, 2011).

Theory

Abend (2013) describes a theory as a basis of understanding, predicting and explaining phenomenon, explaining why the topic of interest exists. It is recognised that the theoretical base in elder abuse is underdeveloped (Roberto and Teaster, 2017), yet, since the 'discovery' of elder abuse, various explanatory frameworks have been postulated to explain why elder abuse occurs. These are presented in Table 13.3.

Table 13.3: Theories of elder abuse

THEORY	EXPLANATION
Psychopathology of the abuser	This theory suggests that there are characteristics inherent in the abuser which predispose to abuse. For example, alcohol and substance abusers may financially abuse to meet their habit. People who are living with mental health disorders, personality disorders or those with intellectual disability may not have the capacity to provide for an older person's needs.
Caregiver stress/situational theory	This theory engenders much attention as it suggests abuse occurs because as the demands of caregiving increase, the stress in the caregiver rises, leading to abuse.
Social exchange theory	The social exchange theory also focuses on the dependency of the older person. Relationships generally involve benefits and outputs. As the older person's dependency rises, the benefit of the relationship is reduced for the caregiver and the outputs (cost) rise, creating the context for abuse to occur.
Social learning/ Intergenerational theory	This theory suggests that abuse is a normalised way that families deal with conflict. Therefore, there can be child abuse, domestic violence and elder abuse occurring across generations. There is some support suggesting elder abuse can represent domestic violence 'grown old'. However, using a life course perspective on elder abuse, a Canadian study, only a history of abuse during childhood was related to the experience of one type of abuse (McDonald and Thomas, 2013).

Domestic violence/ Feminist theory	This theory argues that elder abuse emanates from patriarchal structures of power and control. Violence is used to coerce the older person to comply to the will of the abuser. For feminists, this focuses on the intersection of ageism and sexism
Ecological theory	Based on Bronfenbrenner's (1979) Ecological Model, this theory proposes that we live in environmental networks which range from our immediate experience to the broader cultural and social context (micro, meso, exo and macro levels). Bronfenbrenner also identified that there is a temporal dimension (chrono-system). In order to respond to elder abuse, it is necessary to address the multiple factors inherent in all dimensions of the ecological systems.
Context theory	Roberto and Teaster (2017) proposed the context theory, which is based on a review of existing elder abuse scholarship. Building on socio-ecological models, the context theory proposes four conceptual domains for elder abuse: individual, relational, community and societal. Individual factors include a consideration of the older person's life course perspective and biological perspective. The relational context focuses on the interactions and the relationship dynamics in terms of being a contributory factor in abuse. The community context looks at the sense of belonging and how relationships operate within home and community (church, support systems). The societal context looks at the macro environment within which elder abuse occurs – age-related changes in policy, ageism legislation.

While theories are fundamental to understanding, no single theory has been empirically proven to comprehensively explain why elder abuse happens. This has inevitably been hampered by the complexity and multi-dimensional aspects of elder abuse. However, theoretical frameworks are fundamental in implementing interventions (Roberto and Teaster, 2017). Thus, in order to understand and comprehensively respond to the intricacies of elder abuse, more empirical research is needed to enhance theory and to enable flexibility in explaining its multiple complex elements.

Incidence and Prevalence

Attempts have been made to enumerate elder abuse, both within the community and nursing home environments, through incidence and prevalence studies. Incidence studies measure the number of new cases of a phenomenon in a specified period of time, while prevalence studies examine the total number of cases at a particular point in time. Figures produced in incidence and prevalence studies should be reviewed with caution as they are ‘impressionistic estimates’ (Bonnie and Wallace, 2003: 21). This typifies the iceberg theory, which argues that cases that are identified are only a partial representation of the true experience of abuse by older people. Moreover, prevalence and incidence figures are difficult to compare due to a diverse range of elder abuse definitions applied in the studies and the multiple methodological approaches employed. In addition, such figures are not neutral and may also be influenced by issues of culture, gender, age cut-offs and cognitive status.

In 1998, the National Centre for Elder Abuse and Neglect and Westat undertook an incident study which estimated that 450,000 older people over the age of 60 years were subject to some form of abuse (physical, psychological, sexual, financial or neglect) in 1996; when self-neglect was included in estimations, this figure rose to 551,000. Many countries have conducted prevalence studies based on community-dwelling older people (with mental capacity) and figures range from approximately 1% in Spain (Marmolejo, 2008) to 79.7% in Peru (Silva-Fhon, 2015). A recent study by Yon et al. (2017) examined 52 global prevalence studies of elder abuse and found a pooled prevalence of 15.7%. Psychological abuse was found to be the most common form of maltreatment (11.6%), followed by financial abuse (6.8%), neglect (4.2%) and sexual abuse (0.9%). Community-based studies which have examined abuse of older people living with dementia demonstrate a general higher prevalence (Downes et al., 2013). For example, a United Kingdom study by Cooper et al. (2009) identified that 52% of caregivers of people living with dementia engaged in abusive behaviours while Yan and Kwok (2011) identified a figure of 62.3% in China.

Prevalence studies have also been completed in residential care settings. An Irish study (Drennan et al., 2012) involving 1,316 staff in nursing homes demonstrated that 57.6% of staff had observed abuse. Observing a colleague’s non-response to a resident’s call and not bringing a resident to the bathroom when requested were the most frequently cited forms of abuse. A recent review by Yon et al. (2018) examined nine global studies of elder abuse in residential care demonstrating that overall abuse reported by staff was 64.2% in a 12-month period. Psychological abuse was the most common form of abuse (33.4%) followed by physical abuse (14.1%), financial abuse (13.8%), neglect (11.6%) and sexual abuse (1.6%) (Yon et al., 2018).

Risk Factors for Elder Abuse

Four general risk factor domains have been identified in elder abuse; these are characteristics of the older person, characteristics of the perpetrator, type of relationship and environment. For the older person, cognitive, mental and physical health challenges pose a higher risk of elder abuse (Wu et al., 2012; Johannesen and LoGiudice, 2013; Yan et al., 2015; Pillemer et al., 2016). Other factors related to the older person's functional dependence (Wu et al., 2012; Burnes et al., 2015; Pillemer et al., 2016), being widowed, divorced, single or separated (Wu et al., 2012), being in the younger old age group (Roberto, 2016), being female (Division of Social Policy and Development, 2013) or poor education level (Sebastian and Sekher, 2011), numeracy challenges (Woods et al., 2016), low income (Dong et al., 2007; Naughton et al., 2010; Pillemer et al., 2016) and ethnicity type (Lauman et al., 2008) have been shown to increase risk.

Perpetrators of elder abuse are often known to the older person (Roberto, 2016; Orfila, 2018) and perpetrator traits that increase risk include poor mental health (Johannesen and LoGiudice, 2013; Pillemer et al., 2016), caregiving reluctance and inexperience (Roberto, 2016), substance abuse (Jogerst et al., 2012, Centre for Disease Control and Prevention, 2018), unemployment (Naughton et al., 2010; Kotzé, 2018), caregiver burden (Johannesen and LoGiudice, 2013), a history of interpersonal abuse (i.e. domestic violence grown old) (Roberto, 2016) and dependence of the perpetrator on the older person (Jackson and Hafemeister, 2012; Pillemer et al., 2016). In terms of relationships, some studies point to increased risk within a spousal relationship with the older person (Laumann et al., 2008; Burnes et al., 2015), while a child of the older person has also been identified as a common perpetrator of elder abuse in other studies (Oh et al. 2006; Naughton et al., 2010). In the context of environment, risk increased for older people requiring a high level of social support (Dong and Simon, 2008), those receiving a low-level social support (Acierno et al., 2009; Johannesen and LoGiudice, 2013) and older people who were socially isolated (Naughton et al., 2010). On a wider macro environment context, ageism has been proposed as an influencing factor in enabling abuse (Harbison, 2016), however, additional empirical evidence is needed to support this as an uncontested risk factor (Pillemer et al., 2016).

Consequences of Elder Abuse

The consequences of elder abuse are diverse and can impact the general quality of life of older people, their physical and mental health as well as broader society itself. Older people who have been abused have identified that it has a very serious or serious impact on their lives (Naughton et al., 2010). People who have a history of elder abuse have a higher falls rate (Reyes-Ortiz et al., 2018) and experience higher rates of medical morbidities (Fang et al., 2018) as well as premature death (Dong et al., 2009). Financial abuse has been shown to have a significant impact on mental health (Acierno et al., 2018) and psychological health (Litchenberg et al., 2015). Older people who have been abused experience higher rates of hospital admission (Dong and Simon, 2013) and abuse has an impact on the allocation of resources within health and community care services and justice services (Spencer, 2000) as well as a loss in social capital and the diminishing of the older person's ability to continue to contribute to society (United Nations Economic Commission for Europe, 2013).

Interventions

Many countries have developed services to combat elder abuse. These target prevention, recognition and case management. Countries such as Ireland, under the remit of the National Safeguarding Committee, have funded public awareness campaigns on the manifestations of elder abuse. Other countries, such as the United States, have introduced mandatory reporting and specific policy to both prevent and respond to abuse perpetration. The United Nations Economic Commission for Europe (UNECE) (2013) points to the imperative of having comprehensive education on prevention and intervention in the health and social care curriculum as well as this topic being a component in continuous professional development. Another preventative method is to ensure health policy, legislation and regulation provide standards for care quality (UNECE, 2013). For example, policy should ensure appropriate staffing and skill mix in care services, which is underpinned by a person centred ethos, while in the community setting, caregivers should be supported in caregiving roles in terms of practical help and financial assistance.

A major issue in elder abuse perpetration is its taboo and covert nature. On occasions, older people may not be able to recognise the abuse as maltreatment; for example, if they perceive themselves as a burden, then the maltreatment may be seen as deserving. The use of undue influence may blur the lines of abuse, for example, signing wills may be as a result of family pressure, but may not be seen as abusive due to the assumption that those family members would inherit these assets in future wills. Older people may not wish to disclose the abuse due to embarrassment, a fear of retribution, because the person is a relative or they may fear admission to a nursing home if the perpetrator is also the caregiver (Phelan, 2013). In addition, the older person may be so disempowered that they are unable to disclose maltreatment or may not be able to communicate the abuse due to being isolated by the perpetrator, or where there are communication difficulties. A lack of the older person's corroboration of abuse or a decision not to engage can be difficult for the healthcare professional who can struggle to balance a respect for self-determination with a safeguarding imperative (Moye and Marson, 2007). One method of facilitating disclosure highlights the potential value of helplines and dedicated counsellors to assist older people with neutral advice, which may address any shame and insecurity of seeking help (UNECE, 2013).

To assist in recognising elder abuse, a number of tools, indexes and measures have been developed (see Phelan and Treacy, 2011 or Schofield, 2017) to assist practitioners, however, support for such tools has been limited (NCEA, 2016; USDHHS, 2018) as elder abuse does not follow the typical epidemiological pattern which underpins traditional population screening criteria (Lachs and Pillemer, 2004). Commonly used tools include the Hwalek-Sengstock Elder Abuse Screening Test (Neale et al., 1991), the Elder Assessment Instrument (Fulmer and O'Malley, 1987) or the Indicators of Abuse (Reis and Nahmiash, 1998) tool. In a review by WHO (2008), the Elder Abuse Suspicion Index (EASI) (Yaffe et al., 2008) was identified as a tool useful in primary healthcare. The EASI has good psychometric properties (sensitivity 0.77, specificity 0.44), is brief and can be incorporated into the standard assessment of the older person. The EASI targets questions based on the various types of abuse, however, specific tools on types of abuse have been developed, such as the Older Adult Financial Exploitation Measure (OAFEM) (Conrad et al., 2010), the Elders Psychological Abuse Scale (Wang et al., 2007) or a self-neglect measurement tool (Day and McCarthy, 2016). Other methods of identifying potential elder abuse can focus on the caregiver and risk assessment (Reis and Nahmiash, 1995; Thornton and Travis, 2003) so prevention and early intervention can be initiated if concerns arise.

If there is a suspicion of elder abuse, older people should be referred to adult protective services for investigation. Older people who have been abused may be subject to multiple forms of abuse (Naughton et al., 2010) and case management involves a tailoring of responses to individual needs. Legal advice is also an important component of responsive systems and can help address abuse and violations of human rights. However, legal systems need to accommodate the unique needs of older people in terms increasing legal prosecutions, accelerating court proceedings, and understanding the dynamics of elder abuse (National Centre for State Courts, 2012). In particular, legislation needs to promote and defend human rights, especially in the context of protecting self-determination and supporting the will, preference, values and beliefs of individuals who have decision-making capacity as well as of those whose decision-making capacity is diminished.

In financial abuse, money management programmes can help with numeracy literacy and general budgeting. The involvement of financial institutions in safeguarding is imperative (Phelan et al., 2018) as well as legislative support to rapidly freeze bank accounts if concerns are identified. Moreover, the careful regulation of social protection payments, such as pensions, can combat welfare benefit fraud.

Case management should encompass an evaluation of health status and social support, the need for counselling and the potential for referral to victim assistance services (Ploeg et al., 2009; O'Donnell et al., 2015). As elder abuse is multi-dimensional, case management should involve relevant inter-disciplinary professionals who can jointly review cases and work in an integrated way. While health assessment is important, counselling, the involvement of banking services, police and legal intervention can be necessary when the abuse represents a crime being committed and other responses, such as restorative justice have been shown to be of benefit as an alternative option to remediate the abuse (Groh and Linden, 2011). The involvement of inter-disciplinary teams underpins an important element of case management and contributes to improved outcomes (Rizzo et al., 2015) as elder abuse cases are frequently enmeshed in complex contexts. Case management should encompass the assessment of factors inherent in the abuse and related risk as well as assessing responses in terms of perpetrator treatment, education, prosecution or confinement (UNECE, 2013). What is imperative is that older people experience intervention in a prioritised way and that care planning and legal processes integrate their voice and self-determination while implementing an empowerment-based plan into case management. As observed in the Courts of Protection in the United Kingdom, 'What good is it making someone safer if it merely makes them miserable?' (Munby, 2007: np).

Conclusion

Elder abuse is a significant public health issue encompassing abuses of human rights, yet compared to other areas in the family violence spectrum, it is an under researched and under-prosecuted topic (National Centre for State Courts, 2012; Phelan, 2013; UNECE, 2013). As global populations age, safeguarding within a rights-based approach should become a fundamental imperative for all nations, with the primary focus on prevention as well as having comprehensive, inter-disciplinary and inter-agency services to respond to the diverse complexities inherent in individual cases. Responses need to target policy, legislation, societal attitudes and enhance person centred case management through inter-sector involvement.

Additional scholarship is imperative to develop greater understandings across different environmental settings, within different groups (culture, gender, age groups) and to elicit more information regarding perpetrator intentions and responses (Roberto and Teaster, 2017). Only by generating new research and expanding our understandings can we address the multiple and complex innate factors contributing to elder abuse perpetration and develop innovative, acceptable and robust responses which translate into a safer society for older people.

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CHAPTER FOURTEEN

COUNTERING MISTREATMENT OF OLDER ADULTS: LESSONS LEARNED IN CANADA TO ENHANCE VOLUNTEERING ACTIVITIES IN NON-PROFIT ORGANISATIONS

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Introduction

Within ageing populations, an important focus is the development of the capacity of volunteers within organisations to enhance the quality of life and promote the safety of older people. The mistreatment of older adults[1] is a global problem affecting annually one in six older adults living at home (15.7%) (Yon et al., 2017). In Quebec, Canada, it is now viewed both as a social and public health problem as well as a human rights violation requiring special attention addressed through public policies. Therefore, in 2010, the first *Government Action Plan to Counter Elder Abuse 2010-2015* (Ministère de la Famille et des Aînés, 2010) was adopted

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[1] The Quebec government has provided a mistreatment of older adults definition directly inspired by the one stated in *The Toronto Declaration on the Global Prevention of Elder Abuse*, by World Health Organisation (2002): 'A single, or repeated act, or lack of appropriate action, intentional or not, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person' (Ministère de la Famille and Secrétariat aux aînés, 2017:15).

and later extended to 2017. It has structured the social response given to mistreatment of older adults by putting in place a professional hotline, developing awareness-raising campaigns, creating 20 positions of regional coordinators to counter mistreatment of older adults and creating and funding a research Chair based in Sherbrooke University, Québec, Canada. This policy clearly stated that an intersectoral approach was to be put in place, inviting all agencies and services to work in more coordinated ways to counter the mistreatment of older adults. The first Action Plan was followed in 2017 by a second specific Action Plan for the period 2017-2022 (Ministère de la Famille and Secrétariat aux aînés, 2017). The latter publication ensures the continuity of services deployed to counter the mistreatment of older adults where different organisations assume roles of prevention, identification, intervention, and coordination. Accordingly, non-profit organisations (NPOs) are considered essential partners in countering mistreatment of older adults (Quebec Government, 2016).

The *National Survey of Non-profit and Voluntary Organizations* (Alliance de recherche universités-communautés en économie sociale, 2006) identifies that Quebec is the one province (out of 10) which has the largest number of NPOs (46,000) in Canada (161,000). Out of these NPOs, 15% (12% in Canada) are active in the social services sector and 8% serve older adults (11% in Canada). Moreover, 69% of NPOs in Quebec (79% in Canada) rely on volunteers' active engagement to operate and evolve services. A recent survey involving 1,000 Quebecers (Réseau de l'action bénévole du Québec (RABQ), in 2017, quoted by RABQ, 2018a) shows that 38% of older adults volunteered their time to serve within an organisation.

Even if one can volunteer at any age, volunteer hours are mostly undertaken by retirees and older adults (RABQ, 2018a). *The General Social Survey* conducted in 2013 (Turcotte, 2015) states that 28% of all Canadian volunteers are aged 55 years or more and that those between 65 to 74 years of age have provided the highest number of hours volunteering throughout the year (231 hours), which is almost double that of the one observed in the (122 hours) volunteers aged 35 to 44 years. In Quebec, the last survey conducted in 2018 by the RABQ identified that 43% of volunteers throughout the province were aged 55 years or more (RABQ, 2018b). Within the NPOs fully dedicated to counter mistreatment of older adults or in the ones leading projects on mistreatment of older adults, the older adults' volunteer engagement is of crucial significance (Beaulieu et al., 2014; Gouvernement du Québec, 2016). Their actions are of significance both to mistreated older adults who can identify as such to a peer of the same age and to volunteers themselves who see it as a source of positive engagement (Beaulieu et al., 2014). Even if volunteering within a population of older adults is largely documented (Godbout, 2012), it has received much attention in the broader academic field of mistreatment of older adults.

The research project on *Volunteering to Counter Material or Financial Mistreatment of Older Adults* funded by the Social Sciences and Humanities Research Council of Canada (2015-2019), aimed to document the contribution of NPOs, including volunteers, in actions to counter financial and material mistreatment of older adults. This paper describes the results of the management of field volunteers.[2] The first part of this chapter introduces the reference framework. In the second part, the state of knowledge on management of volunteers in actions to counter mistreatment of older adults is further examined. The research methodology is then identified and developed. The fourth part of the chapter, describes and discusses the main findings and this is followed by a general conclusion.

The Reference Framework

The Evolutive reference framework (2001-2004) on the underlying determinants of the volunteer experience developed by Fortier et al. (2014) was used in this study. It purports that the quality of the volunteer experience is influenced by four determinants: 1) the framework of volunteer engagement (availability, motivations, benefits, and causes) 2) expectations regarding the organisation (recruitment, orientation, support and supervision, tasks, appreciation and atmosphere); 3) expectations towards participants (the person that will receive the services), (volunteer-participant interaction); 4) expectations toward the population (population aware of the work done by volunteers and recognise it as valuable). Volunteers seek to bring a balance between these determinants. The absence or predominance of one determinant can generate an imbalance and thus diminish the quality of their experience. An important imbalance can affect the volunteer's retention. In order to deeply explore the issues related to the management of field volunteers within NPOs engaged in countering mistreatment of older adults, this chapter will focus on the second determinant, specifically volunteers' expectations toward the organisation.

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[2] In this study, field volunteers are those persons who are part of actions aiming to prevent, identify and intervene within the NPOs acting to counter the mistreatment of older adults.

State of Knowledge

Inspired by a systematic review approach, a literature review was conducted on NPOs engaged to counter the mistreatment of older adults. Literature searches from 2005 to 2018 were completed by investigating both francophone (Banque de données en santé publique, CAIRN, Érudit, Persée, Francis, Pascal, and Repère) and anglophone research databases (Abstracts in social gerontology, AgeLine, CINAHL Plus With Full Text, ERIC, MEDLINE With Full Text, PsychINFO, Social Work Abstracts, and SocINDEX). For the purpose of this chapter, the focus is placed solely on management.

When **recruiting** volunteers, NPOs dedicated to counter the mistreatment of older adults seek to recruit persons with specific skills (often acquired during their working experiences) (Beaulieu et al., 2013a, 2014; Miller, 2003; Moulias et al., 2010). It is expected that they will be involved in knowledge transfer (Beaulieu et al., 2014). Advertisement (e.g. brochures, local newspapers, etc.) is the main recruiting strategy. In addition, volunteers are often recruited in Senior's organisations (Filinson, 2001) or professional groups (Huba, Melchior, Philyaw et al., 2010).

Little research has been done on the **orientation** of volunteers engaged to counter the mistreatment of older adults. Therefore, little is known about how the **tasks** that they will have to do are discussed, their availability, their particular interests and abilities in order to match both the needs of the NPO and the expectations of the volunteer (Fortier et al., 2014). Some research examines the activities the volunteers were engaged in to counter the mistreatment of older adults and which of them were related to prevention, identification, and intervention. For prevention, volunteers conduct diverse activities to raise awareness (Beaulieu et al., 2013a, 2014; Miller, 2003; Whitford and Yates, 2002) and to train some practitioners (Anetzberger and Alfonso, 2000; Beaulieu et al., 2013a, 2014; Busby, 2010; Miller, 2003). Based on the volunteers' experience, they can provide legal information to front-line professionals (Lanier and Mandel, 2009); they can take part in research projects aimed at improving the practices of key practitioners in the field of ageing or more specifically on the mistreatment of older adults (Mixson, Dayton and Ramsey-Klawsnik, 2012) and they can inform older adults regarding their rights (Lanier and Mandel, 2009; Nahmiash and Reis, 2000; Whitford and Yates, 2002).

For identification, volunteers are called upon to identify cases of mistreatment among residents living in an institutional setting (Liang, 2006), or, through friendly calls, to older adults living at home (Wilcox, 2014). For intervention, in Quebec, volunteers understand their role as a targeted support allowing them to bridge the gap between professionals and the mistreated older adults (Beaulieu et al., 2014). Studies conducted in different countries show that volunteers are mobilised to listen to mistreated older adults (Beaulieu et al., 2013a, 2014; Beck and Boiffin, 2007a, 2007b; Busby, 2010; Erlingsson et al., 2006; Lanier and Mandel, 2009; Moulias et al., 2010; Moulias et al., 2010), to direct them to services suitable to their situations (Beaulieu et al., 2013a, 2014; Lanier and Mandel, 2009; Moulias et al., 2010 Wilcox, 2014), to defend their rights (Keith, 2001; Mapes, 2009; Pandya, 2008), to intervene in crisis situations, and to be part of multidisciplinary teams (Lanier and Mandel, 2009).

Without proper **training**, volunteers may overlook clues in detecting the mistreatment or feel awkward in responding when in contact with older adults that have experienced mistreatment (Samsi et al., 2014). Certain organisations provide volunteer training which allows a proper understanding of the required abilities for intervention in this field (Beck and Boiffin, 2007a, 2007b; Boiffin and Beck, 2008; Busby, 2010; Mapes, 2009; Moulias et al., 2010; Pandya, 2008; Strümpel and Hackl, 2011; Wilcox, 2014).

The nature of **support and supervision** of volunteers is poorly documented within the field of countering mistreatment of older adults. In certain NPOs, once or twice a month, there are follow-ups with the coordinator (Mixson et al., 2012), or within a multidisciplinary team (Busby, 2010). Volunteers usually feel **appreciated** by the NPOs (Crevier et al., 2016). Different procedures are in place to ensure continuity of volunteer engagement such as ongoing training, regular team gatherings, and implementation of volunteer gained experience and expertise (Beaulieu et al., 2014). Considering this knowledge, a better understanding of volunteer management within the NPOs engaged to counter the mistreatment of older adults became imperative.

Methodology

Research approach

The research project grew from a multiple case study[3] which constitutes one of the five qualitative approaches identified by Creswell and Poth

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[3] The case study can be defined as a ‘research approach consisting of investigating a phenomenon, an event, an organization or a well-defined group of individuals, in order to draw a precise description and interpretation going beyond its own limits’ (free translation, Roy, 2016:199).

(2018). This approach is particularly pertinent for the study of contemporary phenomena regarding behaviours which otherwise cannot be manipulated, especially when they are relatively difficult to perceive in the context where they occur.

Data collection

The data collection took place from November 2005 until June 2016. Three sources were used: organisational documentation within the NPOs (e.g. annual reports from the current year, advertising and promotional materials, training tools, internal policies and documentation, etc.); socio-demographic questionnaires; and semi-directed individual interviews (with salaried personnel, field volunteers and accompanied older adults) and group interviews (with management volunteers who are the members of the board of directors[4]). The data collection tools were developed based on the state of knowledge and the reference framework (Fortier et al., 2014).

Sampling

The research project aimed initially to recruit six French-speaking Canadian NPOs engaged to counter the mistreatment of older adults where some actions were undertaken by volunteers. For this purpose, the research team asked for the participation of the regional coordinators in Quebec, whose role is to conduct intersectional work to counter mistreatment of older adults at a regional level. Therefore, they are aware of all active organisations in their territory. NPOs specialising in countering mistreatment of older adults via the mobilisation of volunteers were targeted. Applying our inclusion criteria, only 5 of the 14 targeted NPOs were selected: certain NPOs were not collaborating with volunteers or were not engaged to counter the mistreatment of older adults; some NPOs' activities to counter the mistreatment of older adults had already ended due to a lack of funding or field response; other NPOs' actions aimed at countering the mistreatment of older adults were just starting to recruit and training of volunteers was lacking. Therefore, the stability or the experience to meet the selection criteria was absent. In addition, two of the targeted NPOs refused to take part in this research project because of a limited availability. Specific eligibility criteria were conceived to recruit participants within each NPO (Table 14.1).

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[4] In this study, the management volunteers are part of the administrative board of an NPO.

Table 14.1: Criteria for selecting participants

Types of participants	Established selection criteria
Management Volunteers	Being a member of the board of directors and, if need be, of the executive committee of the NPO.
Salaried intervention workers	Intervening with older adults susceptible to being mistreated.
Salaried coordinators	Coordinating either the NPO or the volunteers.
Field volunteers	Combining at least six months of volunteering and experience in countering the financial and material mistreatment of older adults, if possible; Supporting mistreated older adults or having a broad experience in actions to counter the mistreatment of older adults.
Older adults	65 years of age or older; Be cognitively and linguistically competent to engage in an interview; Have lived a mistreatment experience (preferably financial and material) which has now ended. Have been supported by an NPO (preferably by a volunteer) during the previous two years.

The final sample was comprised of 64 participants, out of which there were 23 management volunteers, 6 coordinators, 4 intervention workers, 20 field volunteers, and 11 older adults. Table 14.2 shows the distribution of participants according to the five studied cases.

Table 14.2: Distribution of participants according to the five studied cases

Types of participants	Number of participants (n=64)				
	NPO 1	NPO 2	NPO 3	NPO 4	NPO 5
Management volunteer (n=23)	3	5	7	4	4
Salaried coordinators (n=6)	1	2	1	1	1
Salaried intervention workers (n=4)	2	2	0	0	0
Field volunteer (n=20)	5	5	5	4	1
Accompanied older adults (n=11)	3	3	3	2	0
Total	14	17	16	11	6

Within the five cases, two (NPOs 1 and 3) were fully dedicated to countering mistreatment of older adults, whereas the other three (NPOs 2, 3, 5) incorporated projects aimed to counter the mistreatment of older adults in a broader extent of their mission which aimed at assisting and supporting older adults. From the provided organisational documentation, Table 14.3 describes the NPO's mission, and, in three cases, the project aimed to counter mistreatment of older adults.

Table 14.3: Mission of the participant NPOs

	NPO	**Missions**
Mission entirely dedicated to counter the MOA	1	'Providing services and resources to older adults (in their area), as well as to individuals and groups engaged in the field of ageing, aiming to prevent and counter the abuse and mistreatment.' (Free translation, Organisational documentation, NPO 1:2)
	2	*NPO*: 'To develop and foster a sense of belonging and promote different services and activities to older adults in the area and its surroundings through a volunteer service that will allow them to continue to live in their community.' (Free translation, Organisational documentation, NPO 2:4) *Project to counter MOA*: 'To identify the vulnerable older adults facing mistreatment, to direct them to the appropriate services and accompany them, if need be, until the problem is completely resolved.' (Free translation, Organisational documentation, NPO 2:40)
Broader mission	3	'For social purposes only, the organization aims to improve the quality of older adults through activities focusing to prevent, to raise awareness, to inform and secure the older adults in vulnerable positions. It's strictly about non-profit activities where the members of the corporation are concerned.' (Free translation, Organisational documentation, NPO 3:3)
	4	*NPO*: 'To defend the rights and interests of older adults of francophone descent in Canada and to value their needs so as to allow them to thrive in their own culture.' (Free translation, Organisational documentation, NPO 4:1) *Project to counter MOA*: 'To prevent mistreatments and fraud of people aged 50 or older.' (Free translation, Organisational documentation, NPO 4:1)

5	*NPO*: Through a cooperative approach, to inform about the programs and resources available, to prevent or eliminate the abuse or negligence toward older adults. (Free translation, Organisational documentation, NPO 5) *Project to counter mistreatment of older adults*: To provide a social support service and refuge to older adults who are victims of abuse. (Free translation, Organisational documentation, NPO 5)

Data analysis

The organisational documentation was transferred to a Word document; the answers to sociodemographic questionnaires were entered in an Excel document and the content of the individual or group interviews was transcribed verbatim. Using the qualitative data analysis software NVivo10, the content of the data collected via these methods was thematically analysed[5] (Paillé and Mucchielli, 2012), through a deductive approach, starting from the categories described by Fortier et al. (2014), and an inductive approach based on the emergence of themes. An in-depth individual case analysis was done for each of the five cases. It was followed by cross analysis of five cases based using a multiple imbedded-case study approach (Yin, 2009). A thorough analysis of the data regarding the role of coordination was conducted. This chapter examines one of the five objectives pursued through the research project, which aimed to identify the NPOs' specific actions undertaken to counter material and financial mistreatment of older adults related to prevention, identification, intervention and coordination. Specific attention was paid to the components pertaining to the management of field volunteers.

Results

In all five cases, the salaried personnel within the NPO handled the management of the field volunteers, taking care of procedures such as recruitment, orientation, support and supervision, and appreciation.

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[5] The thematic analysis is a method consisting of a 'systematic identification, regrouping, and secondarily, to a discursive exam of the themes that were investigated in a body of literature, be it a transcription of interviews, an organisational documentation or observatory notes' (free translation, Paillé and Mucchielli, 2012: 232).

Recruitment

During the recruitment process, most of the NPOs (1, 3, 4 and 5) are looking for volunteers who have professional experience in specific areas such as education, social services, social gerontology, law, finances, public security (police) and management.

> ‘There were criteria, of course, but we wanted to recruit educated individuals. There were retirees, lawyers… And such. Everything was laid out in the volunteer selection criteria. Individuals working in an office, having experience with older adults.’ (Coordinator, NPO 5).

The candidate’s personal abilities were also taken into account. In fact, all NPOs sought volunteers who were endowed with social abilities and skills (e.g. confidentiality concerns, empathy, respect, listening capacity, ability to entertain a confidentiality environment, etc.). Certain criteria were added such as: to be readily available (NPOs 2, 3, and 4), to want to become more active within their community (NPOs 3 and 4), to aim at improving older adults’ quality of life (NPOs 1 and 4) and to accept to be voluntarily engaged on a non-regular basis (NPO 1).

> ‘We need astute volunteers whose time and abilities are not expected to be solicited on a regular basis, every day of the week, on a fixed schedule and every time during the same intervention.’ (Management volunteer, NPO 1).

The NPOs also used other strategies to favour the recruitment of field volunteers (Table 14.4).

Table 14.4: Recruitment strategies of volunteers

	Recruitment strategies of volunteers	**NPO**
Internal strategies	Word of mouth	1, 2, 3, 4, 5
	Orientation of trainees from postsecondary educational institutions	1, 5
	General activities within the NPO	2
	Registering as a new member to take part in activities organized for older adults in the area covered by the NPO.	2

External strategies	Sensitization and training activities on mistreatment of older adults	1, 3, 5
	Local newspapers	1, 2, 5
	References from community or public milieus	1, 3, 5
	Public bulletin board	1
	Consultation forums	3
	Professional associations	5
	Radio (e.g.: Information capsules)	1
	Social media	1
	Television	5

These strategies were adopted internally and externally as identified by the coordinator in NPO 4.

> Without a doubt, word of mouth is always the best solution. Having direct contact with the person works wonders when looking to elicit participation. (Coordinator, NPO 4).

Certain difficulties may occur when recruiting field volunteers. Among the challenges NPOs encountered, it was noticed that this type of volunteering is difficult to plan on a regular basis – some periods being busier than others – (NPOs 1 and 4), that recruitment was more complex in certain provinces or territories (NPO 4), the fact that volunteers may be less attracted to engage in such a complex problem as mistreatment of older adults (NPO 5), as well as the difficult recruitment for specific tasks (NPO 2).

> There is evolution, without a doubt, especially when there are friendly visits or services rendered, among other things. It is getting harder and harder to address and satisfy this sector. To be brutally honest about it, let's just say that people no longer have the interest to get involved in activities requiring more physical effort or a specific training serving another that sometimes may resemble more to a caregiver service. For instance, the daily calls, they really work. 'Security' calls and friendly visits, it is precisely this type of volunteer that is difficult to cover. (Coordinator, NPO 2).

The initial motivations explaining why the volunteers become involved in countering the mistreatment of older adults differ from one another. Some would like to build upon previous life experiences or gained abilities from past careers which could be transferred to volunteering to counter the mistreatment of older adults. Others get involved to feel useful and give meaning to their lives, to help others, to give back to their community, to build relationships or to engage in a stimulating learning environment.

> 'Let's just say that back when I retired, my children were old enough, married and such, and I decided that it was high time I took care of older adults. Learning to help those in need, but also learning to protect myself, too. This is mainly the reason I started to work with older adults.' (Field volunteer, NPO 4)

Orientation

When orienting the volunteer, the NPO's salaried personnel informs him or her on the expected tasks and responsibilities. The NPOs have ethics codes allowing them to provide their members and clients with information about interventions or quality services (Organisational documentation, NPO 1). Within NPOs 1 and 3, a moral contract committing to respect the values of the organisation is signed by field volunteers. All volunteers described orientation in a positive light; they use terms such as 'friendly', 'warm', 'extraordinary', and 'formidable'.

> 'When I arrived here, the welcome I received was formidable. With open arms and smiles. I felt welcomed. This is why I told myself that I would come back. What can I do to help such a warm and involved organisation? I never once regretted it.' (Field volunteer, NPO 2)

Support and supervision

To better prepare their field volunteers' engagement to counter the mistreatment of older adults, the NPOs choose formal **basic training programmes**. Such programmes usually take place on the organisation's premises, however, NPO 4 offered them via electronic means of communications such as teleconferences and webinars. These training programmes describe the themes, such as services the organisation provide (e.g. history, clientele, mission, operations, etc.) (NPOs 2 and 3), the mistreatment of older adults (e.g. definition, forms and types, indicators of mistreatment, concerns about denunciation, etc.) (NPOs 1, 3, 4, and 5), the volunteer's roles (e.g. roles and responsibilities, abilities and skills, etc.) (NPOs 1, 3, 4, and 5), awareness-raising workshops (e.g. facilitation strategies, workshop preparation, older clientele, etc.) (NPO 4), and the support relationship (e.g. first contact and forming a trust bond climate, the mistreated older adult's intention, available resources, confidentiality and ethics, etc.) (NPOs 1, 3, and 4). They also distribute training material

(NPOs 1 and 4), tools and situational simulations (NPO 3). Video or vignettes, designed to jump-start the discussion, were also common (NPOs 1 and 4). A **mentorship** programme was provided to volunteers affiliated with NPOs 1 and 2, under the supervision of a salaried individual or a more experienced volunteer during prevention or intervention activities. Following this training, the experienced facilitator provides feedback on the volunteer's training.

> 'We don't send them out just like that. For instance, when I give activities on raising awareness, the more they come the better they become. They attend and then we talk after the activity or at a later moment.' (Intervention worker, NPO 1)

Furthermore, volunteers from different professional backgrounds were invited by NPOs (2, 3, and 5) to share their knowledge and expertise through **ongoing training**. They could train others on protection or guardianship regimes, to use electronic tools or how to complete evaluation tools such as the PRISMA-7.[6]

> 'Training is not necessarily always about mistreatment, but it may be on additional information to improve the knowledge of our Scouts [volunteers] on things that may point in that direction… The first we had, as I was saying, was on the powers of attorney and the protection mandates, … As background, they will be equipped with a broader knowledge allowing them to intervene within the community, even if the focus is not on mistreatment. It may pop up eventually. That is why we address additional themes that will improve their knowledge and intervention abilities.' (Coordinator, NPO 3)

The volunteers' basic training, support and supervision were provided **when the volunteer activities had already been accomplished** (NPOs 1 and 5). For instance, after having finished a prevention activity, a salaried individual for NPO 1 gets in contact with volunteers to get their feedback. The same goes for any salaried individual of NPO 5 who compiles and discusses relevant issues in a follow-up with field volunteers based on reports they have completed.

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[6] PRISMA-7 is a case-finding tool to 'quickly, efficiently and in a simpler way, identify older adults with moderate to severe disabilities when brought in contact with a health care practitioner or social worker' (Raîch et al., 2004: 154).

> ‘When I deal with such cases, I need “debriefing”. Mostly because they are sometimes very difficult, and they need to express their frustrations and worries… I always do “debriefings”’. (Coordinator, NPO 5)

The support and supervision of NPOs’ salaried personnel **incorporated the needs expressed by the field volunteers**. It could take the form of a support provided to field volunteers when they experienced difficult moments in their own lives or of availability of, and access to, salaried personnel to provide answers to their questions.

> ‘They always had access to the coordinator. To prepare them, the coordinator was always available for any type of support they required.’ (Coordinator, NPO 4)

S**haring groups** conducted by salaried personnel are also provided (NPOs 1, 3 and 5). These meetings allow field volunteers to address all situations encountered within their reach, to understand their expectations and those of the organisation about their roles, to get to know one another, to boost their motivation, and to express their suggestions.

> ‘We would meet with the volunteers every two weeks. I would always ask for their advice, their expertise within the field, and what they thought we should do next? “Is there anything you would do differently? Is there anything you feel that should be improved?” I was always open to their feedback. […] I always kept their suggestions and feedback. ‘(Coordinator, NPO 5)

Generally, field volunteers were satisfied with the support and supervision they received from the salaried personnel. They said the basic formal training allowed them to improve their social skills such as listening and self-confidence, as well as their practical knowledge or theories about mistreatment of older adults. However, several expressed the need to increase these formal training activities (NPO 3) and to receive more in-depth training focusing directly on their particular tasks (NPO 2).

> ‘For us, we need some tools to rely on when offering support to an older adult. What are we supposed to do? What questions should we ask? […] And I would have liked to talk to the coordinator and suggest that we have one or two training activities with a professional who would come and teach us about the tools and something more even at a personal level. Because, we have the tools, the technical ones. References, papers, documents, resources, directories. We are fully equipped for that. But when in the company of a mistreated person, what should I do? ‘(Field volunteer, NPO 3)

As far as the formal support supervision goes, field volunteers had a high regard for the respect and availability they received from the salaried personnel to improve their abilities when acting to counter mistreatment of older adults.

> ‘If we have a question, we can call the coordinator right where we called when we needed quicker interventions. It works really well. There is a wonderful cooperation with different stakeholders. Everything works well in that area.’ (Field volunteer, NPO 3)

Appreciation

The NPOs acknowledged the volunteers’ involvement to counter the mistreatment of older adults. Firstly, the reimbursement of transportation fees was fully covered (NPOs 1, 2, 3, and 4). Another way to boost engagement was to get them to participate and organise activities striving for a positive atmosphere, such as social activities between volunteers (NPOs 2 and 5) and gatherings during the holidays (NPO 5). Formal appreciation activities were also organised. Moreover, prizes were awarded to volunteers for their involvement and dedication within NPO 4 and annual activities honouring their contributions in NPO 2.

> ‘For services well rendered to the beneficiaries through an exceptional participation of our volunteers… We wouldn’t be what we are today without these generous individuals who gave their time, love and listening.’ (Organisational documentation, NPO 2:15)

Volunteers expected NPOs to show their appreciation by inviting them to take part regularly in actions and give them more autonomy in the way they conduct their cases. They expected the salaried personnel to provide feedback regarding their actions, a show of appreciation for their efforts, and that NPOs would take their needs and opinions into account. Field volunteers expected the older adults to express their appreciation.

> ‘I would like some appreciation for my phone calls. When they tell me: ‘Oh, it’s so nice to hear your voice. Here’s a hug for you!’ […] No, I just want them to appreciate my phone calls, to like to talk to me and to genuinely be happy that I called. I sure hope that helps them, that’s basically it. Really, that is all there is to it.’ (Field volunteer, NPO 2)

The appreciation of activities undertaken by field volunteers facilitated their retention, however, salaried personnel raised the challenge of retention problems. Firstly, it must be acknowledged that volunteers, who were mainly older adults themselves, age and may develop health problems or lose autonomy. Some may no longer be able to volunteer during winters and some passed away. Secondly, stress was generated by the irregular need for volunteers that depended on how many active cases there were in an NPO. It could therefore hamper the volunteer's engagement to counter the mistreatment of older adults.

> 'If there aren't many activities, volunteers feel disengaged and say: 'I will look elsewhere, if my services are no longer required', but… I manage the volunteers since last year and I try to get in contact with them every month.' (Intervention worker, NPO 1)

Field volunteers identified winning conditions to improve their retention. They argued that the organisation's notoriety was precisely the thing that made them continue to work for the NPO. Another factor was the warm and agreeable atmosphere within the NPO and this was the main condition for pursuing their volunteering contribution. The main factors boosting their engagement were the management's high standards as well as the tasks assigned to them which were fully tailored to their expectations. The volunteers' motivation to stay was directly tied to the rich experience they gained and sense of usefulness they felt. The latter was fully evident especially when they witnessed the results of their interventions.

> 'The first thing I noticed was that the intervention was really useful. Therefore, I feel that what we do is useful, and they really gain something out of it. And I gain something, too. The second thing is that I gain something. I feel that I am useful to others.' (Field volunteer, NPO 3)

Discussion

The study entitled 'Bénévolats nouveaux, approches nouvelles' (New volunteers, new approaches) (Thibault, et al., 2011), which aimed at documenting all factors that would explain the actual tendencies and ongoing changing of the volunteers' practices in Quebec, brings forth an 'ecological' management of volunteers meaning that all management dimensions must be consistent with each other and the volunteers considered in their entirety. The salaried personnel engaged in countering mistreatment of older adults ought to master recruitment components such as orientation, support and supervision, and appreciation, and ensure the management of volunteers engaged in countering mistreatment of older adults.

The NPOs engaged in countering mistreatment of older adults are recruiting field volunteers who would prove capable of applying personal abilities to ensure a transfer of their own professional expertise to their volunteer action. This type of volunteering focused on abilities, namely, one ‘that leverages the specialised skills and talents of individuals to help build and sustain the capacity of organisations to successfully achieve their missions’ (Volunteer Canada, 2017:13) which constitutes one condition that will ensure the sustainability of volunteer engagement (Beaulieu et al., 2014). Contrary to other types of volunteering from distinct sectors (e.g. meals-on-wheels, grocery shopping, visits to physicians, etc.), our results show that volunteering in countering mistreatment of older adults requires a more targeted recruitment as well as a certain professional standard because of the risks associated with the intervention with vulnerable older adults (Bédard-Lessard, 2018). However, the national study conducted by Volunteer Canada (2010) shows that a large number of volunteers that have professional abilities and skills are looking for volunteer activities requiring tasks other than those they were used to applying in their field of work. It is worth mentioning the importance of professionalising the work of volunteers in countering the mistreatment of older adults and to question the place the volunteers occupy in connection to that of the professionals. The real place of the existing NPO services offered to counter mistreatment of older adults, brings forth the idea that there is a danger of using volunteers as ‘cheap labour’. In Quebec, since the adoption of Bill no. 21, professional acts are subject to an accountability mostly administered by professional orders whose main mission is to protect the public interest – and not those of professionals or professions themselves (Gouvernement du Québec, 2009). In the mistreatment of older adults, volunteers may be put in the position of taking professional steps with no similar protection for the older adults. This raises questions about the accountability of NPOs, who are accountable not only for the actions of their paid workers but also for those of the volunteers.

Even if different recruitment strategies are used, word of mouth is still an efficient strategy used by NPOs. Several NPOs, active in different areas, face difficulties when recruiting volunteers (Alliance de recherche universités-communautés en économie sociale, 2006; Ministère du Travail, de l’Emploi et de la Solidarité sociale, 2016). Among those that are specifically engaged in countering mistreatment of older adults, the recruitment of baby-boomers who are about to retire and have a different vision as to what their social engagement may be, becomes a challenge (Beaulieu et al., 2013b). Our study revealed that the NPOs are facing a complex recruitment challenge because the specificity of actions to counter mistreatment of older adults differ in various Canadian provinces and territories. Additionally, it is impacted by the sensitive nature of the mistreatment of older adults. Recruitment which targets volunteers who have professional experience of countering mistreatment of older adults raises additional challenges. The more specific the profile is, the harder it becomes to find the best candidate. Moreover, it must be taken into account that volunteers have personal as well collective motivations. They 'take upon themselves to serve causes, individuals and communities looking for social relations, pleasure and a feeling of usefulness' (Thibault et al., 2011: 33). Our findings speak for themselves, since social bonding, learning new things and feeling useful may determine if volunteers become involved in addressing the mistreatment of older adults. Field volunteers are also driven by altruistic motivations, by a need to put to use past life experiences or abilities they knew from their careers, to help someone close to them, to pass it forward or to simply give back to their community. Other studies show that being impacted by the mistreatment of older adults (Crevier et al., 2016), gaining working experience, and making contacts to start a career in a related field can all play an important role in becoming involved to assist in responding to the mistreatment of older adults.

Our findings show that orientation (reception) includes information on the roles and tasks expected from field volunteers. Studies on volunteering show the importance of describing the tasks from the very beginning, otherwise the orientation remains shallow (Bénévoles Canada, 2016; Thibault et al., 2011). All volunteers see this induction in a positive light. A warm orientation can help volunteers to better fit in whereas a negative experience can drive them away and lessen interest, thus the probability of their retention. For instance, in France it is estimated that 1,500,000 volunteers may have been driven away from various associations because of negative contacts, bad orientation and integration (Thierry and Jeger, 2013).

Every volunteer should receive training that suits their individual needs and the role they occupy within the organisation (Bénévoles Canada, 2017). However, NPOs do not always invest in volunteer training (Jamison, 2003). The findings from the current study show that the NPOs that act to counter the mistreatment of older adults are focusing on volunteer training. This may be due to the fact that the mistreatment of older adults requires theoretical and practical knowledge. Following this, their support and supervision take the form of formal training (basic training and ongoing mentoring activities) as well as an informal one (following volunteer activities, training according to their expressed needs), reinforcing the supervision and coaching activities.

Support and induction must be accompanied by a 'coaching' type of training more than a 'supervisor' one (Thibault et al., 2011). Informal training is viewed by volunteers as the most useful one where learning is concerned (Fortier and al., 2014). Such training is beneficial when it includes discussion and practice. Even though volunteers expressed their satisfaction regarding the orientation they received from the organisation, some of them required more training on how to counter the mistreatment of older adults. This concurs with the literature which states that volunteers engaged in activities to counter the mistreatment of older adults would like to be accompanied by an experienced individual especially during their first interventions in order to guide their actions (Beaulieu et al., 2014), to have the possibility to share their experiences with other volunteers (Beaulieu et al., 2014; Keith, 2000, cited by Pandya, 2008) and to have access to written manuals helping them to fulfil their roles (Keith, 2000, cited by Pandya, 2008).

The NPOs engaged in countering the mistreatment of older adults welcome different forms of appreciation such as covering travel expenses, the costs of activities that bring a positive and nurturing atmosphere as well as formal means of appreciation. Where the volunteers are concerned, we have noticed that they want autonomy of action, regular solicitation, feedback, appreciation and consideration of their efforts, needs and opinions. The study conducted by Volunteer Canada (2013) on the appreciation of volunteers highlighted a gap between how volunteers want to be recognised and the volunteer recognition activities in different organisations. The types of appreciation the volunteers dislike the most are in fact the banquets, formal gatherings, and public acknowledgement (e.g. in newspapers or broadcast media). Volunteers would like to be acknowledged more by being informed of the impact of their contributions and to receive the appreciation and thanks in person in an informal or ongoing manner. Such appreciation is essential to ensure their continued motivation and involvement (Bénévole Canada, 2016).

As other studies also note on the volunteer actions in countering mistreatment of older adults (Beaulieu et al., 2013a, 2014; Mapes, 2009), the challenge is both to attract and to retain the volunteers. To ensure the continuity of the volunteer's involvement within the NPOs, the field volunteers have pointed out some winning conditions: the organisation's reputation, a warm and agreeable atmosphere, good management, distribution of tasks to meet their expectations and a sense of fulfilment. In the light of other studies within the general field of volunteering (Demoulin, 2010;

Fortier et al., 2014; Tardif Bourgoin, 2014), the feeling of usefulness stands out as the main motivation factor allowing a better retention of volunteers.

Conclusion

This chapter opens the way to a better understanding of NPOs' management practices to counter the mistreatment of older adults. It examines the practices within five NPOs engaged in countering the mistreatment of older adults. Four volunteer management phases were identified: recruitment, orientation, support and supervision, and appreciation. To our knowledge, this is the first study to explore the management of field volunteers in NPOs engaged in countering the mistreatment of older adults.

This study has certain limits. For example, being based on a case study limits the generalisation of its findings. The study is also culturally focused on Canada where there has been a long tradition of volunteer engagement. During the research process, four out of the five NPOs had encountered financial problems putting their activities at risk. This, consequently, limited volunteers' engagement and put a stress on the services offered to older adults. All NPOs survived, however, one is offering fewer services than before. This raises questions on the funding of NPOs in general, but more specifically on the funding of NPOs active in health care and social services. The findings of this study point to the importance of better training of the salaried personnel in managing volunteers. For instance, how such personnel can encourage the response for volunteering to counter the mistreatment of older adults. Such training on the mistreatment of older adults requires that field volunteers gain specific knowledge of both the theoretical and practical management of the mistreatment of older adults, yet, how can salaried personnel be assured that the field volunteers are sufficiently prepared to counter mistreatment of older adults? Taking into account the optimum conditions expressed by field volunteers regarding their potential retention in this study, personnel need to know how to apply best training and support practices early in the volunteering experience and on a regular basis. Furthermore, this study raises questions about management in NPOs, especially within smaller organisations. Within several NPOs, the salaried personnel have a double responsibility: the management of field volunteers and direct intervention with mistreated older adults. Management of training and support for volunteers can infringe on the time individual salaried personnel have to undertake on-the-ground activities and this could have direct repercussions on older adults who experienced mistreatment. Therefore, it is suggested that more than one salaried individual should share the management of volunteers to encourage a collective approach to this responsibility.

The exploratory nature of our study allows us to identify research paths for the future, such as development, use and evaluation of tools, in the form of practical guides, to support the salaried personnel within the NPOs when managing field volunteers. With the of understanding the subtlety of management practices for comparison purposes, this research could be replicated in other countries. In particular, an action-research project could also be conducted to test management practice guidelines in NPOs dedicated to counter the mistreatment of older adults. In conclusion, our research showed how important it is for NPOs to focus on targeted recruitment as well as on specific professional training. It investigates the thin line between the practice of management of volunteers and the roles of salaried human resources. This has to be clear in order to avoid an undesirable substitution instead of their necessary complementarity.

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SECTION 4:

EMERGING HORIZONS

CHAPTER FIFTEEN

AGEIVISM

ISRAEL (ISSI) DORON

Introduction[1]

From a social policy perspective, it seems that 'active ageing' has become one of the dominant policy frameworks in response to global ageing. International bodies (e.g. UN, WHO) have embraced the concept as a leading policy instrument (Kalache and Gatti, 2002; WHO, 2002); National governments and regional frameworks have embedded it in their strategic plans and policies (Cloos et al., 2010; Engels, 2012; Walker, 2008; Walker and Maltby, 2012), while cities and local communities have embraced the 'active ageing' discourse as part of their 'age-friendly cities' projects (Beard and Petitot, 2010; Buffel and Phillipson, 2012; Green, 2013; Plouffe and Kalache, 2010).

Not surprisingly, critical perspectives to active ageing have also developed in recent years. They have attempted to reveal how 'active ageing' works to preserve existing social power relationships and enforce capitalistic and male-oriented values of production and independence (Biggs, 2001; Dillaway and Byrnes, 2009; Moody, 2013). These critiques have emphasised alternative values such as care and inter-dependence, which were missing, hidden or under-valued. Yet, as this chapter will try to argue, something was, and is still, missing from the existing debates surrounding the active ageing framework. This 'missing element' is an ideological element, and it will be termed: 'Ageivism'.

Similar to feminism, (or at least some streams of feminism), 'ageivism' as will be presented and defined in this chapter, is a term which describes a social cause and a call for social action that attempts to liberate older

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[1] This chapter is a much more developed, expanded and updated version of an original article that was first published as: Israel Doron. (2018). Re-thinking old age: time for ageivism. *The Human Rights Defender, 27(1),* 33-35.

persons from the social oppression which stems from the social construction of old age (i.e. ageism). It embraces social activism within the framework of politics of identity (Fraser, 1997; Goldstein and Rayner, 1994) while aiming to promote the rights and interests of older persons as a distinct social group. Hence, this short theoretical and ideological chapter will try to explain what ‘ageivism’ is, and how and why it should be added on to the existing gerontological social policy discourse. As a trigger for future theoretical and empirical exploration, this chapter will not attempt to describe the full scope of ageivism, but rather–hopefully–set the stage for the beginning of a conceptual discussion and empirical research in this field. Moreover, as part of a book which aims to provide some insights regarding the future developments in the field of ageing, this chapter will provide a perspective which believes that the development of a unique and specific ideology of ageing, is a crucial development for the future of ageing societies.

Ageism

In order to understand the concept and ideology of ageivism, it is necessary to begin with understanding the social phenomena of ageism. In this context, and despite the years that have passed by, Dr Robert Butler's historical definition of ageism still sets the basic platform of conceptualising the phenomenon in defining it as the discrimination of individuals based on their age (Butler, 1969). Ageism, under Butler's definition, is a process of systematic stereotyping and discrimination against people just because they are old.

Butler's definition has been subject to various critical reviews and modifications. Various alternative definitions have been articulated and presented ever since. These new definitions usually broadened the conceptual borders and emphasised that ageism can be both positive and negative (Palmore, 1999); that ageism can occur in all levels of society (micro, mezzo, and macro) (Iversen et al., 2009); that it can be manifested in various forms (prejudices, stereotypes and discriminatory behaviour) (Minichiello et al., 2000); that it may be relevant to all ages and not only to older persons (Bytheway, 2005); and finally, that one can be self-ageist (Nelson, 2005).

Alongside the efforts to better define and conceptualise ageism, scientific attempts have been made to create research instruments to measure the phenomena. Once again, various ‘research instruments’ have been established over the years (e.g. Cherry and Palmore, 2008; Fraboni et al., 1990; Kogan, 1961). These empirical instruments have allowed the growth of a rich body of empirical studies that have shown how ageism not only crosses cultures and national borders (Bodner and Lazar, 2008), but also exists in various professions (Kane, 2004; Topaz and Doron, 2013) and in different social settings (Roscigno et al., 2007).

The developing awareness of ageism and the growing empirical knowledge surrounding it forced scholars to improve its theoretical foundations and explanations. As a result, a whole range of theoretical frameworks have been set forth on the gerontological stage. Beginning with micro-based psychological theories, such as the TMT–Terror Management Theory (Martens et al., 2005), or meso-level of group SIT–Social Identity Theory (Hagestad and Uhlenberg, 2005), ageism has been understood as a psychological response to fear of death or as an instrument of self and group identity. More macro-based theories have explained ageism on modern Western values oriented towards economic productivity, commodification, and managerialism (Glover and Branine, 1997). Other theories have also traced ageism as part of the capitalistic structures which divided one's lifecycle in a generational division and segregation aimed at maximising profit and efficiency (Hagestad and Uhlenberg, 2005).

The outcome of this remarkable growth in both theoretical and empirical knowledge was a development of what may seem as almost a consensual approach, that ageism cannot be ignored or overlooked when shaping future social policy in ageing societies. Moreover, there is also now more awareness of the fact that gerontologists themselves need to be more self-critical of their activities, so as not to fall into the trap of ageism, in theorising and structuring the study of old age (Palmore, 2000).

Active, Positive, Successful, Productive Ageing and More

In what may seem to be a response to growing knowledge on ageism and the critical perspective on the way modern society negatively ‘constructs’ old age, a wealth of new social policy concepts have been introduced to debunk the negative and unproductive image of older persons. Examples of such concepts include ‘healthy ageing’ (Bryant et al., 2001; Alexandre Kalache and Kickbusch, 1997); ‘productive ageing’ (Morrow-Howell et al., 2001; O'Reilly and Caro, 1995); ‘positive ageing’ (Gergen and Gergen, 2001), ‘successful ageing’ (Havighurst, 1963; Rowe and Kahn, 1997), ‘resourceful ageing’ (Heil and Marks, 1991), and more.

While each of the above concepts is different, in its origin, rationale, and mode of operation–it could be argued that to some extent they all share a similar ‘ideology’: an anti-ageist ideology. They are all well aware of the existence of ageism or the negative construction of old age.

Moreover, they all attempt to address ageism by adopting an agenda which goes against the negative stereotypes of old age or at least to support and promote more ‘positive’ experience of ageing and old age. Finally, they are all well aware of the ‘ageist’ history of the traditional gerontological approach towards older persons.

Without attempting to ‘grade’ the importance or significance of these different concepts, at least on the social policy and international levels, it seems that as of today, ‘active ageing’ has been one of the most successful concepts in this field. While its origins can be tracked back to the early 1960s in the United States of America (USA)–as part of ‘successful ageing’ (Walker, 2001); and later on, in the 1980s–as part of ‘productive ageing’ (Neal, 2012); it was only in the late twentieth century that ‘active ageing’ had made its way firmly into mainstream use, with policies seeking actively to promote its use.

Clearly, the World Health Organisation's (WHO) report in this field (2002) had made a significant impact in transforming active ageing into a leading social policy framework. It was used and adopted by the United Nations within its key policy framework on ageing, i.e. MIPAA–the Madrid International Plan of Action on Ageing (2002). It has also become a common rhetorical framework in Europe to many current national and local policies towards older persons (Boudiny, 2013; Hendrickx, 2012; Ney, 2005; Walker, 2008). The European Union (EU) declared 2012 as the ‘European Year for Active Ageing and Solidarity between Generations’ while the European Parliament adopted the strategy ‘to facilitate the creation of an active ageing culture in Europe based on a society for all ages’ (European Parliament, 2011: Article 2). This was also followed up by a number of EU initiatives, such as the European Scaling-Up Strategy in Active and Health Ageing (2015), and by various specific national European programmes (Hendrickx, 2012).

At the risk of over-generalisation, it could be argued that ‘active ageing’ has become part (or even a key part) of the current mainstream social policy framework within social gerontology (Walker, 2002). A good example of its success can be seen in the establishment of the ‘Active Ageing Index’ (AAI) (Zaidi, 2012) which was developed in the context of the European Year for Active Ageing and Solidarity between Generations (2012). The AAI not only methodologically operationalised the concept but moved to empirically measure and compare its implementation in different European countries.

But what is ‘Active Ageing’? Like many similar concepts (e.g. successful, productive, etc.), ‘Active Ageing’ is not only subject to various definitions and descriptions, it is also dynamic as it articulates changes along time and across countries (e.g. Hendrickx, 2012). Nevertheless, one of the more accepted definitions of the term comes from WHO's Ageing and Life Course Programme, which defines it as follows:

> ‘Active ageing is the process of optimizing for health, participation and security in order to enhance quality of life as people age’ (WHO, 2002: 12).

More specifically, the 2002 WHO framework implies policy actions in three main areas: (1) Health – which is understood to be physical health as well as mental and social wellbeing; (2) Participation – which is understood as a multifaceted array of activities by older persons in social, economic, cultural, spiritual and civic affairs, in addition to their participation in the labour force; and (3) Security – which is concerned with the access of older persons to a safe and secure physical and social environment, income security, and the securing of rewarding employment (Sidorenko and Zaidi, 2013; Zaidi, 2012).

Critical Perspectives of Active and Positive Ageing

For at least two decades, many critical gerontologists have pointed out the difficulties and concerns around the ‘positive’ concepts mentioned above (Dillaway and Byrnes, 2009; Katz, 2000, 2001; Moody, 2013; Phillipson, 1998). These critics usually stress the fact that such concepts and policies over-emphasise independence, self-reliance, consumerism, and individual responsibility–which are all traits of capitalistic and individualistic ideologies. As such, they generally ignore values of interdependence, reciprocity, cooperation and filial piety. For example, Scheidt, Humpherys and Yorgason (Scheidt et al., 1999) have pointed out how the concept of ‘successful ageing’ has not only failed to adequately incorporate life course dynamics, but also failed to consider the implications for older persons who cannot age ‘successfully’. In a similar mode, ‘positive ageing’ policies have been criticised for underplaying the experience of people who suffer frailty and dependence in later life. Finally, positive ageing also portrays older people as able to counteract the effects of ageing through personal effort, thus identifying individuals as being personally responsible for their fate (Davey and Glasgow, 2006).

Active, successful, and productive ageing have also been criticized for their capitalistic emphasis on economic activity and contribution (workforce participation specifically) while ignoring the importance, value and benefits of spiritual, familial and other "non-productive" social activities (Biggs, 2001). In particular, the usage of the terminology of ‘being active’ has been viewed as limiting our ability to fully comprehend the diverse subjective and personal experiences of older persons with regard to their ageing bodies (Phoenix and Grant, 2009).

It may be argued then, that the new anti-ageist focus on positive, healthy, productive and active ageing has become in-and-by itself, an agent of a new form of ageism: one that masks old age and tries to eliminate it by ‘transforming’ older persons into ‘active’, ‘healthy’ and ‘productive’. In other words, these policies are attempting to socially ‘eliminate’ old age. The realisation that such policies are yet another form of extreme ageism is not new and have already been pointed out by various critical gerontologists to be a new form of ageism. However, the novelty of the argument that will follow below lies in the answer to the question: what should be the response to these new ageist policies?

Ageivism: The Politics of Identity and Social Activism

The theoretical argument of this chapter is that ageivism is a key element which is currently missing in the discussions around active ageing (as well as other ‘positive’ discourses of social policies for old age). Unlike ‘ageism’ (which refers to social phenomena, i.e. attitudes, prejudices or beliefs regarding older persons), ‘ageivism’ refers to an ideology: a distinct cause and call for social action (echoing similar ‘isms’, e.g. feminism, or socialism). Ageivism advocates social action for rights, powers and opportunities for older persons based on the grounds of political, social and economic principles of identity, dignity and social justice.

Ageivism derives from two well-known bodies of knowledge: (i) the politics of identity; (ii) social activism. The politics of identity is not new to the field of social justice and social policy. Women, Afro-American, Persons with disabilities, the Lesbian, Gay, Bisexual, Transgender, Queer/Questioning (LGBTQ) community, have all used this kind of discourse to utilise their social struggle for equality, dignity, human rights and social justice (Polletta and Jasper, 2001). One very clear and forceful example of how cultural-symbolic social justice is no less important than economic-distributional justice can be found in the feminist writings of Prof. Nancy Fraser (Fraser, 1997). It is beyond the scope of this short chapter to fully discuss and implement Fraser's argument in the context of older persons as this has been already done (Doron, 2015). For the purposes of this chapter, it would be sufficient to argue that older persons experience both symbolic and cultural injustices which justify the development of self-identity politics similar to other excluded and disadvantaged social groups.

Yet, it is surprising in this context to see how relatively little these kinds of rhetoric and calls for action have been used within gerontological discourse. The language of ‘oppression’, ‘humiliation’ or ‘invisibility’ is not new to critical gerontology. However, the political transformation and the formation of the ‘older person's political identity’ or ‘grey power’, has so far played a very limited role in the development of the theoretical, empirical and political landscape of gerontological social policy discourse.

This lacuna has been very recently exposed during the international discussions at the UN level around the need for a new international convention for the rights of older persons. During these discussions the language of social justice or political identity has been almost totally missing or simply ignored (Doron, 2015). Many of the debates, discussions, and policy papers are ‘blind’ to the politics of identity of older persons, or to their unique historical and contextual experiences as a social group.

Ageivism is, however, not only about the evolution of ‘older persons' political identity.’ It is also about social action, social movement and activism. Once again, these terms are not only historically and theoretically rich and complex, but entail diverse sociological, psychological and political contexts, a full discussion of which is beyond the scope of this article (Tilly, 2004). However, in order to provide some context, we will use Saunders (2013) definition for ‘activism’, which is:

> ‘[T]he action that movements undertake in order to challenge some existing element of social or political system and so help fulfill movements' aims.’ (Saunders 2013: 9)

In reality, almost any reader can envision various forms of collective actions that were taken since the early twentieth century by women, and later on, in the 1960s, by Afro-Americans within the civil rights movement, which were then followed up by other racial and ethnic groups, students, persons with disabilities, gays, lesbians, and others to feel and sense the real-life meaning of ‘activism’. In many ways, all these social movements responded to what they viewed as not only their social ‘invisibility’ but also oppressive discrimination, capitalist intrusions, bureaucratic domination, and symbolic humiliation (Buechler, 2000).

From this historical perspective, important questions can (and should) be asked: have the collective social-identity processes matured in the context of the group identity of older persons? Can the various historical examples in this field, e.g. the development of the Grey Panthers movement (Jacobs, 1980); the establishment of recent Senior Citizens' political parties (Vincent, 2003); the new international movement for a new international convention for the rights of older persons (Doron and Apter, 2010); or local older activists' actions such as ‘The Raging Grannies’ (Sawchuk, 2009) – all be signs of a new older persons' social movement?

There are already those who claim that the next generation of social movement will indeed be that of older persons (Kohn, 2010; 2011). Yet, so far, the questions presented above, and their empirical examination have received relatively limited attention in existing gerontological literature and research (Binstock, 2005; Binstock, 2010; Schulz and Binstock, 2008; Vincent, 2005). More importantly, they are rarely discussed or incorporated within the existing conceptualisation of the ‘active’ and ‘positive’ frameworks regarding social policies towards older persons. It is therefore inevitable, that these questions will need to find their answers in the coming future.

Conclusion

This chapter tries to argue that it is not enough to critically expose the capitalist or individualistic ideologies that are at the foundations of what is presented today as ‘positive’ and ‘anti-ageist’ social policies under the hospice of the active-ageing paradigm. It is also not enough to stress the inter-dependency, relational and contextual aspects of the ageing experiences of specific groups within the older population. From a social policy perspective, a course of action is needed not only to eradicate ageism and to transform the ways old age is socially constructed but to insert ideological elements of political identity and social justice.

Current gerontological social policy discourses, which focus on the positive and the ‘active’ dimensions of ageing, are lacking crucial elements: those around ideology, and around the political identity of older persons and those of social activism. From both social justice and social action perspectives, the time is apt to set the stage for a gerontological social policy agenda that is anchored in an ideology of ageing, i.e. ‘ageivism’. Ageivism should and can serve as an ideology which calls for social action and adopts the concept of social justice not only for the liberation of older persons from existing oppression and discrimination which is embedded in ageism.

Ageivism opposes any attempt to eliminate older persons as a distinct social group or eradicate old age as a unique human experience. Ageivism encourages older persons to self-identify as such, and to actively resist the attempts to ignore their unique subjective social experiences of being old, and their unique objective role and place in society. Such unique experiences entail not only 'positive' narratives of growth and renewal in late life, but also those of dependency, disability and death. Ageivism includes the political self-identity of being part of a unique socio-cultural group which experiences distinct ageing experiences of frailty, interdependence and ageism.

Historically, no social transformation has occurred without a social struggle. And no social struggle has evolved the absence of an ideological foundation. Up-to-date knowledge, both in the science of ageing, as well as the social movement of older persons, lacked a clear ideological basis. Looking into the future, ageivism, hopefully, will allow us to fill this gap.

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CHAPTER SIXTEEN

ENVIRONMENTAL DESIGN FOR AN AGEING POPULATION

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Introduction

The ageing of society has been a focus of research since the 1960s (Michael et al., 2006), and population ageing has become a domain of international discussions and research throughout the spectrum of disciplines including housing, urban planning and real estate (Buffel and Phillipson, 2016; van Bronswijk, 2015; Kort 2017). Kazak et al., (2017) describe how the ageing population has a profound impact on the real estate market, which is transforming in terms of availability of retirement accommodation for older people including accessibility, adaptability, and the availability of single-floor dwellings. Older people usually have a strong connection with the environment they know well (van Hoof et al., 2016), enabling them to spend the latter years of their life in a familiar setting, which, in turn, influences their self-confidence and independence.

Older people are encouraged to continue living in their homes in their familiar environment, instead of moving to an institutional care facility, and this is referred to as 'ageing-in-place' (van Hoof, 2010). In the domain of environmental design, a series of home modifications can be identified. The most frequently encountered measures in and around the home are adaptations to improve the accessibility of the home (i.e., removal of barriers such as thresholds, installation of stair lifts in multi-storey homes, and the replacement of bathtubs by walk-in showers,). Apart from these expensive measures and adaptations, simple handgrips can improve the accessibility, safety and mobility of older people (van Hoof et al., 2010; van Hoof et al., 2013). A further concern that should be considered within the living environment is the lack of storage space for wheeled walkers and mobility scooters (including a place to charge batteries) when living in an apartment block with limited space to manoeuvre on corridors (Kazak et al., 2017).

However, with increasing demands for care, it is not always possible to remain living in one's own home and moving into a residential or nursing facility is the only remaining option whereby, nursing care can be provided in these living environments (van Hoof et al., 2009). Policy principles within long-term care also aim to provide a homelike environment for their residents (Moise et al., 2004). Older people should be enabled to continue their lifestyle as before admission to a nursing home. Several specialised housing models have been developed in order to facilitate this person-centred care approach, as more traditional institutional settings often do not match with the new therapeutic goals (Verbeek, 2017). Radical alterations have been made in comparison with traditional nursing homes, implementing changes in the organisational, physical and social environment of settings (Verbeek et al., 2009, van Hoof et al., 2009).

With the increasing demand and popular notion that real estate plays a role in ageing-in-place and living well in old age, there is also a shifting focus on participation, activation, and helping each other. Today's so-called *participation society* requires people to look after one another, instead of being solely dependent on a state-run system of healthcare.

Home modifications and the home environment itself have a profound influence on the care given and received at home. In short, the fewer barriers there are at home, the easier and less burdensome family care can be (Duijnstee, 1992). Family carers themselves need such environmental interventions that support care, and a sense of community and belonging. Enabling one to age-in-place requires more than a simple occupational therapeutic approach to environmental interventions. It requires innovative new housing arrangements that facilitate and enable older adults to live comfortably into old age, preferably with others.

This chapter discusses and provides innovative examples from a Dutch social housing association and their practices, which illustrates a new approach to environmental design that focuses more on building new communities in conjunction with the building itself, as opposed to the occupational therapeutic approaches and environmental support. First, we take a closer look at why we care for each other, which is the basis of the participation society, in which we must look after people who are near to us. This should ideally be the basis of new housing arrangements – in which people are stimulated to meet, engage, survey and care – that social housing associations are developing, retrofitting and developing.

The Meaning of Environmental Design for Care Recipients and Family Carers

For several decades, efficiency and effectiveness seem to have become more important than solidarity and social security in most Western-European states. These changes have gone hand in hand with an increasing focus on individual responsibility for the wellbeing of oneself and others, and with less governmental interference. This increased responsibility of citizens and the withdrawal of governmental interference have consequences. The first is that an *increasing* number of people are *increasingly* expected to take responsibility for their own lives as citizens in society. This expectation and notion is also expected when a person is ill or they have a physical or mental disability.

Society has this notion of expectation, and people who may have physical or mental disabilities are supposed to act as full members of society and live a full and complete life. One example is the closure of large institutional facilities, for instance, for people with a mental disability; it is expected that they live in a regular house situated within the community. However, this requires a process of *socialisation* and integration of ‘unhealthy’ people into society. The second dimension is the so-called *communalisation* of health care. This construct refers to the increasing responsibility of citizens to look after fellow members of society, who are ill or have limitations, and to provide care for them. The question is how can communalisation of health care be performed properly, both with respect to care recipients, family carers and professionals, and how does environmental design fit into this?

The primary question in this domain is why *do* we care, and why *should* we care for each other? This is a philosophical question and it can be answered with the help of the views of two philosophers: Martin Buber and Paul Ricoeur.

The philosopher Martin Buber (Buber, 1957; 1958; 1966) pointed to the fact that long before the small child can say ‘*I*’ and can reflect on things, the child lives a relationship between him/herself and the other. The child has an innate desire and inclination to enter relationships with other people; first with the mother and then with other people. Only within and through such relationships can the child perceive the world in a meaningful way.

Buber distinguishes between *I-Thou* (you) relations and *I-It* relations. *I-It* designates the subject-object relation, in which an active subject controls and utilises a passive object. *I-Thou* designates the subject-subject relation, which is a relation of mutuality and reciprocity. The *I* in the *I-It* relation is a lonely observer and manipulator, whereas the *I* in the *I-Thou* relation exists only within the context of the relationship. Human beings need *I-It* relations to have a grip on the world, to survive. In addition, they need *I-Thou* relations to live a meaningful life, to remain human. Buber's philosophy implies that people *do* care for each other out of an inborn desire to live in relationships with other people, and that people *should* care for each other to be really human and live a meaningful life.

Ricoeur (1992) distinguished between the *idem-identity* and the *ipse-identity*. The idem-identity is a personal identity, the unity of someone’s personal traits and characteristics. The ipse-identity is more fluent and active; it reaches out towards the other and takes responsibility and it constitutes my moral identity. Just like Buber, Ricoeur sees the relation between *I* and the other as symmetrical. Initially, the relation is asymmetrical because I cannot experience the other as immediately as I can experience myself, and because the initiative to take responsibility for the other always starts at one side. But this asymmetry can turn into symmetry when the initiative of the other is acknowledged and when it is understood that I am both different from the other *and* resemble the other. The symmetrical relation origins in acknowledging that the other is both vulnerable and strong: both different from me and just like me. Ricoeur (1995) asserted that we, human beings, give to each other because the world and our existence have been given to us. Ricoeur distinguished between the adage *do ut des* – I give so that you will give – and the adage *do quia mihi datum est* – I give because there has been given to me.

In the first adage, giving occurs with the (sole) intention to receive something in return. It is a selfish kind of giving, in contrast to the giving in the second adage, which Ricoeur prefers. Both types of giving imply some kind of reciprocity: giving requires giving in return. This reciprocity, according to Ricoeur, corrects unique and extreme forms of commitment such as those taken up by Gandhi or Martin Luther King which state:

> ‘love your enemies, do good to those who hate you, et cetera’.

Ricoeur considers these forms of commitment to be undesirable because they presuppose a maxim of action that would set up non-equivalence as a general rule. Ricoeur thinks that we *do* care for each other because caring is a way to do something in return. Moreover, he thinks we *should* care for each other because this enables us to develop a moral identity.

This brief introduction to philosophical anthropology illustrates that people not only have a moral or existential duty of care for each other for the sake of that other, but also for the sake of themselves. We only can be true human beings with a meaningful life if we care for each other. But where does this responsibility end? Care responsibility ends where it starts to cause the reverse of what this very responsibility is intended to achieve. When our care responsibility becomes a burden that it, for instance, threatens the symmetrical relationships we have with others, we have transgressed the boundaries of the caring responsibility and role. Therefore, how can environmental design contribute to maintain the notion of *I-Thou* relations between care recipients and family carers? What is the influence of environmental design on our meaningful lives?

In the succeeding sections, examples of housing models are provided that aim to build new communities in conjunction with the building itself, thereby supporting care recipients and their carers in participating within society and keeping a meaningful life, despite health and social care needs. Furthermore, suggestions and recommendations for future work in this domain are provided.

The Role of Social Housing Associations

The Netherlands has a long and historical tradition of social housing, encapsulating social housing associations which provide housing to people with limited financial resources. There are approximately 360 social housing associations in the Netherlands, which own and maintain approximately 2.4 million housing units (Aedes, 2018). Moreover, a niche in the domain of social housing is formed by real estate encompassing residential houses and nursing care facilities for older people and people who require a high demand for care (van Hoof et al., 2009). The Dutch Government aims to enable people to live at home for as long as possible and reduce the number of institutional beds. There are several rationales for this by the Dutch Government, which include the increase of financial provision associated with professional home care. This includes the maintenance of one's autonomy, independence, a sense of identity, and quality of life, which are all reasons for ageing-in-place (van Hoof, 2010).

This implies that Dutch social housing associations, which have a large number of institutional facilities within their portfolios, are now facing a growing risk of vacant real estate, resulting in financial losses. Given the ageing of society, there is the possibility that these vacant buildings may be able to play an integral role in the current and future housing needs and requirements of older people. This outdated real estate may be given a new lease of life, encapsulating new initiatives which are needed to re-use these buildings.

The Case of *Habion*: Aims and Philosophy

The Dutch social housing association '*Habion*' is proactively working to rejuvenate existing buildings and their communities, not through closure or demolition, but by giving these buildings a second lease of life (Boerenfijn et al., 2018). *Habion* specialises in housing for older people in need of care and support services. Currently, there are only a handful of these specialised housing associations, and *Habion* is the second largest housing association in the Netherlands in this category; it has a total of 4,420 housing units in aged-care facilities and nursing homes, 5,717 dwellings for ageing in place, and a further 725 units which include: shops, garages and parking lots (Habion, 2018). The average age of the residents is 80 years. *Habion's* mission is to provide more than just living accommodation and shelter, namely, to provide comfort, a sense of purpose, meaningful activities, while also taking into account the aspects of sustainability, safety and security (Habion, 2018). *Habion* aims to ensure the 'good life' for their older residents, even when support and care is needed and becomes necessary. In addition to real estate, *Habion* also invests in a positive atmosphere, ensuring social interaction, accessibility and comfort for all residents.

As one ages, the needs and requirements of one's health changes and *Habion* actively monitors these changing needs to ensure residents' living experience is met in a positive way. Therefore, if the needs of a resident change over a period of time, *Habion* aims to maintain the value, flexibility and atmosphere of the living environment which the resident has become accustomed to. This is regardless of the changes which may have occurred over time due to the resident's health and care changing (Habion, 2018). The ethos of *Habion* is to ensure that, through teamwork and communication with local providers of healthcare (i.e. domestic care, nursing home care, care for people with a mental disability), a continuum of housing and health/home care can be delivered to the residents (Boerenfijn et al., 2018). A unique feature of *Habion* and their strategy are their aims to focus across the different levels of the Maslow hierarchy of needs (Maslow, 1943). The majority of Dutch social housing associations generally focus on the two bottom levels of the pyramid, while having an ambition to also cover the third level (Figure 16.1). However, *Habion* aims to be more ambitious than other Dutch housing associations, which entails covering all the levels of the pyramid. *Habion's* motivation to cover all levels of the pyramid will ensure all older residents are supported to live a full life in a comfortable environment and where one feels at home (van Hoof et al., 2016; Rijnaard et al., 2016; Eijkelenboom et al., 2017). In addition to this, by aiming to fulfil these ambitious plans, *Habion* also aims to ensure their residents can live an autonomous life coupled with the physical space within the respective building(s) there is the opportunity to use the communal meeting space to facilitate spontaneous meetings, activities and gatherings. These meeting spaces are essential elements in being able to live a meaningful life (van der Wal, 2018).

Figure 16.1: Maslow's hierarchy of needs, represented as a pyramid, adjusted for the mission statement of Habion (Habion 2018).

The basis of the Maslow pyramid should be covered, namely the first two bottom levels, which describe a dwelling of good quality according to the residents, which is clean and well-maintained, which offers an adequate service level and provides residents with a sense of safety and security. This is the basis for further expansion towards the top of the pyramid. *Habion* aims to achieve this by focusing on (future) residents, as well as the local communities. The latter is undertaken via the local community being invited into the building, which means that frail people can still be part of the society, within the environment and have their views and opinions considered. Taking into account these aims and objectives, *Habion* believes a home is more than just a house and believes in the personal experience and the emotions of all its residents. However, this type of environment does not occur overnight but gradually over time, developed by the person or people who deem that independence, security and their self-identity, choice and memories are essential (Molony, 2010; Rijnaard et al., 2016; van Hoof et al., 2016; Felix et al., 2015; van der Wal, 2018). The development of a sense of home is associated with the concept of place attachment theory. Place attachment is a multi-dimensional phenomenon that describes the emotional bond between people and place, which is influenced by one's personal experiences (Scannell and Gifford, 2010). By inviting the local community to join the residents whether they are frail or not, builds upon the concept of place attachment theory. Essentially, the focus is on ensuring there is a bond between all interested parties and making an environment that all would want to be a part of.

Transforming Existing Real Estate: Housing and Additional Care Services

In 2017, *Habion* witnessed several transformation projects relating to former aged care facilities which have been transformed into new living communities for older and younger residents (Habion, 2018). Within these six transformation environments, the existing amenities for the provision of healthcare are still conducted but the quality of housing, community ethos and communal living aim to prevail over an institutional model of care.

Therefore, this means that old real estate is re-used and retrofitted, which includes the installation of new building services throughout the premises. This undertaking forms part of the sustainability strategy which is referred to within the associations' mission statement (Habion, 2018). Across the Dutch care sector, there is an average of 30-40 years functional life expectancy for all buildings and once a building has reached this age, it is usually deemed to be unfit and disposed of resulting in the building being demolished. Habion expects the transformation of another four aged-care facilities in 2018. In the world of real estate, flexibility in terms of square metres and adaptability of buildings is a key priority. This in turn, leads to a continuous cycle of retrofitting. But the process of retrofitting is costly and coupled with additional issues including increased hindrance and stress (i.e., emotional, physical or mental) to the respective residents; who usually do not request a building to be retrofitted.

Thus, taking this into account, the challenge to ensure the living environment is functional, flexible yet safe, is paramount. Therefore, the resident should have the opportunity and the ability to live and use the same living space as a younger resident, enabling positive and successful ageing-in-place without the use of care services. Consequently, a resident who may require nursing home care provision and a person who requires domestic care only should have the options available to them, which in turn will enable all residents to live in the same living environment/facility as opposed to living in different housing associations.

Subsequently, all residents should receive the same level of care, regardless of the internal layout and designs of their respective living environment. This should also include a reduction of retrofitting and redesigning of residents' space. Taking this notion into account, enables the physical space of social housing associations to become more robust which in turn lead to a reduction in dependency on the national government and respective funding schemes, regarding healthcare real estate. However, future development should consider a flexible design which allows for flexibility within a building with affordable rents, resulting in an environment where residents can live knowing that they will be able to receive support, assistance and care in due time.

Furthermore, the respective building should also accommodate the increasing need for assistance and care (including nursing home care). Enabling those individuals who choose to live independently within the building and who wish to positively and successfully age-in-place. Therefore, the need for retrofitting, or, without the need to move to another premise, is reduced. This in turn enables individuals to continue living within a familiar environment.

The transformation of existing real estate means, first and foremost, the notion of change in the use of the building and its ownership, instead of a costly investment in the structure of the building itself. The basis for these transformations is the concept of living, not the provision of healthcare, keeping in mind it is associated with living with or without the use of care and support services. Thus, implying that there would be a deduction in the risks associated by healthcare organisations, who choose to rent real estate from *Habion*, the possibility of this risk is continual when there is vacant real estate and more so after a resident has moved out. When someone's living condition changes over time, they can stay living in their current home, and only the rental contract is changed to accommodate for a change in care and support services (Figure 16.2).

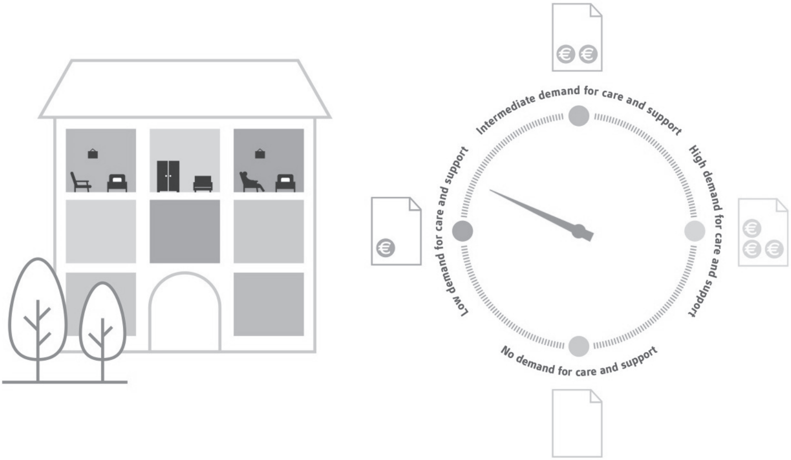

Figure 16.2: A single building can house multiple tenants who use various care arrangements (types of care, and funded through different financial schemes). Apartments that become vacant can be occupied again by any type of tenant, without the need for retrofitting. Residents can remain living in the apartment, but may be given a new rental contract, which come at different price levels depending on the service provision level.

Second Youth Experiments

In 2010, there were approximately 158,000 residential care and nursing home facilities across the Netherlands, while the total number of people aged 80 years and over was 650,000 and is rapidly increasing (Aedes-Actiz Kenniscentrum Wonen-Zorg, 2018). In 2013, the consultancy bureau *Berenschot* had forecast the demolition of approximately 800 residential care facilities in the Netherlands (Castelijns et al., 2013). Yet, in 2017, there were approximately 100,000 residential care and nursing home facilities left for over 700,000 Dutch people above the age of 80 years. Therefore, based on *Habion*'s mission statement, ethos and ambitions, demolition was neither a realistic nor a viable option. The vacant real estate had to be reinvested to accommodate for the increasing number of older people in search for a place to live.

As society ages, there is a higher demand for suitable and appropriate real estate to ensure older adults have the ability, opportunity and choice to age-in-place (van Hoof, 2010; Kazak et al., 2017). Moreover, demolition is not a sustainable option, because it leads to a waste of materials, a loss of affordable housing and a loss of capital.

In collaboration with (future) residents, partners in healthcare, associations and organisations focusing on sheltered employment, and the local community, *Habion* develops and redevelops its real estate portfolio which has aimed to ascertain and understand the needs and requirements of older adults. This has led to older people wishing to continue living independently for as long as possible in their own local communities. This means that existing residential care facilities need to identify an alternative approach.

Currently, *Habion* is involved in several transformation projects with various local partner organisations. Across each location there are separate and individual opportunities and differences in culture. Therefore, it is impossible to provide a unique blueprint for understanding and implementing this transformation process. Every transformation project has to start from scratch, although experiences from previous transformation projects are considered as there are some returning themes that are shared by residents. Such transformation processes are rather iterative, and that is why *Habion* has tried to turn the experiences of the past five years into a methodology coined Røring (based on the Dutch word *reuring*, which means bustle, commotion or buzz) (Maas, 2016; 2017; Boerenfijn, 2017). The methodology enables the creation of a plan and to commence transformations within a one-year period.

Røring is a sequential methodology which involves a kick-off meeting to facilitate and inspire participants, in workshops leading to data analyses, and translating the data to a greater understanding of the needs and requirements, which in turn will be integrated in the implementation phase, followed by a formal evaluation.

Throughout each phase, feedback will be required from residents in a bid to stimulate the ‘life and soul’ of the process (Figure 16.3). It is important and integral to the process that all current and future residents are at the forefront of these plans and discussions, which, in turn, enables future or existing residents to express their thoughts, views and opinions.

All existing and prospective residents need to be supportive of any plans, in conjunction with participating care and welfare organisations, which in turn will enable the support, a commitment for a new attitude and culture within the physical space. The recent discussions and experiments revolve around a positive and shared working goal across all interested partners, organisations and residents.

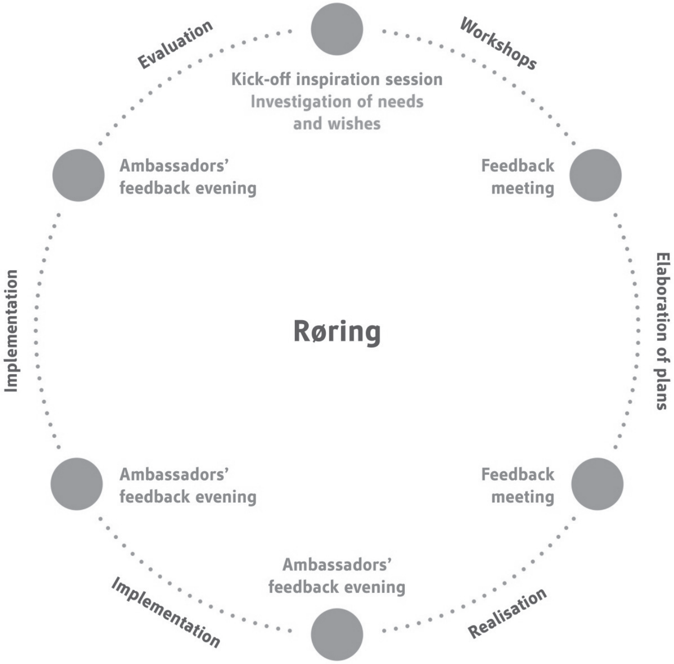

Figure 16.3: The cycle of the Røring methodology as applied in Second Youth projects (Habion, 2018).

To date, the methodology is shown to be successful for *Habion* because it enables people to be motivated and enthusiastic, while maintaining inclusivity by nature, thus enabling people to change and evolve their attitudes and approaches during the process itself, while the experience of the bustling is created in the building that is being transformed.

By integrating and deploying the Røring methodology, *Habion* ensures that collaboration is undertaken with the existing local communities and (future) residents to identify the needs, requirements and wishes of older people and to identify and ascertain solutions to meet these needs and requirements. This methodology enables *Habion* to identify residents' needs, and to engage in co-creation workshops with residents and collaborative partners to identify and ascertain new concepts for ageing in place.

Habion calls for the reinvention of existing residential care facilities, instead of their demolition or disposition. The ownership for such a reinvention is placed with the local communities. This is believed to contribute to a sense of acknowledgement, contact and engagement with others, self-respect and self-worth, and having a good life.

Enabling local communities to have the opportunity and the ability to reinvent their social housing enables the communities to have a sense of self-acknowledgement, self-respect, self-worth, and overall engagement and communication with interested parties, who all share the same ethos and beliefs of enjoying a good life in later life. The transformation makes it much easier for the occupants, society and *Habion* to grant new providers and partners a license to operate in the building. The building, the system and its residents are now flexible and *Habion* itself transforms from being a landlord into a so-called ‘timelord’.

De Benring Case Study

In November 2013, the residential care facility *De Benring* in Voorst (a small village with approximately 2,750 inhabitants in the Dutch Province of Gelderland), which has operated in the Netherlands since 1971, was identified for demolition. This decision was based upon the diminishing demand for this type of housing in conjunction with the change in government policies; which called for the closure of this type of housing and care. Consequently, the local care institution wanted to end the contract lease and relocate the residents to alternative care facilities. This culminated in an advertisement via a public billboard which announced the building would be ‘demolished’ and was the trigger for over 400 people to stand up and speak out, explaining why it was important that the *De Benring* residential care facility should remain as an integral part of the town’s community.

This resulted in the villagers being challenged by the government to take ownership of the building and to express their own dreams and expectations in a co-creation workshop. This led to more than 1,000 wishes that were shared by the participants in a workshop following the Røring method. Several perceptions were shared across these workshops and included:

- Greater involvement from the community (65%);
- Greater privacy and independence (20%);
- Wishes concerning diversity in population (intergenerational population, socio-cultural differences) (15%);
- Residents noted the need for affordable housing (75%); and
- The provision of care (55%).

By taking full responsibility for future functionalities of the building and its prospective future residents, the local community literally ‘stepped into’ the building. While, the institutional partners ‘stepped out’ they still continued to facilitate the transition process which enabled the transformation of the building to take place and the expectations of the residents’ dreams were implemented (Figure16.4)

Figure 16.4: Reinventing existing real estate through extensive retrofitting of old property with involvement of the local community in order to create home-like environments. The concept of Extended Living at De Benring was launched in 2016 after a long process involving tenants and the wider community. The figure shows a view of a communal kitchen area and living room.

De Benring was officially opened in October 2016 and the institutional partners only provide the services that are required by the residents, such as home care. Yet, the primary objectives were to ensure the expectations and functionalities set by the residents alongside the safety and legislation during the transition process. Currently, the residents, who are independent occupants now, requested to have a mix of different functionalities available and easily accessible under one roof, for instance, being able to cook together in a communal kitchen area, meeting others in a shared living room, or to shop together in a commercial second-hand area in *De Benring*. For example, the tenants have their own shared fireplace (Figure 16.4) for meeting fellow residents. Additional involvement in the community has continued since 2016 and includes: the request that the hallways be larger and transformed into extended living/communal areas which support the vitality of the entire community. This extension has enabled greater social inclusion by the villagers and residents related to cooking and social activities, while some of the apartments are even used as bed and breakfast facilities and are run by the community.

When taking into account the safety regulations (i.e. fire regulations), this concept can make things more difficult for the fire services to cooperate and communicate with. This is because there is an increased risk of false alarms, especially if the place is no longer a single care residence but a cluster of independent apartments. *Habion* is now experimenting with the use of so-called smart fire control units which culminate in double detection (at least two sensors in one dwelling) which, in case of an emergency, the alarm would send out an alert to the fire station in order to prevent false alarms from occurring. Examples of false alarms include the steam produced by cooking or showering activities.

The residents had a dream to live a sustainable lifestyle. This was made possible via a crowd-funding initiative encompassing 512 solar panels that were installed on to the roof (Boerenfijn et al., 2018). This installation was another wish of the residents that was granted.

Moreover, every apartment in *De Benring* can facilitate the provision of any kind of healthcare (i.e., domestic care, nursing home care, care for people with a mental disability), whereas in the Netherlands such types of residential healthcare are segregated. Yet, all apartments can either be used as a residential or nursing care unit/dwelling enabling inclusivity of multiple residents and target populations. This concept and flexible transition (if required) ensures that care and housing are future-proofed against changes in government policy. Thus, allowing every resident the choice to use their own home automated system to continue their level of independent living.

Within *De Benring*, there are several residential groups encompassing different age ranges. In the original situation, prior to the transformation of *De Benring*, there were 18 attached accommodations occupied by independent older people in need of surveillance and some domestic care. These attached accommodations were renovated in 2014 and are now occupied by younger people up to the age of approximately 22 years. This contributes to a multi-generational mix of tenants, who are able to provide a positive living approach while learning from one another and in some instances helping one another. On average, about 90% of the tenants are older people (at least 55 years old, but in most cases aged 80 years and over), and about 10% are more vital and young tenants. These younger tenants have to take a test to see if they match with the goals of *Habion* to live together with different age groups, and, for instance, if they would be a suitable candidate for a so-called buddy partnership with a co-resident.

If we take a look at similar approach occurring in the United Kingdom (UK), there is a scheme called *Homeshare* which enables young people to rent a room in a home owned or rented by an older person. There are specific areas across the UK which are affiliated with Age UK (2018) and which form part of the larger *Homeshare* network. The *Homeshare* network is been piloted and using different models and costing to ascertain which approach offers the most benefit in different geographic locations and populations. The notion of *Homeshare* (2018) was to offer viable and affordable housing solutions for young people who may be at University or in professions (i.e., National Health Service (NHS) nurse) who may not be able to afford to rent housing in a specific area. The *Homeshare UK* website details:

- The gap between the least and most affordable parts of England and Wales has increased over the last two decades
- Housing affordability has worsened in all local authority districts since 1997
- The median price paid for a residential property in England and Wales increased by 259% compared to median annual earnings which have increased by only 68%. (Homeshare UK, 2018: NP)

Analysis from Age UK has ascertained *'[...] there are now 1.2 million people aged 65+ who don't get the help they need with daily living activities and nearly one in eight older people now live with some level of unmet need'* (Homeshare UK, 2018). This programme further highlights and notes that those young people who have agreed to the tasks via the contract there is:

> the benefit of having someone in the house during the night time offering extra peace of mind for both householder and home sharer, and also friends and families alike (Homeshare UK, 2018).

Since 2006, *Share and Care* (2018) has been operating across London and the UK to offer elderly adults and people with disabilities the opportunity to share their home with a person who may offer companionship and reduce loneliness. The *Share and Care* organisation is part of the *Homeshare* UK network and complies with the Quality Assurance Framework, while also committed to offering a personal and professional service, ensuring that safeguarding exists. For those individuals who are interested in becoming a sharer or a homeowner who wishes to become involved in the scheme/network, there are several questions that many will be asking such as:

- ‘Do I have to have a TV licence if I become a sharer?
- Can I bring my own bed and/or other furniture if I become a sharer?
- How might my council tax be affected by having a sharer?
- Will I lose my benefits if I have a sharer?
- Who pays the household bills?
- Why should I use a Homeshare agency to facilitate a Homeshare?’ (Homeshare UK website: NP)

Many of these questions and more can be answered from the *Homeshare* website, which provides information for home shares for families, older people or other. The former has the benefit of offering children and young adults with physical and/or learning disabilities such as autism, or Down syndrome the opportunity for further companionship while the family has the opportunity to receive assistance around the home, which may include cooking, shopping, gardening, and other tasks which may be needed. Share and Care note the sharer is usually required to undertake 15 hours per week of assistance around the home and personal or nursing care is not permitted (Share and Care, 2018) If personal or nursing care is required, then a care package can be agreed in place.

Moreover, this concept has been documented in the British media and in 2016 the *Independent* newspaper (Harris, 2016), reported on the approaches of some Dutch Universities providing homes of older adults to those students. Conversely, in 2015 the Guardian newspaper published an article by Slawson (2015) in which he detailed the story of one sharer who did not have a positive experience while renting a room from an elderly woman in London. The sharer a young woman and student said that the expectations of the homeowner far outweighed the signed contract and the sharer was expected to undertake more and additional hours in and around the home. This particular experienced ceased not long after the homeowner had to be admitted into hospital and upon discharge, the sharer recalls:

> ‘Eight hours in to her first day back at home, after being in hospital, I’d done everything a fully trained – and fully paid – carer would have done bar actually shower her.’ (Slawson, 2015)

Furthermore, the sharer explains how in her home sharing contract she was not expected to undertake the personal care of the homeowner. As the article details:

> 'In fact any form of personal care, such as taking her to the toilet, was actually forbidden in my contract. But I wasn't going to let her wet the bed. As my mum had predicted, the pressure was on me. Yet, instead of being paid to do it, I was actually paying for the privilege.' (Slawson, 2015)

The final outcome of this resulted in the homeowner hiring full-time carers to assist in her recovery, which also enabled the sharer to give notice on her contract, with greater ease, knowing the homeowner would have the trained and qualified care needed. However, the sharer notes that there is the likelihood of another student replacing her, yet, she details her own concerns of:

> 'how many other older people there are relying on young people who are unpaid and untrained in order to get cheap care in the home. Since leaving my placement with Amie, I've noticed many more adverts for similar homeshare schemes.' (Slawson, 2015)

Learning Points

Living in dignity in old age is not only a moral imperative as it also makes an economic impact when empowering care recipients to maximise their potential for independent living. Care recipients and their families increasingly demand an active voice and control over their lives. This also includes their living environment and how care can be a part of this. Furthermore, given the growing costs of care and expenditures in long-term care, services are under pressure to improve their accountability and quality for money spent (OECD, 2013). However, care delivery is often based and organised according to medical models, emphasising illness instead of promoting (social) health. Rules and routines then govern daily life of care recipients, thereby permitting little individualisation and control over the living environment.

Nowadays, person centred models of care are prominent in dementia care and emphasise strengthening residents' autonomy and overall wellbeing (Verbeek et al., 2012). Older people should be enabled to continue their lifestyle as it was before admission to a nursing home. The wider social network within the community and families of care recipients should be included within the specialised and supported housing models. New initiatives have been developed worldwide that provide health, social and nursing care in a small-scale and homelike environment (Verbeek et al., 2009). Radical alterations have been made in comparison with traditional nursing homes, implementing changes in the organisational, physical and social environment of settings.

An example in which housing associations closely collaborate with long-term care provision are Shared Housing Arrangements (SHA), developed in Germany and often situated in large apartments in urban areas (Fisher et al., 2011; Gräske et al., 2015). The first SHA was established by family caregivers of people with dementia, seeking alternative concepts of care and support (Fischer et al., 2011). Care providers and housings associations are bound by contract to each tenant individually and not to a group of residents as a whole (Wolf-Osterman et al., 2012). Generally, six to eight tenants live together in these apartments, which have a typical homelike architectural design, including a kitchen, living room and private bedroom. The principle of normalisation is the main objective of SHA, fostering maintenance of self-determination despite high needs for care and support. First results indicate that active participation of family members in SHA contributed to a better quality of life of care recipients, especially in regards to social relationships and social isolation (Gräske et al., 2015).

The flexible use of the real estate, as shown in the transformation projects by *Habion,* makes the building *system-and customer preference proof*. Changes to the funding or the system of care provision have little risks for housing associations or healthcare organisations who rent the property. Furthermore, the building and the partners in the service chain can adapt to changes. This is based on customer preferences, because their work procedures now focus on the services needed instead of the building and its use. In the years to come the building and its occupants can move from a 100% residential model to a 100% nursing home model.

The concept proposed by the authors of this contribution detail a positive notion of shared and co-creation of housing needs and requirements within the community, even when health, nursing and social care is needed. Moreover, the concept of intergenerational living certainly has its benefits for all, including reduced isolation, sharing and learning from different perspectives and generations, assisting with household tasks and activities. However, the possibilities for intergenerational living should be explored. Further work is needed to establish the positive and negative aspects of intergenerational, and co-creation living, and on a more basic level, the exploration of housing design with care models.

Conclusion

The concept of re-inventing existing real estate has the potential to offer the wider and future community populations housing. It provides an opportunity to create additional value and affordable housing for both older and frail adults and younger adults who may be financially restricted to renting or buying property based on their income or studies. By ensuring the trust to our local communities we give them the lead and voice to express how they perceive their future living environments. Moreover, safety can be guaranteed by combining local community involvement, the fire and police services, building services as well as assistive technology. The Røring method is a way to establish co-creation between tenants, care recipients and their families, the local community, long-term care service providers, local municipalities and housing associations, hereby increasing active stakeholder participation. It has the affordability to speed up this process; ensuring the broader community has support for the existing and future plans is crucial for positive but also continual take-up and enthusiasm.

Statement of conflict of interests

Joost van Hoof is a board member of Vastgoed Zorgsector, and member of the supervisory board of Habion.

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CHAPTER SEVENTEEN

URBAN AGEING

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Introduction

The crossroads of living in cities on the one hand and ageing of the population on the other is studied in an interdisciplinary field of research called urban ageing (van Hoof and Kazak, 2018; van Hoof et al., 2018). People live longer and in better health than ever before in Europe. Despite all the positive aspects of population ageing, it poses many challenges. The interaction of population ageing and urbanisation raises issues in various domains of urban living (Phillipson and Buffel, 2016). According to the Organisation for Economic Co-operation and Development (OECD 2015), the population share of those aged 65 years old is expected to climb to 25.1% in 2050 in its member states. Cities in particular have large numbers of older inhabitants and are home to 43.2% of this older population.

The need to develop supportive urban communities is a major issue for public policy in terms of understanding the relationship between population ageing and urban change (Buffel and Phillipson, 2016). Plouffe and Kalache (2010) see older citizens as a precious resource, but in order to tap the full potential these people represent for continued human development (Zaidi et al., 2013), the world's cities must ensure their inclusion and full access to urban spaces, structures, and services. Therefore, cities are called upon to complement the efforts of national governments to address the consequences of the unprecedented demographic shift (OECD, 2015). Additionally, at the city level, there is a need to understand the requirements and preferences of local communities (OECD, 2015). An important question in relation to urban ageing is what exactly makes a city age-friendly (Alley et al., 2007; Lui et al., 2009;

Plouffe and Kalache, 2010; Steels, 2015; Moulaert and Garon, 2016; Age Platform Europe, 2018). Another relevant question is: which factors allow some older people in cities to thrive, while others find it hard to cope with the struggles of daily life? This chapter explores and describes which elements and factors make cities age-friendly, for instance, on the neighbourhood level and in relation to technology for older people.

The City as an Ideal Place for Older People?

Ageing in place (i.e. living in the community, with some level of independence, rather than in residential care), is often seen as an ideal (Kazak et al., 2017). However, there are numerous challenges concerning the adequate provision of services, safety concerns of older people, and affordability issues, which have led some researchers to argue that the focus should be on ageing in the right place (Rosenberg and Wilson, 2018; Golant, 2015). Given the many challenges, one could ask the question whether urban environments are best for an ageing population and, therefore, the right place to age well? Cities may be the best possible environment for older people to live and age in place, if they are under a cycle of continuous reinvention and adaptation to guarantee they are in line with the needs of an older population (van Hoof and Kazak, 2018; van Hoof et al., 2018).

The OECD (2015) report concluded that in the large urban areas, the older population is proportionately growing faster than the total population. This means that the challenges are greater to overcome, however, cities have more and better resources and offer greater opportunities. There are differences between urban and rural ageing. Rural areas offer fewer commercial services, such as supermarkets and banks. Scattered urban structures in rural areas decrease the exposure to some environmental threats, like the urban heat island effect or low level of air quality (Kazak, 2018). In urban areas, closer proximity to public services influences the quality of life of older people. Due to the economic contexts, such conditions often cannot be provided in rural areas (Skinner and Winterton, 2018). Over time, living conditions may improve in non-urban areas, in particular in suburban zones (Kazak and Pilawka, 2013; Kajdanek, 2014), but it is likely that the density of services will never reach that of city centres. Moreover, an analysis of the Active Ageing Index for rural and urban locations suggested that the situation is much better for older people living in cities than for those living in the countryside (Perek-Białas et al., 2017).

One of the concepts which could be used in planning for later life, particularly in the urban context, could be the active ageing concept (WHO, 2002; Walker, 2016). Older adults are seen as important consumers and may continue to participate in various forms of employment. In relation to urban ageing, there should be a focus on promoting mobility within cities (such as walkability, use of public transport), promoting safety and security, and empowering older people in local communities (Buffel and Phillipson, 2018b). Additionally, urban planning should avoid the segregation of older people, such as is the case in so-called retirement villages in the United States of America (Simpson, 2015). Such retirement villages are a type of age-segregated housing (Fitzgerald and Caro, 2018). Ideally, an age-friendly city is inclusive for all generations and its importance is evidenced in the fact that a large number of cities all over the world have joined the age-friendly cities movement (Buffel et al., 2014; Scharlach 2012; Scharlach and Lehning, 2013; Buffel and Phillipson, 2018).

Shaping Age-Friendly Cities

An age-friendly city offers a supportive environment that enables residents to grow older actively within their families, neighbourhoods, and civil society and offers extensive opportunities for their participation in the community, or, in other words, a place where older people are actively involved, valued, and supported with infrastructure and services that effectively accommodate their needs (Fitzgerald and Caro, 2018:2). Plouffe and Kalache (2010) describe the efforts of the World Health Organisation (WHO) to engage and assist cities to become more 'age-friendly', through the Global Age-Friendly Cities Guide and a companion 'Checklist of Essential Features of Age-Friendly Cities'. An age-friendly city is friendly for all ages and not just friendly for older adults. It should ideally be inclusive and offer opportunities to all the people living in the city. The concept itself has old roots, as is described by Plouffe and Kalache (2010), namely in Lawton and Nahemow's ecological perspective (Lawton and Nahemow, 1973), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2937125/ - CR13 which articulated the dynamic interplay between individual adaptation and environmental alteration to maintain optimal functioning in older age. The WHO project proposed that an 'age-friendly' city is one that promotes active ageing (WHO, 2002). Such a city optimises opportunities for health, participation, and security in order to enhance quality of life as people age (Plouffe and Kalache, 2010).

For the WHO project, numerous partners from 35 cities from around the world collaborated to develop what constitutes an age friendly city; for instance, through conducting large-scale focus group sessions with various groups of stakeholders (WHO, 2002). Based on this research, the features of age-friendly cities were determined in eight domains of urban life. These domains are: outdoor spaces and buildings; transportation; housing; social participation; respect and social inclusion; civic participation and employment; communication and information; and community support and health services. One of the noteworthy aspects of this global study was that there were no systematic differences in focus group themes between cities in developed and developing countries, although the positive, age-friendly features were more numerous in cities in developed countries.

One of the major world cities to have adopted the principles of age-friendly cities is Hong Kong. The Hong Kong Special Administrative Region Government (2017) stimulates active and healthy ageing by focusing on a multi-dimensional approach. The dimensions include financial adequacy, general and hospital care, community and residential care, transport and mobility, housing and the built environment, active ageing, more flexible employment, and family-friendly measures. The local government takes actions in all these domains to make cities more inclusive for the older population and for others as well. It is just one example of local governments taking actions in the field of urban ageing, while later we aim to show in more detail how the idea of active ageing is present in concrete actions taken by these cities.

Building Friendly Places and Inclusive Neighbourhoods for an Ageing Population

What does it mean for the built environment and urban planning when a city’s population is ageing? How can related services meet the needs of the ever-diversifying urban population and who are the stakeholders responsible for providing these services? First, large and economically growing cities are known for high real estate prices and a high demand for residential space. This implies that one needs to design and develop small dwellings, which also meet the needs for older people who are less affluent and have difficulty paying the rent or find it hard to obtain a mortgage as they may no longer actively participate in a work life after retirement. But the lack of space and financial means is not the main driver for small dwellings: it is a fact that the growing number of older people are, in fact, single-person households, made up of people who have been single all their lives (without having any offspring), or who divorced or became widowed. In various studies (for example, Onolemhemhen, 2009), it was found that there was also a gender and socio-economic difference among older people; there is a larger percentage of poor women than men (Marin and Zaidi, 2017). Nevertheless, both groups are at risk of dropping out of society (social exclusion), despite numerous personal and environmental strengths, particularly when costs of housing take up a disproportionate share of the living allowances.

Instead of building smaller homes and apartments, larger dwellings could accommodate multiple tenants at the same time. This kind of group living encompasses living with like-minded people, with friends or old acquaintances who share similar interests. Having bonds with co-residents and other people is known to contribute to a sense of home among nursing home residents, and it is probable that the same is true for people living in the community. Moreover, the beauty of it all is that social housing associations can help provide such spaces to live, as well as private investors and people with financial resources themselves. Imagine the opportunities for people who want to live together in terms of shared resources, cooking and eating together, keeping an eye and helping a fellow occupant too if he or she falls ill. Again, people who have found themselves divorced or widowed may find it attractive to start living together and the same goes for people who have always been single but miss the interaction with others that they used to have when still employed or active in organisations. For many people, it seems ideal: to live together with like-minded people. This notion goes even further in multicultural urban environments, where we have witnessed the emergence of nursing homes and housing for older people with a comparable cultural, ethnic, social or religious background. Despite the discussions on whether such buildings and communities are or are not an example of segregation in society, they do serve a role in getting people to live with like-minded others. Many of the world's large cities have a multicultural and multi-ethnic build-up of their societies (Buffel, 2017), and each of the groups have their own needs and preferences in terms of housing and interaction with each other. Community building is about stimulating the sense of belonging and sense of community among older people and between the generations. The importance of it was also noted by Rémillard-Boilard et al. (2017), who called for the promotion of social connectedness within urban environments. Cities are important sites for building social networks but can also trigger marginalisation and social exclusion.

It should be stressed that so far, we have not dealt with the many home modifications that are available to adapt dwellings (van Hoof et al., 2010; Kazak et al., 2017). Easy-access and single-level dwellings will be needed to house the growing group of older people, who may be at a higher risk of reduced mobility and who are prone to falls. Again, age-friendly architecture can help, as accessible dwellings are also advantageous for young parents with prams. In addition, when talking about accessibility of buildings and homes, one should also consider the concept of egressability – are people able to leave a building in case of calamities. Such events include fires or being taken away on a stretcher by an ambulance worker, or in extreme and terminal cases, in a coffin upon death. Less extreme examples of mobility are found in public transport with accessible busses that take people from A to B, multi outdoor seats for people to take a rest, sufficient public toilets, and even adjusted sidewalks that are accessible for people using wheelchairs and wheeled walkers (and again, younger people with prams). All those facilities and elements of urban design have an impact on walkability of neighbourhoods. Access to public services, better commutes and proximity to other people and places make neighbourhoods happier, healthier and more sustainable. Neighbourhood walkability is not a new approach in academic research as a measurement of promoting active urban ageing (Hall and Ram, 2018; Weiss et al., 2010; Bogen et al., 2018). In order to make cities more age-friendly, there is a need to undertake actions to improve urban walkability conditions, as they are strongly related with quality of life of citizens (Zhao and Chung, 2017). In addition, legible and familiar environments (both indoors and outdoors) are beneficial to the community as a whole. The outdoor environment can be a place where people meet, with fitting adaptations for the local climate. Most importantly, when the weather does not permit outdoor activities, the indoor environment should also be comfortable for older people. Urban planning challenges include an even and accessible distribution of services, including shops and health centres, which do not require large distances to travel. Inner cities should be easy to reach by public transportation, have sufficient seats to take a rest, have public toilets and a place to enjoy a cup of coffee, and perhaps inviting to older clients to spend cash while shopping.

When redeveloping urban environments, in order to face the needs of older people, one should not focus solely on one selected vulnerable or frail group (Szewrański et al., 2018). A more comprehensive approach should encompass social inclusion of all (or as many as possible) groups, that have specific needs in regard to the design of the urban structure. Such approaches can be supported through the concept of universal design (de Souza and de Oliveira Post, 2016). Instead of implementing the idea of an age-friendly city, and then, for instance a cyclist-friendly city, it seems rational to integrate all vulnerable groups at once, define their needs and requirements, and then decide about the final solutions that would combine solutions that contribute to the requirements of the wider community. An integrated approach that focuses on eliminating architectural and technical barriers seems to be necessary, especially due to limited availability of financial resources (Hełdak et al., 2018).

Technology as a Solution for Urban Ageing?

The use of smart technology is increasingly considered as a possible solution for dealing with the challenges related to urban ageing mostly because of exponential technological advances in the last decades. Although technology is often seen as a solution for sustainable urban ageing, there are numerous issues and challenges (Righi et al., 2015). Righi et al., (2015) provided a vision of a smart city, which conceives older people as embedded in intergenerational urban communities and capable of creating new engagement situations by reconfiguring information technology-driven scenarios to their interests and social practices. Looking at the concept of smart cities, many definitions of a smart city exist, none of which has been universally acknowledged (Cocchia, 2014). The concept of smart cities may be understood as urban areas that widely utilise information and communication technologies (ICTs) to organise and provide all urban functions, for instance, to reduce costs of infrastructure maintenance (such as roads, bridges, subways, airports, seaports, public transport, and sewerage), consumption of resources (such as gas, electricity, and water supply), better use of free spaces as well as to engage citizens in local governance (Batty et al., 2012; Klimczuk and Tomczyk, 2016). Some examples of smart city technologies are smart power grids to enable a reduction of energy consumption, digitalised supervision of pedestrian traffic to increase safety and security, and electronic monitoring of the activity of urban municipal services (Klimczuk and Tomczyk, 2016). As can be seen in these examples, smart city technologies rely heavily on both Big Data analytics and the Internet of Things, which include the diffusion of sensors and wireless sensor networks in the city with the capability of real-time data gathering (Pierce and Andersson, 2017). Such real-time data gathering can also be accomplished inside older adults' dwellings, effectively turning these into so-called smart homes. Smart homes have been postulated as a potential solution to support ageing in place. For example, smart homes technologies are aimed at supporting independent living by facilitating tasks such as preparing food and cleaning. Furthermore, smart home technology can assist in monitoring and maintaining health status (Mitzner et al., 2010). Despite the emphasis on smart homes by government agencies, policymakers, and the industry, their existence is not widespread (Sixsmith and Sixsmith, 2008; Wilson et al., 2015). Consequently, their suggested potential for older adults in alleviating pressure on (family) carers, and decreasing health care expenditure, has not yet reached its full potential. One of the reasons for this is the low-level adoption of smart home technology by older adults (Balta-Ozkan et al., 2013; Peek et al., 2016).

Many studies confirm that the older adult population is highly heterogeneous (Gunter, 1998; Yoon et al., 2013) and in seeking to understand technology acceptance by older persons who are ageing in place, it is important to acknowledge this diversity. Older adults not only vary with regards to their values, attitudes, needs and wants, but also with regards to how these are affected by ageing, life events, and changes in their social and physical environment (Moschis, 2012). These differences are also reflected in their use of technologies that could help them to age in place (Peek et al., 2017). Whether or not a new technology is considered a welcome addition by a senior is dependent on the perceived benefits and costs of the technology, perceived need for technology, social influences, and the degree to which a technology is in line with the older adult’s self-concept (Ahn et al., 2008; Chen and Chan, 2013; Lee and Coughlin, 2015; Mitzner et al., 2010; Peek et al., 2014). Furthermore, the use of technology is dependent on the availability and use of technological and non-technological alternatives (Peek et al., 2016; Greenhalgh et al., 2016). For example, older adults who have family members that visit them daily are less interested in smart home monitoring technologies that are designed to watch over them; they see no need for it.

As long as there is technological development, there will likely exist a gap between those that grew up with certain technologies, and those that did not (Fozard and Wahl, 2012; Lim, 2010). Consequently, older adults can benefit from people around them who can help them encounter technologies, and who can also help them in using technologies. For seniors, assessing what is the most appropriate technology for their ageing in place needs can be difficult. Professionals (i.e. technology consultants) specifically tasked with matching seniors’ needs with technology solutions can help greatly here. In the municipality of The Hague, a participatory action research project was conducted to determine the challenges these professionals face and to co-design a tool for optimising their matchmaking service. Results showed that important challenges for technology consultants in their current matchmaking practice were: making the matchmaking service more demand oriented and creating an accurate and complete overview of relevant factors within the seniors' individual situation so that an optimal match could be made. A matchmaking tool was created to help overcome these challenges. The tool entails a structured approach to better match technologies to a senior's individual ageing in place needs and circumstances (Haufe et al., 2019).

Conclusion

There is an urgent need to reiterate that the global ageing of the urban populations calls for more age-friendly approaches to be implemented in cities (van Hoof et al., 2018). It is an imperative, even when it is a challenge for policymakers to prepare environments to accommodate both current and future generations of older people and such plans can benefit from age-friendly solutions. This requires public and many private partners to collaborate, for instance, in the redesign of the public space, healthcare and welfare services, and the design of new housing concepts and technologies. In order to achieve the objective of being an age-friendly city, initiatives which fit the needs and expectations of the citizens should be under a continuous cycle of monitoring, evaluation and validation of the age-friendly city concept of WHO through the active involvement of older people who voice their opinions and experiences. Cities with a proper approach and responsive actions can adjust to future population profiles taking into account their preferences and needs which will without a doubt be *more senior friendly* than ever.

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CHAPTER EIGHTEEN

MEDIA POSITIONINGS OF OLDER PEOPLE

VIRPI YLÄNNE

Introduction

The role and degree of influence of specific social groups, such as older people, is reflected in their presence (or absence) and type of portrayal in the media. This view is proposed, for example, by the ethnolinguistic vitality theory (e.g. Harwood and Anderson, 2002; Zhang et al., 2006). But more importantly, the media is a resource for both older and younger people to understand and model ageing, as proposed by social cognitive theory (Bandura, 2009), for example. The media help shape and sustain hegemonic conceptualisations and discourses about ageing in the modern world. Studying media positionings of older people and ageing gives access to current age stereotypes and is useful in understanding ageism in its many forms (see Phelan, 2018). This chapter will review selected recent studies on how older adults are represented in the media, focusing in particular on newspapers, magazines, advertising and film, in order to explore patterns in such representations.

Newspaper Discourse

> '[J]ournalism has more power to shape our understanding about events, ideas, people and the relationships between people, than many other forms of communication' (Richardson, 2007:220).

Newspapers retain their influential role in today's media-saturated world. A critical perspective to news discourse examines the links of news frames with hegemonic processes and looks for journalists' creation of 'interpretive packages' about topical issues (D'Angelo, 2002). News producers and the audience can be seen to share a cultural stock of frames, including those regarding ageing and older age.

Editorial newspaper publication decisions are influenced by stories' perceived news values. News values might include reference to the power elite; surprise/unexpectedness/superlativeness; good news/bad news; magnitude; relevance (cultural proximity); and the newspaper's own agenda, such as its political and ideological stance (Bednarek and Caple, 2014). In other words, stories of a particular kind are more likely to find their way into news(papers) and are considered more 'newsworthy' in preference to other stories.

Fealy et al. (2012) examined discursive formations of ageing and age identities in Irish print media. The study focused on newspaper articles following the Irish government's proposal to revoke older adults' (70+) entitlement to free access to state health and welfare services. It concluded that the coverage was ageist, depicting older people with 'a uniform identity of implied dependency' (Fealy et al., 2012: 98).

Adopting critical discourse analysis, Fealy et al. (2012) uncovered frequent use of collective nouns such as 'older folk', 'senior citizens', 'the pensioners', 'the over-70s', 'the retired', and 'grannies and granddads', together with the use of '[the] old and vulnerable'. The language discursively positioned older people into five identity 'types': 'victims'; 'frail, infirm and vulnerable'; 'radicalised citizens'; 'deserving old' and 'undeserving old' (Fealy et al., 2012:90-91), which, collectively, constructed an identity of 'otherness' that assumed homogeneity of the social group. The texts resorted to negative stereotypes of vulnerability in older age, or, in contrast, represented radical older activists as counter-stereotypical 'grey warriors', which rely on the readers' decoding such behaviour as untypical and so are still negatively based. The subject matter of the Irish reporting arguably foregrounded the news value of negativity, which can partly explain the prominence of negative stereotyping in these texts, yet the study highlights how accessible such frames and stereotypes are to journalists and readers.

News media often discuss ageing from an alarmist stance, highlighting demographic trajectories of increased longevity that result in older people posing a 'burden' and a threat to resources, especially those in healthcare and welfare. Rozanova's (2006) Canadian study explored how *The Globe and Mail* newspaper portrayed illness and health among older adults. Thematic analysis uncovered three broad themes in the texts: (inseparable) associations between ageing and disease; various ways to individual responsibility for healthy ageing (via lifestyle choices); and societal costs of ageing and maintaining health in later life (Rozanova 2006: 119)—via the notion of 'apocalyptic demography' (Rozanova 2006: 131).

In a follow-up study, Rozanova (2010) investigated the same newspaper over 2004-2006 about its portrayal of ‘successful ageing’. From a critical gerontological and critical discourse analysis perspective, Rozanova (2010: 213) shows how the texts construct this ideology of ageing via themes of:

> ‘…successful ageing as an individual choice, individual responsibility for unsuccessful ageing, and how to age successfully by staying engaged…[and how these] embody the neo-liberal principles of containing the costs of eldercare and maximizing individual effort and responsibility for managing risks of disease and decline in later life.’

A Finnish study by Koskinen et al. (2014), also focusing on newspaper coverage of older people and health, on the other hand, did not find evidence of the ‘burden’ discourse. Applying an ethnographic approach in textual reality, the study linked the articles with societal attitudes towards older adults. The three global themes found were ‘being advocated for’, which implies concern for the care of older people’s health and advocating fairness and equality; ‘being looked after’, indexing a more negative portrayal of weak, passive and institutionalised older people; and ‘being engaged with’, which consists of portrayals of independence and activity and taking responsibility for own health. Unlike Rozanova’s (2010) data, though, frailer older people were not blamed for their condition. The authors suggest that the Finnish data resonate with a Nordic model of healthcare, which promotes equal access to social and healthcare services.

Magazines

Media discourses about ageing and older people both reflect and can also, in turn, influence social policy on ageing. Wilińska and Cedersund’s (2010) study on Polish weekly opinion news magazines focused on this link. In their data, the depiction of ageing and older people varied according to the main topic and theme of the article. When older people are discussed in a family sphere, in grand parenting roles, they are mainly portrayed as respected and appreciated (especially grandmothers). Older people, seen from a market perspective, on the other hand, are depicted as pensioners of post-productive age. But as a growing consumer demographic, and also if they continue to work, they are appreciated and constructed as usefully contributing to the economy. Thirdly, ‘the ageing of society is one theme that evokes very negative attitudes, arousing fear, despair and worry’ (Wilińska and Cedersund, 2010:339). This is where apocalyptic discourse and metaphors of avalanche describing an ageing society are voiced. It seems that two forces shape the life of older adults in these texts: the family and the market. And so the processes of ‘familiarisation’ and marketisation define the role of older people in this context and their value is assessed in terms of their familial or economic ‘usefulness’.

One strand of research on media depictions of older adults has investigated ‘Third Age’ magazines, such as *Saga Magazine* and *Choice* in the UK and *ET* in Finland, for example, where the ‘commercialised retirement culture’ (Katz, 2013:36) is foregrounded. In these magazines, images of middle-aged and older adults looking relatively glamorous, healthy, youthful and indeed somewhat ‘ageless’ predominate. As discussed by Bytheway (2003) and Featherstone and Hepworth (1995), for example, these magazines present editorial and advertising content that deviates from twentieth century negative stereotypes of ageing and older age and, instead, focus on positive images of ‘successful ageing’. Such mediated construction of successful ageing is aimed to appeal to a specific demographic, the baby boomer cohort, and also to those who have the financial means to afford a comfortable late lifestyle, promoted in these publications.

Lumme-Sandt (2011) and Lumme-Sandt and Uotila (2012), analysing a Finnish third age magazine, *ET*, suggest that the coverage centres on discourses of freedom from work and predetermined roles, and the potential for new identities in later life. Other foci include maintenance of physical and mental activity, looking good and taking care of one’s appearance, which are themes echoed in much third age marketing across the globe. Love and the maintenance of intimate relationships at older age is also a notable theme in *ET*, but one which tends to be presented as a marker of successful ageing, thus promoting a somewhat narrow construction of this aspect of later life.

The representation of age(ing) in women’s magazines has been examined by Twigg (2012; 2013). In her investigation of how fashion operates in magazines aimed at older women, Twigg looks at the textual and visual imagery that they provide of the successful management of female age(ing). Such magazines offer a particular construction of later years: ‘one that emphasises being positive, remaining part of the mainstream, presenting yourself well and engaging in beauty practices and anti-ageing strategies. It rests on an active engagement with consumption’ (Twigg 2013:117). Magazines aimed at older readership deploy a systematic ‘age slippage’, whereby the target readership is described as younger than is really the case. The subsequent younger visual world in the magazine enables the older readership to identify with a younger self. The challenge in this media is to showcase fashion in ways that does not alienate the older readership. This is managed in different ways, ranging from illustrating clothes without models, presenting reader makeovers and focusing on older celebrities as aspirational images. The 'ageless' styles that are offered, however, tend to erase age(ing), perpetuating ageism not just in the fashion industry but more widely.

Hurd Clarke et al. (2014), on the other hand, focus on ageing and masculinity, as represented in interest stories and advertisements in six North American high circulating male-targeted magazines. They note that older men are largely absent in these publications. The visual thematic analysis reveals two main depictions: experienced and powerful, and healthy and happy. The former comprise older celebrities in interest stories; the latter feature in both interest stories and adverts and are both celebrities and unknown older males. The authors conclude: 'idealized male ageing across all six magazines was associated with wealth, celebrity status, power, health, independence, self-fulfilment, active sexuality, and youthfulness, and thus with one's ability to continue to demonstrate membership in the Third Age' (2014: 32). Whilst the portrayals counteract negative age stereotypes, the authors point out the unattainability of such ageing pathways for the majority of older (male) readers.

Advertising

Content analysis is a method widely used in researching the mass media (Rose, 2012), including advertising, as it can effectively uncover general trends and patterns and has also been used in cross-cultural comparisons (e.g. Chen, 2015; Prieler et al., 2016). In terms of degree of presence, under-representation of older adults in the media has been found to be a world-wide phenomenon. For example, studies in the USA (Roy and Harwood, 1997; Miller et al., 2004); the UK (Simcock and Sudbury, 2006); the Netherlands (Westerhof et al., 2010) and Germany (Kessler et al., 2010) have reported the scarcity of older models in the media, compared to their proportion in the population. In Asian contexts, research in China (Zhang et al., 2008), Taiwan (Chen, 2015), Japan (Prieler et al., 2011; 2016), and South Korea (Lee et al., 2006) has echoed these findings. The only study to date not reporting under-representation is by Idris and Sudbury-Riley (2016), on Malaysian adverts: the percentage of over 50s in TV adverts (16%) and print adverts (19.5%) roughly corresponds to their proportion in the population. But it seems that in most contexts, old age discrimination in advertising is evidenced by the absence of older characters, especially females (for an overview of 'visual ageism', see Loos and Ivan, 2018). However, different studies across the globe define the cut-off point for 'older adults' as the data selection criterion differently, ranging from 50 to 65 years, which restricts direct comparison.

In addition to the presence or absence of older characters in adverts, their status or prominence in advertising media has been investigated. Research suggests that where older adults do appear, they are often cast as the main characters, especially in adverts targeting older consumers (Williams et al., 2010b), although it is suggested that in general older adults are more likely to appear as major characters in Asian contexts, as opposed to Western contexts (Prieler et al., 2016). Another finding pertains to the role of older characters as indexing specific qualities of the product, such as reliability or implying that the company represented by the older adult is well-established (e.g. Williams et al., 2010a). So the roles and contexts are likely to be age-marked in some way, which suggests that older characters tend to appear in adverts for a specific reason, rather than just to represent 'people'.

Research has identified patterns relating to what kinds of products older models are typically found to be advertising. Food, pharmaceutical products, health aids and financial/insurance products and services are the categories of adverts which most often use older models in both Western and Asian contexts (Williams et al., 2010b; Prieler, 2012; Chen, 2015), even though some cross-cultural differences also exist. For example, older adults do not appear in food adverts as prominently in Japan as in the West. These product associations reflect stereotypical expectations about older people as a social group. For example, food adverts might depict inter-generational family groups, and health aids typically target older consumers (and their families) with products aimed to alleviate various 'problems of ageing'. Some financial/insurance products are also specifically marketed for the over 50s and often employ celebrity endorsers who are over 50 years themselves (e.g. Chen and Ylänne, 2012).

Research by Williams and colleagues (2010a and b) investigated a sample of wide circulation UK magazines, aimed at different audiences. They focused on the main thematic portrayals of older adults in advertising in these magazines (221 adverts; corpus 1). A thematic typology of six image types of older adults emerged. The 'golden-ager' describes older people who are youthful and full of zest, often having glamorous and luxurious lifestyles. 'Perfect grandparents' are shown with grandchildren in very positive images, often close-ups of smiling and happy families, sometimes depicting several generations. 'Legacy' theme refers to older persons with 'gravitas' and status, often as mentors with implied experience and wisdom and these were almost exclusively males rather than females. 'The coper', in turn, is an older person who has a problem–perhaps a disability–but is coping with it, because of the product being sold. ‘Comedic’ older people are those depicted in humorous situations and/or poses, whereas ‘celebrity endorsers’ are well-known older adults in the public eye who endorse products, acting as positive role models.

The six types were offered as candidates for a typology of current advertising images of older people, at least within a British context. A current follow-up study is seeking to test its applicability in a more recent corpus of adverts (N= 313; corpus 2) covering the period of 2011-2016 (Ylänne, 2017). Table 18.1 presents the results of this part of the analysis.

Table 18.1: Typology of depiction

Type	**N in corpus 1**	**%**	**N in corpus 2**	**%**
Golden ager	79	35.7	96	30.5
Coper	53	24	85	27
Mentor/ legacy	32	14.5	26	8.3
Celebrity endorser	22	10	45	14.3
Perfect grandparent	17	7.7	29	9.2
Comedic	13	5.9	2	.6
Other	5	2.3	32	10.2
Total	221		315*	

*two adverts included two types

It appears that the ‘golden ager’ type depiction is still the most common. This is specifically the case in older-targeted advertising, such as that appearing in *Saga Magazine* and *Yours*. The prevalence of ‘coper’ types has remained high, and celebrity endorsers have increased slightly, as have grandparent depictions. The mentor/legacy type has decreased and most notably corpus 2 has hardly any examples of humorous depictions. The slight differences in the magazines sampled might be one reason for this difference, but it is also possible that humorous advertising images of older adults have lost their appeal and are deemed to perpetuate ageist stereotypes. It can also be noted that a significant number (10%) of adverts in the follow-up study were coded as ‘other’, suggesting that the earlier typology needs some revising and the ‘other’ category some further scrutiny.

These results suggest that the six-fold typology is still mostly applicable for categorising adverts portraying older adults in United Kingdom print media in the twenty-first century. However, we can detect some blurring of boundaries, in that the ‘golden ager’ depictions do not uniformly consist of glamorous images, but rather fit and healthy older adults more generally, and the ‘coper’ category seems to have lost many negative aspects of representation–they are more typically now smiling images, not helpless images.

The basis of positivity in the adverts is typically coupledom, communality and a relatively active lifestyle, especially in older-targeted adverts. A vast majority of the images are of smiling older adults. Any age-related problems, such as those relating to mobility, hearing, eyesight or personal care are presented as ones that can be successfully managed. Family support and network also create positive connotations. Against these potential positive qualities, we need to acknowledge, though, that the activities engaged in by older protagonists tend to be limited to daily personal activities, socialising, leisure pursuits or acting in a grandparent role. Older adults as experts do feature, but these are mostly in food-related contexts, continuing the domestic theme. And apart from a well-known older British female celebrity cook, men typically occupy expert roles. Retirement housing adverts voice loneliness, insecurity and vulnerability as implicitly age-related concerns, whilst packaging the residential locations as attractive safe havens for a care-free and socially engaged retirement lifestyle.

Although the imagery of active and healthy ‘golden agers’ appears positive, it arguably promotes idealistic notions of individual agency in the management of the ageing process. Negative imagery also works to this end in highlighting age-related risks as problems for which solutions are provided. Variation in ageing successfully or in lifestyles is not promoted in advertising (Ylänne, 2015). Older adults continue to be depicted in (UK) magazine adverts in limited ways and in ways that predominantly promote agelessness (cf. Andrews, 2018). However, we need to approach advertising as a specific genre with specific aims and priorities and also acknowledge that other age groups are often stereotyped in this context, too.

Film

Turning now to a different media genre, namely film, Swinnen (2015: 69), for example, points out the ‘current proliferation of films about later life’. She comments on how such films (produced in the USA/UK) mainly fall into two types. Love stories include, for example, *Something’s Gotta Give* (2003), starring Jack Nicholson and Diane Keaton; *The Best Exotic Marigold Hotel* (2011) and its sequel (2015), with a cast including Judi Dench, Maggie Smith, Bill Nighy and Roland Pickup; and *Hampstead*

(2017) (with Diane Keaton and Brendan Gleeson), among others. In these films, ‘successful’ ageing is typically linked with (heterosexual) coupling. This suggests, firstly, that sexuality in older age is becoming less taboo and, secondly, that older sexual bodies are now more acceptable (‘watchable’). On the other hand, the cultural imperative of a ‘forever young’ (and sexually active) older age in current consumer society has been critically discussed, especially as it relates to ageing masculinity (e.g. Katz and Marshall, 2003).

The second strand of current western films on later life, such as *The Iron Lady* (2011) and *Amour* (2012) are about dementia. Such films, according to Swinnen (2015: 71), ‘show…how the disease now epitomizes fear of old age’, and

> ‘…not only…reinforce…the fear of ageing into cognitive decline, but also offers alternatives to the predominant negative discourses, for instance by drawing attention to elements sustaining the personhood of people with dementia.’

In the case of *Amour*, Swinnen argues, however, that the viewers are invited to identify with the caregiver and his burden of caring for his wife with dementia, and not the person with dementia herself.

Dolan (2017) outlines the ‘silvering’ of current cinema – on- and offscreen. Older (‘silver’) audiences are central to the survival of cinema theatres as they comprise a good proportion of cinemagoers. Dolan argues that film makers are starting to respond to a current demographic shift in the composition of cinema audiences to which the increase in old age narrative films can be linked. The film industry benefits from the increased disposable income of the over 55s (who are ‘silvering’ film industry profits).

Silver audiences are imagined in specific ways. They are expected to prefer ‘intelligent, high quality dramas…dramatized histories… adaptations of stage plays and musical theatre…and fantasy genres’ (Dolan, 2017: 35). Films addressing older audiences that explore ageing and feature older protagonists include genres such as romantic comedies (as mentioned above); ‘older bird’ ‘chick flicks’ such as *Mamma Mia!* (2008); contemporary ‘women’s films’ such as *Hope Springs* (2012); ‘masculine’ road movies like *The Bucket List* (2007); and comedies such as *Dirty Grandpa* (2016). Such films tend to portray gendered successful ageing agendas, emphasising the ageing feminine/masculine binary, foregrounding different challenges for ageing women and men (Dolan, 2017: 36; 159-160). Also, ‘old age characters depict very little of the diversity and richness of lived experience' (Dolan 2017: 245), with mainly all-white casts and heteronormative storylines.

Whilst Dolan (2017:71) argues that 'old age is aligned with femininity at a much earlier chronological point than masculinity', Lemish and Muhlbauer (2012) discuss the 'double marginalisation' of age and gender in popular media, including film. This marginalisation is manifest via invisibility (whereby older women are invisible except in roles of mother or grandmother) and stereotypisation (whereby older women are more negatively stereotyped than men), for example. Although some recent English-speaking films positively validate older women's sexuality (e.g. in *Something's Gotta Give*), such sexuality is constrained to women who are 'slim, white, affluent, and involved in committed romantic relationships with age-appropriate partners within the comfort of the nuclear family' (Lemish and Muhlbauer 2012: 168). Other more innovative and powerful older female roles are played by Meryl Streep in *It's Complicated* (2009), Susan Sarandon in *The Banger Sisters* (2002), Helen Mirren in *The Queen* (2006), among others, but, as Lemish and Muhlbauer point out, these roles do not represent diversity as they are white, rich, beautiful and desirable to men. Representations of older women in film continue to perpetuate the dichotomous option of either motherhood or sexuality, prominent in the representation of women of all ages.

Conclusion

Rozanova (2010:214) argues that

> '…[t]he stereotypes about old age in the media are dichotomized: a 'good' old age characterized by health, independence, and economic and social vitality, and a 'bad' old age, characterized by illness, physical and social decline, and dependency.'

We have seen that positive Third Age imagery predominate in advertising and magazine content, as well as in many films. These, however, often favour agelessness, a notion which arguably contributes to ageism in the form of age denial. Newspaper discourse, on the other hand, especially when reporting on health and social issues, typically depicts old age as a decline more explicitly.

Research on portrayals of older people in the media has spread over the past couple of decades across the world. Some challenges in this research remain. It is important to take into account the genre of the media, the target audience and the thematic as well as cultural context of depiction. Media targeting the 'silver market' is likely to use strategies and imagery that differ from those used for younger cohorts. The methodology therefore needs to be context sensitive. The advantages of participatory research have been demonstrated – such as interviewing older media users about how portrayals of older adults are received (e.g. Lövgren, 2012) and also editors about how decisions are made in the industry (e.g. Twigg, 2012 and see also other chapters in Ylänne, 2012). With the increase in the use of social media by all age groups, content in this sphere might continue to be more age targeted and age segregated, so that different age cohorts in fact see different stories and adverts, for example. This will pose challenges in collecting and analysing media data and their potential effects. Stereotypes and conceptualisations of ageing and older age will no doubt change and develop with ageing populations. We need to remain critical, though, about whose definitions and what kinds of portrayals predominate our various screens and pages.

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INDEX