Older People Making Decisions about Care in Scotland: A Mixed Methods Research Approach

Doctor of Philosophy Thesis

in the

Faculty of Social Sciences

University of Stirling

Scotland

By: Ms. Kari D. Velzke

27th May, 2020

UNIVERSITY of STIRLING

Acknowledgments

My PhD has been an exciting adventure. Along the way, I have met many lovely people. I would like to start by saying a special thank you to my professors in the USA. To Julie Forderer from my undergraduate days; thank you for planting the seeds for a PhD and thanks to my Master of Social Work (MSW) professors who fostered me on the road to research. To Dr Alvarez who took the time to mentor me throughout the process, thank you for everything and also to Dr Zammitt who conveys her love of research and clinical practice to others. To Dr Beimers, thank you for your ongoing support and assistance with my PhD application and questions after my MSW. To Dr Fitzsimons, thank you for fostering my love of policy that carried over into my PhD, and taking time to teach me APA writing. To Missy, thank you for being the glue that holds everyone together. Thank you all - and also to those I didn't mention, especially my MSW classmates!

Thank you to those individuals I met for my PhD, who did not meet participant criteria. I valued your time and interest. Recruitment was a team effort with many people along the way, and I appreciate everyone who assisted me.

My lunch clubs, daycentres, care homes and focus groups deserve special recognition; thank you for your warmth, hospitality and my Scottish education. Thank you to my research participants for your consent in participation. I deeply appreciated your active participation and I am happy you found a place to be heard.

My PhD research supervisors deserve much credit for their continuing support of my academic writing and studies and I thank you. Many professors have added support and input to my research and I appreciate your time and expertise. Thank you, also, to University of Stirling's Dementia and Social Gerontology Research Group as you supported my writing and research.

I would not have made it without my support systems. My girls, Zoe and Zadie, continue to inspire me to do better. My brother, Thomas, I think you're the best and you know all the reasons why. To my friends in the U.S. and Scotland, thank you for your support. Thank you to my parents, and to my father who has always loved me unconditionally and believes I can do anything. To those who have passed on, you live on in my heart. Finally, thank you Edward for strengthening my hope and courage to stay on course and carry on. My deepest appreciation extends to you all.

Table of Contents

Older People Making Decisions about Care in Scotland: A Mixed Methods Research Approach

Abstract:

Limited information is available as to how older people with higher care needs make decisions about care and resource utilisation based on actual behaviours, and how this influences their quality of life. This research project was set in one local authority (LA) in Scotland with fifteen older participants and eighteen professionals from care homes, day centres, in-home care, hospitals, and technology programmes. In addition, focus groups with twenty-two carers in two lunch clubs were involved in the project. The objectives of the research were to explore views of decision-making by older adults, carers, and professionals. Data included qualitative, quantitative, visual and participatory methods. The techniques used comprised focus groups, interviews, vignettes, photo elicitations, psychometric quality of life measures (QoL), and a reconvened focus group for assistance with research tools and analysis. This research contains topics of influence on older people's decisions about care and support, participatory and visual methods and policy in practice issues including reablement, self-directed support, and Section 13ZA of the Social Work (Scotland) Act.

Findings which suggest that decision-making is non-linear and is based on emotions align with existing research. New findings suggest that a number of influences determine the extent to which older people have control in decision-making, as this is a complex and fluid process. Decisions are not made in isolation. Relationships and support networks play a key role in how older people meet care needs in their decision-making. Three key things were found to be needed for older adults to be included; individuals needed the ability to make decisions, needed the opportunity to make decisions and to be provided with the information to make educated decisions. This led to multiple decision-making styles, which varied depending on the level of involvement of individuals and support people involved in the process - both directly and indirectly on the micro, meso and macro levels. Overall, this study advances understanding of perceptions, attitudes, and behaviours which older people fulfil when receiving formal (paid), informal (unpaid) care, and resource utilisation. This is a multi-faceted process that involves many people. It demonstrates the importance of how understanding the relationship of QoL and decision-making impacts the individual holistically on future policy, practice and resource allocation for older adults.

Chapter One: How Older People Make Decisions about Care

Introduction

This research for the Doctor of Philosophy (PhD) in Sociology and Social Policy focuses on older people with higher care needs. It centres on older adults in Scotland who need formal (paid) and informal (unpaid) care services. Care services, for the purpose of this study, are services utilised by a person aged 65 or older to meet basic daily needs. They consist of formal or informal services or a combination of both. Formal care is the use of paid services to meet the basic, daily needs of individuals. Informal care is the use of unpaid services to meet the daily needs of individuals. This research examines how older people make decisions in utilising this care, their quality of life (QoL), and resource utilisation. As such, the research scrutinises the perceptions and attitudes of older people, professionals and carers. The research also explores environmental factors and investigates how Scottish Government policy influences choices for older adults.

Chapter One addresses a number of issues. To begin, this starts with philosophy for the research, with an explanation in *Professional Interests Research Interests and the Project*, p. 7. Research objectives and the main theoretical framework of General System Theory are highlighted, p.11. The chapter concludes by *Signposting* the thesis on p. 12.

This PhD has evolved over time. The narrative has enhanced this thesis with contextual details of methods, methodology, and findings. This provided a coherence that started as interdisciplinary and evolved with the theoretical frameworks. It drew upon social work, health care, sociology and social policy and it used non-mainstreamed methods with active participants and a General Systems Theory (GST) framework. GST underlying fundamentals are based on Aristotle's philosophy: "in order to understand an organised whole we must know both the parts and the relations between them" (Von Bertalanffy, 1972, p. 411). It has evolved through the literature review, data collection, analysis, and publication of this research of innovative methods and data during the PhD in three peer reviewed journals which included academic, nursing and social work disciplines. These three publications with data from this project will be referenced throughout the thesis (Velzke, 2017; Velzke, 2016; Velzke & Baumann, 2017). This multi-disciplinary PhD research is focussed on care decisions. GST is also explored in Chapter Two (the literature review), in Chapter Three (the methods section) and in Chapter Seven (the discussion).

Professional Interests Research Interests and the Project

One reason the research uses an interdisciplinary approach was the background of the researcher. This is important in understanding the context of the research. The researcher is also a Master of Social Work (MSW) Practitioner. It is necessary to understand the contextual background of being a MSW as it relates to clinical and medical practice. This includes the holistic treatment of individuals and their empowerment to be active within their own decision-making in care. Barker (2003) described being ‘holistic’ as,

> “oriented toward the understanding and treatment of the whole person or phenomenon. In this view, an individual is seen as being more than the sum of separate parts, and problems are seen in a broader context rather than specific symptoms. One who maintains a holistic philosophy seeks to integrate all the social, cultural, psychological and physical influences in an individual.” (p. 197)

This holistic philosophy has reinforced the use of GST. The overall practice philosophy of a MSW is to take a bigger picture of the individual and the world around them. This philosophy has had influence on the overall research project, the theoretical frameworks, and the utilisation of GST which is discussed throughout the thesis. The researcher routinely assessed the holistic view when interacting with individuals, groups, or larger systems and applied GST in practice situations.

The foundation for using GST stemmed from the idea of a participatory approach, which was supported by social policy in practice. It was also a main reason in the selection of Scotland for PhD research. Initially, it was Scotland’s free personal care (FPC) social policy, and the health and social care systems utilised in Scotland which the researcher favoured. These provided all the essential elements needed to reinforce success for the desired context of the research and empowered an active participant framework at a system, group, and individual level for older populations to be active in care decisions. Kirst-Ashman and Hull (2012) stated that empowerment means, “emphasizing, developing, and nurturing strengths and positive attributes. It aims at enhancing individuals’, groups’, families’, and communities’ power and control over their destinies” (p.22). All the key systems, services and access are improved for individuals to be involved and there is improved availability of services in Scotland compared with other social systems previously studied in other regions.

The researcher wanted to examine the research issues at many levels in Scotland to see how an improved system (from others such as the USA) might differ. For instance, a systems weakness involving Medicaid in the USA has a focus on institutional nursing home care, but less focus on home and community based services for the older population. These include home health care, home health assistants, assisted living and adult daycare and are addressed less by state Medicaid programmes in the USA (NASW, 2006). The researcher viewed essential elements already present in the favourable environment in Scotland that provide support for older people to function in a more positive environment and felt that these merited additional study. At the time of the research proposal, there was a current movement in U.S. legislation for nationalised healthcare. This research would allow for comparison with American programmes as part of the researcher's post-doctorate research agenda.

Decision-making was identified as a focus for the project. The researcher determined that essential elements appeared to be present in the social systems for successful empowerment. However, areas of interest that emerged were the relationship with decision-making, choice, and utilisation within services (Kirst-Ashman & Hull, 2012). In addition, the researcher determined it was necessary to conduct the research as there was limited research on how older adults with higher care needs made decisions about care based on actual behaviours (Velzke, 2016).

The initial idea for the thesis stemmed from the idea of a participatory framework and Scotland as an ideal location for PhD research because of the policies which the Scottish Government had enacted. Scotland provided the environment, systems, and opportunities for individuals to be actively involved in care if they desired. Velzke (2017) investigated the influences of Scottish policy on older people's decision-making. This research project explored how involved older people are when making decisions about care. This participation was also demonstrated in the participatory research methods in this thesis and which were reported in Velzke and Baumann (2017).

Active participation, in many fields of study, has a range of definitions. For the purpose of this project, active participation adopts the definition that Rowe (2015) suggested, "Active participation is an approach that enables individuals to be included in their care and have a greater say in how they live their life in ways that matter to them" (para. 4).

As such, the overall project discusses the influential factors in decision-making; what is important to older people and what influences their QoL. An active participation framework is highlighted within the project evidenced by utilising participatory methods and exploring decision-making from the viewpoint of older participants; for example, investigating influential factors in decision-making, what is important to older people, and what influences QoL. Chapter Two discusses the literature on decision-making, ageing well, residential and stay at home care and includes a critical overview of General Systems Theory. Chapter Three details an active participation framework using and exploring visual and participatory methods. Chapter Four demonstrates the different levels of participation that older people demonstrate in care decisions. There are issues with the systems that influence how individuals maintain an equal balance to get needs met on many levels that influence individuals. These will be explored in the following chapters that utilise GST as a framework. This can be further supported through different policies in practice programmes such as self-directed support (SDS). Velzke (2017) reported that choice and control in SDS were determined by older people retaining control of their own budget or giving control back to the local authority (LA). Chapter Four also explores a micro-level perspective of care decisions of the lived experiences of older people. Chapter Five offers a meso perspective of the systems encountered and Chapter Six offers a macro-level of system issues that support or inhibit how individuals make choices within their lived experiences of care and support, QoL and resource utilisation.

Research Objectives

The thesis aims to explore views of the decision-making of older adults, carers, and professionals in the complexities of how older people set out to fulfil their needs for care, support and resource utilisation. These, therefore, are the Research Objectives.

- To explore the underlying phenomena of why people take up particular services, what is important to them, and what guides their decisions about how to pay (or not) for care.
- To identify older people’s wishes about care, QoL, and to identify the complexities of decision-making from their own viewpoints, in the contexts of their daily lives, environments and policy regime.
- To explore the influences of social policy on older people’s decisions and choices for care.

The first objective explores older people’s attitudes, behaviours and perceptions as they find ways to fulfil care needs with paid or unpaid care. Lindley et al. (2012) reported that, “making decisions about older people’s care can be a complex social process. It includes the older person needing care, the formal care providers, informal carers and the wider community" (p. 1). This may include decisions to forgo any assistance with care. Some individuals may elect for alternative options such as self-payment for care when they have sources that can assist with needs and resources. The pursuit of choice varies from multiple options to individuals who may have no options. Multiple participant perspectives were examined in the research to gain a better understanding of the complex process. These perspectives included older adults, professionals, and carers in order to gain a clearer picture of the complexities of the decision-making process. Thus decision-making is explored at multiple levels through a GST framework considering micro, meso and macro levels. Lindley et al. (2012) said that, "older people rely more on gut instinct, feelings and experience than deliberate cognitive processes when making decisions but this does not lead to poorer decisions" (p.1). Chapter Seven develops further discussion on research questions about how older people make decisions.

The second objective identifies individual influences on decision-making. This is designed to explore relationships between environmental factors and decision-making. QoL is determined as being important to older people in decision-making (Velzke, 2016). Kelley-Gillespie (2011) conducted a secondary analysis of older adults' perceptions of QoL and found an effective and comprehensive integrated model utilising six life domains. These are physical well-being, social well-being, psychological well-being, cognitive well-being, spiritual well-being, and environmental well-being (Kelley-Gillespie, 2011). The interconnected dynamics of QoL are to be found within these issues of well-being on a multi-dimensional level. Choice allows individuals to make decisions that might vary from the person living next door but under similar circumstances. Some issues were unique to individuals whereas others were similar or identical. How options are presented influences decisions and has many multi-dimensional considerations.

The project had an active involvement framework with research participants. Reed et al. (2006) reported that older adults had added interest in outcomes when they were actively involved in research. The project also used a GST framework in assessing and evaluating overall systems holistically to ascertain and identify influential factors affecting the broader environmental factors of decision-making.

The final objective examines how social policy influences the choices available to older people and how older people make decisions. Older people report that they value any assistance that promotes health, wellbeing, and quality of life in support that allows them to continue living in their own homes (Centre for Policy on Ageing, 2011). Multiple settings where people reside and utilise care were investigated in the research. Decision-making is also influenced by policy in practice. The roles of professionals within the social care system are an area that emerged as a major factor which influenced decision-making and choice for older adults. This was explored in greater detail; however, that influence may be either a positive or negative influence. The relationships between perceptions of older adults and the influences of professionals and other key individuals were explored and this illustrated the influences on care decisions and resource utilisation. "There is a strongly held view that, in spite of rhetoric, older people do not get the services they want" (Clough et al., 2007, p. 27). There are many reasons why care needs do not get fulfilled and these are explored in Chapters Four to Six.

By focusing on these objectives, the overall project considers a broader picture of decision-making from many perspectives. Multiple forms of data are needed to address the complexities that decision-making generates. This is established in Chapter Three (Methods). It was necessary to collect snapshots and ideas from specific views and perspectives that captured various situations in the range of decision-making that older adults encountered in order to formulate a more complete picture. The project explores these broader issues through the lens of GST across micro, meso and macro levels. The complexities of the decision-making process are not limited to older people alone. The project investigates environmental factors and the multi-faceted influences in Chapters Four to Six. Investigating options available in the care arena is one of many areas within choice and decision-making, and decision-making in care choices is the focus of this thesis. The next section reviews GST and how it fits into choice and decision-making.

General Systems Theory

GST implies that changes in one part of the system are carried over to affect change in the whole system (Barker, 2003). Kirst-Ashman and Hull (2012) described a system as "a set of elements that forms an orderly, interrelated and functional whole" (p. 9). Ludwig Von Bertalanffy, the 'father of GST' (Von Bertalanffy, 1972), first discussed his ideas on GST in the 1920s, and wrote his first paper in the 1930s (Von Bertalanffy, 1934). Drack and Schwarz (2010) also considered GST and how it provided an overall worldview. GST involves multiple steps. First, GST is important to understand the individual's role in decision-making. Then, it is important to understand the relationships that connect them all and how these fit within a bigger worldview.

GST is the main theoretical framework that guided the project. It is a conceptual framework that guides individuals on how to view the world (Kirst-Ashman & Hull, 2012). Using GST, the research looked at complex ideas of how people made decisions. In addition, the research examined QoL which necessitates an integrative logical approach**.** This logical approach provides an overall framework for how the different parts of the data are merged together to form one big picture (Mason, 2005). For example, Mason (2005) discussed mixed methods and integrative data, methods and analysis using different approaches such as qualitative and quantitative, and addressed specific areas of the problems dealing with integrated parts of the whole. This integrative approach looks at the broader picture based on what was happening within.

Early in the research process, this participatory framework was conceptualised so that it could be applied in several areas. The main area was the idea that older people are entitled to be active participants (or not, if they so desire) in the care decisions that directly and indirectly influence and affect their lives. Active participation is seen by many as a basic human right. As the researcher witnessed, this was not the standard practice in care with older people and was often overlooked.

Signposting the Thesis

The thesis is structured as follows. The theoretical frameworks and connections to the literature are also listed throughout the remaining chapters. Chapter Two presents the literature review. This chapter discusses some of the processes needed for individuals to successfully engage in decision-making using a GST framework to support understanding of the complex system that older people live within and which influences their decision-making processes. Furthermore, the literature review identified gaps in the literature, for example, decision-making based on actual behaviours. The literature review highlights decision-making which includes independence, and the influence of professionals. GST is highlighted in the Literature Review and is discussed in greater detail in Chapter Three as it is a theoretical basis of the project. The Literature Review identifies additional influential factors on the decision-making process: QoL, independence, choice, environmental factors, and complex experiences such as prior care experiences (Qureshi et al., 1999). This chapter also explores other influences on decision-making and resource utilisation for older adults including the influence of professionals on decision-making, ageing well, independence, healthy and active ageing, and residential and stay at home care.

Next, Chapter Three discusses research methods and frameworks. The chapter provides a more comprehensive overview of the two guiding frameworks of how GST provides guidance throughout the project for holistic exploration and how an active participant framework was implemented. This chapter looks at participatory and visual methods and provides an overview of the research. Visual methods included photo elicitations: older adults taking photos of what they thought influenced their QoL. The project also included participatory methods using focus groups in the creation of research tools (vignettes and research questions) and assistance in the analysis process. Data collection and the challenges that emerged with recruitment issues for access and gatekeeping were discussed when working with individuals with dementia and Alzheimer's disease (AD) as the project accepted participants who had both. Ethical issues were explored as the informed consent process had special care and additional consideration for the project, with asking older participants' mid-project what they thought the project was about. The chapter concludes by discussing analysis, triangulation, and project limitations.

Subsequently, the three findings chapters cover micro (Chapter Four), meso (Chapter Five) and macro (Chapter Six) aspects of decision-making for older people. This structure allows the thesis to build up the wider systems that surround older people starting from individuals and then looking at the people, organisations and policy that create the wider system.

Chapter Four focuses on micro level ways to support decision-making and it discusses individuals and different decision-making styles such as shared decision-making, the status quo, and differences of opinions. This chapter also reports on what supports decision-making. It highlights the importance of SDS and how this supported decision-making on informed choices in care decisions for older adults and their carers. Chapter Four also discusses the roles of assistive devices and individuals' levels of independence.

Chapter Five concentrates on the meso level issues of relationships and support networks. It explores the roles of support networks and the importance of perceptions. It also considers the many roles of professionals and how these influence decision-making and resource utilisation. The importance of working with people with dementia and AD is reviewed as well as how differences in views can be accommodated in decision-making.

Chapter Six contains more macro discussion on environments and resources and this chapter emphasises where individuals decide to live and the types of services utilised.

There are various satisfaction levels reported by individuals related to decision-making. Resources are discussed including how money influences choice and decision-making. Good care and decision inhibitions are discussed with an emphasis on constraints and barriers to overall decision and resource utilisation. This includes care decisions in hospital settings, and the overall lack of choice and control. Participants (and their selection is discussed in Chapter Three) discuss how they discovered relevant information. Some larger systems level issues re-emerge and are discussed; assessments, discipline-specific frameworks, and approaches to care.

The thesis moves on to Chapter Seven (Discussion and Conclusion). The research questions are addressed and answered within this chapter. This chapter brings together discussion of the micro, meso and macro levels of the lived experiences of individuals which have been used to create understanding, using a GST framework, of the wider systems that influenced decision-making for older adults and how this impacted QoL. This research has connected multiple parts of existing research and theory and linked them together to demonstrate a broader perspective about the care choices of older people with care needs living in Scotland. It has focussed on older people's wishes and the complexities of their decision-making processes from their individual viewpoints, in the context of daily life, environments, and influences within their support systems. It has also explored the perspectives of professionals and challenges to policy in practice as this is found to influence the options and restrictions which older people encounter.

Conclusion

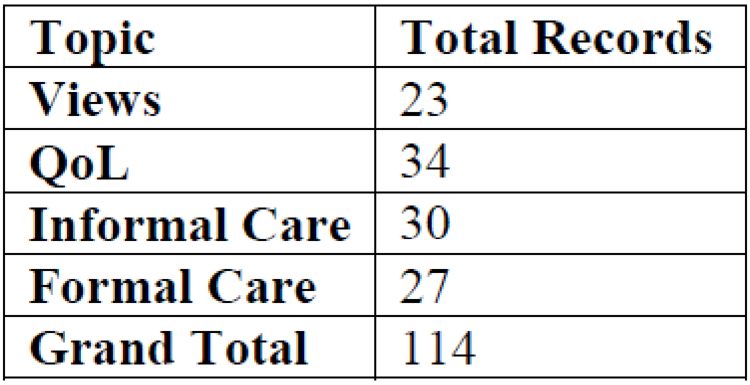
Chapter One has established the ideology of the two main frameworks that support the research: GST and an active participant framework, and how these were manifested into the research process. This chapter is fundamental in understanding the setting of the research, and the perspective of the researcher. It explains why it is important to know more about the decision-making of older adults in Scotland. The decisions we make influence multiple actions beyond ourselves and the world in which we live. The Research Objectives foreshadow the story of the project and how the research is significant in the overall contribution to knowledge in the field and discipline. This exploration, of the level of participation of older adults within their care, holds a unique story for each individual. As the research will show and the data will reveal, each individual has a unique story of choice, opportunity, decision-making or constraint.

Chapter Two: Literature Review: How People Make Decisions

Introduction

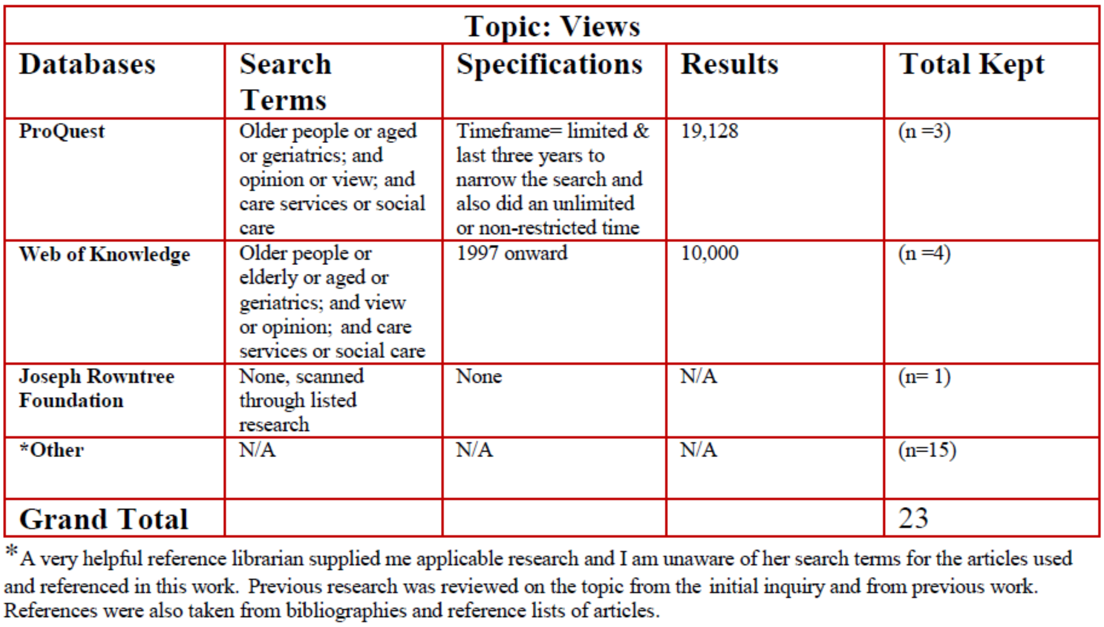
This chapter gives an overall view of the decision-making process and explores the relationship between Quality of Life (QoL) and decision-making. The literature examines the importance of independence and choice in how older adults view decision-making about care and resource utilisation. There are three main areas of study to be examined in the literature; decision making, older people and their perspectives on care and utilisation, and care and support for what older people want.

The three main issues in the literature include the following questions. *What is important to older people about care, support and resource utilisation? How do older people make decisions about care, support and resource utilisation?* These three areas of study came from narrowing a number of areas of study (from 114 total records, see Table 1). Table 2 lists older people's views (23), Table 3 lists QoL (34) Table 4 lists informal care (30) and Table 5 lists formal care (27). Research librarians helped find sources as well as checking bibliographies and reference lists of related sources. These questions led to further investigation about the importance of getting the perspective of older adults from the older adult themselves and this also revealed the ways in which individuals went about making decisions and how society views ageing and the influence this has on resources as well as the importance of policy and practice.



Topic	Total Records
Views	23
QoL	34
Informal Care	30
Formal Care	27
Grand Total	114

Table 1. Total Records



Topic: Views				
Databases	**Search Terms**	**Specifications**	**Results**	**Total Kept**
ProQuest	Older people or aged or geriatrics; and opinion or view; and care services or social care	Timeframe= limited & last three years to narrow the search and also did an unlimited or non-restricted time	19,128	(n =3)
Web of Knowledge	Older people or elderly or aged or geriatrics; and view or opinion; and care services or social care	1997 onward	10,000	(n =4)
Joseph Rowntree Foundation	None, scanned through listed research	None	N/A	(n= 1)
***Other**	N/A	N/A	N/A	(n=15)
Grand Total				23

*A very helpful reference librarian supplied me applicable research and I am unaware of her search terms for the articles used and referenced in this work. Previous research was reviewed on the topic from the initial inquiry and from previous work. References were also taken from bibliographies and reference lists of articles.

Table 2. Older People's Views

Topic: QoL				
Databases	**Search Terms**	**Specifications**	**Results**	**Total Kept**
Social Care Online	Quality of life; care, older people and quality of life; "quality of life" and care" and "older people or elderly or geriatric" none	None	1389	(n= 0)
Social Services Knowledge Scotland	Quality of life and care;	Articles only: 3, search within journals: Journal "Applied Research in QL"; Applied Research in Quality of Life Volume 1 / 2006 - Volume 6 / 2011; Health and Quality of Life Outcomes journal	180, 100	(n= 4)
	Quality of life and care; Quality of life and care and older adults	2010 and 2011	808, 287, 36	(n= 1)
Web of Knowledge	Quality of life and care; older adults, geriatrics	2010, UK, Europe or Scotland	93,592, 7197, 375, 2	(n= 0)

Google Scholar	"quality of life" and "care" and elderly, aged, older people or geriatrics;		16,200	
	"quality of life" and "care", relationships and elderly, aged, older people or geriatrics;	UK or Scotland	1,990	
	"quality of life" and relationship with "care", relationships and elderly, aged, older people or geriatrics;	UK or Scotland	1,170	
	"quality of life" and relationship with "care," relationships and elderly, aged, older people or geriatrics;	UK or Scotland	1,080	
	relationship between "quality of life and care" UK or Scotland, and elderly, aged, older people or geriatrics; Measuring "quality of life and care" and elderly, aged, older people or geriatrics	UK or Scotland	11	(n= 1) (n= 9)
Sociological Abstracts	"quality of life" and "care" and elderly, aged, older people or geriatrics;	2011	368 45	
	relationship between "quality of life" AND "care" AND elderly, aged, older people OR geriatrics);	2011	1598	
	relationship between "quality of life" AND "care" AND elderly, aged, older people OR geriatrics;	2011 and UK	6652	
	"relationship between quality of life and care" AND elderly, aged, older people OR geriatrics;	2011 and UK	6649	
	"relationship between quality of life and care" AND elderly, aged, older people OR geriatrics;	UK or Scotland	6255	
	quality of life measures		44926	
	Quality of life measures or assessments and aging, older adults or geriatrics;		8605	
	Quality of life measures or assessments and		2691	

	aging, older adults or geriatrics and UK; Quality of life measures or assessments and aging, older adults or geriatrics and UK and relationships between care and quality of life; defining Quality of life" and aging, older adults or geriatrics and UK; defining Quality of life, relationships and care" and aging, older adults or geriatrics and UK		2203 519	(n=6)
Joseph Rowntree Foundation	Quality of life and care, visual search	None	N/A	(n= 2)
***Other**	N/A	N/A	N/A	(n=11)
Grand Total				34

Table 3. QoL

Topic: Informal Care				
Databases	**Search Terms**	**Specifications**	**Results**	**Total Kept**
ASSIA	Intersectionality, care and older people; intersectionality; intersectionality and older people; intersectionality and care all (unpaid care) OR (family care) AND (older people); (“unpaid care”) OR (family care) AND (older people) AND (Scotland)	Scotland	72 6 2200 43	(n=5)
Searched online	Scottish government statistics and informal care	Looked for specific characteristics and demographics in Scotland	(massive search results)	(n=4)
***Other**	N/A	N/A	N/A	(n=21)
Grand Total				30

Table 4. Informal Care

Topic: Formal Care

Databases	Search Terms	Specifications	Results	Total Kept
Joseph Rowntree Foundation	Formal Care, Long Term Care, Free Personal Care, visual search			(n=7)
Searched online	Government statistics, policy, legislation and reports			(n=15)
***Other**	N/A	N/A	N/A	(n=5)
Updated Search-Collective Journals, online search of statistics…	Formal Care, Paid Care, Long Term Care, Personal Care, Free Personal Care, Free Personal Care in Scotland, Free Personal Care in England,	UK or Scotland	**no new relevant data**	
Grand Total				27

Table 5. Formal Care

There were many records that came up as the tables indicate. Narrowing and refining searches was completed with criteria with more recent dates, only including peer reviewed articles and then examining the studies themselves. This included comparing sample sizes and statistical significance of studies, or the sample size if this was applicable to rule out less strong studies or studies with less generalizable results to my search.

The research literature indicates that there are key themes of importance within these three main areas that influenced older peoples' decision-making about care beyond basic needs. These themes assisted in refining research questions by identifying gaps in the literature as the chapter will discuss. Themes are discussed in the following areas; *Older People Making Decisions* including decision-making, choice, ageing well, healthy and active ageing; *Care of Older People* including service availability and utilisation, care at home, care homes, and influence of professionals; and *What Older People Want*, including older people's preferences, QoL, independence, and capacity.

Older People Making Decisions

The literature on decision-making for older adults appeared to be somewhat inconclusive and sparse in areas. There are policies in place for older adults, individuals with dementia, Alzheimer's disease (AD), and those deemed vulnerable that influence choice. For example, in Scotland, interventions guided by agency protocols, legislation, adult protection, and inter-agency collaborations that related to capacity, have all influenced individual decision-making opportunities (Stewart, 2012). Stewart explained that capacity in Scotland was regulated by the Adults with Incapacity (Scotland) Act 2000, "Through this legislation a legal decision can be made that an adult lacks capacity to make decisions themselves and empowers someone else to make decisions for them" (p. 5). Much of this choice was also determined at a policy level and individual participation in government initiatives influenced social change (Irvin & Stansbury, 2004). However, Wada (2015) stated that choice was encouraged for individuals whenever possible. Individuals had opportunities to participate in choice on multiple levels, sometimes even if they were restricted in the levels of decision-making.

Chapter One indicated some changes in traditional views in decision-making, "based on logic and rationale are outdated, many factors influence the 'players' in decision making; among them negative stereotypes of older people, risk avoidance, cultural perceptions and the need to feel they are 'doing the right thing'" (Lindley et al , 2012, p. 1). Other research suggested that external factors influenced decision-making. An example of extrinsic factors playing a role was in support from social networks, health care professionals, and health care services which assisted with decision-making in care (Claassens et al., 2014). In addition, Qureshi et al. (1999) explored environmental factors, the meeting of basic physical needs, safety and security, living environment, social connections and control in life which influenced decision-making.

The literature found older people were reluctant to express concerns or complaints when something went wrong (Ware et al, 2003). Bowers et al., (2009) explored reasons for this reluctance and individuals expressed their concerns. Some research concluded that older people did not like to complain (Bowers et al., 2009; Ware et al., 2003); but there was limited information on this in the research literature. The idea that older people are less likely to complain could have implications on how they make decisions, as the literature suggested people were hesitant to get anyone in trouble (Ware et al., 2003), they didn't feel heard (Bowers et al., 2009). They were confused about professional roles (Leadbeater & Lownsbrough 2005), or staff assumed what individuals needed (Glynn et al., 2008). Ebrahimipour et al. (2013) reported that family members were more likely to complain than individuals and that there was a trend in healthcare with an increase in complaints attributed to an increased awareness of individual rights and choice of treatments available. As families become more active and involved in care, they also become better advocates.

Decision-making is limited at times because of family involvement. Sometimes, how people conceptualised both formal and informal care to meet their needs was not specific to one service, policy or programme. At times, services seemed to blur together in one overarching category from older people's perspectives (Bell et al., 2006). For example, older people saw personal care needs as “holistic and do not single out personal care as a specific separate category” (Bell et al., 2006, p. 1). Multiple types of services were utilised to get needs met.

Decision-Making

Research has shown that the decision-making process was not a new concept in any discipline (Glasser, 1975; Howatt, 2001). In fact, the decision-making process has been disputed since the 1950s (Edwards, 1954). Some theorists, such as Glasser (described as the father of ‘Choice Theory’) indicated decision-making was intrinsic (Glasser, 1975; Howatt, 2001) and Howatt described these needs as love, power, fun, freedom, recognition, and survival. Maslow (1943) highlighted motivation and stated that basic needs are to be taken care of prior to other needs being addressed. Other decision-making was also based on intrinsic motivations of emotion (Brown, 2011; Sanfey et al., 2003). It was explained that, when older people made decisions, they used “gut instinct, feelings and experience” and less “deliberate cognitive processes” (Lindley et al., 2012, p. 1). Similarly, Von Bertalanffy (1972) believed previous experience and senses were part of the unseen conceptual constructs involved with how individuals made sense of the world.

The literature indicates that older people utilise many decision-making styles: individual (Elliott et al., 2016; Vahdat et al., 2014), group and family (Bowes et al., 1997; Charles et al., 1997; Wada, 2015) community level (Vahdat et al., 2014) and status quo (Kirst-Ashman, 2014; Sanfey et al., 2003). For example, this included rational decision-making from some that was detached self-interest (Wada, 2015). Some individuals preferred to make decisions alone, other times with other people. Thus, it became a multi-step process. Others made related or joint decisions (Wada, 2015). This was also referred to as collective decision-making (Bowes et al., 1997; Charles et al., 1997). Some decision-making was done at the community level and included public involvement (Vahdat et al., 2014). Research also reported on status quo decisions of making no change or no decision (Sanfey et al., 2003).

There is much debate on the allocation of decisions in care. This has included individuals themselves, family members, durable powers of attorney, and influences by professionals (Wada, 2015). Moore and Hollett (2003) also examined advanced directives and how these were used with pre-planning with advanced wishes regarding research participation. Older adults planned ahead with some recording wishes in advance of diminishing memory issues to ensure wishes were in place. Some individual's decision-making was completed for them at times. In other roles, decisions were taken away from individuals. Ware et al. (2003) reported this to be a complex issue with relationships between individuals and professionals.

Hicks et al. (2012) identified that there may be differences in what choice individuals wanted compared to what professionals suggested and refusal of services was not a new topic as individuals' choice may be against recommendations (Hicks et al., 2012). Decision-making included having values of freedom (Wada, 2015) and one issue that influenced decision-making was which perceptions had the most weight or were deemed the most important.

There was limited literature on how older people made decisions at times but for older people to be successfully empowered in decision makers many factors were involved. Reed (2006) suggested that, in order to be involved in the care process, active participation was needed as opportunity in decision-making processes itself was not enough. The use of participatory decision making described taking part or sharing in something (Merriam-Webster, 2018). Elliott et al. (2016) suggested that individuals should understand and select their own levels of engagement, which is important in the decision-making process.

Information to make an informed choice, in a format that was recognisable was also needed (Glynn et al., 2008). Those without opportunity, information and active participation were not able to fully engage in decision-making. Providing information to individuals in medical decision-making on diagnosis and treatment was essential for both "safe and quality services" (Vahdat et al., p. 4, 2014). Then, decisions were made based on the quality of the information (Glynn et al., 2008) and this accessibility to information often resulted in improved outcomes and compliance (Vahdat et al., 2014).

There were many issues that emerged in literature regarding decisions. Claassens et al. (2014) explained that older people declared a number of things that assisted them with health care decisions. These included self-confidence in organising formal and informal care, health management in the home and having a sense of self-esteem (Wada, 2015). However, Wada reported that some perspectives have been lacking in this process of being involved in active participation and these included being involved, having control, and having a say. In addition, support from social networks, support from health care professionals, organisational support from health care infrastructures, and services assisted with decision-making in care (Claassens et al., 2014). These suggested a combination of internalised perceptions and external influences on decision-making.

Decision-making included voicing preferences (Wada, 2015). Researchers suggested older people were encouraged and empowered to be more involved in care decisions (Elliott et al., 2016; Vahdat et al., 2014). Empowerment was discussed with the fundamental idea that decision-making added control (Qureshi et al., 1999). This ideal progressed over time, with changes in policy such as Self-Directed Support (SDS) (Rummery et al., 2012) for individuals to have options to be more involved in care and in wider attitudes and changing ideas within society leaving behind the passive older adult (Kelly & Innes, 2012). This led to a healthier more active older ageing population (Toze & Ray, 2018).

Choice

Choice is a newer concept within care (including older people) and active decision-making has replaced the changing ideals of the past that an individual needing service constituted being passive (Petriwskyj et al., 2014). Choice is giving older people the opportunity to make their own choices. In Scotland, choice has been encouraged since 1993 for older people to work to keep themselves fit, healthy and encouraging the value of older people (NHS, 2005).

This change includes past negative stereotypes influencing how older people made decisions (Lindley et al., 2012). Over time, the ongoing view of older people who needed care was that they were viewed passively and devalued in decision-making when needing care options (Neuberger, 1999), although this, on occasion, has been challenged. For example, Bland (1999) researched a ‘hotel’ model of care that promoted individual independence in a way that accommodated people and that can challenge more traditional social care approaches for individuals needing care as, “dependent…socially incompetent… incapable of remaining independent” (p. 545). Toze and Ray (2018) said that the Old Age Support Ratio (OADR) suggests individuals over 65 to be independent and reported other results that show increases in people over 65 engaged in volunteering, work and care giving. As the literature revealed, there was a changing view over time. Bland (1999) described that the idea of getting older implied dependency and passive participation. Petriwskyj et al. (2014) found personal, relational or organisational constraints influenced individual roles in decision-making.

There is literature which suggests that having financial security or additional options in payment regarding decision-making in care adds independence, and the ideals in care of older age are changing over time. Toze and Ray (2018) discussed the importance of perception, and how statistics in policy were previously reflective of society's views on ageing but which had moved to more practical ways of presentation.

The idea of choice and control within care for older people was further supported and strengthened through the introduction of policies that promoted independence and choice such as The Social Care (Self-Directed Support [SDS] Scotland) Act 2013. SDS measures assessed need and, based on this, the local authority assists individuals with preparing a plan of care (Scottish Government, 2003). Individuals decide how to spend their SDS budgets, which is a change from having professionals allocate budget decisions (Manthorpe et al., 2014). The Scottish Government (n.d.) empowers individuals to manage their budgets by allowing four options for an individual's control over their budgets:

1. Individuals direct payment to hire care through an organisation,
2. The local authority or agency keeps the budget and individuals work out how to spend budgets,
3. The local authority or agency keeps the budget and manages spending, or
4. A combination of these three.

Current trends are illustrated in the contemporary policy of SDS. Manthorpe et al., (2014) discussed how this gave individuals the ability to direct their care or to designate a support person of their choice. This represented a progression of individuals being seen as competent in managing care and support for themselves and this deviated from the longstanding belief of passive service options (Neuberger, 1999).

However, Wada (2015) explained that some people receiving services through personalised agendas (choice and control in care in that setting) had lower satisfaction levels, and "thus developments intended to increase individual choice might have exacerbated isolation" (p. 1206). Phillips (2007) argued that the person-centred approach did not fit well with people nearing end of life when they became more dependent. This was a time when independence, citizenship, and autonomy were limited and this illustrated that decision-making could be relinquished both voluntarily and involuntarily.

Some individuals paid for their own care as they did not meet eligibility criteria or exceeded income limits for care qualifications, but this did not necessarily enable them to be better consumers (Tanner et al., 2018). These researchers reported that, as older people worked to engage service options, a range of issues were intertwined for individuals to overcome. Recommendations for help were based on chance, and those with the highest needs were least likely to get help based on having the smallest number of contacts to get help, and those signposted (given referrals by the local authority to get help they needed) could not overcome the barriers that individuals had, such as sensory or mobility impairments, lack of confidence, depression or cultural attitudes that inhibited services. As individuals became self-directed consumers, they encountered more barriers.

The growing population also has to be taken into consideration with consequences on choice, with more individuals with illness needing access to services with fewer young people to provide care (Scottish Executive, 2005). The current population growth will impact both individuals and society in many ways, on both individual and systems levels. For example, WHO (2015a) reported that “Disability is thus not just a health problem… Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers” (p. 1).

The increase in the population of older people is projected to continue to rise. The proportion of older people over 65 in Scotland is estimated to be one in four over the next 25 years with one in twelve over age 80 (NHS, 2005). In turn, this will have an influence on resource allocation. Older populations have been estimated to reach twenty one percent of the total population by 2050 (United Nations, U.N., n.d.). WHO (2015b) stated some consequences of ageing including increased chronic health issues; however, the estimated health care expenditures on a systems level were not as high as originally projected contingent on the individual, influences, environment, and lifestyle choices. WHO have called for additional inquiries and investigation; for example, the influences, environment, and lifestyle choices included medical technologies and the physical and social environment (WHO, 2015b).

Ideals changed in some ways with barriers and added options for choice (Bland, 1999; Lindley et al., 2012). Researchers recounted changes adding choice and added decision-making the importance of individual participation marked within civil rights (Vahdat el al., 2014). These changed ideas have been promoted on individual and community levels to promote QoL and the mental health of older people, by reducing disability, chronic pain, social isolation through increasing cost effectiveness of medical and social interventions to influence policy making at local and national levels (NHS, 2005). Researchers have suggested that the probable reasons for these changes could be attributed to “changes in community expectations, changes in patterns of disease, increased life expectancy and increasing emphasis on maximum level on health and quality of life...” (Vahdat et al., 2014, p. 3).

Choice involves many considerations such as active involvement and SDS for older adults making care decisions. As individuals have become more involved in care decisions, they have become more aware of options or the lack of these when they do not qualify for services. This has encouraged individuals to be more mindful of considering the ageing process in order to remain healthier as this thesis will demonstrate.

Ageing Well

Within the literature it is clear that choice and decision-making are influenced by how an older person experiences ageing. For those who are considered to be ‘ageing well’ decision-making is easier and this is highlighted in the literature. Smith et al. (2019) report that ageing well is determined by resilience and healthy ways of coping with challenges, finding meaning and joy in life, maintaining support networks, staying active to maintain vitality and keeping your mind active. Lifestyle and decision-making have influence on how a person ages; for instance, WHO (2015b) explained that medical, physical and social lifestyle influenced medical service utilisation rates.

The power and control in determining the extent of ageing well, or not, needs to secure resources in important areas such as assessments. In Scotland, assessments are based on need but in other places (e.g. USA) ADL assessments determine benefits for disability insurance and care home benefits (Edemekong et al., 2020). However, Toze and Ray (2018) reported that individuals cannot easily be categorised into whether they are ageing well or not. Carver and Buchanan (2016) reviewed the literature on ageing well in non-biomedical constructs between 2006-2015 and reported that ageing well is a complex process and discriminatory needing a multi-dimensional model as the older population experiences illness and disease.

However, Kusumastuti et al. (2016) conducted an international review of the literature from 1902-2015 with two “citation networks” identified. This meant they isolated two perspectives: one from older people themselves with coping strategies, psycho-social engagement and cultural differences and what ageing well meant from their perspective. The other point of view looked at ways to assess levels of functioning (Kusumastuti et al., 2016). They reported that these were two different views of disability and ageing well dependent on who was reporting: the older person (lived experience) or the researcher (observation).

The literature suggests ageing affects people at different rates in different ways. For instance, "Some 80-year-olds have levels of physical and mental capacity comparable to those of many 20-year-olds…people in their 60s may require help from others to undertake even basic activities" (WHO, 2015b, p. 6). In this case, utilising levels of function would be one way to offer a more universal measure of whether someone was ageing well or not. There are some individuals who are defined as 'super-agers' and these individuals aged over eighty performed as well as fifty to sixty-five year olds and resisted age related memory issues when looking at brain development and composition for successful cognitive ageing measures (Harrison et al., 2012). Biological age does not always determine physical or mental decline.

Multiple factors contribute to ageing well. Truscott (2000) found that, when determining ageing well, there was an interest in biological age first, then in professionals measuring genetic and environmental influences. Ageing well was defined as enjoying maximum QoL (O'Brien, 2015). Although it was reported biological age is not an indicator in ageing well, there are other elements to consider when measuring the impact of disability and QoL. Toze and Ray (2018) reported morbidity and mortality statistics are not conclusive measures and individuals who have a purpose, pleasure, and healthy lifestyles all contributed to successful ageing (O'Brien, 2015) as this thesis will explain.

In Scotland, the NHS (2005) launched the Ageing Well initiative, a programme for those 50 and over to help prolong an active, independent life by promoting good health and reducing illness and disability with focus on prevention. This model influences decision-making at individual and community levels offering everyone the opportunity to make healthy choices, improve health in later life and challenges stereotypes of older age, disability and disease (NHS, 2005). Ageing Well went to the local level, forming alliances and capacity building, launching in four local authorities to positively affect over 50,000 individuals in the UK and 200,000 individuals received programme materials. MacGregor and Sheehy (2004) reported Ageing Well in Lothian's Ageing Well program was successful and supported wider implementation across Scotland as health and social activities and environments were promoted in group activities to people age 50 and older to impact physical and mental health.

Ageing well as opposed to ageing poorly has many implications for how older adults make decisions and choices. The implications on policy can be influenced and need determines who will be eligible for some policies and programmes and who would be excluded from care services, which can be influenced by lifestyle choices and preventive measures which can be related to perception of how well someone is ageing. One person may view an individual as ageing well and another may disagree. This is important in relation to labels and influences on legal definitions such as disability or social supports in how this may qualify someone for services. Toze and Ray (2018) reported categorising ageing can be subjective and had judgmental problems. It is important to know who accurately measures and sets baselines for resources to be determined by indicators such as ageing and it is these indicators, and their contribution to the debate, that this thesis will examine.

Healthy and Active Ageing

There are many ways to formally, and informally, judge how well individuals are ageing and if a person is healthy or not based on activity levels and disability. There is the normal and gradual decline expected in memory and cognitive measures as an individual gets older (Harrison et al. (2012). Smith et al., (2019) report that, "healthy aging means continually reinventing yourself… finding new things you enjoy, learning to adapt to change, staying physically and socially active, and feeling connected to your community…" (p.1). However, how this is measured can be challenging.

There is some variation in the literature on the definitions of disability. The activity levels in the ageing process are known as levels of function to measure or assess disability. WHO (2015b) reports that "the current metrics and methods used in the field of ageing are limited, preventing a sound understanding of key aspects of Healthy Ageing" (p. 22). Truscott (2000) suggested that Instrumental Activities of Daily Living (IADLs) in measuring independence should be used as a universal measure of function for those in different geographical backgrounds and cultures. IADLs are higher level activities that allow independent living such as managing finances, medications, food preparation, housekeeping and laundry (Edemekong et al., 2020). LaPlante (2010) reported IADLs are more useful than activities of daily living (ADL) (balance, strength and self-sufficiency) as a more complete and sensitive measure. ADLs are used to determine functional status in areas such as walking, feeding, dressing, personal hygiene and continence with deficiencies that call for individual aid or mobility devices (Edemekong et al., 2020). Using functional status or IADLS is one way to compare individuals to each other in universal measures, depending on what type of assessment is desired.

The influences of health, environmental, and social aspects of peoples' lives often raise or lower QoL and when lowered this is viewed negatively in society (O'Brien 2015).

In many cases it was defined by law or agency policy. Oxford (2015) defined disability as “a physical or mental condition that limits a person’s movements, senses, or activities. A disadvantage or handicap, especially one imposed or recognized by the law” (p. 1). It is important if one or more individuals do not consider someone who is legally defined disabled as such; for example, if an individual did not consider themselves disabled, or if a GP did not consider an individual disabled. In addition, there might be instances where a legal guideline does not consider an individual to be disabled while an individual is undergoing an assessment for service eligibility, and the individual thought they would be. It would be good, to avoid discrepancies in the definition of disability, to clarify that baseline. However, even with this, the interpretation of policy in practice and the influence of professionals is fluid. This is particularly important with older people in society as they are often stigmatised when experiencing decline and this thesis will highlight some of their actual lived experience.

Active ageing has set minimum standards in ageing well and falling below those active standards can be considered a failure (Sinding & Aronson, 2003). Older people with a diminished activity level or disability were viewed negatively (Toze & Ray, 2018) Lloyd et al. (2014) reported that social workers are paramount in supporting older adults when independence failed and society condemned them or they blamed themselves. Cordingly et al. (2001) discussed whether an older person had fallen below this standard of active ageing with a loss in independence and refused to have care services in home as they were unable to clean their house themselves as the stigma of having a dirty home stopped them from having carers come in to assist. This raises questions between the perceptions of healthy and active ageing and falling short of that when additional support is warranted so individuals can get the increased support and services needed to be successful. For instance, Lloyd et al. (2014) discussed social work interventions provided to get the care needed. This is one area where social workers as opposed to other disciplines can build relationships with individuals for a more personalised assessment based on specific roles (Ray et al., 2015).

The literature raises question of what constituted thresholds for opt-in service eligibilities with regard to policy and practice issues. The perceptions of QoL issues using labels are questioned as labels can impact on how QoL and resource allocation are defined as not all programmes are means tested as some need a diagnosis to trigger services and this involves labels. Eligibility can be determined by individuals, family, and professionals conducting assessments and service eligibility. This may also include GPs, hospital staff, caregivers, policymakers, and others in positions of power and influence.

Looking ahead to people living longer, there is the potential of living healthier into older age with lifestyle changes (WHO, 2015b). Additional research was needed as QoL and its implications appeared unclear; “Because declines generally start much earlier, how the intrinsic capacity of people who still have 10-20 years to live compares with that of previous generations remains largely unknown” (WHO, 2015b, p. 9-10). Understanding more about these cohorts and the issues raised and how people make decisions is important as individuals are living longer and learning more about trends in how individuals are utilising resources can assist in better planning for policy and practice. It is also helpful to have a more accurate resource in terms of resource allocation for those in need, how they make decisions and not just those in crisis. Toze and Ray (2018) reported revised social norms with diet, and specific physiological features may influence cohorts differently, thus influencing interventions differently. This literature has established the importance of accurate resource allocation. The WHOQOL Group (1995) reported that QoL had implications on treatment decisions, pharmaceutical manufacturing, and policy research for both programme evaluation and resource allocation. This means that resources will be a deciding factor in raising or lowering a person’s level of QoL and the implications that will have resource allocations. The importance of setting baselines was discussed in determining how someone was ageing well, who is healthy, how this was defined in policy, and how this is changing in the next cohorts of individuals as living longer and influences on healthy ageing may have changes on resource utilisation.

Care of Older People

It was recognised that the family system and structure is changing from previous inter-generational systems, and this has influenced both care and support (Nolan et al., 2003; Phillips, 2007). The literature identified there was a need for additional research in the area of family relationships (Nolan et al., 2003). This merits further inquiry because of the limited scope of information offered on how it influences older people’s decision-making. Kemp et al. (2013) demonstrated complexities of care relationships in formal and informal care settings where individual roles, expectations and preferences influenced outcomes. These included interpersonal influences, facility influences, community influences, and the type of care industry.

The literature has identified some gaps with services with people living fifteen to twenty years longer with unknown outcomes (WHO, 2015b). Lloyd et al. (2014) reported evidence that ageing was diverse and variable as behaviours of older people were shown to be active by community engagement, caring for grandchildren and paid employment. This report of healthier and active ageing could be an indication that older adults are more empowered to have higher QoL, which may in turn, have an impact on how care utilisation and resources could be allocated to individuals in the future with healthier and active older adults, who may not need additional services until older age.

Service Availability and Utilisation

How individuals found out about services was an issue (which will be examined when they discuss their own lived experiences later in this thesis). Some individuals may rely on family and friends for information (Ware et al., 2003), whereas others rely on previous experience (Cordingly et al., 2001; Qureshi et al., 1999) or the media (Audit Scotland, 2008). Kelly and Innes (2012) considered the positive and negative influences of professionals on choices, and reported on how individuals found out about information and services and could become more socially included.

Changes in policy brought many changes in care and support for older people and their carers. Rummery et al., (2012) identified some of those emerging changes which additional caregiver assessments and benefits within the SDS policy, additional policy to provide and inform individuals of advocacy and to provide information to individuals mandated in policy. Previously, individuals had limited decision-making options. Tanner et al. (2018) reported disabled people advocated for independent living and personalisation; however, this was not always met with positive reactions.

Care at Home

The literature suggested that the majority of older people were likely to move to a new home closer to their family or ‘age in place’ while they were still able to remain in the home (Scheibel et al. 2019). Individuals reported they wanted to remain in the home setting surrounded by a familiar environment (Bowers et al., 2009) with care at home flexible to their needs (Centre for Policy on Ageing, 2011). Most people want to remain at home for as long as possible (Phillips, 2007) and were thankful for resources that supported this option (Centre for Policy on Ageing, 2011).

Care at home was affected by informal care relationships such as smaller family size, divorce, step families, same gender couples, geographic dispersal, and longer work commutes (Phillips, 2007). The nature of this support network influenced the level of choice and options. Kemp et al. (2013) also indicated research in the formal-informal care relationships had been of interest for many decades but remained "theoretically underdeveloped" (p. 16). This calls for additional research based on actual behaviours.

In addition, where individuals lived had an impact on care at home and decision-making. Phillips (2007) reported families were having children later in life as mothers found themselves torn between offering dual care to their children and ageing parents. The literature reports older adults whose, "complex and changing needs are particularly likely to experience difficulties if fulfilling the role of informed, proactive and skilled navigators in the care market (Tanner et al., 2018, p. 263). Literature reveals more about the behaviours of this sub-set of the population (older people with higher care needs), including what is important to some older people, who need additional assistance and how that impacts their relationships.

Changes in moral values and commitment to care have greatly influenced informal care (Phillips, 2007). These changes had the potential to influence choice, decision-making, and were linked to the relationships influencing care (Bowers et al., 2009). These factors promoted relationships within care settings.

Family support was one way used to navigate through most systems (Phillips 2007). Tanner et al. (2018) reported self-funding as part of personalisation with ideologies of choice, control and managed care by their defined outcomes. SDS allowed individuals to remain in home and this supported independence (Rummery et al., 2012).

Another option for care at home is SDS policy which promotes care and choice in the home setting. Rummery et al. (2012) identified outcomes utilised for increased independence, with control and choice being implemented at local levels, consistent to national policy initiatives. However, Tanner et al. (2018) stated that much is not known about self-funders who have navigated care systems and reported that this is needed to support local authorities to fulfil obligations, and avoid unnecessary cost in health and social care. Manthorpe et al. (2014) reported limited studies as small or pilot programmes involving individuals and caregivers providing little follow up to SDS policy. More research is needed to investigate the implications and behaviours of individuals, as well as the overall influences of policy on independence and the longer term effects these have on individuals, families and communities.

The literature highlights changing trends in relationships in healthcare. Predicted trends in future changes were in telehealth and telecare as another support because of more widespread use of the services. Dawson et al. (2015) reported tele-healthcare was used with individuals with mild to moderate dementia. For example, researchers discussed effective practice which included options to reinforce safety, to have a presence at night and to give value for money (Dawson et al., 2015). This was important as overnight care is difficult to secure; this adds options and influences decision-making. Technology was demonstrated as influencing decision-making in extending relationships and often added decision-making opportunities.

Care Homes

The literature reported decision-making in moving to a care home was complex (Rhynas et al., 2018; Scheibl et al., 2019). Scheibl et al. reported that many older people’s moves to a care home were often triggered by a crisis often followed by a hospital stay. Few older people moved voluntarily or had full participation in decision-making (Scheibl et al., 2019). This is consistent with Rhynas et al. (2018) who explained that the older adults’ voices were missing from the records reviewed and that improved documentation with the clients’ voices is “essential” (p.1). Scheibl et al. (2019) reported more support was needed for family prior to any crisis to support older people’s decision-making. Rhynas et al. (2018) reported that more research was needed in experiences with older people, families, and team members to better understand care home decision-making from hospital settings and to identify best practice. This thesis (Chapter Six) allows people with lived experience of elderly care to give voice to their own feelings about that experience.

LeLow (2018) discussed older peoples’ decision-making processes of managing the transition to a care home and settling in - with three stages: “making the unknown familiar, finding out what I can do and want, and negotiating-compromising the past to fit the present” (p. 228). She discussed the patterns and elements of clients as they worked into routines and listed the elements of being “accompanied and supervised, being told and observing, trial and error testing, asking and questioning, suggesting and negotiating, and compromising” (p. 228). This literature explained that clients needed to learn new contexts as they compared this to similar experiences (comparable to general systems theory, GST) with findings that suggested daily life decisions were clients’ main concerns.

Many organisations are looking to improve services. Cranley et al. (2020) reported on strategies to facilitate shared decision-making in care homes in Canada for more effective information sharing and communication between family staff and residents to support decisions and autonomy. The literature reported shared decision-making was used in four areas: information sharing, support decision autonomy, relational aspects of care decisions, and lack of communication causing barriers to shared decisions. Cranley et al. (2020) suggested that future research is needed to explore how staff can involve personal support workers in shared decision-making and ways to engage family and residents in care planning.

Care services, it has been suggested, are also improved by using person-centred care (Santana et al., 2018) although this is not exclusively used only by care homes. Person-centred care is care based on the unique needs of an individual which is understood through inter-personal relationships (Fazio et al., 2018). Kim and Park (2017) report that person-centred care can be an approach that includes individuals, carers and families from a holistic and integrative approach to maintain wellbeing and QoL for people with dementia. Person-centred care places individual holistic needs at the centre of decision-making of a person’s beliefs, values, needs, wants and desires (Kmetec et al., 2020). Many organisations are looking to implement person-centred care which has many frameworks but there is a gap on implementation (Santana et al., 2018) and the use of person-centred care to empower clients and improve the quality of care (Moore et al., 2017). Recommendations by Fazio et al., (2018, p. 18) include:

1. Know the person living with dementia
2. Recognise and accept the person’s reality
3. Identify and support ongoing opportunities for meaningful engagement
4. Build and nurture authentic, caring relationships
5. Create and maintain a supportive community for individuals, families and staff, and
6. Evaluate care practices regularly and make appropriate changes.

Cranley et al. (2020) reported shared decision-making was one way to include personal support workers and to support person-centred care. Moore et al. (2017) reported on person-centred care issues with Swedish researchers whose clients had a range of health issues, and found when deviating from usual care to open questioning, getting the persons narrative and using effective listening skills and the active participation of individuals, person-centred care was effective. Person-centred care in clinical practice was found to reduce agitation, neuro-psychiatric symptoms, depression and to improve QoL (Kim & Park, 2017).

Influence of Professionals

The professional role was found to be an important influence on decision-making abilities. This was particularly true for the choices revealed in healthcare for older people (Hicks et al., 2012). One area, relationships, included power differentials in the contexts of choice and control in balanced roles between staff and individuals receiving care. It was reported this was not an area in which had received much research (Petriwskyj et al., 2015). Some of the external influences on decision-making included the roles of the individual and how engaged they were with their care decisions. Some of the influencing factors on individual engagement were found to be relationships, and power dynamics between staff and individuals in care.

Bowers et al. (2009) discussed the importance of how decision-making was influenced by meaningful relationships with professionals as these were found to be a decision-making factor in addition to family members (Wada, 2015). Vahdat et al. (2014) reported on factors influencing individuals' health care decision-making, which included doctor-client relationships and the emotional connections influencing decision-making. It was suggested that assumptions and assessments of professionals had a direct impact on how information was presented to individuals and how older people were treated in being offered care choices and services. Petriwskyj et al. (2015) reported some of the power differentials were between direct care staff and older people, as well as older people and managers. Researchers reported policy being made reality between people and frontline workers (Scourfield, 2015) and other professionals included social workers and doctors as the professionals of influence on individuals decision-making (Wada, 2015).

In addition, there were many influences on decision-making which included how information was presented to the individuals who influenced the decision-making as well as which professional or family member the information was coming from. Individuals were often limited in choice with personal, relational, or organisational constraints limiting short term involvement in decision-making (Petriwskyj et al., 2014).

Professionals have influence on decision-making through policy implementation but the ways policies are interpreted and implemented can vary. For example, Scourfield (2015) implied that professionals who implement policy had significant control on how it was interpreted depending on their varying approaches:

> "whilst managerialism is a powerful set of beliefs and processes, when put into practice 'it' does not work evenly, coherently or in a uniform way in every

> organization where it is introduced even when there is a strong performance culture" (p. 929).

Things were different in each environment, even when utilising identical policies. This was illustrated with the use of free personal care (FPC) policy. What was covered in one local authority was not covered in another. This practice was based on the identical policy of The Community Care and Health Scotland Act (2002) (Bell & Bowes, 2008; Bell et al., 2007; Bell et al., 2006; Vestri, 2007). So, an individual who lived a couple of miles from another, and was located in a different local authority, may not be covered by one service when the other person does and they have the same assessed need. This variation in the influences of professionals has a significant impact on options and choices in care and how decisions are made.

Power differentials were identified between professionals and older people (Petriwskyj et al., 2015). A professional's interpretations of policy and rights emerged in the literature and how this influenced older adults to make decisions for themselves (Ware et al., 2003). Professionals were seen as having high status and standards. Individuals submitted to agreement based on a professional's status, regardless of personal opinions as Hicks et al. (2012) illustrated. They outlined professional healthcare provider roles, how they influenced care options by how they were offered, and how the influences of professionals and institutions on care decisions over time detracted from personal choice (Hicks et al., 2012). For this reason, most older people consulted and deferred to what was recommended by those in a position of power.

What Older People Want

There were several areas of literature that provided the perspectives of older adults on care and support. This was defined in how older people thought of themselves and the roles between professionals and in literature in service availability that older people wanted decision-making options. Kmetec et al. (2020) saw this from a human rights' point of view; "one of the important human rights is access to the most appropriate care as well as treatment of disease with accompanying disturbing symptoms. These disturbing symptoms can have a major impact on persons' quality of life, as well as care partners" (p. 162).

Researchers spoke of many perceptions on why lack of choice and opportunity were issues for older people. Bowers et al. (2009) said that staff did not think individuals would be interested or were too tired to participate. Cranley et al. (2020) found the opposite was true and that individuals wanted to be involved in choices. Kelly and Innes (2012) described how choices were inhibited for older people (with dementia) and how they preferred to be treated focused on social inclusion, dignity and active citizenship.

Negative perspectives on ageing included ageism (Boissonnault, 2008) and this referenced prejudices and stereotyping of individuals or groups based on age. Citizen rights affecting their rights in care decisions were denied at times and that undermined self-determination (Kelly & Innes, 2012).

However, there is a gap in the evidence base on older people's preferences that actual behaviours were not matched by care decisions (Velzke, 2016). This was also found to be true for vulnerable populations. Tanner et al. (2018) reported complexities as older adults with multiple needs found, arranged and managed care. Toze and Ray (2018) reported a variety of life experience older adults experienced were interconnected and influenced experiences in later life and revealed the importance of this in policy development. The following sections will discuss more about these complexities and includes: older people's preferences, QoL, independence and capacity.

Older People's Preferences

Additional research on spending money for older adults with higher care needs is needed. Tanner et al. (2018) found the process in securing care went beyond having the means to purchase this, to the influence of environmental and personal factors such as relationships. The literature revealed people do not get the services they want (Clough et al., 2007). Individuals were often supported financially by family or others or needed to take money out of savings to pay for care (Tanner et al., 2018).

An example of an identified barrier was when people were charged for services, when they asked for less or no services. This is supported by research that demonstrates when care imposes a fee, individuals ask for less (Couffinhal & Paris, 2001; Glynn et al., 2008; Reid, 2009). Other research reported a drop in social care spending trends for decreased personalised care service that attested that, for alternative reasons, support was not used: exclusion of individuals with complex needs or viewed as needed in the short term (Ray et al., 2015).

How older people perceive themselves has implications on QoL, resources and what people want. This includes perceptions about labels and influence such as disabilities and finances. Those who had money enjoyed more choice in care options. Earlier discussion in healthy ageing introduced discussion on the implications that macro-level issues have with definitions. Labels and policy controls, which influenced power in relation to the ageing population, were strong indicators for resource allocation. Toze and Ray (2018) reported older people's attitudes were similar, as they did not consider themselves old because of activity levels and community involvement. The macro systems are systems that determine choice for individuals. Perceptions, realities, and how individuals see themselves were important as the literature found that this is how they presented themselves to others.

QoL

There were multiple definitions of QoL in the literature but QoL is a complex matter, particularly as these issues have some influence on older adults' QoL. As a multi-dimensional phenomenon, QoL interconnects in many areas. For example, Kelley-Gillespie (2009) stated that QoL was a fluid idea with several interpretations. Fernandez-Ballesteros (2011) defined QoL as: "environmental and physical factors (climate, residential facilities) economic factors (pension systems, micro-credit facilities) social factors (social networks, social services availability) and health factors (life expectancy, health services)" (p.25). The World Health Organization Quality of Life [WHOQOL] Group (1995) also identified six QoL domains: the physical domain, the psychological domain, the level of independence, social relationships, environment, and spiritual/religious/personal beliefs. For the purpose of this research and its relevance to older people, QoL is defined as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHOQOL, 1995, p. 1405).

QoL, and how people decide to live their lives, has strong implications on decision-making and the care choices that are centred on individual goals. Part of those considerations includes locations near family, medical care, groceries, transportation, or climate (Fernandez-Ballesteros, 2011). Considerations are unique to each individual. These choices vary because of gender, education, and other influences. This relate to experiences as each individual has their own conceptual constructs based on prior experiences.

A change within one domain influences the decision-making of older adults and family systems in other domains. For instance, if a person had a stroke, QoL would be raised and lowered in more areas than just medical aspects and individual changes. The literature explained that individuals encountered QoL difficulties in other areas as evidenced in physical functioning (changes in appetite, sleeping habits, ambulation, feeding or bathing oneself), communicating, social networking, or a change in mental health (Kelley-Gillespie, 2009). One area, in turn, influenced another. A change within one domain influences the decision-making of older adults and family systems in other domains. This implies that the role of QoL in decision-making is intrinsic and extrinsic.

There were limitations and restrictions reported in measuring QoL. Kelley-Gillespie (2009) encouraged the use of QoL measurements from multiple sources to include individuals, family, friends and carers. Kelley-Gillespie also argued limitations in measuring QoL included restricting measurements to one model such as the Health Related Quality of Life model (HRQoL) that tends to focus on physical or medical status, well-being and functional ability. This limits perspectives to one source (such as the clinical provider) and limits the evaluation of QoL for people with disabilities or mental health issues such as dementia or AD. Those participants might not have been able to accurately self-report QoL because of cognitive impairments. Fernandez-Ballesteros (2011) described HRQoL as: "consisting of subjective appraisal of symptoms in specific pathologies and their repercussions on the individual functioning" (p. 30). HRQoL also extended from negative to positive measurements of health that ranged from death and near death to happiness and full health (Guyatt et al., 1993).

Some research does not support the use of any standardised QoL measurement. For example, "Most measurements of quality of life in the medical literature seem to aim at the wrong target. Quality of life was suitably measured only by determining the opinions of patients and by supplementing (or replacing) the instruments developed by 'experts'" (Gill & Feinstein, 1994, p. 619).

There were also debates on who was most effective in measuring QoL: individuals, professionals, carers, or family. Kelley-Gillespie (2009 and 2011) suggested there was bias in reporting QoL if measured from anyone other than the individuals themselves. Levels of satisfaction were reported differently between care professionals and individuals. Slevin et al. (1988) reported that doctors and family members did not accurately identify QoL in cancer clients when measuring anxiety and depression of the individual when compared to individual measures on QoL. It did matter who measured QoL because the perception was reported to have a marked difference and different outcomes were reported based on who completed the measurements. This, in turn, infers that individuals would have different outcomes as to where they may end up on a continuum for service eligibility guidelines.

Older adults' experiences and views with QoL and identifying what had the most power and influence in decision-making with QoL is debatable. Varying QoL from one individual to the next was an issue to be discussed because of trends emerging from one cohort to the next that were uncharted, with people living longer. This may vary drastically from the way professionals and lawmakers view older adults. QoL influences many things in life and is, itself, influenced by policy, expenditure, legal definitions and individuals. Capturing what is healthy and determining a baseline of QoL may continue to be a challenge. Thus, there are hurdles in determining whose perspective is most valid as older adults' views on QoL and perceptions of this are changing with people living longer.

Independence

Independence is an important criterion in older people's decision-making processes (Bell et al., 2006; Phillips, 2007). Barker (2003) described independent living as,

> "the capability of a person to be self-governing and not dependent on others for care, well-being or livelihood… manage one's own finances, and to perform necessary activities of daily living (ADL) without the necessity of continued reliance on others. Program to help people achieve independent living provide for social and medical services and also for the modification of homes that permit access to all rooms and facilities." (p. 213)

For example, there were people willing to make accommodations for their care (Katz et al., 2013). Individuals made compromises and shifted priorities to maintain independence. For instance, Katz et al. reported that some older people with high support needs in the UK accepted that some choices were not for them and they maintained self-worth in doing so. There were those who struggled with the loss of independence as a result of frailty, accident, or illness related to ageing. In doing so, individuals were able to live independently by making changes and by living in such a way to maintain independence with changes.

Capacity

Capacity in Scotland assumes that individuals aged 16 and older make their own decisions and manage their own affairs (Office of the Public Guardian [Scotland], n.d.). Capacity was implied until proven otherwise. However, this was revealed to be problematic on multiple levels as professionals lacked understanding related to conceptualising capacity. For example, 'incapable' meant, "incapable of acting; or making decisions; or communicating decisions; or understanding decisions; or retaining the memory of decisions" (Office of the Public Guardian [Scotland], n.d., Para, 1). The literature raised several points. One was that people had the right to make risky decisions if they retained capacity (Brown, 2011). Research also revealed an additional concern related to how professionals applied laws to older people to promote choice, inclusion and citizenship (Bowers et al., 2009; Brown, 2011).

In addition, researchers were challenged when it came to questions of capacity when completing research. DiazOrdaz et al. (2013) argued: "Since capacity is decision specific, researchers must assess capacity for each potential participant during the recruitment process…" (p. 2). Nevertheless, even though capacity was not clearly defined, researchers were bound by legal and regulatory rules (DiazOrdaz et al., 2013). Determining capacity depended on the ruling of a court of law or determination by a physician and it was often a starting point of reference for researchers. Capacity was linked to an individual's ability to consent to both research and medical treatment which influenced the decision-making process for care. Capacity was continually monitored and not a one-off procedure.

Dewing (2007) reported on consent being established initially and being reviewed each time researchers met with participants. Determining capacity for researchers was also influenced by having as much preliminary information as possible on individuals, particularly in determining the baseline for consent and how that changed over time. This is similar to informed consent for treatment (Barker, 2003).

A Conceptual Framework: General Systems Theory (GST)

Much of the literature reviewed suggested it is timely for a study to examine how older people make decisions about care (Rummery et al., 2012; Toze & Ray, 2018) but this was seen to be a complex area, involving a policy and practice context, and older people themselves in the context of their lived experiences, family and community relationships. This also highlighted individual preferences and priorities. Chapter One had introduced the integrative logical approach (Mason, 2005) that examines the broader picture based on what is happening within. As a result of working to understand all of these complex factors and how they come into play, the use of GST as a conceptual framework is proposed, particularly as literature indicates older people utilise multiple decision-making styles: individual (Elliott et al., 2016; Vahdat et al., 2014), group and family (Bowes et al., 1997; Charles et al., 1997; Wada, 2015) community level (Vahdat et al., 2014) and status quo (Kirst-Ashman, 2014; Sanfey et al., 2003).

GST according to Barker (2003) is,

> “a conceptual orientation that attempts to explain holistically the behaviour of people and societies by identifying the interacting components of the system and the controls that keep these components (subsystems) stable and in a state of *equilibrium*. It is concerned with the boundaries, roles, relationships, and flow of information between people.” (p. 176)

Within the structure of GST and this research, it is important to understand what is meant by a system. Chapter One started to discuss a system (Barker 2003):

> “A combination of elements with mutual reciprocity and identifiable *boundaries* [author italics] that form a complex or unitary whole. Systems may be physical and mechanical, living and social, or combinations of these. Examples of social systems include individual, families, groups, a specific social welfare agency or a nation’s entire organizational process of education.” (p. 427)

That is, a group is a system, inter-related with an identity that has boundaries defining who is within that system and who is not (Kirst-Ashman, 2014). Some examples of a system, members or various groups in a social system for older people would be an adult daycare centre or a lunch club.

All parts of a system interconnect (Walsh, 2010). “The nature of systems is that the factors within and between them have influence on each other” (Corcoran & Walsh, 2006, p. 5). The inter-relationships of different elements within the system influence each other and those around them outside the system. This inter-relationship is intricate and involves system members. There are multiple tiers or levels of systems to consider. This includes micro (individual), meso (group), and macro (community) levels (Kirst-Ashman & Hull, 2012). A micro system is that of the individual, and in this thesis, this is the older person, taking into account personality, strengths, goals, weaknesses, behaviours, beliefs, interests, and emotions that make individuals unique (Kirst-Ashman, 2014). Any small group would be classified within the meso system, such as an organisation or community. In the context of this thesis, this would include service institutions and prior issues discussed with institutional cultures. Anything larger than a small group is macro level (Kirst-Ashman, 2014). Policy factors such as prior discussion of SDS are macro level. For the purposes of this project, the older person is at the centre of the systems’ perspective. GST is also important in this project as the literature reports the multiple decision-making styles of older people with individual (Elliott et al., 2016), shared (Bowes et al., 1997) and status quo (Kirst-Ashman, 2014) decision-making on micro, meso and macro levels.

Measuring QoL is particularly important with the use of GST, as QoL was raised and lowered depending on an individual's situation and an individual's goal is to maintain a state of homeostasis (Kirst-Ashman & Hull, 2012). In order to survive or thrive, individuals work toward homeostasis or the status quo (Kirst-Ashman, 2014). Homeostasis is defined in the literature as the tendency of a system or organism to maintain stability and, when disrupted, to adapt and strive to restore the stability previously restored (Barker, 2003, p. 199). If an individual's preferred QoL falls below a minimum standard, GST suggests he/she will work to change decisions to get what he/she desired, to regain homeostasis.

On the same note, Kirst-Ashman and Hull (2012) reported a systems theory concept of equifinality which meant that: "the fact that there are many different means to the same end…many ways of viewing a problem and, thus many potential means of solving it." (p. 11). Barker (2003) described equifinality as:

> 1. The property of living systems that permits them to reach identical points, although by different routes.
> 2. A concept in systems theories stating that different behaviours by living organisms can lead to the same or "equal final" results (p. 146).

In defining equifinality, in the context of this study, there may be multiple options for a person's goal or target. As an example, there might be various reactions to having a stroke. GST frameworks draw attention to the broader issues of the individual. There might have been consequences of needing to move out of residences, e.g., paralysis, need for increased care, mobility issues, and a host of other holistic considerations. Therefore, short and long term planning and resource utilisation would vary for each individual in identical situations depending on the individual and their goals. Also, the focus of GST is not on a cure for the individual, but rather improvement in interactions with other systems (Kirst-Ashman & Hull, 2012). This is identified as unique and will be highlighted in the thesis. GST is different in this way from other disciplines and specific models are revealed in the research that is curative models.

One weakness of GST is the number of multiple definitions and interpretations of GST (Bernard et al., 2005). There were over 35 definitions of a system listed (Bernard et al., 2005). Drack and Schwartz (2010) report a literature review on new development on GST shortcomings and that GST should be more unified. They discuss the work of Lin et al. (1997) with blending of philosophy, mathematics and physics. Lin and Wang (1998) developed this further in their work of difficulties of quantifying GST, and created a working new mathematical approach. Lin (2005) suggests this mathematical approach can be used with GST to be applied to multiple interdisciplinary fields.

This thesis includes influences from both direct practice influences and research in areas of policy, environmental factors, communities, behaviours and perceptions of people, relationships and individuals' view of multiple disciplines and professions. This will be examined from the multiple perspectives of carers, professionals, and older people to get that broader, overall view as well as micro (individual), meso (group), and macro (community) levels (Kirst-Ashman & Hull, 2012). In addition, mixed methods and a wider lens for a holistic perspective (Tanner et al., 2018) may be necessary to address the range within the Research Questions, QoL (Kelley-Gellespie, 2009 & 2011), and decision-making (Velzke, 2016).

Conceptual Constructs

The use of GST is an attempt to decrease the issue of multiple realities and to improve the understanding of roles within the multiple systems investigated and their mutual influences. A GST framework uses the fundamental idea that the way individuals formulate cognitive processes and decision-making is through conceptual constructs (Von Bertalanffy, 1972). This thesis will explore multiple realties and perspectives using visual methods e.g. photographs. The researcher will take steps within these methods to minimise the multiple realities within the project.

GST has evolved over time and has become interdisciplinary. It has adopted mathematical approaches as well as social science backgrounds (Drack & Schwarz, 2010) and as Von Bertalanffy (1972) originally predicted, there is not a universal approach or language for GST between disciplines. In this case, some researchers reported this was a positive aspect in the progression of GST (Drack & Schwarz, 2010). However, GST is utilised in explaining the ways individuals conceptualise information (Von Bertalanffy, 1972) and how properties and relationships are categorised (Drack and Schwarz, 2010). For example, how people think has been conceptualised based on GST. This is based on cognitive processes and conceptual constructs, "Interactions (or, more generally interrelations), however, are never directly seen or perceived; they are conceptual constructs" (Von Bertalanffy, 1972, p. 422). Von Bertalanffy reported that these constructs were based on things such as learned categories or innate properties such as:

"senses, previous experience, learning processes, naming (i.e.., symbolic processes), ecte., all of which we actually see or perceive" (p. 422). Human behaviour is a learned behaviour from these constructs, which can be from the family of origin modelling or the environment they encounter and less from individual characteristics (Walsh, 2010). Conceptual constructs originate from a variety of sources and change as individual experiences change.

There are many positives to GST. For example, there are many ways to categorise through GST and one such way is new logic; for example, Drack and Schwarz (2010) reported new logic in the GST field and included Uyemov's work of "non-classical deviant logic." This contained basic categories of "properties and relations" and stated that, "what is a thing in one context can become a property or a relation in another context" (Drack & Schwarz, 2010, p. 603). An example provided was love. It was reported to be affection, a property/category, and to have many descriptions such as definite, indefinite and arbitrary (Drack & Schwarz, 2010). This is one example of multiple perceptions and views on how to categorise identical properties and relations. The way in which people develop conceptual constructs is unique to their own way of thinking and will be developed later in the thesis when looking at how older people make decisions.

Conclusion

This Literature Review has identified several key gaps in the existing research. It would appear that limited research has been carried out on older peoples' decision-making based on actual behaviours and on services and policy with people living longer. There is also little research on self-funders and how they are navigating care which is needed so local authorities will be able to fulfil their obligations and funding allocated for health and social care, especially on person-centred care and practice.

This chapter has brought up many unanswered questions in how people make decisions and why they pursue those decisions. The review has identified the limited research available for older adults with higher care needs on how they make decisions based on actual behaviours. The Literature Review reported that professionals influenced older adults by power and authority that was both implied and assertive. Individuals were reported to make decisions based on how information was presented, based on who did the presenting, and on the type of relationship that was established between the individual and the professional. Furthermore, there were also reports of changes in the behaviours of older people based solely on the professional's position of power and influence and the individual disregarded their own desires. Some influencing factors prompt further investigation of decision-making behaviours from older adults. Perceptions of older adults in the literature suggested this influenced behaviour changes in care decisions and this has prompted the first Research Question. The literature suggests that decision-making has multiple factors unique to each individual, and, at times, this may involve ungovernable influences. This made it unlikely to be able to predict decision-making behaviours, without additional research with actual behaviours. This led to Research Question 1 on the attitudes, behaviours, and perceptions of older people as they set out to fulfil needs for care and support.

The literature suggested there are complexities involved in relationships and the roles these played in decision-making processes. This include questions raised in changes in family structures and reported some unknown consequences in how that influenced the need for informal care. There was a gap in the research that individuals were living longer and relationships were a factor on how care decisions were being made. Families are spread out and living in different geographic areas. It has been suggested that there are differences in family structures, and how these equate to the care needs of older adults. For example, if an individual needed an adult child for informal care, but they lived 200 miles away this influenced that role. The options and decisions individuals pursue would influence choices on care or if scenarios were different based on family structure. The literature inferred the role of family relationships, influencing the overall QoL, and in turn the services older people would need for themselves. Investigation is merited on decision-making. This is also true as there was another gap in research for how self-funders were navigating and managing care. These complexities suggested the basis for Research Question 2 that examined what influences decision-making on which services older people use.

Perceptions of labels such as ageing well and QoL were discussed in the literature and older adults' perceptions were at times different from others. There were also debates in the literature about measuring QoL, which was found to be multi-dimensional, with QoL changes, as this was raised and lowered by health, environment and social factors. The literature identified that the perceptions of older people themselves were deemed to be important, and, as such, it was imperative to include older adults as actively empowered decision makers involved in care decisions as often as possible by investigating what QoL issues were important to older people. This questions what happens in other situations when individuals were not the main decision makers. This was a stepping stone to Research Question 3 investigating more about the relationship between QoL and decision-making.

There were many issues reported in the literature that raised and lowered QoL. There were barriers reported and individuals did not always get the services they wanted or needed. The literature suggested environmental factors could make up for these deficits as it reported some multi-dimensional influences on decision-making which included environmental factors. This led to Research Question 4 on how environmental factors come into play.

There were multiple influences in the literature that affected policy and how that influenced the choice available to older people. However, the unknowns associated with the projected population growths with older people, and the estimated longer life spans, raised many unanswered questions. There were little data to support growth and the trends to come. This included policy and questions about care, health, healthy living, and the implications of QoL. The literature also reported that QoL had implications for treatment decisions, pharmaceutical manufacturing, and resource allocation. These issues led to exploration of the fifth and final research question of how current policy in Scotland influences the choices available to and for older people.

The review also implied that GST would provide a useful framework for the study as decision-making was not limited to an individual level but involved the family, groups and community decision-making as well as the status quo. This warranted a framework that looked at systems from multiple viewpoints and as well as GST.

The literature led to refining the following research questions:

- ✓ *What are the attitudes, behaviours and perceptions of older people as they set out to fulfil their needs for care and support?*
- ✓ *What influences older people's decision-making about which services they use?*
- ✓ *What is the relationship between quality of life, and the decision-making process?*
- ✓ *What environmental factors come into play?*
- ✓ *How does current policy in Scotland influence the choices available to/made by older people?*

Overall, the Literature Review has led to the formulation of five research questions which will discussed in Chapter Three (methods) and throughout the thesis. The methods and research frameworks of GST, and an active participant framework are explored in the following chapter as are data collection, analysis and ethical considerations.

Chapter Three: Methods and Research Framework

Introduction

This chapter details the methodology and methods for data collection and analysis. The data collection included a mix of qualitative, quantitative, participatory and visual methods and the participants included older people, family carers and professionals working with these groups. Multiple sets of data were used to develop a complex, multi-dimensional understanding of decision-making and Quality of Life (QoL) for older people to answer the research questions. The conceptual constructs which older people develop to support decision-making are defined within the methods in this chapter.

Two main frameworks were utilised in the project: General System's theory (GST) and an active participant framework. Existing research has not explored the many complex pieces together within the overall system that older adults encounter when making care decisions. The existing research did not factor in the more complex understanding of the impact of the higher care needs of a single issue. Rather, this research expanded into a broader systems view that can consider how influences and choice come into play within the system looking at the multiple perspectives for a more holistic view. The GST framework was used to address these multi-faceted issues.

A combination of datasets was used to generate a wider perspective and a more detailed portrayal of older people as they set out to fulfil their needs for care and support. This included qualitative, quantitative, participatory and visual methods. The research included the contextual factors that framed decision-making, including the roles and perceptions of service providers and the landscape of care provision. At the core of the project, were the participants' stories of lived experiences. These encapsulated the conceptual constructs (Drack and Schwarz, 2010; Von Bertalanffy, 1972) individuals formulated in the decision-making process for care, resources and QoL.

In the project, multiple system elements were examined to enable understanding of the whole system older people encountered, to help in identifying a better understanding of their experiences. To accomplish this, many methods of data collection and analysis were needed to enable a grasp of the system elements and their mutual interactions at micro- meso- and macro-levels.

The overall data management process included the use of tools to organise data in multiple ways including use of Microsoft Excel and Word, mind maps (Prosser & Loxley, 2008; Reason, 2010), NVIVO, note taking (Kid and Parchall 2000), spider diagrams

(Punch, 2017; Reason, 2010), and Statistical Package for the Social Sciences (SPSS). These will be discussed below.

Analysis was an iterative process through the stages of the project. The analysis of focus groups utilised framework analysis (Gibbs, 2011) of care situations. This analysis was then used to produce vignettes employed in interviews, which were subsequently managed in NVIVO and subjected to thematic analysis (Silverman, 2011). Reconvened focus groups utilised thematic analysis and interviews from Professional Participants utilised NVIVO to manage data and employed thematic analysis. Quantitative analysis utilised Microsoft Excel to manage data for descriptive statistics, and utilised SPSS and thematic analysis (Silverman, 2011) for the answers to the open-ended questions. Photographs were analysed utilising spider diagrams (Punch (2017) and comparative analysis was employed to look at similarities and differences (Gibbs, 2011). The photo elicitation themes were cross referenced, examining issues such as assistive devices and types of services and triangulated with other data in areas such as QoL and environmental factors to ensure that the wider system perspective offered by GST was being built.

Methodology

The thesis aims to understand older people’s attitudes, behaviours, and perceptions related to decision-making processes about care in later life. It also intends to understand the underlying phenomena of why people take up particular services, what is important to them and what guides their decisions about how to pay (or not) for care. It has a focus on people’s wishes, the complexities of decision-making from their own viewpoints, the contexts of daily lives, the environment and the policy regime in Scotland. The research also examines the relationship between decision-making and QoL. The research explores the relationship of choice on the decision-making process.

The research was purposefully limited to one local authority to reduce external variables as local authority contexts differed. Each of the thirty-two local authorities may have implemented policies differently. Services that might have been covered by one local authority might not have been covered by another local authority (Bell et al., 2007; Bell et al., 2006).

Research Questions

The research is directed by the following questions:

- ✓ *What are the attitudes, behaviours and perceptions of older people as they set out to fulfil their needs for care and support?*

- ✓ *What influences older people's decision-making about which services they use?*
- ✓ *What is the relationship between quality of life, and the decision-making process?*
- ✓ *What environmental factors come into play?*
- ✓ *How does current policy in Scotland influence the choices available to/made by older people?*

The attitudes, behaviours and perceptions of older adults will be explored from the views of older adults, carers, professionals and family members. Environmental factors are defined as anything that influences or changes the environment and include relationships, support networks, financial implications, environmental issues (that relate to a person's social or physical environment), transportation issues, or how people learned new skills or acquired new knowledge. Velzke (2016) discussed a number of environmental factors and this is explored in additional detail in Chapters Four-Six.

Mixed Methods

The study has employed a mixed methods methodology with a collection of multiple types of data through various stages of the research process (Teddlie & Tashakkori, 2006). The project included mixture of quantitative, qualitative, visual, and participatory methods. Moran-Ellis et al., (2006) reported mixed methods were "the processes by which methods (or data) are brought into relationship with each other (combined, integrated, mixed)" (p. 45).

A mixed methods approach allowed for an expanded understanding to address the complexity of the issues and added additional strength and insight (Creswell, 2009; Leech & Onwuegbuzie, 2007). It also allowed the capability to ask confirmatory and exploratory questions that verified and generated theory in the same study (Teddlie & Tashakkori, 2006). Qualitative components included the use of focus groups (Kidd & Parshall, 2000), semi-structured interviews (Andersson et al., 2006), vignettes (Hughes & Huby, 2002), and photo elicitations (Gotschi et al., 2009). Photo elicitation incorporated photographs in an interview (Harper, 2002) and quantitative components included two measures of QoL assessments and a DEMQOL (Dementia Quality of Life) evaluation.

Mixed methods were utilised to capture deeper meanings in care decisions as a result of the Research Questions. Kus (2003) reported that the use of quantitative or qualitative methods should be based on a suitability established from the research problem. Many mixed methods designs required combinations of methods and strengths to answer research questions (Prosser & Loxley, 2008) and Rubin and Bellamy (2012) commented that qualitative data gathered new insight, a deeper understanding of individual experience, and tentative insights that were riskier to generalise. On the other hand, quantitative data produced more objective statistical findings that were easier to generalise. The integration of mixed methods (Moran-Ellis, 2006) was identified early in the project to address the multiple research questions, and varied types of data collection needed to answer the proposed questions.

For example, Leech and Onwuegbuzie (2007) reported quantitative research is not appropriate in answering how and why questions (such as how policy affects older people's choices in care) and that it is qualitative research that addresses process oriented questions (such as how people make decisions). As such, investigation during the second year of study confirmed the inclusion of vignettes and photographs for additional data collections and triangulation on how people made decisions about care.

Rubin and Bellamy (2012) stated that qualitative research is used to answer questions about an individual's perceptions. The initial Research Question was: *what are the attitudes, behaviours and perceptions of older people as they set out to fulfil needs for care and support?* Interviews collected valid and reliable information and insights about subjective social phenomena (Sinding & Aronson, 2003). The use of additional methods assisted in gaining the participant's viewpoint.

Data Collection

The first stage in this research was the active participation of carers in focus groups for those involved in care of a significant other, friend, family member or related person. This stage gathered data from care experiences to allow work on creating vignettes and updating the topic guides for interviews for the participants. The initial topic guide was updated based on focus group findings. It was flexible during the semi-structured interviews by allowing use of further questions emerging from interview dialogue (DiCicco-Bloom & Crabtree, 2006). A direct result of the initial focus groups were additions to the topic guide with some predetermined, open-ended questions, Those discussion questions explored older participants' attitudes and behaviours about paid and unpaid care, things of importance, reasons for seeking specific types of care, and guidance on decisions about care, support, and QoL. This interview guide was used to ensure relevant questions were asked and to maintain focus (Audet & d'Amboise, 2001).

The second stage comprised of interviews with fifteen older people. This included an initial interview and a follow up interview three weeks after the primary interview.

This incorporated use of a vignette with a story/scenario (see also Appendix A) of an older person who faced the need to express care choices during the initial interview session. A quantitative general World Health Quality of Life (WHOQOL) scale and a DEMQOL evaluation were also conducted during the first interview session. The WHOQOL scale (WHOQOL, 1995) measured general QoL and the DEMQOL evaluation (Smith et al., 2007) measured services and older participants' abilities to complete personal care and mobility tasks. Older participants included individuals with dementia and AD. This DEMQOL was given to all older participants, even those without diagnosed dementia so all participants had a standardised measure of activities of daily living. The WHOQOL assessment (QoL scale) was administered once during the first visit with OP, and once again during the final visit.

Vignettes were used to improve data quality by decreasing social desirability bias (Hughes & Huby, 2002). Social desirability bias (Fernandez-Ballesteros, 2011; Puhan et al., 2011; Rubin & Babbie, 2008) means a skewed report by participants and was reduced in reporting bias when questions were asked, rather than when self-reporting. Older participants were verbally asked all questions in this project in an attempt to minimise this bias of self reporting. Trigger et al. (2012) used brief vignettes from research experience to argue the methodological significance of memorable events encountered in ethnographic studies. They reported the play on emotion to use vignettes to trigger thoughts in the moment which simulated decision-making situations from the older participant which was similar to experiences in this research project.

The interview schedules and vignettes provided ways to understand how people acted when faced with care decisions in response to life risk situations and dilemmas. The use of vignettes simulated discussion of the decision-making processes to get more accurate data in a safe, non-threatening manner. To get to the crux of the issues addressed in the project, it was necessary to engage with participants in the moment of decision-making processes. The vignettes were particularly helpful for this.

Hearing other peoples' stories, as represented in the vignettes, appeared to trigger personal memories and emotions of participants. At times, the decision-making associated with the scenarios was emotional for individuals. Moore and Hollett (2003) suggested catching people (with dementia) close to actual situations to recall details of interest. Vignettes were thought of in advance to be a possible alternative when or if that was not a possibility. Cognitive levels of participants and the abilities of those participating impacted information recall. All participants were able to fully participate within this study; however, in future studies this could be an alternative method.

A camera was also left during the first older participant interviews with directions (available upon request from the author) and discussion about taking pictures of things the participants thought affected their QoL. A second meeting was arranged approximately one week after the first interview for camera pick up. The final older participant interview was set approximately three weeks after the initial interview to discuss the photographs, complete the second QoL scale, and to answer any follow up questions that remained.

The next stage of the study was the Professional Participant (PP) interviews that were conducted as the OP interviews were being completed. One professional interview meeting was conducted per participant and their roles, content and importance were emphasised. Snowball sampling, a non-probability sampling method was utilised where the researcher started with interviews, and then had assistance with locating additional participants (Rubin & Bellamy, 2012). This was initiated for recruitment in a purposeful sampling technique to get a selection of participants from each of the care representations that the participants utilised within the local authority which continued to the point of saturation.

The final stage was the reconvening of the focus group near the end of the study for review of findings that were recognisable to participants. Figure 1 (created by the Researcher) identifies the timeline and sequence of research from start to finish. This includes the initial focus groups, then the series of the interviews with the OP and the PP.

Figure 1. Research Timeline

Next came the second meeting with OPs with leaving the camera. Then, the second follow up interview with OPs. This concluded with the reconvened focus group.

Participants

There were three sets of participants in the study. Ethical approval to complete this project was granted from the University of Stirling's Ethics Committee (see Appendix B). First, there were focus groups which included two initial focus groups with carers at the start of the project, and a reconvened focus group at the end of the study. Then, there were the participants themselves. A third set consisted of professional people. The consent papers, that guided discussion for each of these participant groups, are available upon request.

Focus Group Participants

There were three focus group meetings involved in the research. The groups consisted of two initial focus groups, and a reconvened focus group. Initially, two pre-established groups met separately to discuss care experiences. Nine participants in an Over 50s Lunch Club and ten participants in a volunteer network support group participated (see also Appendix C for Agenda and Timeline Activity). These groups met regularly, so improved rapport amongst members was likely. This influenced some of the increased quality of participant responses and increased engagement in the research process. The relaxed atmosphere and existing rapport were evidenced by participants' willingness to share experiences and speak in a straightforward manner.

One reconvened group, at the end of the research process, had twelve participants, including the original nine from an initial group, with additional members not at the initial meeting from the over 50s lunch group. Reconvening the focus group allowed for findings to be presented to the same focus group for feedback. This was pre-planned as part of the participatory approach to get participant feedback on the research process.

Focus groups were selected in favour of interviews at this stage because of the specific interactions and conversations between participants. The focus groups explored experiences and encouraged difficult conversation in a variety of ways that might have been underdeveloped in interviews (Kitzinger, 1994). The value of focus groups was in the opportunity to see how people engaged in collective 'sense making' of how views were constructed, expressed, and changed during conversations (Wibeck et al., 2007). This was also part of a GST framework looking at systems from a group perspective to gain a broader holistic perspective that the group process provided.

Older Participants

Fifteen older participants (OP) who received formal care services were interviewed and completed photographs (see also Appendix D for topic guide). They also received informal care and if they were not receiving informal care on a daily basis, they received it periodically. The oldest participant was aged 96 and the youngest was 71 years old. Table 6 lists their characteristics.

Older Participant Characteristics

Index	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Gender	F	F	M	M	F	M	M	F	F	F	F	F	F	F	F
Age	88	96	83	85	78	86	71	91	80	85	73	86	90	91	81
Residence	CH	H-HC	H-HC	H-HC	H-HC	H-AD	H-AD; HC	CH	H-AD; HC	H-AD; HC	H-AD; HC	H-AD; HC	CH	CH	H-TAD; HC
Diagnosis (Dx)	--	--	AD Dx	--	Self reports Dx- wears memory patch	Self Reports AD Dx	--	Formal Carer reported Memory Problems, no dx	--	--	Self Reports daughter/ nurse told her thought she had mild dementia, no dx	--	Formal Carer Reported Memory Problem, no dx	--	--

Table 6. Older Participant Characteristics

Residence (H=Home, CH=Care Home; HC=Home Care, AD=Adult Daycare, TAD=Therapeutic Adult Daycare)

The OP mean age was 84 years old. Four of them lived in care homes and eleven lived on their own (or resided with a family member). Of those who remained in their own homes, five attended the council day centre and one attended an eight week therapeutic day centre that had a focus on falls prevention. Out of those who lived at home, nine had a gardener (either paid or informal carers) and nine also had assistance with housekeeping (either paid or informal carers).

People with Dementia and Alzheimer's disease

There were additional considerations when working with people with dementia and AD who were older. Table 6 lists older participants with dementia and AD. The study included one participant that had a diagnosis of early onset Alzheimer's disease from a General Practitioner (GP) (OP #03) and three participants (OP #05, #06 and #11) self-reported AD, dementia, or memory issues on the first visit (and this decreased to two participants [thirteen percent] of self-reported cases on the last visit, as the third did not re-report). Additionally, two formal carers reported they suspected participants had some type of memory deficits such as dementia (OP #08 and #13). At the time of the research, no formal physician diagnosis had been given or was expected from a GP.

It was noted that, regardless of any suspected memory issues or diagnosed memory loss or AD, all participants had 'capacity' as outlined under the Adults with Incapacity (Scotland) Act (2000) to make their own decisions, and this is discussed in additional detail when discussing possible ethical issues. In addition, all participants offered ongoing consent. Velzke (2017) also detailed more about participants with dementia and AD involved in research and how this included policy in practice issues such as recommendations with more training time, more engagement time with clients and less administration and paperwork time.

Professional Participants

The eighteen professional participants (PP) interviewed were involved in a variety of care settings (see also Appendix E for topic guide). Table 7 (created by the Researcher, Velzke, 2017) lists the PP characteristics, with their role and the type of care setting they worked.

Professional Participant #	Role	Type of Care
Participant # 16	Care at Home Manager and Health & Safety Support Officer (Senior Manager) - manage frontline staff, quality monitoring and assurance and ensuring care plans are put in place and implemented	Care at Home
Participant # 17	Care Inspector -member of the team inspects all care services in Scotland	Range of Older People Services (care homes, care at home, day care, respite services)
Participant # 18	Care Home Manager- in charge of the overall day-to-day management of the home, responsibility for the supervision of the staff and the health and safety of everybody	Care Home
Participant # 19	Care Inspector - member of team inspects all care services in Scotland	Range of Older People Services (care homes, care at home, day care, respite services)
Participant # 20	Team Manager Hospital Services - manages the hospital team, including the hospital intake team who takes all the referrals for anybody that's in the hospital, who deal with all the complex discharges and manages social care officers who work in reablement and liaisons to other care	Hospital Teams, Hospital, Reablement and Assessments, discharges….
Participant # 21	Hospital Social Worker	Social Work Hospital Team
Participant # 22	Occupational Therapist/Senior Practitioner-Hospital Services	Social Work Hospital Team
Participant # 23	SDS Programme Manager (Senior Manager) -to help lead on the implementation of SDS	Self-Directed Support
Participant # 24	Senior Service Manager - oversees multiple services offered in LA	Direct Provisions Manager, Older People Services (over 65s) residential care, day care, care at home, reablement, MECS-Mobile Emergency Care Service, Adults with Disabilities, rapid support, (with a number of different services within the services); Under 65s day care, day services for adults with disability
Participant # 25	Change Fund Engagement Officer- has funding to enable older people to stay home in their own communities or in a homely setting	Range of Older Peoples Services
Participant # 26	Senior Daycare Officer - day-to-day operational management of a day support service for older people	Adult Daycare
Participant # 27	Project Manager National Technology Project-Scotland consortium of testing what works with technology and older people	Assistive Technology
Participant # 28	Assistant Service Manager -day care co-ordinator, link worker (works with people & families when somebody's been diagnosed initially to make sure they're getting the right support), runs education and support groups	Dementia Care
Participant # 29	Assistant Manager, Senior Social Care Worker-general day-to-day running of the home, answering the phones, making appointments, answering the door, supporting care workers, supporting the domestics, supporting all the staff and staff supervisions	Care Home

Participant # 30	Social Care Worker -Front Line Staff/ Carer that assesses and delivers the care to those individuals (includes administering medication)	Care Home
Participant # 31	Registered Nurse- responsible for learning and development in dementia care	Dementia Care
Participant # 32	Programme Coordinator, Change Fund - role is to coordinate relationships between organisations in SDS in the LA, programme co-ordinator for the change fund, member of the change fund support team (small group of people who are representative of the four main sectors that are involved in the Reshaping of Older People's Care agenda)	Range of Older People Services
Participant # 33	Hospital Doctor -sees older people in hospital in crisis, acute illness plus a breakdown in their ability to cope at home or a breakdown in the caring structure at home, planning discharge from acute hospital or community hospital after a period of rehabilitation; runs a multi-disciplinary memory clinic	Hospital, Dementia Care

Table 7. Professional Participant Characteristics

Interviews were conducted to investigate their perceptions of constraints and facilitators for choice embodied in current Scottish policy. Interviews with professionals included a variety of settings. The mix of professionals (see Table 7) interviewed was necessary to uncover a range of perspective within care services as well as what happened in response to legislation and policy in practice.

The geographic location for these interviews coincided within the same local authority where the participants were interviewed. These interviews allowed an opportunity to compare established models of practice and emerging models in operation and delivery of care services (Velzke, 2017). This discussed how care was perceived by older people and professionals and the 2014 launch of SDS in one local authority. This was also relevant for service delivery of care in hospitals as will be shown in Chapter Six.

The professionals were initially contacted by telephone or email by the researcher or the local authority contact person who was designated and approved by the local authority to assist the researcher to invite participation and screen for participant criteria. The professionals were recruited as a result of purposive sampling based on referrals and networking within in the local authority. In addition, this was grounded in a series of different settings of professional positions held within the local authorities (frontline carers, service providers and a range in levels of managers) in the region. This targeted, non-probability, stratified sampling method was centred on the type of care that was available (care home, in home care or day centres) as this was the type of care offered to older people within the local authority system. This was an effort to have an overall representation reflecting some generalised aspects of the larger population within a local authority.

Development of Methods, Theory and Research Philosophy

The development of methods progressed as the project progressed. A gap in the literature was identified regarding older people's actual behaviours, and this assisted in formulating Research Question One, *what are the attitudes, behaviours and perceptions of older people as they set out to fulfil their needs for care and support*. It was apparent that decision-making is influenced on multiple levels (micro, meso and macro) and a wider framework was needed, leading to GST as a guiding framework.

As the project evolved, analysis of decision-making suggested the use of conceptual constructs (Von Bertalanffy, 1972) and the lived experiences of older individuals' ideations became clearer. These conceptual constructs and the different ways they can be categorised, such as how love can be conceptualised (Drack and Schwartz 2010).

However, other concepts such as QoL were revealed to be even more complex and multi-faceted, necessitating investigation of wider systems issues. Kelley-Gillespie (2009, 2011) provide a useful discussion about how having a stroke impacts on many different parts of an individual's life and QoL, using GST to demonstrate the complexity within individual systems. Changes in the system impacted on how decisions were made to maintain a balance of homeostasis (Barker, 2003). The changes the stroke inflicted had meant that other areas such as social, financial or emotional issues could be influenced as a result and not just medical issues. To maintain homeostasis, individuals may need to make adaptations to compensate for loss in some areas, for example, by increasing levels of care or community resources (Kelley-Gillespie, 2009).

Equifinality, and the many pathways utilised to get to the same destination, which was an influential concept in understanding decision-making by older people (Drack & Schwartz, 2010). Despite facing similar challenges, older people take different pathways within their systems and make different decisions to reach the same end point. Thus, using a systems approach was important in understanding the lived experiences of older people as they set out to fulfil their needs for care and support.

The researcher has a strong social work practitioner background that has also been influenced by GST. This was evidenced by taking a number of steps to reduce researcher bias such as reading aloud the quantitative questions and working to increase participant engagement in the research process. In addition, in the middle of the interviews older participants were asked what the project was about. Some were able to identify the objectives of the research, some thought the project was designed for their needs and a few were confused and were not sure what the project was really about so some review was needed. These processes were all influenced by the researchers' social work background and training.

This research aims to offer a holistic overview of the systems that influence older people's decision-making about care. This decision to take a holistic approach was influenced by Harper's (2002) mixed methods research about dairy farms including qualitative, quantitative and visual methods to achieve a holistic view of farmers. Similarly, this researcher expanded from quantitative and qualitative methods into visual and participatory methods to achieve a holistic view, to capture the participant view and lived experience of older people. The expansion of methods was further beneficial in encouraging visual and participatory methods and reconvened focus groups that created participant involvement through photographs and for participants to become experts within the research (Prosser & Loxley, 2008). Further, this approach created the opportunity for multiple peer reviewed publications (Velzke, 2016; Velzke & Baumann, 2017; Velzke, 2017) and added depth to answering the Research Questions. For example, by having older participants take photos of things they identified as important and identifying and discussing what these were, provided additional depth to understanding the Research Questions, especially Question Three by giving more descriptive data about the relationship between QoL and decision-making processes.

General System Theory

The research employed a GST framework. There are multiple key points that highlight how GST is used within the project. These are;

1. GST utilises a whole context approach
2. GST allows identification of multiple influences on decision-making
3. GST supports efforts to understand multiple perspectives and to see how they interact
4. GST assists in tracing how processes work through the system. and

5. GST highlights the systems approach by encouraging a focus on different levels within the system.

GST utilises a whole context approach. GST was discussed as conceptualising how individual parts inter-connect and influence the overall system. This also offered an explanation on the interpretation of events on how to view the world (Drack and Schwarz, 2010). These conceptual constructs outlined intrinsic and extrinsic motivations of decision-making in the how and why that people make their decisions. Constructs offer some explanations of GST as a framework with participants in active engagement within the research in paid and unpaid care, QoL and resource utilisation that directly and indirectly influences relevant and personal situations.

GST allows identification of multiple influences on decision-making. Chapter Two discussed GST as focusing on how individual parts inter-connect and influence the overall system. It also included an interpretation of events on how to view the world. For example, in QoL, the interconnecting domains have many inter-relationships that are influenced overall by changes within one small part (Kelley-Gillespie, 2009). The author gave an example of an individual who had a stroke and the far reaching areas this would influence beyond the medical concerns. There are several examples of factors that influence QoL; Tanner et al. (2018) reported on broader factors, such as paying for care themselves which explored issues holistically on how this influenced outcomes, and examined experiences and relational factors of how individuals met their care needs when they did not qualify for social care and self-funded social care.

GST supports efforts to understand multiple perspectives of older people and to see how they interact. As a result, the research examined many small parts that formulated an overall, broader view of decision-making than what was presented in the literature. This expanded systems issues into a bigger picture and into more holistic broader perspectives. GST concurred with reviewing the broader perspective of external relationships (Kirst-Ashman & Hull, 2012) on decision-making perspectives of older people on how they interacted with each other, as well as professional perspectives and carers' perspectives for an overall systems view of QoL, care, support and resource utilisation. Chapter Two reviewed an example from the literature of where someone would want to live, and some of the influencing factors related to this decision. It was about family, carers, support systems. professionals and support networks as well as the individual. Similarly, Thorton, (2000) stated health and social care were only part of the broader picture that influenced QoL. How individuals worked to maintain homeostasis was unique for each individual depending on the care and support that was available, and looking at the overall bigger picture from multiple perspectives provided clearer understanding on how decisions were achieved.

GST assisted in tracing how processes work through the system. As previously discussed in Chapter Two, the literature suggests that individuals navigated through systems and yet achieved the same end results, demonstrating equifinality. Older people were seen to make decisions that enabled them to reach a place of balance; that is, to regain homeostasis within their care systems. Changes in QoL could be indicative of a loss or gain of homeostasis. Many issues in turn, influenced individuals' decision-making to maintain a homeostasis balance as they navigated through multiple systems.

GST highlights the systems approach by encouraging a focus on different levels within the system. The research demonstrated that there are many influencing factors that impact on how older people make decisions. The GST framework examined issues on a multi-tiered systems level, including exploration of micro (individual), meso (group), and macro (community) levels (Kirst-Ashman & Hull, 2012). Because of the range of data collected it was possible to examine the overall phenomenon from multiple perspectives and to collate and aggregate data collectively to support a broader systems perspective. Chapter Seven discusses this GST concept and decision-making in additional detail on the micro (individual), meso (group), and macro (community) levels (Kirst-Ashman & Hull, 2012).

Active Participant Framework

This research utilised an active participant framework (Phillips, 2007). Decision-making has long been an ongoing literature discussion at the levels of individual participation, especially in health related disciplines (Vahdat et al., 2014). This was often lacking in the healthcare system. This thesis investigated decision-making from the perspective that it was often encouraged and suggested to empower participation from older adults. Researchers (Elliott et al., 2016; Vahdat et al., 2014) shared multiple ways to engage older adults in decision-making about care. Engagement is one way for individuals to get back to homeostasis.

Participatory analysis approaches are reportedly used less often than other methods (Nind, 2011). Nind (2011) highlighted a challenge in finding scarce examples of participatory interpretation, limited data analysis, and lack of basic validation techniques of member checking. Velzke (2017) discusses the merits of utilising a participatory approach that includes a lesser used method of member checking.

Active participant frameworks mitigated against negative perspectives e.g. the idea of not ageing well. This research has explored ways active participation assisted in decisions that profoundly influenced people’s decision-making and QoL, including participatory methods within carer focus groups and older participants. The researcher and focus group participants created research tools and those participants participated in analysis. The older participant interviews used visual methods (individuals took photographs of things that influenced their QoL).

This research was set up to explore whether older adults were actively involved in decision-making in care. This included exploring the levels of involvement in care decisions and the research process. The participatory approach promoted rebuilding participant knowledge in a way that encouraged understanding and empowerment (Bergold & Thomas, 2012). Participatory and visual methods increased participant involvement of those deemed “unsuitable” for traditional research processes due to physical or cognitive limitations. Velzke and Baumann (2017) and this research outlined ways to enable participation and implications for direct practice situations as a result of the project, as well as demonstrating ways to empower older adults with higher care needs to become more active in the research process.

The initial focus group was convened to assist in development of the research tools. The data from the focus group directly influenced creation and refinement of the research tools (vignettes and interview questions). This thesis, therefore, has included data from interviews, focus groups, visual methods, and the reconvened focus group that assisted with the review of the research results in the analysis process.

Focus Groups

Two lunch club focus groups met at the start of the project. The main goal of the focus group was to gather data for three vignettes that reflected similar situations to those in the focus group (see Appendix C for agenda and timeline activity). Velzke and Baumann (2017) discussed this research and one participatory method of focus groups and data that was transformed into vignettes, which were used in the OP interviews. The first vignette (see Appendix A for vignette listings) described a woman in the home setting and changes in independence and care needs. The second vignette detailed a man, who resided in the home setting with changes in independence and needing care. The third vignette listed a woman who resided in a care home and discussed some changes in independence.

After review of the common themes from the focus group data, topic guides proposed for older participant and professional interviews were reviewed and changed accordingly. One emerging area of interest, that was not explored prior to the focus group, was assistive technology and assistive devices and added to the interview guide.

Visual Methods

Another participatory method used to capture what was important to older people in fulfilling care needs was photographs. This participatory method also encapsulated support, relationships between QoL, decision-making processes and resource utilisation. This was to gather literal snapshots of how people decided to live their lives, from an older person's point of view. This was completed by individuals (or on their behalf if they had physical limitations).

GST consistently looks at the overall system. Photos captured overall snapshots of a broader picture that included decisions about how and where older people lived. QoL was also subjective. It was unique to each individual as individual photos varied between perspectives and interpretations with some main themes emerging. For example, OP #03's view was important to him and is discussed later in this section through the photograph of his view out his window. Other participants might not have had a concern about views but had a preference about living closer to family or closer to community resources.

One advantage of photographs during interviews was the ability to engage and improve communication with participants (Kolb, 2008). The photographs served as prompts for some individuals for discussion points to further explore what was important to them and revealed thoughts, and behaviours. Photographs that used participant images assisted in empowering participants in ownership of the data and to share stories to gain different perspectives (Prosser & Loxley, 2008). The older people were able to pick the topics and they were not limited to what was in the photos for discussion; they were free to discuss subjects of their choice. There were no parameters to the discussion. Individuals were able to self-dictate the quantity of photographs to ensure nothing would get overlooked which was similar to communication practice of Moore and Hollett (2003). They suggested research in nursing practice for people with dementia should catch participants in the moment to trigger thought processes.

A challenge with interviews relates to how non-verbal meanings are, often, left out of conversations (Prosser & Loxley, 2008). This is important for vulnerable populations and those often overlooked in the research process and it is necessary to seek alternatives. Thus, the use of mixed-methods was more inclusive of disadvantaged populations. For example, this photograph, Treasured View from Front Window, (Figure 2) was taken by OP #03. He was recently diagnosed with Alzheimer's disease (AD), and he was able to articulate thoughts and feels better on some days than others. He reported that this view offered him feelings of "contentment…happy feeling…interesting to watch the different seasons change." The photograph stimulated conversation that he would not reside where he did if he had a view of "houses or factories." The photograph pulled together information that he did not initially report. He also spoke of "a very nice situation and a lovely view" and said it was nice to see farmland.

Figure 2. Treasured View from Front Window

There are many non-verbal messages communicated in this conversation and if there had been a focus only on verbal linguistics (Prosser & Loxley, 2008), much non-verbal communication might have been missed. For instance, some things were inferred that were not directly discussed. This participant had the time and means to be able to look out his window. He had options to have a choice about where he lived. It was important to him to remain in an environment that was not surrounded by other houses or factories. He preferred privacy and a view. He was also interested in watching the changes of the seasons from the window. He might have spent most of his time at this window as opposed to other windows in his home. He was satisfied with where he lived as he reported contentment.

The visual data had a theme that was unique and not openly discussed in other areas of the research. The majority of OP, (60%) discussed the importance of their views during photo discussions. This referenced views outside a favourite window and views from property or where they resided. This influenced QoL, decision-making and where individuals resided.

Photographs expanded the empirical value and revealed feelings, information, and memories highlighted as a result of the image (Harper, 2002). This looked at individuals' situations in a broader context and opened up conversation for exploration. This was consistent with GST looking at a holistic, overall perspective of multiple issues of influence within a system from individual perspectives.

Reconvened Focus Groups

This project had the initial focus groups reconvene for a follow up meeting. One reconvened focus group met with twelve participants (see also Appendix F for topic guide). Nine of the participants were from the original lunch club group. Thomas and O'Kane (2006) revealed that individuals (children) were offered opportunities to interpret data by having multiple sessions to review and refine what was said. The research project used the focus group processes in the same manner with data from interviews.

There was a topic guide with six areas of discussion, (see Appendix F) that resulted from the main themes extracted from older participant and professional findings from the research project for the reconvened focus group. These were pre-planned and worked into discussions in the reconvened focus group. These areas had emerged directly from data findings from participant interviews and photographs. This discussion was important to the analysis process as the researcher was able to evaluate findings in greater detail. Thus, perspectives that were not previously considered emerged. Additional inquiry was generated to be followed up after the reconvened focus group concluded with additional analysis. There did not appear to be any gaps in the findings as reported in Velzke and Baumann (2017).

Reconvened focus group participants received a summary sheet outlining research findings and had discussions about the overall project findings (available upon request). Similarly, Evans and Kotchetkova (2009) used in-depth interviews, roundtable workshops, and reconvened focus groups to investigate how clients, carers and lay citizens evaluated treatment for Type I Diabetes. This sheet stimulated the start of the conversation.

Ethical Issues

Research was not conducted with participants who could not offer consent. Wiles et al. (2005) have argued that research should not be carried out with people who lack the capacity to give consent if there was opportunity to conduct the research with those with capacity. The project was participatory oriented in methods. As such, there was additional care given to the informed consent process and what the project was about as the researcher was also interested in the thought process of older adults. This was because it was an investigation into older people's thought processes, decision-making, and reasons they wanted to be involved in the research. Informed consent was thought out in how the project would be presented to participants.

The validity of informed consent is a multi-step process that requires educated decision-making. "The term 'informed consent' stems from a legal doctrine in the United States that consent to treatment will only be valid if patients [clients] have been given the information that they need to make an autonomous decision" (Jamieson & Victor, 2002, p. 214). Informed consent in this research process also required necessary information, in addition to other considerations. For example, Wiles et al. (2005) suggested that informed consent means that participants should receive:

> "**adequate information** (so people know what they are consenting to); **voluntariness** (so people are aware they are under no obligation to participate and have a right to withdrawal at any stage); and, **competence** (that potential participants are capable of understanding what consent will entail and of deciding whether or not they wish to participate)." (p.1)

This required a multi-part process in which all criteria were met for consent to be valid. Therefore, without all three parts, consent was not a binding process. Capacity was regulated by Adults with Incapacity (Scotland) Act (2000) (Scottish Government, 2008a); medical diagnosis, and inputs on memory issues granted by individuals, professionals, carers, family members were assessed by the researcher.

Older participants were asked, in the middle of the research project, what they thought the project was about. They had varied responses on how they interpreted the research (accurate aims of the project, personal to them, or rather vague), and some other motivations were revealed for participation in the project.

Some participants had a diagnosis of dementia but retained the capacity to make their own decisions. Those not retaining this capacity were excluded from the study.

Conversations with participants, professionals, carers, and family members occurred regarding individual's abilities to make decisions throughout the research process. As part of recruitment, staff spoke with individuals and verified records to see if they had met research criteria of being their own decision-makers prior to recommending them to the researcher for the study.

Gatekeepers were involved in interviews for people with, and without, dementia and AD. Two older individual participants had spouses present as per their preference during interviews (with and without memory issues). Not all married couples had a spouse present for the interview. Others had carers present for one or more of the visits. Those carers were part of the discussions during the research.

It was also noted that, after the initial interview in the home setting, one interview with OP #02 resulted in a follow up interview in an alternative setting of a hospital. This final interview was given additional consideration to consent as compared to the first interview because the participant had been a hospital admission during the interview time (changing the vulnerable status of the participant). Additional authorisation was given by family and professional gate-keepers; it was both the participant and family's wish (and reported to be in the best interest of the OP) to complete the interview in this setting rather than home after the release date. This practice was consistent to the researcher reporting that additional considerations were necessary when participants were under the influence of medication or in settings such as hospitals because of the change in vulnerable status. The interviews and vignettes followed proper ethical guidelines and maintained ethical integrity of the research (similar to Hughes & Huby, 2002).

Data Analysis

Data analysis used analysis tools that assisted in supporting the overall analysis process. These data consisted of focus group transcripts, photographs taken by older people, participant interview transcripts, quantitative QoL scale data, and reconvened focus group transcripts.

Analysis Tools

Several tools assisted in the analysis process and this included note taking, spider diagrams, mind maps, NVivo, SPSS, and Microsoft Excel.

Note taking was beneficial for recording non-verbal body language and debriefing or discussing the productive and non-productive part of the focus group or interview (Kidd & Parshall, 2000). This was particularly important during one professional interview in the local authority. During a discussion about a proposed care village, the professional offered praise to the project while shaking his/her head and waving her hand back and forth (indicating that he/she may not have agreed). Sinding and Aronson (2003) reported implications in interview practice with participants that set boundaries showing signs of ‘don’t go there.’; that there were times needed to retreat from pursuing additional detail similarly to this professional interviewed. Notetaking was helpful in this case. This participant waved their hand indicating they did not want to talk about it.

Marshall (2002) reported multiple coding strategies and general guidance about the importance of using memos from the start of the analysis which assisted in transitioning between the logic of a subject and theoretical levels. Coding is the process of categorising data into assigned categories (Barker, 2003). Notetaking was also helpful during discussion of photos. Marshall also stated ways to enhance reliability and trustworthiness of coding by describing real situations and dilemmas in coding and how they were managed. This was helpful regarding higher levels of emotion and tears. OP #11 discussed all she had to give up as a disabled person and was tearful, showing a higher level of emotion showing this was important to her. Marshall detailed several step by step plans to code and this project blended those ideas into a plan that fitted the research and adapted to the research questions. Note taking was also beneficial when technical issues arose and the recorder had issues with sound quality and batteries, and notes were relied on when sound was unknowingly indistinguishable.

Spider diagrams were used throughout the research process to map out concepts, to review literature findings, and for analysis. This was helpful during visual analysis and photo reviews. Spider diagrams also helped to triangulate data from multiple data sets into themes as seen with Figure 8 (photo) and explored the meaning of photographs after the interviews were concluded with topics such as Mobile Emergency Care Service (MECS) and QoL. The researcher created spider diagrams based on the data from discussions of photographs. Spider diagrams and visual mapping occasionally appeared in publications and were more prevalent in the process used prior to the final written publication paper (Reason, 2010). This visual mapping was also advantageous in the literature review stage of the project with mapping out concepts and tracking searches. This use of visual mapping in this project was effective from the conceptual stage of the research proposal through the literature review stages as the project progressed through analysis with visual methods utilising the spider diagrams.

Notes taken during the interview were utilised while the researcher created the spider diagrams for each participant. The images and further discussion were valuable in understanding the relationship between QoL and decision-making. The photos were what individuals identified as influencing their QoL and clarified their perceptions as the first Research Question indicated based on their attitudes, perceptions and actual behaviours. Many researchers have utilised spider diagrams in analysis. Nind (2011) employed spider diagram in analysis with reconvened focus groups and (Punch, 2017) utilised spider diagrams in having children create pictures. Prosser and Loxley (2008) reported on the dynamic relationships of how images were read and used. They cited Rieger's visual research in 1996 that used an empiricist approach of internal comparative analysis. As each spider diagram was created for this project, it was compared to previous diagrams that had already been completed to compare similarities and differences between participants.

Mind maps demonstrated 'particular forms of knowing' in a visual projection that allowed a holistic overview. This was helpful in mapping out data and the environmental factors as the research progressed, and the relationship these had to other systems. Reason (2010) examined the use of creative and visual approaches by utilising mind maps (graphic and interactive with technology) as a research tool in practice-based research. Reason (2010) also reviewed its holistic value in working through and understanding research materials.

NVIVO was used for data management, interview coding, and analysis and it was used for grouping data into themes and categories. As each new participant was coded, NVIVO software (through the use of reports, and charts), monitored data changes. This assisted in the research process in the overall monitoring of data and in the reflection of the development and progression of themes along with the reflective research diary.

SPSS and Microsoft **Excel** was utilised for the analysis of the WHOQOL scales. The demographics for the participants were also managed in Excel sheets, as were DEMQOL data. Descriptive statistics were pulled from these data pools. This has explained in additional detail in the quantitative analysis section of this chapter p. 77. The WHOQOL scales employed a combination of SPSS and Excel.

Focus Groups and Framework Analysis

Framework analysis was employed in the analysis of focus group data. An overall view (consistent with GST) of how individual's overall care experiences progressed from start finish was explored. **Framework Analysis** (Gibbs, 2011) is a hierarchical thematical framework, which classified and organised data according to key themes, concepts, and emergent categories. This was employed in the analysis of participant storytelling. Each main theme had a matrix or table where each case had a row and columns representing sub-topics (consistent to Barnard, 2010) from the start of care and progression to daily care, onto 24 hour care seven days per week with appropriate levels of care for the measured experiences (called timeline activity to participants, see Appendix C).

This mapping exercise was given to focus group participants as part of the framework analysis that participants completed on their own or the researcher filled out for them as they talked about relevant experiences with the group process. The data gathered basic (voluntary) demographic information, details about the relationship with the person (or people) they were involved with in care decisions, details about how the process of needing care started, and the care progression (if it did progress). There was also space available for other thoughts and observations.

Data were transposed thematically from the mapping exercises in each of the areas of care. Frameworks were set up in vignettes based on themes as one for initial care, one for daily care, and one for a higher level of care, and then analysed thematically.

Thematic Analysis

Thematic analysis (Silverman, 2011) was used on data collected from reconvened focus groups and interviews. Focus group data were collected from the templates that the participants completed and these assisted in the creation of vignettes used during the initial interview with older participants, and these data were analysed thematically. Wibeck et al. (2007) suggested the researcher generally categorised the material at the content level and analysed recurrent and clusters of themes when analysing empirical data. This is demonstrated within the project in the next section.

After the data were gathered, responses and categorised ‘key passages’ (Silverman, 2011) were typed up in categories. The categories were framed by how care started, evolution to daily care, and progression into full time 24/7 hour care. The researcher identified the key issues in the care during each at the time of start of care, daily care, and full time care from the discussions by theme. Then, based on the data and situations, the themes were combined into sentence form for stories for the vignettes. The vignettes were read to OP as written, based on focus group data.

The research considered the validity of the vignettes, which were found to be recognisable to participants (Velzke & Baumann, 2017). For example, OP #11 in the home setting stating immediately after the vignette, “Yes, you want your own independence…yes, yes… [agreeing independence is important and wanting to live at home for as long as possible]…I’ve been in respite now and again. You know it’s no’ for me.” The validity of vignettes was also confirmed in the reconvened focus group discussions.

The topic guide for these interviews was updated based on focus group findings with some predetermined, open-ended questions. For example, one area added was assistive technologies and devices that were not previously considered. It was found to be an important area of support that offered older people additional options to help them stay at home.

Data on QoL was enriched in other ways too, as there were also carers in the focus groups that had experiences of direct pay systems that were different from those of the participants. This influenced the topic guide about choice, preferences, quality of care, navigating systems, decision-making styles, and person-centred care options. This gave a richer perspective on influences as to how policy may or may not influence choice. In terms of the global perspective of the research project, this was key to supporting choice and influencing factors affecting decisions in care.

Interviews were recorded, transcribed, and analysed for key themes (Gibbs, 2011). Initially, the researcher read and coded the transcripts. During this process, the researcher clustered groups of themes together and linked examples of raw data to illustrate each theme associated with the transcript and line number (similar to methods in Fade, 2004). In addition, similar to Mauthner and Doucet (1998), the researcher benefited from reading and reviewing transcripts and audio prior to analysis in order to improve comprehension of each participant.

The first step was to read transcripts prior to starting the coding process even though the researcher conducted all interviews. Mauthner and Doucet (1998) reported that this process reduced the risk of confirming what was already known about the participants. Typical analysis divides transcripts into themes, and traditionally codes data collectively whereas, “tracing voices through individual interview transcripts, as opposed to linking themes across interviews, helps maintain differences between respondents” (p. 19). A research diary was kept during this process and incorporated reflections of each participant coded, themes reviewed as interviews and analysis progressed and use of member checking processes in the reconvened focus group. Member checking is “a strategy for improving the trustworthiness of qualitative research in which researchers share their interpretations with the research participants to see if the participants indicate whether the interpretations ring true to them” (Rubin & Bellamy, 2012, p. 339).

Velzke (2017) described a theory building approach for the SDS data. The coding process was updated and codes changed as each new participant was classified. Older participants were coded first and then, when coding started for PPs, a list of codes had already been generated to start the process from older participants.

Participant Interview Themes

Eleven primary themes emerged from the data after completing the initial open coding in NVIVO with OP data from interviews. This meant as each interview was classified, the codes were re-evaluated during the progression. These themes were options and choices in care, paid care, relationships, support networks, assistive devices, help if something went wrong, tasks older people do independently, things they were no longer able to do, independence, where OP want to reside, and QoL (see Table 8).

Older Participant Themes		
Primary Themes	**Secondary Themes**	**Themes that Overlap**
options and choices in care	co-ordination of formal and informal care	OP are no longer able to do
paid care	not getting the services OP want	QoL
relationships	self-paid care and services	tasks OP do independently
support networks	what is good care	assistive devices
assistive devices	complain	where people reside
help if something went wrong	how find out about services	formal care
tasks older people do independently	typical day and activities	things no longer able to do
things no longer able to do	community group or activity	independence
independence	fear or dislike of care homes	support networks
where OP want to reside	happiness	relationships
QoL	social isolation	options and choices in care

Table 8. Older Participant Themes

These themes were guided by the Research Questions, and themes were updated from the data as this progressed, which resulted in three main themes of care, how people make decisions, and QoL.

There were also eleven secondary sub-themes that were of interest as listed in Table 8. These were co-ordination of formal and informal care, not getting the services OP want, self-paid care and services, what is good care, complain, how find out about services, typical day and activities, community group or activity, fear or dislike of care homes, happiness, and social isolation.

Many of the themes that emerged were categorised in more than one themed area, as listed in the third column of themes that overlap. This was to be expected with taking multiple ideas and weaving them together into a larger picture. Consistent to GST, the parts were inter-related and affected more than one system. For example, the theme of things participants were no longer able to do and tasks that participants did independently were a struggle to place as they might have been relevant in more than one system. The theme of things participants are no longer able to do, seemed to have more influence about how and why decisions were made. Some passages were coded in more than one area, and some sub-nodes were combined in other nodes as the research progressed.

Resources and environmental factors that made up for deficiencies were other areas that were found to assist participants to maintain the homeostasis process within the theme ‘Tasks OP did independently’ which detailed supports which were in place to maintain independence. For example, walking was done independently if they had a Zimmer (they needed no other person to assist) and could influence whether they remained at home if they lived alone. Issues of independence and how they supported homeostasis both affected how they made decisions. This is discussed further in Chapter Four and also impacts QoL. There was evidence of some themes that overlapped even if they were not coded accordingly. For example, *Assistive Devices* might have been included under *QoL*, but might not always end up coded in that way. This was also evidenced in *Where People Reside* as this linked to *QoL.* The same was seen in *Formal Care* as this was linked with things *No Longer Able to Do,* but was not always directly reflected in a consistent manner directly from participant viewpoints. The overlap went into multiple systems and fitted into multiple areas of the lived experiences of individuals, as the participants worked to balance homeostasis.

The same coding process was utilised with PP as with OP and codes were compared as each additional participant was coded.

Visual Analysis

Transcripts of the photograph discussion were not verbatim, as an alternative note-taking approach was taken although all interviews were recorded. Photographs were shown to individuals in the order they were taken for discussion. As Collier and Collier (1996) highlighted, looking at photographs created a model or sequence of events and enabled comparability. This was particularly true in the case of OP #05 as her photographs tracked the healing progression of her wound. This is described further in Chapter Five. The progression went from being bedbound to her mobility. Examining photographs in the sequential order they were taken was helpful. Comparisons were also made between participants as themes from initial interviews were already completed and themes from the interviews emerged from these initial meetings.

Comparative analysis (Bohnsack, 2008; Gibbs, 2011) was used to identify the similarities and differences within photographs and discussions. Notes on conversation during the interviews and quotes were reviewed. In addition, the photographs were examined in sequential order and spider diagrams were created for each OP and utilised in analysis to identify individual themes.

Then, the spider diagrams were utilised in the triangulation of data after the analysis of the initial interviews. Triangulation was achieved by cross referencing between data sets (spider diagrams, interview data, and focus groups) to check accuracy for participants with assistive technologies and devices, types of services individuals hired, and support systems. QoL data were also triangulated by comparing the spider diagrams to the overall themes from interviews and WHOQOL scales. This substantiated other themes already established such as the overall importance of relationships and decision-making styles as is discussed in Chapters Four and Five. Discussion and images in the visual analysis spider diagrams (drawn by the researcher) assisted with calculating what types of care individuals utilised and the technology and assistive devices operated. Individuals identified favourite places, favourite chairs, and things they were no longer able to do that they once enjoyed and these were listed in spider diagrams. The diagrams assisted in helping to understand relationships between decision-making and QoL in more detail. Additional themes also emerged as a result of the images, for example, discussion and diagrams about attending church.

Some of the photographs and interviews told a story based on images and were enhanced with narratives. An example of this was OP #05 and the visual tracking of her healing process. Punch (2017) also had participants take photographs as part of her research methods, although, she had participants write a summary for their photographs and did not verbally discuss photographs. She also had limitations because of the number of photographs (only six photographs taken), time of year, and poverty issues. These were not limitations within this research, but limitations caused by holding the camera and being homebound (also discussed by Velzke & Baumann, 2017). The researcher was able to discuss which photographs these individuals wanted, and took them for them or they were assisted by a family member.

Quantitative Analysis

Quantitative analysis included two items, the WHOQOL BREF and Part One of the DEMQOL evaluation, so measures of independence could be quantified for more universal measures between OPs. These two tools were also used to gather data to get a clearer picture of individual QoL and to understand the relationship between QoL and decision-making. These data explored a better understanding of OP independence levels, limitations and self perceptions.

The WHOQOL assessment utilised a holistic approach to measure twenty-four facets of QoL and measured multi-dimensions of QoL. The assessment included physical domain, psychological domain, level of independence, social relationships, environment, spirituality, religion, and personal beliefs (WHOQOL Group, 1995). This was consistent with a GST overview of a broad perspective. The WHOQOL BREF had twenty-six items that focused on overall QoL. General health was ranked on a five point Likert scale and covered physical health, psychological, social relationships, and environment. The rankings were as follows;

a. 1= to be very poor, very dissatisfied, not at all or never ranging to more neutral measures.
b. 2= poor, dissatisfied, a little, slightly, dissatisfied, and seldom.
c. 3= a moderate amount, neither poor nor well, neither satisfied nor dissatisfied, and the last question of quite often.
d. 4= good, satisfied, very much, mostly, well, and very often.
e. 5= very good, very satisfied, an extreme amount, extremely, completely, very well, very satisfied, always.

All questions were asked of participants verbally and included a visual representation of the Likert scale for participants to refer to for ranking answers on cards with larger print (available upon request).

Considerations for the choice of the QoL scale included an instrument that was multi-dimensional and measured multiple domains (Fernandez-Ballesteros, 2011). The researcher also wanted a scale to have evidence-based research to support and test reliability and validity with multi-cultural and multi-lingual populations. The WHOQOL Group (1995) piloted the WHOQOL assessment over four years in fifteen cultural settings with 4,500 participants and reported that "individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (p. 1403). This resulted in an evidenced based QoL assessment that was translated to multiple languages (WHOQOL Group, 1995); for example, Chachamovich et al. (2006) utilised the WHOQOL BREF with 424 Brazilian older adults and confirmed a "suitable psychometric performance" while measuring QoL in older adults. Asnani et al. (2009) reported internal consistency on the WHOQOL BREF on 491 individuals with sickle cell disease in Jamaica. Multiple individuals, in a variety of cultures, settings and languages, therefore confirmed the evidence base of the WHOQOL scale.

The WHOQOL BREF instrument was selected for the holistic approach to the QoL measures that it offered. The instrument was consistent with GST. It measured multi-dimensions and had a shortened version that was more appropriate to the older age of OP.

The DEMQOL evaluation Part One was a twenty-eight item interviewer-administered questionnaire administered to OP which was designed to measure Health Related Quality of Life (HRQoL) (Smith et al., 2007) and Instrumental Activities of Daily Living (IADLs). All IADL questions were asked verbally by the researcher. IADLs include questions regarding mobility such as walking, stooping, kneeling or crouching, sitting, getting out of a chair, climbing stairs, and reaching above the shoulder. Other questions asked about pushing, or pulling, heavy objects, lifting or carrying weights over 10 lbs/5 kilos, picking up a coin from a table, eating difficulties, and/or difficulties working around the house or garden. Personal care questions included possible difficulties with dressing, bathing, toileting, getting in and out of bed, and preparing a hot meal. Additional questions included any difficulty in using a map, shopping for groceries, making telephone calls, taking medications, and managing money paying bills and expenses.

The DEMQOL was added as it has an evaluation of services and activities of daily living that were expected to be key issues linked to perceived QoL. The physical abilities of older people varied, and often influenced QoL as evidenced by living arrangements that are often centred on mobility capabilities and influenced decision-making. For example, sometimes people who were confined to a wheelchair preferred single level living or needed assistive devices to compensate for the inability to physically climb stairs found in multi-level homes. The use of a chair-lift, or other device, to navigate steps might help people who needed assistance with stairs. The DEMQOL first became of interest because it was designed specifically for participants that might have lacked capacity and had dementia or AD.

The DEMQOL was a scientifically rigorous measure that was used with participants in all stages of dementia severity and evidenced psychometric properties that were rated among the best available dementia specific HRQOL measures (Smith et al., 2007). Smith et al. reported that, “DEMQOL shows high reliability (internal consistency and test-retest) and moderate validity in people with mild/moderate dementia” (p. 737). The twenty-eight item DEMQOL was suitable for use in the UK and underwent rigorous evaluation in the two-stage field testing with 241 participants with dementia. Mulhern et al. (2013) conducted a multi-phase study including 644 participants with a diagnosis of mild/moderate dementia and a valuation portion of 600 general population participants of which seventy-one people had dementia. “All four phases were successful and this report details this development process leading to the first condition-specific preference-based measures in dementia, an important new development in this field” (Mulhern et al., 2013, p. vi). Mulhern et al. (2013) encouraged the use of the DEMQOL along with a generic QoL measure for future studies because of the evidence of more sensitivity with participants with mild dementia and possible measures that reflected deterioration. QoL was measured with two scales, photographs, and interviews in order to formulate the overall relationship of QoL and decision-making. The DEMQOL had a focus on HRQoL. This was one reason why other measures were also put in place to attempt to capture the multi-dimensions of QoL that are in constant flux.

Microsoft Excel was used to enter data from the DEMQOL. Descriptive statistics were utilised and these are discussed in greater detail in Chapter Four. The numbers were entered into the spreadsheet and counted and computations were completed.

SPSS was used for the analysis in the WHOQOL scale evaluation. First, a Microsoft Excel sheet was created with the questions and the coded answers.

Once the data for the two administered WHOQOL scales were coded and entered in Excel, they were double checked for accuracy. The WHOQOL were also scored according to the directions to calculate the raw domain score and final scores.

Next, the WHOQOL Excel sheets were imported into the SPSS programme. They were assigned value labels to the questions and the data entered into SPSS into the specific variable sets of physical health, psychological, social relationships, and environment as outlined in the four main domains in the WHOQOL scale. The WHOQOL scores were compared between individuals on Visit One and Visit Two. There was then a collective comparison overall between participants and conversion into charts for the thesis in SPSS, Microsoft Word and PowerPoint with appropriate data were used. Questions on QoL and general health were also scored in addition to an open-ended question which was thematically analysed, “if something is wrong with your health, what do you think it is?” (p. 2) and this was completed in Excel.

The WHOQOL were scored according to instrument specific guidelines (to calculate the raw domain score and final scores). The assessment was scored and transformed to the 0-100 scale for comparison as outlined in WHOQOL scoring instructions by the researcher. Calculations were double checked by another statistician. The WHOQOL scores were compared between Visit One, Visit Two and collectively overall.

Triangulation

Moran-Ellis (2006) defines triangulation as “an epistemological claim concerning what more can be known about a phenomenon when the findings from data generated by two or more methods are brought together” (p. 47). Triangulation, or the use of multiple methods for data collection and analysis of identical topics, was used here to bolster accuracy and reliability for a more consistent, credible account of findings (Cho & Trent, 2006).

Triangulation was used to strengthen research outcomes by combining multiple methods to collect the same information (Rubin and Babbie, 2008) on QoL, IADLs and decision-making. IADLs were analysed utilising descriptive statistics and Microsoft Excel. Data were compared between psychometric evaluations of the WHOQOL BREF scale. Leech and Onwuegbuzie (2007) related, “the importance of utilising more than one type of analysis, thus utilising data analysis triangulation, in order to understand phenomenon more fully for school psychology research and beyond” (p. 557). Supporters of triangulation reported the "necessity of using mixed methods to understand the social world from theoretically driven bases" (Moran-Ellis, 2006, p. 48). GST offers a broader basis of understanding on how to view multiple systems and how they interact, exploring individuals, groups, and communities.

Some researchers used similar mixed methods to capture deep reflections of social structures, and addressed multiple realities by triangulation (Harper, 2002). Harper reported the use of qualitative, quantitative, and visual methods needed to capture the social structures of dairy farms in New York but initially struggled to capture the deep reflections needed from researcher-taken photographs and found the needed perspective through aerial photographs (Harper, 2002). The use of multiple methods and triangulation was utilised similarly as this captured the relationship *of the culture under study* in how older people make decisions about care, the relationship with QoL and resource utilisation explored in the thesis.

Chapter Two discussed QoL as a subjective, multi-faceted issue that constantly changed. One way to gain a better understanding of QoL in this project was through triangulation. One part of this study compared data from WHOQOL BREF scales, IADLs, and interviews and other evaluated data were gathered from focus groups, vignettes, photographs, and reconvened focus groups. These measures captured single snapshots of QoL but when triangulated revealed a different picture. For instance, OP reported illness, yet reported neutrality in being neither satisfied nor dissatisfied with QoL levels that offers a different perspective when looking at broader system issues. Similarly, decision-making was a complex process and needed multiple data points supporting these conceptual constructs.

QoL was triangulated across a standardised quantitative scale, through OP photographs and personal interviews. To capture a subjective topic such as QoL, triangulation was one solution to gain a better understanding of relationships between QoL and decision-making. Chan et al. (2011) suggested not all measurement scales were equivalent when compared even "…when questions are identically phrased, but considerable evidence suggests the importance for testing for it, particularly when cross-cultural comparison are involved" (p. 129). Fernandez-Ballesteros (2011) stated QoL measures often had minimal external validation with mono-method reporting when no triangulation was used in QoL measurements. As a result, one solution was the triangulation of multiple datasets when measuring QoL, such as Chock et al. (2013) methods of triangulating data utilising an interdisciplinary approach while measuring QoL in older people with cancer. Chadwick et al. (2013) also used triangulation when working with family carers and people with disabilities as well as previously discussed member checking methods. In the present study, the use of multiple methods supported a deeper understanding of QoL and captured multiple points in time, as a way to explore a fuller individual perspective of QoL.

When considering QoL scales during the first year of study, many factors of importance such as social desirability bias, and benefits of multiple data collection and triangulation were considered. Social Desirability bias reported to be “a source of systematic measurement error involving the tendencies of people to say or do things that will make them or their reference group look good” (Rubin & Babbie, 2008, p. 645). One compromise to reduce social desirability bias was having a questionnaire completed with supervision (Guyatt et al., 1993). This was the approach taken in the project when administering the WHOQOL assessment and the DEMQOL evaluation.

In response to the research questions, older people’s attitudes, perceptions and behaviours, and how they made decisions (which influences QoL), were explored within the thesis. There were many parts of investigation within the research that were multi-faceted such as: QoL, dignity, and decision-making. The purpose of utilising multiple measuring tools and mixed methods, with the aid of triangulation was to explore new ways of understanding decisions, health, and QoL from older peoples’ perceptions of daily care needs, professionals, and carers. Triangulation corroborated the validity of decision-making in multiple points of time, from multiple systems, to get a richer nuance of influencing factors that were multi-faceted.

Reconvened Focus Groups

The older participant findings were discussed during the reconvened focus group. The data were evaluated by themes and validated, particularly when it came to the times when decision-making was lacking involvement and older people needed more of a voice. This was discussed in Velzke and Baumann (2017); for example, “The concern about silenced voices of older people was validated by the focus group” (p.71).

The reconvened focus groups discussed situations where older people lacked choice and were unable to have a voice. This was an example of outcomes that were recognisable to participants in member checking and validated findings; for example, “such as the quality of care discussions about care inspectors that became the voice of those who have no families and others with and without family in care homes having no voice" (Velzke & Baumann, 2017, p. 71). One reconvened focus group member said,

> "I get that, I get told that as well when I go up to the care home to see my brother. I'm very vocal but as I said I'm his voice."

Another reconvened focus group member said,

> "That's right yes, it's like when my Aunt Margaret was alive. She wouldnae have got half the things if I hadnae went and looked into them for her, you know."

This extended into the home setting as well. For instance, another reconvened focus group member reported,

> "I know when my mum was ill she was assigned special care, they sometimes came and they sometimes didnae come so you had tae [to] fight tae get them tae come when they should have been coming. I mean there was one time it was four days and I answered the door and I went oh finally…"

There is further discussion of the reconvened focus groups in Chapter Seven.

Limitations

The researcher encountered several limitations with the sample. It is possible, for example, that the OP could have been influenced by other reasons (beyond methods) in disclosing data. They had three meetings in this project with the researcher; thus, rapport and comfort levels may have strengthened with each additional meeting. Furthermore, there were three additional members present at the reconvened focus group who were not present in one of the initial focus groups. Not having participants involved from the beginning could have been problematic as those participants may not have had the same level of understanding of the project as the rest of participants. Another limitation included a small sample size of older participants and professional participants. This would have been expected in qualitative research, and caution was recommended about generalising results. District nurses would also have been a good addition to the professionals who were interviewed as their role was mentioned once or twice during interviews and exploring this perspective may have diversified the data.

Another limitation was that the focus groups were not the same population participating in the bulk of the data collection. Having the same sample was recommended to be optimal for participatory methods; however, it turned out that the different members had influence on that data as there were carers in the focus groups who had experiences with direct pay systems that were different from the participant pool of the older participants who were interviewed. This gave a richer perspective on the launch of SDS options being implemented in the local authority area for older people. The data that resulted was important for the aims of the wider research project in supporting choice and influencing factors affecting decisions in care and this will be discussed in the following chapters. The data influenced the topic guide about choice, preferences, quality of care, navigating systems, decision-making styles, and person-centred care options.

Another limitation was the age range of the older participants. Ages ranged from 71 to 96 years old (mean= 84 years old). The project specifically wanted individuals with higher care needs (as per participant criteria of needing both formal and informal care), and this happened to be an older population of participants that came into the participant pool of candidates. The addition of relatively younger participants in each of the formal care settings (home setting, care home setting and adult day settings) might have possibly yielded different results.

Conclusion

This chapter outlined research methods and analysis. It summarised two key theoretical frameworks that underpinned the work done in the thesis: GST and participation. GST has offered a framework to help understand the complexity in the decision-making process for older people and the involvement of different stakeholders in this. GST supported the approach to data analysis that was outlined within this chapter. Triangulation of datasets was utilised to gain a better understanding of the decision-making process and the relationship this had with QoL. Participation was also a key concept within the thesis. This included the participation of older people in their own lives and decision-making processes, as well as the direct participation of older people in the research process. Participatory methods addressed the goal of inclusion, as well as offering innovative ways to directly engage with the experiences of older people. GST and participatory approaches were presented along with literature on these topics. This demonstrated that decisions made to include these approaches were assisted by prior work in the field. This chapter illustrated how these two approaches were used in a complementary manner to shape the mixed research methods and data collection in the project.

The use of a GST framework to support the broader understanding of decision-making has influenced the structure of the findings chapters which present in turn findings relevant to the micro (Chapter Four), meso (Chapter Five) and macro (Chapter Six). The micro levels were found to be ways to support individual decision-making, and will be discussed in Chapter Four. The meso levels were found to be relationships and support networks will be discussed in Chapter Five. The macro levels were found to be focused on the environment and resources and will be discussed in Chapter Six. Decision-making is a multi-faceted process as previously discussed with complex links to QoL (Kelley-Gillespie 2009; 2011) and with multiple factors of influence that raise and lower QoL for individuals and that change the balance of homeostasis. Individuals utilise multiple decision-making styles and resources which will be explored in further detail in Chapters Four to Six.

GST assists to guide and expand the broader perspectives of decision-making through better understanding of older people's conceptualised constructs and observed behaviours into operationalised categories (Rubin and Babbie, 2008). This lived experience is better understood through the process of equifinality (Drack and Schwarz, 2010; Von Bertalanffy, 1972) observed behaviours in older people to work toward a process of homeostasis. Individuals want to find a sense and place of stability of not only their physiological processes, but also to find a sense of stability within QoL and their lives as well as a better understanding of how to work towards maintaining this.

Chapter Four Findings: Ways to Support Decision-Making

Introduction

This chapter discusses how older people make decisions about care. Generally, it demonstrates that decision-making is a collective process and it explores the micro perspective of older people's decision-making. The ways in which older people's decision-making reflects their desire to remain independent, and the measures they take to support this, are considered. The use of assistive devices and technologies was investigated, as these also support independence. Finally, through the use of objective mixed-methods, the relative independence and added control of participants are considered.

Decision-making is revealed to be complex. General systems theory (GST) assisted in tracing how processes work through the system and drew attention to equifinality and homeostasis. During the research process, some older people took ownership of decisions, while others did not. This varied from individual to individual and their choices in equifinality depended on circumstance and situations. Equifinality is demonstrated by considering OPs #04 and #07. They were both well supported at home, had gardeners and paid carers. OP #04 was also well supported by his son and spouse. He was getting a wet room so he could remain in his home. OP #07 was supported by his spouse, children and grandchildren as well as many other friends and the community who came together with a pub night out to raise money for a special bed costing over £5000. Both participants were able to report a good QoL and show involvement in decision-making in different ways. Decision-making was demonstrated as a multi-faceted process, and this chapter explores the micro perspectives of decision-making processes in the chapter as individuals work to maintain homeostasis.

The data revealed many ways in which older people were supported in decision-making about care. Von Bertalanffy (1972) argued that individuals formulate conceptual constructs based on previous experiences that guide intrinsic influences on decision-making within their wider social support systems. The GST framework uses a contextual approach looking at how individuals view the world. This is similar to Glasser (1975) and Howatt (2001) in expressing the importance of intrinsic decision-making to meet basic needs. Findings suggested that the status quo was an intrinsic conscious choice for some people to refrain from involvement in decision-making (Kirst-Ashman, 2014; Sanfey et al., 2003). Others were denied options and were not involved when they wanted to be, because of extrinsic circumstances such as limited and changing levels of independence.

The complex issue of QoL affected issues such as decision-making and care. Indeed, QoL and choice appeared throughout the data. This is consistent with GST as it looks at the broader system and the overall factors that influence decisions. GST assisted in examining how processes work through the system. Thus, there are important links to explore between the first Research Question and the third Research Question about the relationship between QoL and the decision-making process. There were influencing factors that impacted on decision-making such as QoL and individual responses to crisis. This often triggered shared decision-making or assistance from others to get through challenging situations. Homeostasis fluctuated at times and was influenced by the raising and lowering of QoL. Only one participant (OP #10) deliberated about the negative things in her life and mentioned having no QoL; “That’s the worst o’ this. Quality of life? I’ve none” (OP #10, line 414 transcript #01). Others had negative issues, but they were less focused on the broader impacts this had on overall well-being. Most of the other participants viewed QoL as positive. In the visual analysis, there were specific QoL indicators from OPs that identified basic needs. In addition, findings went beyond this to identifying the favourite places they preferred in their residences (rooms), their favourite views out of the windows, favourite chairs, important people involved in their life, and favourite activities.

QoL was also explored quantitatively in four main focus areas; physical, psychological, social relationships, and the environment using WHOQOL measures. This quantitative data was integrated throughout the qualitative findings as was expected with QoL being multi-faceted (Velzke, 2016). This mixed data enhanced understanding of the links between QoL and decision-making and helped in addressing Research Question 3. GST allowed identification of multiple influences on decision-making and the interconnecting areas of systems’ influences on each other, taking a whole system view.

The qualitative data included focus group data, data from PP interviews, and OP interviews. Other data are derived from quantitative questionnaires and photos. First, this chapter explores the data on how people report decision-making. Decision-making involves the individual and, possibly, others. The individual also might elect to make no decisions at times. Secondly, this chapter discusses the ways in which older people are supported in making decisions and their perceptions of that process.

How People Make Decisions

How people make decisions includes individual and shared decision-making styles and the status quo. For some, this has a direct impact on individual care and QoL. Velzke (2017) reported on the role of individuals who supported older people to navigate systems. This paper and research considered many situations reported in the data that expressed relationships and shared decision-making. For Research Question 1, the paper reviewed how that information influences the way in which older people make decisions about care and, for Research Question 4; it examined the environmental factors that sway these decisions. OPs had many examples used for support systems to assist them in navigating systems and environmental factors that supported decision-making (Velzke, 2017). This included many people assisting in the co-ordination of informal and formal care services including spouses, adult children and their spouses, cousins, doctors, and social workers. They also supported navigating barriers through shared decision-making processes. GST was used to understand these multiple perspectives and how they interact, starting with an investigation of an individual’s level of independence (IADL) with an overview of how people make decisions, moving into examining behaviours and how decisions are made.

Individuals Levels of Independence

OPs (n=15) reported on IADLs at the time of the first visit (see Table 9, completed by the Researcher). Approximately half of the participants had difficulty in walking 100 metres, difficulty in stooping, kneeling, or crouching, difficulty walking across a room, difficulty using the toilet (including getting up or down), difficulty taking medications, and difficulty in managing money (such as paying bills and keeping track of expenses).

Instrumental Activities of Daily Living (IADL)		
Question	**Yes**	**No**
14.1 difficulty walking 100 metres	47%	53%
14.2 difficulty sitting for about two hours	27%	73%
14.3 difficulty getting up from a chair after sitting for long periods	67%	33%
14.4 difficulty climbing several flights of stairs without resting	80%	20%
14.5 difficulty climbing one flight of stairs without resting	67%	33%
14.6 difficulty stooping, kneeling, or crouching	53%	47%
14.7 difficulty reaching or extending your arms above shoulder level	93%	7%
14.8 difficulty pulling or pushing large objects like a living room chair	80%	20%
14.9 difficulty lifting or carrying weights over 10 pounds/5 kilos, like a heavy bag of groceries	100%	0%
14.10 difficulty picking up a small coin from a table	93%	7%
15.1 difficulty dressing, including putting on shoes and socks	67%	33%
15.2 difficulty walking across a room	47%	53%
15.3 difficulty bathing or showering	67%	33%
15.4 difficulty eating, such as cutting up your food	33%	67%
15.5 difficulty getting in or out of bed	26%	73%
15.6 difficulty using the toilet, including getting up or down	47%	53%
15.7 difficulty using a map to figure out how to get around in a strange place	27%	73%
15.8 difficulty preparing a hot meal	60%	40%
15.9 difficulty shopping for groceries	80%	20%
15.10 difficulty making telephone calls	7%	93%
15.11 difficulty taking medications	53%	47%
15.12 difficulty doing work around the house or garden	100%	0%
15.13 difficulty managing money, such as paying bills and keeping track of expenses	47%	53%

Table 9. IADLs

Of all IADLs, all participants reported having difficulties doing work around the house or garden, and difficulty lifting or carrying weights over 10 pounds/5 kilos (i.e. a heavy bag of groceries). These measures helped to build evidence to answer the first Research Question about individual behaviours as independence and limitations triggered the need for resources and services. This in turn led to data for Research Question 2 about which services were used. GST was used to better understand the multiple influences on decision-making. For example, OP #03 had more difficulties at times than others as he had been recently diagnosed with Alzheimer’s disease (AD) and, some days, had difficulties transferring to the commode whereas other days were much better for ambulating and getting around. He had a live-in spouse who assisted with all his needs, whereas OP #15 was also at risk of falling but had less support at home, as she lived alone but had a supportive daughter and granddaughter who stopped in to assist with her needs. She went to a therapeutic day centre. Her daughter helped her to pay the bills, and to go through her mail. She had a trolley which she used to carry her food and other items as needed. She also had multiple walkers on each floor of her residence to help her, and crutches to support her ambulation.

Each participant had different levels of independence, and met homeostasis in different ways with support networks, paid resources. They maintained homeostasis with these individual resources as QoL fluctuated and relied heavily on support systems when QoL was diminished. For example, OP #03 had his wife do more when he was unable to do much, and OP #15 had family to do more when she could do less.

Behaviours and levels of independence also influenced the types of resources used if individuals were living at home. The types of services and care needed varied from what was required in a flat or apartment. The type of residence changed the types of resources needed. These findings helped to build evidence for the second Research Question. This focused on what influenced older people’s decision-making about what services they used. This depended on multiple factors such as the type of residence they lived in as levels of IADLs for some who were more, or less capable, at times for levels of independence changed. What OP #01 needed living in a care home with care home staff and family assistance was different to OP #02 living at home with family assistance, a gardener, paid carers, and neighbours helping with her care needs.

The wider system of support had some influence as there were bigger pictures of influence to consider for individuals and their individual situations. GST supported efforts to understand the multiple perspectives and highlighted how they interacted and many small parts were pulled together to formulate this bigger picture, such as behaviours, levels of independence, and types of resources that were utilised by OPs. So someone at home needing more support, they may need the gardener, domestic help, informal family help, and paid carer as well as going to a day centre for levels of support to remain successful in the home, as many OPs reported. GST assisted in looking at wider issues that helped to see that someone in a care home had different needs than someone at home such as home maintenance and gardening.

The levels of IADLs, and how independent older people can remain, differed for each individual. The level of independence might not always have been an indicator for hiring services, as someone might have been fully capable of taking care of the lawn, for example, but might have hired someone out of preference. However, if an individual's IADLs declined and they lived in a house with a garden, the likelihood was increased that the level of care and resources they might have needed was higher than someone in a flat or care home to ensure home maintenance. This was different as there were outside chores to consider such as gardening and as QoL decreased the ability to complete these tasks on their own decreased as well. Other settings, that had less outdoor maintenance, required less individual responsibility. There was also the influence of transportation, location to doctor, medical, groceries, and other necessities linked to the residence. There are multiple issues at hand; the first is responsibility with living in different environments as well as QoL as this diminishes within these environments. GST assisted in tracing how these processes work through the system and the equifinality of decision-making that the OP indicated that there may have been more QoL considerations for some, linked to their available systems of support. OP #01 lived in a care home. She had no outdoor responsibilities. She did have a bird feeder she liked to fill as she watched birds out her window. Staff took care of all other needs, and staff and family filled this feeder for her. QoL was more than care needs. This was about what was important to individuals' lived experiences such as birds and gardens.

OP #05 had a house and was fond of her gardens as her photos indicated (Figure 9). Her diminished independence and fluctuating health were a big part of her fluctuating QoL. She was unable to manage her gardens during her recovery period, and this was left to her spouse to manage. This OP relied on her support network, (spouse) to maintain the things that were important to her (garden) when she was not able to and she returned to this activity as soon as she was able by the end of the research, pointing out her plants to the researcher.

As a result of the difficulties with IADLs, OP needed to ask others for assistance to stay in the home setting; alternatively, if unable to find support, they had to seek other care arrangements outside the home setting to maintain homeostasis. These alternative forms of support were an important consideration when deciding where to live; home or care home. OP # 14 reported she went to a care home to be closer to her family but had no other needs at the time, while in contrast OP #01 was looking for the higher level of support offered in the care home while being able to have privacy following prior negative experiences with care at home. These resources for service provisions provided data for Research Question 4 on environmental factors that came into play and their study revealed how GST supported efforts to understand multiple perspectives. These OP pathways of equifinality demonstrated how they interact for a broader view of systems and constructs of prior experiences and family influences within these multiple influences on decision-making about their QoL. One participant decided at home was not for her because of her past negative experiences, and the other wanted to be closer to family so care homes were best for both.

The research shows that some OP did not make decisions on their own and sought assistance from others for added support. This depended on their available support systems and their style of decision-making. The options might have been family decision-making or professional support if the family was not available. These decisions varied for each individual, depending on background and circumstance, as the data revealed individuals’ conceptual constructs displaying both intrinsic and extrinsic motivations of shared decision-making.

Independence is a complex issue as Plath (2009) explained; it was not enough to have an individual manage alone. There was also an emphasis on the importance of social inclusion. The majority of OP reported having informal support to assist them with guidance through systems for care services. Some individuals utilised options for increases in socialization (Sinding & Aronson, 2003). They chronicled family members making calls, acquiring equipment, getting added services, and assisting with overall care. Bowers et al. (2009) discussed independent living in the context of control and upholding dignity (Craig, 2004). Three OP had help with a live-in spouse, and two lived with an adult child and one lived at home with family staying overnight two nights each week. The four OP had no-one to stay because of their higher independence or no available support networks. MECS was also used as a support system. Plath (2009) commented that adequate information and support were recommended to assist individual independence in decision-making. Some needed more assistance than some others who needed no support; however, different situations involving illness or crisis merited varied levels of support. Many individuals were consulted in shared decision-making with both families and professionals. This was important for those utilising the family for assistance in shared decision-making. There were also ramifications for OP who refused to make decisions until a professional was consulted.

The process of OP getting their needs met was unique to each individual demonstrating equifinality in that all of them achieved the status they wished. This also related to the third Research Question and to the way in which QoL and the decision-making process interrelate. OP #12 spent time in church activities and going to the church coffee morning, as well as adult daycare. OP #15 was in a therapeutic day centre working through a falls prevention programme, whereas, OP# 07 needed a wider range of supports but was also in an adult daycare programme and had home carers, as well as informal support from his spouse and other individuals/resources to support his success (gardener). They may have needed to have in-home care to go to a day centre or lunch clubs for added support. OPs are where they wish to be as demonstrated by vignettes discussed in Chapter Three. GST assisted in understanding how individuals worked to maintain homeostasis as QoL was raised and lowered. When QoL was out of balance, the lived experiences of individuals were revealed and OPs made lifestyle changes of adding additional services such as paid carers, adult daycare, gardeners and informal supports and services to maintain homeostasis. The case for different OP in atypical circumstances was discussed in the following areas: shared and status quo decision-making, and differences of opinions.

Shared Decision-Making

Support networks were available through informal care, family, and in several areas of shared decision-making. One major finding that emerged was the significance of support in guiding older people through systems. The majority of OP reported having informal support to assist them with guidance through systems for care services. They described family members making calls, acquiring equipment, getting additional services, and assisting with overall care. This was consistent with triangulated findings from visual data in photos taken of individuals of importance: spouses, family members, and carers who were identified as key people who influenced QoL. GST was used to support efforts to understand multiple perspectives and to see how they interact, and looked at wider issues of who OP identified were individuals of influence in care decisions in photos and interviews. OP #02 explained how she made decisions about care,

> “I discuss everything with Frank… And, in fact, he does, you know, he gets things for me off the internet and things but he is my first port of call when I need help.”

Frank was her nephew and closest living relative.

Similarly, OP #05 related she had assistance with navigating systems and acquiring what she needed,

> "Well apart from this rabbit hutch [frame] as I call it down here which keeps the weight of the bedclothes off my feet and my ankles and it was my daughter-in-law who organised that for me which is a great help" (OP #05).

This family member was in contact with carers and assisted in getting equipment.

OP #09 reported,

> "I'd talk to my daughter and she would get in touch with, she's always on the phone to, somebody."

This family member was an advocate for the participant.

OP #10 also said that she mulled over decisions with a family member,

> "Well there's one daughter-in-law…… she's quite good. I can sit and talk to her aboot [about] things that's happening."

This family member was in an advisor role.

OP #11 explained that her daughter assisted her with guidance with setting up routines,

> "My daughter's got it all worked out and she puts it up, she's got it written up on the cupboard on bits of paper mum needs this for breakfast, teatime and bedtime… though she [daughter] guides me a lot on my medication."

This daughter was involved in the daily care and assisted in managing paid carers as well.

OP #15 also stated:

> "Yes, I include my family in everything... Oh yes I never do anything on my own. No, I always talk over with my girls. In fact I don't take care o' my paperwork, my daughter does it all. She comes in and checks my paperwork and my mail, I phone her if I've had any mail and she says keep it mum, I'll pop in and see it and I'll get it sorted out."

In this relationship, the daughter took care of all paperwork and was involved in all aspects of care.

Family decision-making and shared roles were reported in most of the decision-making and in assistance with care and resource utilisation. GST assisted in tracing how relationships had formed and assisted OP when they worked through the system and identifying what roles these relationships took on. This was seen in many tasks ranging from taking care of everything, to being advisors, advocates, hands-on help, and managing paid help to assisting people to remain independent. It was a full spectrum within shared decision-making related to care options. A conceptual construct is the thinking and logic behind the OPs decision-making, and how they are constantly working to get needs met. These examples were the actual behaviours displayed based on the conceptual constructs of past experiences with relationships and discussed roles in those relationships and shared decision-making with their support networks through internalised decision-making processes of older adults with how they developed relationships with others displayed in decision-making and the external behaviours of individuals and their environments of their lived experiences to maintain homeostasis. The whole approach that GST supported was demonstrated in how individuals conceptualised decision-making as a result of both intrinsic and extrinsic motivators and revealed individual conceptual constructs on how individuals viewed the world and approached decision-making to get their needs met. This was different for individuals for who they identified as important, as well as the tasks they completed. This was from constructs such as prior experience, how they categorised and prioritised need, as well as their unique situation to social supports and relationships.

There were professionals held in high esteem, such as ministers (from the Church of Scotland), who influenced decision-making. This appeared in photos. For example, ministers were discussed as being important to those homebound in supporting decision-making. OP #04 reported he was homebound and received a regular visit from his minister. OP #01 received no visits and it had a strong influence on her as she felt she should have had visits for added support. She was upset by the lack of support when she reported:

> "I'm quite bitter about it…they don't come, no church service and no communion."

OP #03 stated he had not gone to church "in a while" but discussed his church friends' visits. OP #03 also communicated about a strong support system with his church friends. OP #12 and OP #14 described going to church services regularly. One of those participants was involved with additional weekly church activities. In Figure 3. Church, OP #12 illustrated volunteering twice per week two mornings per week for the church.

Figure 3. Church

OP #12 had social systems through the church; she went to coffee mornings, participated in activities like playing dominoes and getting a 'wee cup of tea'. She also explained that she went to church on Sundays and was, therefore, socially connected three days per week through her local church in addition to meals, snacks, and activities. OPs mentioned the importance of having visits (sometimes weekly), staying connected, and talking things over with spiritual leaders, such as ministers or priests. Having a professional as another form of advisor or advocate seemed helpful to decision-making. Other OPs felt disappointment and loss because of the lack of a minister or other clergy involvement in their lives. They wished it were improved. Similarly, spiritual matters were found to have positive impacts on QoL, Solomon et al. (2010) reported better QoL outcomes in individuals with relationships with religious communities and declining QoL related to depression.

Shared decision-making is rooted in support systems, relationships, and the roles of other professionals. This is an example of GST when one area influences another and the many environmental factors of how QoL is embedded throughout choice and decision-making. The influence of ministers in a role of influence is can illustrate how parts interconnect. The absence of a minister's presence caused some distress. OP #01 reported that she would not step foot in a church again because of the way things had gone and the lack of follow up support from that community resource. She felt it was a personal betrayal as her adult child had previously been an elder, and she had a personal connection with the church that she reported had been neglected. Her past experience with her family had created an expectation; her current experience influenced her decision-making on how she continued in the future. She stated that she would no longer be going to church as she was without the services of a minister. How this would continue to influence her decisions toward end of life care remains to be seen as she has had no recent communion. Spiritual matters are one area of the multi-faceted issues involved in QoL and they also have significant influence on the relationship between QoL and a decision-making process as homeostasis is out of balance. At the time of the interview, OP #01 was out of balance with homeostasis as a result of her spiritual status (her unease with the relationship with the church and minister) and her unfulfilled obligations and expectations. This finding has added substance to identifying conceptual constructs of both intrinsic and extrinsic motivators on decision-making of how the extrinsic constructs of professional roles and intrinsic constructs of prior experiences can influence the decision-making processes. Her constructs of prior negative experiences influenced her thought processes reportedly for future relationships and behaviours and decision-making with clergy. It adds credence to the roles of relationships and the importance of prior experiences and how this influences future behaviours.

There was also much discussion around shared decision-making and the pre-planning people sometimes needed to have in place. This end of life planning included involving lawyers and legal guardians. End of life planning received additional input as a result of the reconvened focus group and additional meanings were identified in the findings. Velzke and Baumann (2017) emphasised end of life planning with advanced directives in ways to plan for this before decision-making abilities diminished and individuals with dementia and AD were encouraged to record wishes early for future participation in research involvement prior to memory diminishing.

Choice was reported in reference to ascertaining options and choices in the care available. However, there was dialogue by both OP and PP of the role and status professionals held in influencing the decision-making of older people in care, and how that affected choice. This was evidenced by reports of people not making any decisions until they had had consultations with people in professional positions; therefore, this was also a support system for older people. OP #02 reported she would consult with her GP prior to making decisions. GST allows the identification of multiple influences on decision-making and identifies some of the inter-relationships with professionals and environmental factors that influenced other areas of care decisions based on perceived status and the roles professionals held. OP #05 reported she would not make a decision until she had spoken with her GP. This is different from other participants such as OP #07 who utilised a status quo style and let his spouse and social worker decide the majority of his care decisions as he reported he did not mind that except for one point concerning respite as he refused any respite care and wanted to remain at home. GST allowed exploration of larger issues to discover the lived experiences of individuals within a more developed data picture of how parts came together. For OP #02 not only does she consult her GP, but she has close ties to family, carers and those in her community which enabled her to remain successfully in the home setting.

Status Quo Decision-Making

The status quo in decision-making is, "the state of a situation as it is… (to) not make any changes" (Longman, n.d., para 1). At times, OP did not make a decision even when choice was available. Others, such as family or professionals needed to make these decisions for people. Velzke (2017) reported, for example, that those utilising SDS often had family members assisting them (PP #16). In one case, OP #07 used direct payments and explained that his wife took care of most details,

> "The council pay money into the bank, the carers give us a cheque (bill) every month and the wife just pays it…Oh aye, she [wife] does most of it."

In this case, the OP rarely made his decisions on care and left it up to his spouse. This was usual and customary for their relationship. OP #07 reported,

> "I sometimes talk yes but very seldom. She [wife] just makes up her own mind… I've left everything tae [to] her for forty-nine year."

This was mentioned later with little objection noted when he was released from hospital. His care had already been planned for him when he explained,

> "I took the stroke in the factory and I landed up in hospital for a year and everything was sorted in the house before I came home and the carers in position and everything like that, social workers took care of all that."

He had no objection to others planning his care options (except in the case of respite as it was reported he would not go).

Similarly, OP #09 also stated she could have had more choice but left it to others,

> "Yes, I do [have choice] although I'm very lazy and I prefer everybody to do

> it for me but I have if I wanted to I could have a choice."

In both these cases, it was not that OP lacked choices. They decided not to make choices for themselves and left the decisions up to others. The opportunity was available anytime they desired to have a more active role. This was illustrated with OP #09 when he said that he would not go into respite care. One choice was the result of the style of the relationship in the marriage (OP#7); the other example was where OP #09 reported herself as being "lazy."

GST framework allowed deeper meanings to emerge by exploring a holistic overview of the individual working within the system to illustrate conceptual constructs in pulling together multiple smaller parts of how individuals made choices for themselves or had choices available to them displaying the how and why decisions were made. This included utilising individual, shared and group decision-making as well as status quo so needs were met evidencing how individuals lived experiences played out. These examples provide better understanding in how individuals' conceptual constructs are acted out in displaying actual behaviours. Such as, the status quo of OP #09 found satisfaction in letting others do things for him while still maintaining the right to let them.

Differences of Opinions during Shared Decision-Making

However, a strong overall theme emerged in that there is not always agreement when family assist with decisions.

OP #03 decided when to accept help or not. OP #03 reported, during conversation discussing visual methods, that,

> "I am perfectly capable and I don't need it [swivel shower chair] the powers that be [points at his wife] say that I need it."

The participant's wife responded,

> "He does not admit he needs help."

Similarly, the OP stated he did not admit to needing help. In this case, the participant had a swivel shower chair and was influenced by what the family member wanted. Martin (2017) suggested by the language used "...the powers that be..." indicated established authority revealing the conceptual construct of the OP and how he viewed the strong intrinsic and extrinsic influences that motivated his decision-making. Originally, this phrase had references to Romans 13 from the Bible and discussed the powers of God, and in OP #03's case the established authority was his wife. This addressed the first Research Question on an individual's perceptions as well as the conceptual constructs of prior experiences. GST was also helpful in examining this whole contextual approach on how the perceived belief system of the individual conceptualised the events and the manner in which they viewed the world. Not only was incite gained on his relationship with his spouse, this also said much about where this participant was with his medical condition that he was in a different mind-set than what those around him who were observing and working with him. However, as seen in his support system, this had some influence on his supported independence at home and swayed his shared decision-making. However, grudgingly, as he did use what was provided (shower chair).

OP #07 reported a difference of opinion of where he and his wife thought he should be,

> "No, the wife's been at me for tae [to] go intae [into] respite but I prefer tae be at home…"

This participant had remained at home at the time of the interview; although he stated that, typically, he did what his wife wanted in all matters and in care planning (except respite placement). He reported prior negative care experiences. Here again is an example of how the prior experiences and conceptual constructs combine with all the environmental factors to influence decision-making on where to live. He explained that he preferred home as his family (grandchildren) were there. At home, he explained that he had a more comfortable bed (it adjusts to his comfort with the head or foot). He reiterated that he liked his bed as it also had a lift and this made it easier to get up and down from the bed. These were all environmental factors that influenced his decision-making and the broader picture of his circumstances.

PPs reported that they needed to intercede on differences in what the family wanted as opposed to what OP wanted for themselves. There were times that an individual's choice was not supported by informal carers. PP #20, PP #18, and PP #30 also gave accounts of differences between what the family and informal carers wanted as opposed to what the older person wanted. PP #20 reported that the professional ended up stepping in to correct those situations on behalf of the older people (i.e. they became advocates). PP #30 described a professional role of also being a buffer between the family and the individual. This was consistent to Wada's (2015) findings about putting individual choice first.

In contrast, PP #19 reported, in the case of people with dementia (who did not create any advance care planning), that professionals did not know what the wishes were. In those cases, they needed to rely on family,

> "That's probably OK possibly for quite a lot of people but maybe not for some people."

Family systems were revealed to be important for older people in facilitating decision-making in advance care planning - especially in situations where wishes were documented prior to individuals now not being able to communicate personal choice or decision-making. GST assisted in looking at the wider systems such as family decision-making and the support systems and networks that were included within the decision-making. This process of documenting wishes was an important part of QoL as this assisted in maintaining homeostasis through advance care planning. Some researchers also suggested discussing individual wishes for participation in research when discussing advance care planning so they are able to participate if consent diminishes at a later time (Moore & Hollett, 2003; Velzke & Baumann, 2017).

Ways Older People Support Their Decisions and Their Perceptions

There were several things OP reported they did to remain independent and support decision-making. Part of this was perception, and how individuals perceived themselves for example in the area of illness. These findings helped to answer Research Question 2 by revealing what influenced decision-making about which services to use. Another part of this were the additional options that Self Directed Support (SDS) allowed. This added options for individuals who wished for opportunities for enhanced control in care. Velzke (2017) reported that in a number of cases individuals accepted to remain independent. One example was implementing informal care in order to complement SDS services. OP #07 had to pay Social Services for carers at home. His wife and social worker helped to get this set up for him prior to his release from hospital. A third part of decision-making was assistive devices and technology and how this assisted to support decision-making. Levels of illness, SDS and assistive devices and technology will be discussed further.

Individual Levels of Illness

When asked if they were currently ill, 40% of OP reported "No" on the first visit and 60% reported "Yes." Approximately three weeks later, 33% reported "No" and 67% reported "Yes." There was not a significant change between visits; although, what was reported as illness had changed. When asked, "if something is wrong with your health, what do you think it is," the participants' top responses, for health concerns at the first visit, were AD, dementia, memory issues, arthritis (rheumatoid), pain, and broken bones. On the second visit, they reported the top concerns to be arthritis and chronic pain. Tables

10 and 11 (created by the Researcher), list the concerns of OP from the first and second WHOQOL BREF.

Top Primary Illnesses/Problems OP Reported			
Illness/Problem **First Visit**	Total	Illness/Problem **Second Visit**	Total
Alzheimer’s, Dementia or Memory Issues	20%	Arthritis	20%
Arthritis-Rheumatoid	20%	Pain-Chronic	20%
Pain	20%	Alzheimer’s, Dementia or Memory Issues	13%
Broken Bones	20%	Chest Infection	13%
Heart Surgery	13%	Bones/Muscles Wearing Out*	13%
New Lease on Life/Well Enough/Bursting with Life	13%	Not as Young as Used to Be/Getting Old*	13%
Asthma/Shortness of Breath	13%	Fall=Hospital Admittance*	13%
Stroke	13%	Cannot Walk/Walk with Difficulties*	13%
Falls	13%	“I’m Alright”*	13%
“None Really”	13%	Blind/Partially Blind*	7%

Table 10. OP Primary Health Concerns during WHOQOL

Secondary Illnesses/Problems OP Reported			
Illness/Problem **First Visit**	Total	Illness/Problem **Second Visit**	Total
Mentally Ill	7%	Mentally Ill	7%
Partial Paralysis	7%	Paralysis* (partial last time)	7%
Can’t Do Much/Need Help	7%	Always Been Good/Same As Last Time*	7%
Physically Ill	7%	Physically Ill	7%
Chest Infection	7%	Asthma*	7%
Blood Infection	7%	Blood Infection	7%
Urine Infection	7%	Urine Infection	7%
Toxic Confusion	7%	Toxic Confusion	0%
Prolapsed Bladder	7%	Prolapsed Bladder	7%
Rapid Heart Rate	7%	Racing Heart* (angina?)	7%
Thrombosis	7%	Better Since Last Time (2 Weeks)*	7%
Cellulitis	7%	Eyes*	7%
Swelling in Feet	7%	Swelling	7%
Strained Muscles	7%	Hernia*	7%
Angina/Heart Failure	7%	Heart Surgery*	7%
Diverticulitis	7%	Hearing Decrease	7%
Gall Bladder Removed	7%	More Confident	7%
Gout	7%	Bruised/Black Eye (from Fall)*	7%
Chronic Fatigue	7%	Fatigue* (not chronic this time)	7%
Stomach Issues	7%	Stomach Problems	7%
Blood Pressure (high)	7%	Vertigo*	7%
Joint Replacements	7%	Broken Bones*	7%
Irritated Bowels	7%	Wheelchair Bound	7%
Leg Ulcer	7%	No Change From Last Time*	7%
Diabetic	7%	Stroke*	7%
Epilepsy	7%	Epilepsy	7%
Brain Haemorrhage	7%	Joint Replacement	7%
Pregnancy	7%		
“New Legs Would Be Fine”	7%		
Osteoporosis	7%		

Table 11. OP Secondary Health Concerns during WHOQOL

However, participants were asked how satisfied they were with their health (see Table 12, created by the Researcher). The first WHOQOL measure reported a mean score of 3.07 (10.67 transformed). The second visit yielded a mean score of 3.2 (12 transformed). Three OP ranked as neither satisfied nor dissatisfied on the Likert scale.

OPs identified themselves as ill; although their responses implied they were neutral overall. They had some identified illnesses. Between both visits, they were not dissatisfied with health and they were not satisfied with their level of wellness either. This was consistent with Tables 10 and 11 where OP listed the illnesses they had. They confirmed that they were ill and acknowledged a decline but were not necessarily unhappy with this as they did not score this negatively.

There were no significant relationship changes between WHOQOL scores from Visit One to Visit Two as is illustrated in Table 12. As such, collectively, QoL was reported to remain about the same because reported changes were minimal. QoL was described to have a minimal decrease between the first visit and the second. Similarly, reports of participants' increases in illnesses from the first visit to the second were not significant as shown in Tables 10 and 11.

WHOQOL BREF Descriptive Statistics										
	N	Min, 1st Visit	Max, 1st Visit	Mean, 1st Visit	Std Deviation, 1st Visit	Min, 2nd Visit	Max, 2nd Visit	Mean, 2nd Visit	Std Deviation, 2nd Visit	Difference in Mean Scores
QoL (Transformed)	15	10.00	70.00	47.33	18.31	20.00	70.00	46.66	13.45	**0.67**
Physical Health (Transformed)	15	22.86	65.71	43.05	14.83	20.00	74.29	39.81	14.86	**3.24**
Psychological (Transformed)	15	11.11	60.00	39.92	14.99	11.11	63.33	34.07	18.11	**5.85**
Social Relations (Transformed)	15	40.00	73.33	56.44	10.04	40.00	80.00	54.67	11.60	**1.77**
Environment (Transformed)	15	35.00	77.50	57.97	10.21	32.50	72.50	55.50	11.74	**2.47**
Satisfied With Health (Transformed)	15	-10	20	10.67	11.63	0	30	12.00	10.14	**-1.33**

Table 12. WHOQOL BREF Descriptive Statistics

The QoL mean score from the first visit was 47.33 while the mean score from the second visit was 46.66. This is noted in Table 12 and this lists the descriptive statistics for the first and second visits. The largest spread was reported as psychological (39.92 and second visit was 34.07), then physical health (43.05 and second visit was 39.81), environment (57.97 and second visit was 55.50), and finally in social relations (56.44 and second visit was 54.67). Overall, homeostasis was maintained through the reporting period for QoL and for reported illnesses. Individuals had no significant outliers of note. Homeostasis was evidenced by participants who reported satisfaction levels with their health. It remained near a constant level at neither 'satisfied' nor 'dissatisfied' for both visits.

Ways to Remain Independent with Resources and Policy

One area found to influence choice and personal independence was Scottish policy and so this section helps to answer the final research question about how current policy in Scotland influences the choices available to older people, with an emphasis on the micro level and the individuals themselves. These changes emerging in the ideology have empowered people to do more for themselves. SDS will have some influence on decisions and choices for older people (see also Table 8). As OP found themselves in situations of not being able to do things on their own, they had other options. They would be able to use services through SDS and other support systems depending on eligibility.

SDS is one way by which older adults can be more active in decision-making and maintaining independence. There were several considerations that needed to be in place for this to be successful. A strong support system was necessary for individuals to be able to navigate their own care, in particular, if a paid carer needed a day off or became ill. With added independence came an increase in responsibility within the decision-making arena, although there were those who elected to give control back to the local authority to manage their care. Then, they were still involved with SDS, but had a less active role. This was similar to the situation before SDS was launched. This had been more of a status quo type of decision-making, of going with local authority decisions.

Independence and control emerged from OP discussions. The majority of PP also reported that they wanted to offer independence and control to individuals. This was viable in the majority of options and services offered to individuals. Velzke (2017) discussed SDS and how this offered additional options to individuals for independence, choice and control in their own homes.

Independence was promoted through choice, control and decision-making options with the upcoming launch of SDS (in this local authority at the time of the research in 2014 when the data was collected) as PP #23 stated,

> "perception of support might change a little bit and they'll see that they're just being enabled to access something rather than having people do something for them because if the choice and control and power is more in the hands of the individual they're not just a kind of passive recipient of support that they're maybe hopefully more involved in that…"

SDS policy enabled options for individuals when it was launched in 2014 in this specific local authority, so individuals had more decision-making options and capabilities. This would be particularly important for those who had limited control within service options or limited choices in the services available.

The tasks older people completed independently often included modifications, assistive devices, or technology to maintain independence. Velzke (2017) also discussed the importance of independence and options for older people to remain independent. This paper considered the wider systems influencing the delivery of SDS and explained the importance of SDS, person-centred support, informal care and support systems, telehealth, and telecare as trends for the future. This meant that some people were able to maintain a regular day without much assistance and most OP were able to continue activities with additional support and assistance. This was different for everyone because of the personalisation of needs at the individual level. Velzke (2017) suggested that professionals anticipated changes with future technology and care options offering changes in the next five to ten years with increases in telehealth and telecare delivery.

Continued independence was made possible with both paid (formal) and unpaid (informal) care. Many issues within independence can be better understood through a GST lens; for example, changes in one area influenced others. This could be observed in diminishing physical abilities. Individuals were able to remain independent by adapting the use of assistive devices and technology. A shortage of resources in telehealth and telecare, for example, was identified in rural areas and this would, if sorted, assist in additional choice in decision-making. In addition, for individuals who are socially isolated and homebound, having a wellness check at home through a conference with a professional via technology might have had a significant impact. However, this is individualised based on life experience, with different populations having different needs depending on the influence of social isolation and loneliness (Toze & Ray, 2018).

The data also revealed a recurring theme in multiple areas of loss or things that older people were not able to do. Sinding and Aronson (2003) discussed loss and how people shared their stories. They also examined how researchers responded with social and psychological resources to assist in coping with losses. However, some OP recognised and identified loss of mobility, favourite activities, or leaving the home setting. In other cases, this was harder for individuals to grasp as evidenced in photos. OP #05 discussed some of these as she started out unable to do much as she was bedbound.

Many examples were discussed by OP in the visual methods that reinforced the struggles that individuals experienced. This demonstrated examples of when individuals were out of balance of homeostasis. This included struggles with the loss of independence, as they were struggling with stability during these times. For example, some reports explained that OP #06 could no longer go to the pub, as demonstrated in Figure 6. OP #01 could no longer leave her residence to attend church. Figure 4, picture of a cross, portrays this.

Figure 4. Cross as Representation of not being Able to Attend Church

She said that a friend from church had visited one time but previous discussion said her minister involvement was shared decision-making and highlighted her disappointment in lack of contact.

Similarly, OP #05 was no longer able to hill walk. She liked to be outdoors but was unable to do many things she once did but her mobility increased as time progressed.

Figure 5. Hillwalking and Loss of Independence

Many OP no longer navigated stairs: OP #07 and OP #02 had stair lifts. Several OP were unable to get in the bath and many had a lift chair to assist them. Three had a wet room: OP #04, OP #07 and OP #12. OP #04 discussed how he had been unable to have a barbecue for three years and that he looked forward to doing this again. Situations were different for each individual in each setting, based on how the loss of independence influenced them in other areas. This was consistent with GST.

OPs were able to maintain homeostasis; however, each individual's pathway through equifinality was varied as noted by the different ways used to raise QoL to maintain homeostasis. For some it was physical, if they were unable to climb the stairs they had stair lifts. It influenced the types of caregivers and resources they employed but there were also emotional and psychological concerns. For example, some people were upset over the loss and contact of spiritual issues (not having contact with the minister, for example). This could have influenced their sleep patterns, eating habits, emotional responses, or other areas of QoL. It affected individuals uniquely in the multi-faceted areas of QoL.

Some OPs recognised and mourned the loss of certain activities. Others felt the loss of activities to be part of changing independence. For example, OP #06 was no longer able to go to the pub. He was used to taking short walks, but this was a loss for him. He reported,

> "Oh aye I didnae [did not] go oot [out] tae [to] the (pub), I used to, I stopped going two or three weeks ago."

Figure 6, the photograph of his Pint, shows an example of his loss of independence through no longer being able to take walks to the pub.

Figure 6. Pint and Loss of Independence at the Pub

These losses of independence discussions are examples of triangulation of data and the themes OP discussed as examples are seen in photos, in discussions and recognised in reconvened focused groups. OP #05 previously reported she was no longer able to hill walk. OP #03 reported he had been involved in many clubs and activities and no longer did any of these. Other activities which were discussed in terms of diminished activities included OP #15 who had been active in her community and club activities, but was unable to pursue them at the time of the interview. OP #02 was housebound at the time of the interview and did not feel well enough to go out to the spa, shop, or other activities because of vertigo and nausea. She had not pursued those activities for some time as a result of declining health. Her physical health was reportedly diminishing her other areas of overall QoL. Velzke (2016) discussed these issues of influence and QoL and how they affected independence, interconnected in many areas within the research findings, and influenced the balance of homeostasis.

Another factor emerging with people who lived in their own homes was the influence of live-in assistance or the start of overnight assistance. Many programmes and policy do not provide for overnight care (Velzke, 2017) but this may be changing with SDS as a solution to this issue (PP #20), by providing more options for overnight care choices (Velzke, 2017). Many participants had help from a live-in spouse (OP #03, #04 #07), or lived with an adult child (OP #06, #09). OP #02 lived at home and had a cousin stay overnight two nights each week offering informal care. A smaller number of participants (OP #15, #10, #12, #11) had no one to come and stay with them, either as a result of greater independence or because there were no support networks to offer those opportunities. In addition, independence influenced decision-making which resulted in raising or lowering individual QoL.

There were many who did not have overnight care and expressed a need for this but had limited decision-making options. They may not have had informal support systems to give them the help they needed. However, for many, the lack of overnight care resulted in needing facility placements; although, this might have depended on options in choice for at home care and SDS. OP #01 moved to a care home, wanted additional support during the night, and found comfort knowing someone was available if needed. Some rural areas lacked services options and that limited independence. Toze and Ray (2018) reported that this caused difficulty when professionals worked to empower individuals to have more control as communities with fewer resources may cause additional barriers for individuals. When no family or carers were available and overnight care was needed, care homes were the only option left.

There were limits in the programmes offered by the council and other care providers. In the home setting, overnight care was not offered which was as a gap in service that was identified during the research. However, SDS assisted with this (Velzke, 2017) although the option of securing private care, paid for out of personal funds, covered this overnight care if OP had the means to access the option. This was particularly true for OP who were housebound and had limited mobility. The other OP, who had informal care overnight, appeared to have assistance when they were ill, had sleep issues, or needed to use the toilet during the night hours. Individuals who had no support systems for overnight care needed to have money to have the additional choice of remaining at home and to hire carers if they could find them. The difference in these perceptions inferred that money was required to have options for care. Tanner et al. (2018) indicated that individuals self pay for care as a result of tighter qualification guidelines or they had too many personal resources for means tested programmes. This is also an example of equifinality as there are many ways to address overnight care with SDS, family carer support, or self-payment for care.

Independence was also seen in the ways older people were able to set up services to remain independent. Equifinality and the pathways older adult's implemented for services and resources to get their needs met varied. This was consistent to the initial Research Question on the behaviours, attitudes and perceptions required to fulfil needs for care and support. There were similarities that were seen in needs based on the *vignettes* utilised. For example, OP #15 who stayed at home reported,

> "Yes and I'll tell you a similarity because I have to get, I have to pay to get my garden done and my family have to come and change my bed and hoover [vacuum] for me because I can't hoover and they have to do my shopping for me so I'm similar in that but I can understand where that story's coming fae [from] because I cannae [cannot] change my bed and I cannae [cannot] hoover."

OP #15 discussed her independence and MECS supported this as discussed previously.

Some participants felt that the loss of options forced choice on them leading to the loss of independence. Emotions, for an example, were a part of OP #11's response when she reported struggling with her loss of independence as that had been a factor in her decision-making. It also impacted her care decisions. Figure 7 displays a photograph of her wheelchair and she stated,

> "Hated the sight of it and I didnae [did not] use it when I first got it. I didnae [did not] want to be associated with it-horrible looking thing. I was sad to be relied on it. I wanted to be out of it and walk."

Figure 7. Wheelchair

She explained that she did use her wheelchair when she left her house and outside. She did not like the loss of independence; although, she had come to accept this was a change and GST assisted in looking at this OPs changes in lifestyle that led to various influences on her decision-making. As a result, she needed to make adaptations. She discussed this when describing how she navigated at home. The wheelchair did not fit through her doorways, so it had influencing effects in many areas of living beyond her emotional state to physical alterations.

Assistive Devices and Technology

Visual methods revealed the perceived importance of the role of the local authority. One way the council provided support was through the provision of equipment and assistive devices to various OP who stated they were thankful for having the added support.

The majority of OPs, (93%) typically had a positive outlook for QoL when discussing these during interviews. However, 7% of OP reported negative issues in their life in qualitative findings and "no QoL" was reported by one participant. For example, "That's the worst o' this. Quality of life? I've none" (OP #10, line 414 transcript #01). She said this when she struggled to stand having been sitting in a chair. She then referenced having accessories for a raised chair at home to assist with this issue. Assistive devices were found to influence all OPs and QoL, and therefore, were linked to decision-making and this has helped to answer Question 3. Table 13 (created by the Researcher) indicates the main devices that participants reported using. MECS was a device that was highlighted again in visual methods discussion as were commodes, zimmers, walking sticks, raised toilets, rails, wet rooms, and/or bath accessories.

Assistive Device or Technology	Totals
Walking Sticks	12
Handles by toilet	11
MECS	10
Zimmer	9
Shower Chair	2
Commode	8
Raised chair-easier to get up	8
Raised Toilet	8
Wheel Chair	6
Rails in shower or bathtub	6
Electric Scooter	5
Buzzer in bedroom on the wall	4
Hearing Aids	4
Glasses	4
Rise and Recline Chair	4

Table 13. Most Used Older Participants Assistive Devices

There were also various other devices reported that were unique to needs as Table 14 (created by the Researcher) shows. This included specific types of walkers, ramps, trolleys to assist in carrying trays, food and other items from room to room, and adaptions to assist in cutting up food such as scissors. Some individuals were unable to hold a knife to do this. Kindle and Skype were some of the technology devices used. Individuals made adaptions to assist with personalised care and preferences to remain in the residence of choice. They did this to live the way they chose which influenced QoL. The wet room was an example of a way to remain in the home setting for three participants. Getting in and out of a tub at home was problematic because of changing mobility needs.

Assistive Device or Technology	Totals
3 wheeled walker	3
Walk in shower	3
Ramps to get in out exterior doors	3
Tub that lifts and transfers into it	3
Wet Room-shower/bathroom	3
Table with wheels like hospital bedside table	3
Trolley-carry meals	2
Rails Stairs	2
Chairlift to navigate up stairs	2
Help Up-lifts feet up onto bed	2
Rails beside bed	2
Clos-o-matic toilet	2
Leg Brace to assist in walking support	2
3 wheeled walking stick	2
Kindle	2
Elbow crutches	1
Skype	1
Gadget-socks	1
Handy Hand-pick up	1
High Countertops-helps walk	1
Stool sit in kitchen to cook	1
Device to assist getting jar covers off	1
Turner (transferring when could not walk)	1
Scissors to cut food and other things	1
Glider chair-chair on wheels to go from room to room	1
Chair insert to sit higher in chair	1
Leg lifter to get into and out of car	1
hoist in car to get scooter and wheelchair in / out	1
High Back Chair	1
Bed Lever	1
"Rabbit Hutch" keeps blankets off foot in bed	1
Nightlight-gets disoriented in the dark	1
Rubber sheet-incontinence protection	1

Table 14. Additional Older Participants Assistive Devices

OP reported a range of assistive technologies and devices that influenced QoL and health (see Tables 13 and 14). Many of these supports allowed participants to remain at home. These included Mobile Emergency Care Service (MECS), electric scooters, hearing aids, home modifications, and a range of assistive devices. Visual analysis allowed for some triangulation with interview data for assistive technologies and devices and some new data that were not revealed during initial interviews. Items that were not revealed initially were Kindles, wet rooms, the total number of individual walking sticks, zimmers, rollators, and other individual items that were identified in the visual analysis. OP took photos of things that influenced QoL. This illustrated that certain categories were present - just not the extent of use of the items.

The examples of assistive devices varied. For example, 80% of participants reported using walking sticks. 73% had handles by toilets to assist getting on and off safely and used a shower chair. 67% used MECS. 60% employed a zimmer (walker) and 53% of participants reported having a raised toilet, 40% had wheel chairs, and rails in showers or the bath. There were other individual reports of items, unique to each person, as seen in Tables 13 and 14. This indicated that QoL and health factors were individualised no matter their residential setting or any other unique traits they exhibited.

PP also reported that technology was a helpful resource. For example, PP #22 stated that, if the client was capable and refused services (the word ‘stubborn’ was used), they respected the client’s right to take risks. The staff tried to minimise risks when possibly evidenced by the use of fall detectors or MECS. PP #22 recounted when she was building relationships, the clients were receptive to options. However, she shared that, if there was reduced capacity, it was then difficult because they could not force people to do things. For example, there were prompts suggested by the carer to use the walking stick.

OPs utilised 47 types of assistive technology and devices, each unique to an individual’s needs. This did not include any assistance with medication management, although, this was also a popular item with participants (but this was not tracked specifically, and numbers were not collected). There could have been additional assistive devices and technology in use that were not listed or discussed. Toze and Ray (2018) explained that assistive technology was also pertinent to an individual and their situation.

There was a strong support network that included MECS for the people who stayed at home. This suggested that for individuals to remain at home, many people had MECS and this was confirmed by the discussion of MECS in interviews and by the many photos of MECS. This fitted QoL for Research Question 2 and what services individuals used and for Research Question three in the relationship between QoL and decision-making processes. MECS was similar to the call buttons available in nursing facilities to get the attention of staff. This assistive technology also had an impact on the success of people staying in their own homes for as long as possible and promoted added independence and added security for many participants (see Figure 8 for OP#15 and her device).

Figure 8. MECS

OP #15 explained she self-paid for her MECS and that this had saved her life a few times as she reported use of the MECS on the many occasions when she had fallen. This added to her independence and fostered a sense of safety and security in her life.

OP #02 had a photograph of MECS. She explained that it, “helps me survive and they talk to me… I pay a small amount every month and it is well worth it… makes sure I am safe and they arrange ambulance…never let me down…great boon, not praise enough.”

OP #11 reported on MECS, “…safe, secure, more well-being and happy…take off when get in bed and put on if I get up…Greatest invention, wear around the neck…only works in the house…greatest thing in the world.”

OP #12 outlined the benefits ,, “feel more secure…get in touch right away…had it 12 years…wear all the time…used multiple times…reliable…I want to stay at home as long as possible.”

OP #10 also saw similar benefits, “feel safe and secure…had several years…fell out of bed when just home from hospital and used it one month ago…wrist…my lifeline.”

OP #03 had two pictures of MECS and described is as a “bracelet…telephone call and they ask if I’m okay…invaluable if I have an accident…I don’t need to press this if I fall [has automatic fall detector installed]…key safe outside so they get in if I don’t answer the door.”

In order to remain independent and sustain decision-making, individuals utilised MECS. The use of MECS was initiated by many participants in response to changing situations and loss of independence. OP #15 discussed her independence. Like many participants, as part of this discussion, MECS entered the conversation. Many individuals explained that the MECS provided safety, security, and peace of mind.

In addition, many home modifications were made to enable people to remain in place such as a wet room or ramps. Visual methods confirmed the benefits of this as three OPs discussed having wet rooms that made a difference for them. One participant was in process of remodelling a wet room to remain at home. For those in care homes, emergency call systems were already installed and enabled privacy and a sense of security.

Not all attempts to remain independent were reported as empowering such as the OP using the wheelchair and hating the sight of it. The nuances of equifinality and how individuals maintain homeostasis ranged in experience from positives to negatives at times based on how a person will navigate the care systems to get needs met and choices made available to them such as using MECS in the home or going to a care home. Many environmental factors impacted on decision-making. The conceptual constructs of each individual were different as was shown by the negative aspects of OP #11’s perception of her wheelchair. Others’ conceptions of a wheelchair could be different. Other environmental factors for individuals were wet rooms, emergency call systems and even a new bed that helped to maintain homeostasis with raising QoL.

Conclusion

This chapter has focused on the micro level, considering the individual at the heart of the decision-making, emphasising their own perspectives on their lives, but, as GST suggests, the focus on the individual provides only partial understanding of a system. The next chapter builds on the picture so far by building on the meso level. This chapter has established a baseline of information regarding how older people made micro-level decisions about care and the factors involved. It has discussed the support upon which they draw as well as their levels of independence. The range of ways independence was supported included technology and policy in the micro systems which older people encountered. Another key factor was identifying the importance of the people who supported decision-making and it was highlighted that decision-making was not a one-off process because of changes over time in people's needs for support and care.

This chapter has established the significance of independence, and what individuals themselves desire, which is a key driver of QoL. Levels of illness and disability are part of an individual's perceptions of their own identity. However, as the data indicate, illness and disability are reported to be lesser areas of concern for themselves by older adults, and the next chapter explores this topic examining how professionals categorise older adults differently. This is not unusual as GST reports how differently individuals can conceptualise these areas based on issues such as prior experiences (Von Bertalanffy, 1972) and identical issues can be categorised differently (Drack and Schwarz, 2010).

There were many decision-making styles used by older adults and there were times when OP took ownership in the decision-making. Shared decision-making was reported to be important and relationships and conceptual constructs on how older people looked to others when making decisions. This was especially marked when decisions were far from what older people desired. The research also revealed that decision-making may change from one style to another and at times retain the status quo, but there were several situations where decision-making may be contested. Independence was a key concern in how older people made decisions, and they wanted to be involved in care decisions. Even the status quo, as they wanted to have the option even if they did not exercise it.

This study has highlighted the importance of multiple measures by looking at the overall perspective in a holistic manner and getting the individuals' perspective. The perceptions of OP and QoL are important particularly for those who measured QoL because of perception and accuracy in reporting. QoL can be subjective and the results can have serious consequences for individuals particularly if they have influence on health and social care. Individuals reported results that, if taken in isolation, indicated issues that told one story. However, looking at those data collectively, following this research, they told a different story. The importance of looking at a broader perspective was illustrated. Examining reported illnesses in isolation for OP may offer different conclusions for a sick population, rather than considering all the data collectively in how individuals rated themselves, particularly as IADLs' ratings were also diminished. However, comparing these with other QoL data, it should be noted that QoL supported health and satisfaction levels from a broader perspective and revealed a different outcome when aggregating the results OP reported.

The relationship between positive and negative QoL and decision-making is better understood by pulling together multiple parts of decision-making and examining behaviours and perceptions to demonstrate a wider perspective of care decisions. QoL rises and drops and was found to maintain homeostasis on a micro level. This also indicates that decision-making is more complex, and needs further exploration, than what is offered at a micro level. Issues such as relationships and support networks intertwine and are also part of meso and macro systems.

The actions of older people themselves in decision-making within the wider system were identified as there were policies that directly affected the individual, which led to resource utilisation and ways to maintain independence. There were also assistive devices and technology that were adapted by individuals, as each individual's pathway of equifinality depended on their unique needs to balance homeostasis. There were some complex issues that influenced the systems OP encountered and these balances are better understood on the micro level. However, many issues lead into meso and macro areas and will continue to be explored.

Chapter Five Findings: Relationships with Self, Families and Professionals

Introduction

This chapter discusses how the roles of relationships influence the broader issues of how older people make decisions at the meso level. The meso level involves focusing on the people around the individual and how they support or hinder decision-making. GST suggests that multiple perspectives and interactions will be involved. This chapter will build on Chapter Four and its focus on the micro-level aspects of the systems within which older people make decisions. Relationships and support networks are the main areas explored in this chapter.

Individuals utilise support in many ways for decision-making and assistance in care. Decision-making options are influenced by community resources and network availability. In addition, social connections with friends, neighbours, and communities enable or restrict independence. These findings formulate evidence in support of wider systems in a meso framework building on findings and literature in how GST can be used to understand multiple perspectives and how they interact with each other. These social connections also address Research Question 4 on how environmental factors come into play, which explains more about the meso systems of individuals and how their needs are being met through the pathway of equifinality as OPs revealed how support networks and relationships influenced how homeostasis was maintained as QoL was raised and lowered. GST was highlighted in tracing how OP revealed their unique equifinality pathways and individual ways they were working through the systems. This chapter reveals circumstances where there is a need for self-advocacy. Perceptions of care (both good and negative) are discussed.

The chapter also examines older adult’s preferences and how relationships are important. The perceptions of older people became better defined through discussions of how they saw themselves. This was often different from other standards (such as being ill or disabled as seen by others) and how OP were viewed by professionals. These views assisted to better understand perceptions of older people and their behaviours as they set out to fulfil the needs for care and support in Research Question 1. This was evidenced in the distinctive roles taken on by individuals or assigned by professionals for older adults within their care. Professional perceptions are discussed. Boundaries and models of care emerge as policy in practice differs between disciplines. These roles impact decision-making options for older adults. A person-centred outcome focus, which promotes independence and achieves an individual's own target, is substantiated as a result of the thesis (Velzke (2017). The influence of professional opinions is considered. Furthermore, the perceptions and influences of power and support are discussed. Finally, the chapter explores how accommodations are made by professionals for older adults through differences of opinions, feelings of reluctance, or complaints.

Many of the topics interconnected in multiple areas influencing the decision-making of OP. For example, relationships and support networks touched many areas in navigating systems to informal carers. This related to individual QoL and was entwined in Research Question 1 on the influences on the decision-making of older people about care. Through exploring the networks, it is possible to use GST to better understand these influences and how they affect other areas as well as each other. Velzke (2017) discussed many of these coinciding topics that influenced each other such as: relationships, support networks, decisions about SDS, and system navigation.

There are three main focus areas in this chapter: relationships in general, how these build support networks, and the role of the professional within the networks. Exploration of how OP work with relationships is the focus, with the individual at the centre of the system. Professional opinions were found to be key in support systems; for example, some OP would do nothing unless they consulted the GP first. Depending on perspective, this was considered a constraint that limited some decision-making and the autonomy of individual choice. This depended on where this was in the continuum of personal preference of individuals and this is explored later in the chapter. To begin, relationships and support networks are discussed as part of the overall findings.

Relationships

Relationships were the second most prevalent theme in the OPs' interviews. For example, the majority of OP had one or more people who assisted them with navigating through systems. Informal care and support was one area of discussion and the importance of relationships carried over into photographs. The majority of participants (67% of OP) indicated that family and carers had some influence on their QoL as evidenced by photographs and discussion. However, the data revealed a complexity in the importance of sense of self and relationships.

Paid care was another area of relationships identified by OPs as indicated in Table 5. This included the perceptions of OP and perceptions and roles of professionals.

Moreover, it showed the impact on decision-making related to care. Other influences included power and support during decision-making as a result of some perceptions that are held by OP and others that impacted decision-making and choice. As references to perceptions within Research Question 1 became clearer, this assisted to formulate better understanding in the wider systems within the complexities of decision-making and QoL. The evidence of understanding the different ways older people make decisions and the different systemic factors which influence decisions are illuminated between QoL and decision-making. This can clarify nuances within relationships between QoL and the decision-making in Research Question 3 which was aided by visual methods and ongoing discussion as the research progressed.

A key part of the research findings were the relationships that OP had with others such as professionals and other services to get needs met. Those relationships directly influenced QoL improvement and included participation in both group activities and individual relationships. These environmental factors (relationships) were fundamental influences within the decision-making process, and key findings that helped address Research Question 4 and which details how environmental factors come into play. Equifinality, and how individuals navigated systems was unique for each person as was shown by the relationships and support systems identified by individuals. QoL was found to increase and reduce for both intrinsic and extrinsic factors and relationships were one area that assisted individuals to return to homeostasis.

QoL was enhanced by informal care and support along with other services as indicated in Table 5. This table listed the type of care individuals utilised and the added services they employed. At the same time, the loss of independence was a traumatic experience when OPs lost the ability to do the things they wanted to do for themselves. Relationships, social supports, and support networks came into play in these examples highlighting the meso level and how these systems intertwine and how they live in their homes of choice by adapting assistive devices, depending on paid services, support networks, relationships and technology to achieve personal goals.

Complexities of Relationships

Relationships, support networks, and shared decision-making were all themes that interconnected and there were times when discussions of all were interlaced within each theme, and influenced each other. The quality of relationships depended on the ability to maintain a support network and this also influenced the relationships in shared decision-making. This was seen when change in one area influenced another. GST has supported efforts to understand multiple perspectives and how they interacted. This influenced QoL in care in multiple ways, and influenced the increase or reduction in homeostasis. This assisted in Research Question 4 which looks at environmental factors and how they come into play and the improved understanding of some of these relationships. For example, if an older person's main support person who had assisted with navigating systems and paying bills, unexpectedly passed away, (and they lived at home), they could lose carers if they had SDS. Homeostasis would be disrupted and their basic needs might not be met. They also might not understand what to do to remedy the situation. During these times, relationships assisted with individuals remaining in a state of homeostasis and maintaining stability through support networks. Other relationships, and continued support through crisis or navigating systems, would be needed.

One professional worker reported that it comes down to relationships and communication;

> "I don't know if it'll address that specifically, it may. It may help in that I guess a lot of the time especially older people don't want to admit they need help and so there's something about the skilled conversation that the practitioners need to have to help kind of win them round and open their eyes to maybe it's a small element of support that can make a large difference in their life so that's not going to change too much it's still going to be a real skilled conversation between the practitioners and the individual." (PP #23)

Relationships are complicated, and those environmental factors can be different in every situation. They are important on many levels and assist in building perceptions and the identities of people involved. These findings revealed this in caregiving for both formal and informal care, in companionships, family ties and other professional roles such as advocates, experts, and confidantes.

OP #02 reported on the companionship of friends and family,

> "I've always been an outgoing person and I find I would be pretty lonely if I didn't have my friends and my family coming to see me and I enjoy every minute of their company, that makes me very happy."

OP #02 also explained that,

> "my main aids are people, I'm very fortunate, I have no direct family, no daughters, sons or daughters but I have in particular there are three cousins who are very attentive."

These relationships also intertwined with support networks.

OP #03 discussed how his relationships had also interconnected with his support networks. He was close to his wife of 53 years and had just been diagnosed with Alzheimer's disease. He had two close male friends and companions and said

> "I didn't want anyone else."

He explained that he,

> "didn't want to admit what was happening and did not want to look at myself."

OP #03 explained that he was a member of a walking group and a speaking club but he was unsure if he would return to those groups. He said he had not been to church for "a while." He gave an account of strong support systems with his church friends and he attended a Gentleman's lunch club and activities. He also said that he had strong supports through friends on the telephone. As a result of his recent diagnosis, he was unsure if he would attend any of these groups again or what he would do with those relationships. In addition, he shared that he had undergone a drastic transformation. He admitted that he knew, for some time, about the memory deficits. He had been under his doctor's care for three years, but the difference was it had an official label: Alzheimer's disease. There are many complex issues that needed to be considered for this individual as he had strong support systems although he is does not appear willing to access these at this time and his main support is his wife. He has an official label now with Alzheimer's disease (AD) and he is internalising what this means for him. He is currently working on stabilising his homeostasis from an intrinsic perspective (struggling with his self-identity now that there is an official diagnosis for his memory deficits) because of how he perceives himself, or how he thinks others may perceive him, now that he has a name for what he is dealing with in his memory deficits. He is not ready to allow his additional supports to know about his new developments and to talk about it with them. His relationships are complex and he is still struggling with his self-identity and has not been able to move on to his other relationships at this time. This one change has had many impacts in different areas of his life.

Church Relationships

Photographs revealed feelings on the theme of the importance of church support. This support clearly influenced decision-making and QoL. The roles of ministers and the spiritual support that individuals received (or not) from church settings were discussed in Chapter Three. The way relationships were established and maintained, not only by church leaders, but also by members within the church community influenced older individuals. OP #03 had enough church friends to sustain him and that was enough; he did not need to attend services or see a minister. Others attended services and that sustained them in their relationships. OP #12 and OP #14 both reported they attended church regularly and this influenced QoL. In addition, OP #12 reportedly spent several days each week at church activities - volunteering at the lunch club. This was an integral part of both her relationships and support systems. OP #12 reported that she received visits from her minister in her care home and her relationship and support network needs were met through those visits. Homeostasis with all these participants was in balance as expectations were met and participants were satisfied with support and relationships. Equifinality was evidenced as each individual achieved the level of QoL they desired in these different ways.

The opposite was reported for OP #01 her views of the church in both relationships and support networks. She shared negative experiences as she was not able to go out and attend services. She had had two visits in two years and stated “disappointment” in the local church. She was “quite bitter about it” and reported she did not receive communion. OP was not in a state of homeostasis as she was not in balance; she was below the minimum standards as she was not where she wanted to be with relationships, support, or spiritual guidance within the church networks, particularly as communion was still important to her.

Another example of church relationships came from OP #04. He was housebound and supported by his son and daughter-in-law with informal care. He was visited by his pastor and said that he was an active church goer when able. However, because he was now housebound, the pastor called on him. This was a support network for this OP and he reported he was happy. He was in a state of homeostasis as he felt things in life were stable and in balance. This also demonstrated another example of equifinality as the participant’s needs were met and he made decisions unique to him.

Importance of Relationships

OP #05 explained that one of the reasons she was able to return home from hospital was because the relationship she had with her partner,

“Well I think they accepted (my husband) as being a carer.”

This was an example of equifinality as she was able to return to the home setting. One of the solutions was because her husband was an approved care giver for her in the home setting so she was able to be released from hospital. She did get additional paid carers to assist and had these in place at the time of the first interview. Thus, she was able to utilise formal (paid) and informal (unpaid) care to get her needs met in addition to assistive devices. Her QoL was increased and reduced at times and she worked to keep her homeostasis in balance as her needs changed. She needed more care at the beginning of the research as she could do less for herself and her QoL was lower at that time and this worked to gain homeostasis.

OP #02 spoke of the relationships she had with her hired domestic help and formal care staff. She could connect with them using her MECS device when things went wrong. This participant often relied on her GP to be part of shared decision-making, prior to finalizing any important decisions she made. This was all part of the bigger picture of a holistic systems view, as her support was a crucial role in her wider systems and relationships with those connections to work toward homeostasis. She turned to them for practical support as well as advice and help with decision-making. Thus the meso level for this individual, with her wider support, was important for homeostasis. This demonstrated relationships, support networks, and how she utilised services.

> "It's a great, it's a terrific service. I've used them [MECS] on about seven or eight occasions and they will come and just pick you up off the ground you know if you can't get to your feet but they had to take me, they had to take me in the ambulance to the hospital and I ended up in hospital for three months in hospital with a broken arm and then I had a fall in the hospital and various things happened but so that's what this is round my neck [MECS] and it's a life thing…"

MECS for many participants was a contributing factor that allowed them to remain at home when they were socially isolated, and linked to family when needed in emergency. This gave them the perception of safety and security. Homeostasis was achieved as OP #02 was back from hospital and stable at the time of the interview and she was at peace with life. In addition, MECS had achieved the goal of improving interactions with other systems and did not have the aim of "curing" which was consistent with GST.

OP #07 reported on the relationship he had with his friends, how they were a support network, and what they did to assist him when he needed help.

> "Well my friends all got together when we were looking for a bed and they organised a night oot [out] in the big pub and did bingo and raffle and a' the rest of it but they arranged funds for this bed. We paid about four, it's under four thousand pounds for this bed."

Many relationships influenced support networks and these benefited individuals in various ways. This often improved QoL, adding substance to Research Question 3 with regard to QoL and decision-making. Relationships showed ways that often led to support networks that influenced decision-making, which also addressed research question four on how environmental factors influence decision-making. The relationships had a direct impact on how people spent money and used resources. Examples of resource utilisation included MECS and other services such as domestic help, or for OP #07 who needed a specialised bed. MECS, for example, also brought peace of mind to family members and OP #07 was able to get his bed as a result of his relationship with his support systems who had played an active role in raising the money needed for this.

In turn, this influenced homeostasis for the OP to return to balance and return to stability. It demonstrated the many paths of equifinality required to get to the same goals of acceptable levels of QoL and to meet changing care needs. Relationships, and the perceptions that accompany the relationships, influenced other areas in the broader spectrum of how people make decisions.

Support Networks

Support networks were the primary theme from OP interviews. Indeed support networks and relationships are both environmental factors linked to informal care and fostered choice. This relationship has contributed to decision-making, how resources were utilised (as established with MECS), and how relationships influenced support networks which included the broader implications on care and resource utilisation.

Support networks were formed through family, friends, churches, and formal care associations. This was also true with informal care. Velzke (2017) detailed instances where, without informal care, the OP would have died without the extra family support added into services. Networks were sustained through ongoing efforts by the individuals, friends, family, professional roles, and other supports. These support networks supported homeostasis and had direct influence on raising and lowering QoL -and in this case made the difference between life and death.

GPs and other professionals were a support network for some participants. Data disclosed reports of support networks which included influences of family members, friends, and those in professional roles such as carers, doctors, social workers, and ministers. Equifinality depended on how the support networks were established for each individual and what was important to the OP. Support networks linked to multiple issues including relationships, shared decision-making, assistance during times of crisis, help in navigating systems, and influences on decision-making. GST helped to highlight the wider issues of the systems, part of this related to prior experiences and part related to the conceptual constructs (Von Bertalanffy, 1972) of individuals.

This research has revealed that support networks in data can be considered as community assistance systems. Community resources were reported to be an extensive part of the success system by allowing older adults to remain in the home setting. Velzke and Baumann (2017) discussed reconvened focus group discussions in communities and shared decision-making. For instance, in some communities, people looked out for each other more than others and had deeper personal connections. On the other hand, in some communities people did not even know their neighbours. Participant reports of struggles, in some rural areas and having fewer resources and challenges for people with dementia and AD as they also reportedly had fewer resources for services. However, support systems in rural areas were closer and more established because of this lack of resources. In smaller communities, people knew each other and looked out for one another. Support networks also included links and support that supplemented individual formal care services. The data showed shared decision-making influenced activities they performed with and for OPs.

There were mixed reviews of MECS that illustrated its relationship with support networks. There was one case of a MECS frightening an older person with a voice talking out of a box. Another example reported the person being deaf, so the call re-routed and went to the daughter instead. These are examples of wider systems issues, and how some services were individualised based on decisions about what services OPs used (Research Question 2). Not all services are for everyone. Individuals get needs met differently at times (equifinality) to stabilise homeostasis. The environmental factors on the reliable support network in this example were that the calls were re-routed for the MECS to the daughter. This provides an example of the conceptual constructs of this OP that transitions from something frightful (voice talking out of the box) to the familiar of the daughter for both intrinsic (prior experience of daughters voice) and extrinsic (voice talking out of the box) in a positive solution. The visual data revealed 40% of participants discussed MECS and its positive influence on QoL and this data highlighted themes of added safety and security to individuals.

Residential circumstances often related to support networks. OPs reported relocating to be closer to family members. Some decided to relocate to where they lived growing up but others chose to stay in their current community as that was where the majority of family and friends resided. There were adult children who stayed too far away to offer informal care. They were supportive by phoning daily and also spoke directly with formal carers. These were examples of equifinality as there were multiple ways OPs had informal needs met. Velzke and Baumann (2017) discussed some examples of participants' family relocating to give informal care and support (such as finding a home with a Grannie flat). OP #14 utilised Skype to communicate with their family who were located farther away. The following examples provided added insight between relationships and support networks and the levels of support offered to individuals.

One instance of support networks was OP #01 and the relationship she had with her daughter,

> "You know and my daughter does come, she comes maybe twice a week so we go out usually although sometimes she has a clear out of my wardrobe [laughs]…"

She also reported other family as supportive and remained in close contact with them,

> "And my granddaughters and my grandson you know well he works down in Birmingham but he always comes to see me when he's up here and Jessie comes every Wednesday to see me on a Wednesday night, they're coming this evening and Gillian well we were over seeing them just about over a week ago I think."

OP #02 shared that a number of people were in her support network, and she had three cousins;

> "They help me in every way and in particular they phone, they're always on the phone and do I need anything and they are there and they can be with me within three-quarters of an hour in an emergency…"

She also had friends and neighbours and other paid and unpaid carers to assist her,

> "I've got neighbours that are never inside my house who never and yet they keep an eye on me and if they see my curtains are drawn too long they phone me are you all right, I couldn't have better neighbours and there are neighbours who bring me beautiful homemade soup but I have well the two ladies who come to clean are great friends, they're friends and they come in and out and then I have someone who does the garden, he lives up the road, he lives alone, he's mind you he's seventy, over seventy now but he does about six hours in the summer every week cutting the grass and so on so but he comes in every day with my paper so I see someone apart from the carers. I see a neighbour or a friend or a relative every day, I see someone every day so I don't feel neglected and I know I'm safe."

She also explained the role of her GP was important.

OP #05 stated she had a network of family and neighbours if needed,

> “Yes well I mean neighbours would help out if I asked but generally it’s my husband and the family are too far away to be of direct though one of my daughters-in-law is very good she phones every day to find out what the situation is [laughs] and so on and then she speaks to the care folk I think and she was a nurse so she knows what she’s about.”

OP #07 spoke of support networks with her spouse and professional workers. These workers also interconnected into relationships, quality care, and QoL,

> “Well there was social workers, physios, the physios got me walking, the social workers got the stair lift, different things done in the house. When I come home I was, everything was there [on being released from hospital].”

Caregiving was a result of relationships and support networks that generated both negative and positive outcomes. Caregiving, while employed, might have caused lost career opportunities and lost hours that affected both current income and future pension (Phillips, 2007). In addition, caregiving leads to higher stress and illness for caregivers (Philip et al., 2003). However, Age Scotland (2012) estimated those providing unpaid care saved the UK economy £87 billion per year with £8 billion of this in Scotland. Looking at the broader perspective, informal caregiving is a positive influence on the economy for cost-savings. This was important in the broader perspective of stringent budget cuts and resource scarcities. It also had implications on the final research question of the role of policy and the influences this had on the choices that older people have. The role of informal carers provided much needed relief to the overall care system; it was essential in meeting needs for care. Informal care was one option that supplemented formal care and a way to meet care needs in an individual way through support networks.

The visual data reported that the social structures for those in care homes were important. Individuals said that they enjoyed spending time in the lounge with other people. However, OP #11 and OP #14 revealed, in the photos discussions, that they also appreciated having the privacy of their own rooms. Many people appreciated different aspects of support networks and this was expected in examination of the broader perspective of decision-making.

The Interplay of Perceptions Regarding Older Adults

The self perceptions of OP were not always the same as how they were viewed by others. This was important as labels and definitions set standards, benchmarks, and QoL. Issues appeared when there were differences of perception for these labels. Velzke (2016) discussed the stigma of labels and how this kept individuals from utilising services because of labels; such as gender, class, or disability (Cordingly et al. 2001). Many issues influenced the ways in which decisions were made by older adults related to service utilisation and care as part of the wider systems of support that older people accessed.

For example, different disciplines and perspectives have questioned who best measures QoL of an individual and additional consideration was given to who had the strongest input on QoL. Earlier Von Bertalanffy (1972) examined how individuals perceived QoL and assembled constructs accordingly. The thesis establishes many strategies to minimise multiple realities. GST highlighted that the individual's reality is the most valid construct of the perceived QoL viewpoint. Photographs (evidenced in Chapters Three through Six) captured an individual's perceptions as evidenced by free flowing discussion about QoL, environmental factors, and issues that influenced care and decision-making that correlated to many of the Research Questions e.g. perception relates to Question 1 on how older adults set out to fulfil needs for care and support.

Self-identified labels are an area of discourse for OP. Labels were a common factor in specific categories in most societies. The thesis demonstrated a change in Chapter Four in behaviour and perception with OP #03 and the official diagnosis of AD. The label influenced his extended social system and situation, even though he had prior onset of symptoms for an extended period of time on his reactions. Barker (2003) discussed labelling theory. He explained that when people are labelled, behaviours change for others as well as the individual. The behavioural change may be to meet others' expectations such as a "self-fulfilling prophesy and an example of the Hawthorne effect" (p, 241). The Hawthorne effect is the change in behaviour when someone knows they are being watched (Barker, 2003). Therefore, it was of interest to examine the broader systems of the OP as they related to decision-making, QoL, and resource utilisation. This thesis has looked at how his diagnosis, as an environmental factor, influenced other areas of care and decision-making because of the label and his perception of that label.

How OP perceived themselves was measured in several ways and data were triangulated to minimise possible bias. First, this was measured quantitatively in QoL measures to be comparable between participants. Quantitative data were interspersed within themes. Perception was also measured qualitatively in interviews and emerged in photographs. Toze and Ray (2018) reported concern with measurement for older people that was not comparable between different interventions. The thesis looks at QoL in general and has not applied a specific intervention. However, triangulation of data has been completed with QoL.

Some people identified themselves as disabled, while others, who appeared to be disabled, did not. Barker (2003) reported a disability as "temporary or permanent reduction in function; the inability to perform some activities that most others can perform, usually as a result of a physical or mental condition or infirmary" (p. 121). Some participants were content to be housebound because they had what they felt they needed and they were living in their location of choice (home setting or care home). They had stable homeostasis, while others did not. Other OPs' health declined and they were admitted to hospital during the research.

Data revealed 13% of OP identified themselves as disabled following paralysis as a result of a stroke; 87% did not report themselves as disabled. This was evidenced by OP #11 and #07 self-identifying as disabled (due to partial paralysis on one side of the body). This caused life altering changes. Wider systems issues of changes individuals made due to diminished abilities, loss of independence and what some assistive devices represented influenced the perceptions that OPs reported, and the changes that they had experienced as a result of paralysis by needing to use a wheelchair. This construct of a wheelchair for one was negative. The environmental factors and prior experiences in how individuals viewed themselves and how they perceived someone who was disabled also influenced OP conceptual constructs on identifying as disabled or not and the things they had had to give up because of the loss of the abilities. OP #11 reported being unhappy about the changes a stroke provoked. OP #07 was less distressed and reported a stronger support system with a live-in spouse. OP #11's spouse was deceased, which resulted in her living alone. She reported having difficulties as a disabled person and cried while she talked about all she was forced to give up on account of her stroke and paralysis,

> "The life and all that about disabled people, right…It's a completely, I've had two lives I feel, I was born normal in 1939, now I'm living the life of a disabled person which is, it's terrible, it's really terrible, you'll never know what like it is till you go through it yourself."

All OPs had limitations that included them as disabled because of limited and restricted mobility; however, only two participants, or 13%, self-identified as disabled. Other OPs did not identify themselves as disabled as strongly as OP #11 had. QoL appeared to be influenced by assistive technology and devices, relationships, support networks, and other issues that resulted in many participants being in a state of homeostasis. On the other hand, OP #11 was disrupted and not in harmony. OP #07 was more difficult to categorise due to less distress than OP #11. The overall status quo of decision-making reported with OP #07 and his strong support system was within homeostasis.

For both participants OP #07 and OP #11, the paralysis only affected one side of the body in those two cases of self-identified physical disability. OP #07 was still able to walk short distances with walking aids. Assistive technology and devices were other environmental factors that influenced QoL and MECS enabled people to live where they chose (see Figure 8). OP #11 discussed her wheel chair, the loss of her mobility, and how her chair enabled her to go places, although, her perception of what the chair represented was of her loss and she “hated the sight of it.” She accepted it in time, and gave a positive outcome physically. Emotionally it had lingering effects.

Another marked difference between the OPs with paralysis was the length of time they had had to deal with their paralysis, and support partners to assist with personal independence. This had persisted for twenty years for OP #11 as she “hates not having the independence and the loss.” OP #07 appeared as if he was not aggravated by his limitations. He seemed in good spirits when he discussed his situation as he focused primarily on positive issues. OP #07 had a live-in partner that offered informal care and support while OP #11 received informal care from an adult child who did not live at home. OP #11 received support less frequently when compared to OP #07. OP #11 was not in a state of homeostasis, while OP #07 was. This was illustrated in the stability and ramifications they expressed about personal situations linked to disabilities and overall life situations.

OP #05 displayed different affects at each of the three interview visits. Her level of care was different at each visit, and her carers had not yet been in for the day at the first visit and it was afternoon. She appeared grouchy, dishevelled, and in pain as she was yelling when the researcher entered her room. This was because the construction work going on outside was “relentless” and her carers had not been there yet for the day to dress and bath her. She was excited to complete the interview.

At next visit, OP #05 was sitting in a chair in her living room with a guest for a visit (with her leg propped up). She was dressed and observed laughing and smiling when the researcher collected the camera. In her final visit, she unexpectedly received guests and she was in the garden entertaining. Figure 9 displays one of the photographs she took of her garden. There she discussed the importance of her garden and overall themes of being outside. She reported she liked to sit outside.

Figure 9. Daily Garden

OP #05 reported sitting in her garden daily. She progressed to being mobile and navigated stairs. She did not resemble the person who was in bed the first day of the interview by the final interview. Sinding and Aronson (2003) reported witnessing change over time - often a decline in an elderly women's circumstances, physical health, and the capabilities to 'make do' and refrain from complaint. Although, OP #05 was the reverse; she improved in health. The progression stood out in the spider diagram that was completed after the interviews when the individual had explained what the images meant to her. For example, Figure 10 'Rabbit Hutch' exhibits her time bedbound.

Figure 10. Rabbit Hutch

The rabbit hutch was the silver mechanism (as she called it) in the bed that held the blankets up; off the foot and the wound she had so that they would not rub on the blankets. Next, Figure 11 shows OP #05 up in a chair wearing a brace.

Figure 11. Wearing Foot Brace

Then, Figure 12 shows OP #05 when she has healed to the point of needing no brace.

Figure 12. Healed With No Foot Brace

The last photo in Figure 13, is of the bench OP #05 discussed when she exercised daily and needed to be seated to rest.

Figure 13. The Bench

This series of photographs tracked her healing process as she ranged from bedbound to mobile. She progressed over the three weeks' with minimal weight and no blankets touching her wound. Then, a brace, but progressed to no brace and to longer exercise (walking out to the road). The photos tracked her progression along with her perception of her story through the images. There are a series of wider issues of influence that GST highlighted her lived experiences that were linked to relationships and helped balance homeostasis. QoL was raised and lowered and influenced by: environmental factors, relationships and support networks. This had influence on the paid care she received, and an informal carer in the home allowed her to return to the home setting and have her friends to visit. She also had what she needed to exercise (although she found this to be limited as she was a former hillwalker).

Overall, there were reports of illnesses and problems at the first visit from OPs that were not mentioned at the second and vice versa. For example, hearing loss and eyesight (blindness/partial blindness) was mentioned on the second measure overall for OP. It was not revealed during the first visit, though it was present during both visits. Falls in the second WHOQOL measure were linked to hospital admittance, but the falls mentioned in first measure were not linked to the hospital. There was no mention of strained muscles, osteoporosis, need help/can't do much, leg ulcer, "none really," new legs, no second mention of issues from pregnancy, brain haemorrhage, irritated bowels, gout, gall bladder, diverticulitis, or angina during the first visit but these were reported at the second visit.

Other health concerns were also reported less frequently from visit to visit. Heart surgery, asthma, and stroke dropped from 13% to 7%. Broken bones went from 20% to

7% from the first visit to the second. Overall, these reports appeared to be consistent with other age related health and QoL topics evidenced by WHO (2015b) report, “By age 60, disability and death largely result from age-related losses in hearing, seeing and moving, and noncommunicable diseases, including heart disease, stroke, chronic respiratory disorders, cancers and dementia” (p.12).

Overall, the majority of OP had no visible outward differences or major changes between visits. However, there was a decline in a couple of OPs (hospitalised, had a fall) and improvement in a couple of OPs from the first visit to the last visit (within a space of two to four weeks). Many OPs reported staying the same when asked verbally during the interview and this was consistent to WHOQOL scores with the exception of two. OP #04 had fallen in between the visits and had physical bruising evidenced on the face and arms; otherwise, he was unhurt. This OP reported QoL as “good” because he had remained at home even with the bruising evidenced (he also stated he was happy). OP #02 was hospitalised and remained there through the final interview.

The importance of remaining in his own home for OP #4 was evident in his photos; he had many photos of his home and garden. He discussed why his home was so important and why he was “happy” to be in that setting. Some things allowed him to remain at home including, assistive technology and devices, home modifications (such as a ramp), wet room, and his formal and informal care and support networks. Others might have viewed his QoL differently. He was an individual that many professions might question his level of QoL and safety, depending on discipline specific viewpoints about their construct for these. He had multiple falls, looked bruised and battered, had a wrapped foot due to gout, hobbled around, and needed assistive devices (zimmer) to walk. This raised the question of who was best qualified to measure QoL.

OP #02 initially received homecare services. Then, she was admitted to the hospital because of illness. This hospital was where the final interview was conducted. In both cases, (OP #02 being temporarily in hospital and the OP #04 who fell) were OPs who lived in the home setting, used assistive technology and devices, and received both formal and informal care. Both OPs wanted to remain at home for as long as possible. This was possible through all the resources, strong external support systems, and family. The OP #02 perception of her level of QoL and functioning might have varied from the professionals in hospital when she was admitted. This had happened in the past and will be discussed in self advocacy. There was a letter written about OP #02 that recommended she go to a care home. Her perception was different. Decision-making was influenced by multiple factors as it is a complex issue; however, one theme emerged and that was the importance of the setting where people wanted to reside. Supports that assisted them in staying there were important: relationships, support networks, informal care, assistive technologies and how they have adapted based on changes of independence, ADLs, and IADLs.

Self-Advocacy and Decision-Making

OP's active participation in relationships and interactions were demonstrated by self-advocacy and decision-making when OP reported ownership and engagement in the decision-making process. Emotion motivated some decision-making choices as some OPs reported the perception that they did not matter and were left out of the decision-making process completely. This promoted self-advocacy and brought out emotions and other influences that were important to older people. Self-advocacy was a product of threats to individuals about losing the residence of choice, or other care decisions which had an effect on them. Research has suggested that emotion was a key part in decision-making processes (Brown 2011; Sanfey et al., 2003; Velzke & Baumann, 2017). This was reported in the case of OP #02 who was admitted to the hospital and did not have a voice in her care decisions. This spurred her to self-advocate as she preferred to be at home.

Some decisions were incited by emotion (Brown 2011; Sanfey et al., 2003; Velzke & Baumann, 2017). Upon hospital discharge, the process of including older people in decision-making had varying levels of participation by the clients. OP #02 reported she was not consulted in her care choices and not involved in the process. She self-advocated staying at home, and out of a care home, upon release from hospital and this influenced her decisions,

> "…But in the letter it said discharge from the hospital to a care home had been discussed. They had gone, they went behind my back and they phoned the social services and they said did they not think it was high time that [OP #02] was in a [care] home and the last thing I want to do is go into a home, I'll be very unhappy because I'd be with people who won't be able to have a proper conversation and I'm moving heaven and earth to stay in my own home…"

She made the decision to speak up for herself and self-advocated as to why she should remain at home. She recounted her story of her success from her perception. Some research has reported that care options were based on professional assessment and what they ascertained as best, and the patient's (client) wishes may be against professional recommendations (Hicks et al., 2012). OP #02 might have been opposed to recommendations to go home; however, there could have been other factors involved or limitations of the assessment process upon hospital discharge. OP #02 had strong support systems with paid and unpaid care givers. She also had community supports which might not have been considered at the time of the letter. These combined issues taken collectively as part of the wider system influenced the outcome of this OPs decision-making and QoL.

OP #02 informed the researcher that it was important to remain in her own home. She displayed emotion when she discussed why her home was important during discussion with photographs. OP interviews included discussions of photographs that resulted in triggering additional unrelated topics that did not match the photograph being discussed. This was important in understanding how and why decisions about care, and resource utilisation, were made. One example of this discussion was illustrated in Figure 14 “The Cart.” OP #02 talked about what was in the photograph. She ended up speaking about other things, seemingly unrelated, but had strong links and emotion to the photo. The photo brought back ties to her late husband and this was why staying in the home was important to her.

Figure 14. The Cart

OP #02 explained that this was a dog cart for use when people went out shooting (the back part was space for the dogs). She reported that she still had people stopping and wanting to buy this every month; however, she refused to sell. She talked about having the cart refurbished. She talked about having a shed built especially for the cart. This then led into another discussion about her husband and his love for his boat. She explained that the boat was his pride and joy at Loch [name of Loch] and “all the village turned out when he launched it” (OP #02). She also spoke about her community and how fortunate her life had been even when it was not easy. She had been “happy with a good life.” These phenomena all determined how she made decisions and why she wanted to remain in her own home. Thus, she self-advocated doing so. She had a strong community support system.

OP #02 also talked about how she almost left at one point before,

> “I nearly located to France after he [spouse] died but I couldn't bear
> to leave all my friends but I am going to stay in my own home as long as I can. (INT: Sounds like that’s very important to you.) Aha, that’s very important and with the people who look after me, with the help I’m getting I think it’s on the cards that I’ll manage it”

Another OP reported an example of self-advocacy and her perception on how she made this decision about care. OP #01 stated she decided to move to a care home as she felt that was the best setting for her. It was the setting that she felt she was treated to feel she mattered,

> “And they make you feel important, they make you feel that you know
> that you matter but I’m still a very independent person” (OP #01).

OP #12 revealed that she felt forced to self-advocate or she would get nothing. She stated,

> “You’ve to fight for everything you get, you don't just ask
> for it and you get it right away you have to wait, wait, wait.”

She discussed how frustrated she was with the changes she went through in the loss of her independence and the things she enjoyed. She had mobility issues, was often dizzy, and fell two weeks before her interview. She walked short distances with a cane, or if it was longer, she was forced to use a wheelchair. Ambulation was one area of difficulty for her. Her daughter took her shopping and for days out. She needed the wheelchair for those outings. Her daughter also supervised housework and the garden as needed. Her daughter changed the bedding. Her daughter did things that OP #12 reported she was used to taking care of herself. She had to adapt to the changes and role reversals within the family system for things she could no longer do alone. These wider systems issues influenced her decision-making to remain at home as she had her own prior experiences and conceptual constructs of things she enjoyed and doing things on her own that guided her decision-making for homeostasis. As an independent person, she reported that it had been difficult for her to ask for help. Then, when she had difficulty (when she was not able to get what was needed in due time), it added difficulty in her perception to ask others for help. She was in the process of developing homeostasis, and waiting was an issue that disrupted the process. Also, her role reversal and adapting to her diminished independence unsettled the achievement of homeostasis.

OP #12 had other decision-making influences. She had a strong support network that allowed her the independence to remain in her home. She had paid carers in at noon and teatime (5 pm), although she often ate prior to the meal the 5 pm carer prepared. She reported she was often hungry and could not wait until 5 pm to eat. This was a source of frustration for her, and did not suit her needs. She was made to wait, and waiting disrupted her homeostasis. She reset this by eating sooner and this allowed her to get her basic needs met and reduced her hunger. One way was to self-advocate and she made a meal for herself.

How People Determined if they Received Good Care

Relationships are a significant element of the meso level within wider support systems. Quality of care was a theme that was raised in the initial focus groups and emerged in data with interview participants, in photographs, and again during the reconvened focus group. This addressed data on what influences OP on what services they use for the second Research Question. Common care experiences were discussed in Velzke & Baumann (2017). This examined what OPs needed assistance with, some dissatisfaction with the quality of some formal care services, and how some OPs responded to this. Velzke (2017) discussed the way SDS assisted with decreasing the stigma of dependence on formal care services and explored added options in care from SDS. Quality care and quality caregivers were different issues. The following examples illustrated how people met their needs and how OP maintained homeostasis.

OP preferences in caregivers varied. For example, OP #02 reported what she liked in her caregiver was,

> "…He sees things that I need that I haven't noticed and he attends to that. He will do anything, he won't, he will do things even if he knows that strictly speaking is not his job but somebody needs to do it at that point and he'll do it… I've had carers who do a good enough job but their heart isn't in it, their heart isn't in it, they're not caring."

She continued to speak about the personal relationships and friendships she had with caregivers that moved caregiving beyond providing for basic needs. She discussed how needs and homeostasis were met. She, also, discussed the importance of relationships in the interactions,

> ”so when I’m in hospital of course he’s sent somewhere else [paid caregiver] and during that time that I’m in hospital he phones my cousin to find out how I am, he doesn't need to do that.”

She reported on the level of relationship built through working together, from her perspective, with her paid caregivers,

> “He’s a friend and I’ve got a personal relationship with him now and that means so much, it means so much to me and I can't really and he makes me good meals, he made me lovely meals because he was a chef before he did the job he’s doing, oh dear he’s a lovely man.”

This OP reported, through the caregiver’s relations, who had and who had not assisted her in maintaining homeostasis. This was not a stable thing. Her most recent carer was stable, but she reported instability with past carers.

OP #02 explained that the things important to her were,

> “My comfort, getting enough to eat [laughs], I think my comfort and getting medical attention when I need it.”

This OP needed less to maintain homeostasis at this time, as she reported what she needed to continue in order to maintain her current pathway.

OP #05 detailed what was important to her from her carers.

> “Erm, well obviously you trust them and they all have a very good manner you don't mind somebody helping you with very personal things you know if there’s something you can't do yourself that you normally would do yourself they all have a very good manner in not making you feel embarrassed, so that sort of thing.”

Relationships were also important issues for this participant.

OP #11 commented that independence was important to her,

> “I hate having a carer who just dives in and cuts your food up and doesnae ask me.
>
> [Interviewer] Does that happen a lot?
>
> [OP #11] No because if she’s cooking me sausage I’ll say by the way
>
> after you’ve cooked my sausage dinnae [do not] cut it up, by the time I go to get it it’s frozen and anyway if it’s a link sausage I can hold it in one hand and eat it…Yes, you want your own independence.”

This OP quote could be categorised in multiple areas; relationships, what is good care, independence or QoL. Many individuals reported if they were not happy with a caregiver, they did not have that carer for an extended period of time (if they had alternatives). That was how they returned to a balanced homeostasis. Velzke and Baumann (2017) discussed some examples, during the reconvened focus groups, of individuals who did not have a voice and who, therefore, needed some advocacy. The carers discussed, during the reconvened focus groups (to review findings), that care might not have been to the standard OPs would have liked. Care, at times, sustained homeostasis. At other times, it was not in harmony and relationships were found to have much to do with this in how decisions were made and how needs were met.

Importance of Working with People with Dementia

There were many issues that emerged with regard to working with people with dementia and AD. Adverse behaviours were discussed and PP reported that most practitioners "fail miserably" in intervening with adverse behaviours. Some decision-making of individuals resulted from not being able to communicate in traditional ways such as verbal communication for some was better some days than others. At times, frustration of not getting needs met, and not being heard, resulted in adverse behaviours. These all resulted in the lack of decision-making opportunities and a failure in communication as a result of perceived behaviours of individuals with dementia and AD.

For example, there were reports of lack of understanding with staff in regard to older people who could not communicate verbally, but acted out in other ways such as adverse behaviours,

> "My concern about that is that there's still a lack of understanding amongst staff working in care services about behaviour which they find challenging. So for example if somebody says to me oh you know if Mary's unhappy because she'll scream at you or hit you I'll say well why else would she demonstrate that behaviour do you think? Has Mary demonstrated that when she's been feeling pain before or when she's hungry or tired or and a lot of people have never considered you know that, those as options and that's quite worrying particularly for people who have dementia" (PP #19, Care Inspector).

The lowest paid staff were the frontline staff and they spent the most time with clients. They had the least amount of training, the lowest level of support, and they looked for opportunities to learn (PP #19). "There is a lack of funds to support training at this level and we trust them the most with the most vulnerable" (PP #19). Workers indicated concerns about the lack of understanding of adverse behaviours; there was question as to whether staff were listening to what older people wanted. Of particular concern were those with communication disorders who could not communicate in the traditional sense. Indeed, this lack of understanding may have translated to those with dementia who had no advance care planning in place. However, some of the efforts of professionals were making positive efforts to improve training for the frontline staff. SDS aims to get people independent and more active within their own plan of care in home settings.

Another example illustrated a Care Inspector's perception of the staff's lack of understanding in relation to medication management,

> "…And I think another thing that's been a concern in terms of people with dementia in particular is this medication of people so in terms of working out whether people are unhappy actually what service might or some services might tend to do is seek medication to manage some behaviour and actually we won't know then if that person's unhappy and we won't know if they're in pain because they wouldn't express that because they'll be fairly well tranquilised or sedated would be a better word to use about that wouldn't it [laughs] but you know what I mean. I'm seeing well we're all seeing less evidence of that there seems to be a bit more knowledge and understanding but there's still homes that I go into where somebody's on a medication that they've been on you know for years and years and I'm asking why and they don't really know" (PP #19, Care Inspector).

The role of medication management supported or inhibited decision-making; although, much of this might have been professional perceptions of individuals behaviours. Velzke (2014) reported that medication played a role in understanding individual's behaviours, being able to offer alternatives (especially with adverse incidences), and using of antipsychotic medications with the use of best practice. Similarly, a PP reported,

> "An example of best practice in this area entailed inclusion of the individuals' wishes. If they were not able to give them, they were to search out past wishes,
>
> So but yes every effort would be made to kind of ascertain what the person's views were, what their past wishes were. We would look at as I said before if somebody was resistant to taking medication on the ward and was always trying to leave with intent, sometimes you know folk who have got a cognitive impairment and a visitor goes out, the door's open they try and go out but it's just because the door's open. If it had been the door to somewhere else they

> would have tried to get out as well but then there's other folk that kept trying to get out with intent or they're disruptive in the ward in terms of their behaviours you know are they showing just through any of that type of behaviour are they unhappy, are they resistant to care because if they're resistant in hospital it's likely they'd be resistant wherever else they went as well" (PP #20, SS Manager, Hospital Team).

This examined issues from a broader perspective, in terms of an overall system of change. This individual might have been resistant in other areas, not just this one. Thus, they were considered for person-centred care. Velzke (2014) reported on best practice programmes in multiple settings (care homes, hospitals, day centres, and domiciliary care) that increased awareness in dementia care. Programmes assisted in reductions of adverse incidents, and promoted person-centred care with training that was flexible to agency programming and timescales. This assisted staff in successfully working with people with dementia and AD. Vahdat et al. (2014) discussed QoL and looked at a macro view suggesting that the adoption of policy influenced daily life for all (not just those with dementia), and encouraged individuals' level of participation in decision-making.

There were family members who gave individuals with dementia added care that was needed in care homes, that was person-centred and above what the facility offered. PP #17 reported the individual would have died without the additional care and it would not have been from lack of care (from the facility), just needing a higher level of care than some facilities could provide,

"…It wouldn't have necessarily been a lack of care but that's the level of care that somebody wi' dementia to rehabilitate from an illness or injury [needs]…" (PP #17).

There were many creative ways in which PPs offered person-centred choice that extended control to individuals with communication issues or those with dementia to stimulate decision-making. For example,

> "So you kind of narrow the choices down for them and help but giving choice to people with dementia is very important because it impacts on their self-esteem, it makes them feel in control even like at mealtimes in our day care they will come out with two plates of food to show somebody and say what would you like to eat today because the visual, they often understand the visual better than the words although they might have ordered their meal at eleven o'clock they're still given the choice visually about what they would like to eat" (PP. 23).

This allowed individuals an active role in decision-making and permitted choice in a way that, without it, would not as readily meet their needs. It is also consistent with GST as it allows improvement of interactions between systems without any attempt to cure and works to maintain a state of homeostasis by allowing individuals improved options for meals.

Different facilities that implemented identical policies, procedures, and managerial approaches had varying environmental atmospheres and it took two years to implement a new policy effectively (Foster, 2010). This affected decision-making based on power differentials of staff to the individual and facility policies (Scourfield, 2015). Whatever level individuals were involved in decision-making for care, QoL was multi-faceted and interconnected into many areas of decision-making for care (Velzke, 2016).

Perceptions and Roles of GPs and other Professionals

Professionals played a dominant role in the decision-making process for older people. The roles of the minister and the church were established as important. Velzke (2017) highlighted the influential roles that professionals played. For example, social workers influenced choice and decision-making based on how they assessed levels of need. Personal assistants are also important professionals, however their qualifications (or lack of) was an important point due to older people who are sometimes deemed vulnerable (Velzke, 2017).

When thinking of vulnerability, the consent of older people for both treatments in care and in research was considered. While consent was surely a serious concern, the root of the concept of vulnerability remained in the possibility of physical harm. The term is derived from the Latin *vulnus* (wound). In ordinary language, vulnerable means

> "'capable of being attacked, harmed, or injured in some way' or, in psychology, 'susceptible of being emotionally damaged or offended'" (Levine et al., 2004, p. 47).

Safeguards were in place for specific populations for those deemed vulnerable. An example of protection is the Adults with Incapacity Scotland Act (2000).

However, vulnerability was also based on individual staff perceptions in addition to the overall environment. For example,

> "I suppose it's about looking out too if there's clients who are very apathetic and not themselves you know are they actually depressed or you know taking into account because also what quite often happens is in a medical, physical

> environment then they don't necessarily always pick up [staff] if somebody's a bit slow or again that's not always because some of the wards are really good at that but others are not" (PP #20, SS Manager, Hospital Team).

Some disciplines' models of practice viewed and treated individuals different to others, including social work, nursing, GPs, and other professionals. Social work reportedly utilised a holistic approach as they considered wider systems issues. Kirst-Ashman and Hull (2012) stated that the holistic approach was an assessment of client need in multiples areas such as: "income, shelter, work, education, physical, mental health, social and other relationships, recreation and other leisure time, transportation, legal, and so on" (p. 554). This was consistent with GST. Kirst-Ashman and Hull (2012) reported that GST frameworks highlighted improving interactions with other systems. The focus was not on curing individuals which was a noted difference from the medical model, which aligned with the perceptions and behaviours of other professionals.

Most medical personnel (outside of social work) followed a medical model.

> "An approach to helping people that is patterned after the orientation used by many physicians, This includes looking after the client as an individual with an illness to be treated, giving relatively less attention to factors in the clients environment, diagnosing the condition with fairly specific labels, and treating the problem through regular clinic appointments." (Barker, 2003, p. 267).

Different disciplines assessed various resources and changes within an individual's background and environments. For example, social work professionals explored environments, social systems, cultural considerations and psychological issues. Other medical professionals were sometimes less likely to notice these areas. This was of interest as this emerged in data many times through differences noted between disciplines and models of practice and had direct bearing on OP decision-making. Toze and Ray (2018) reported the importance of considering the health of older people holistically. Models of practice were important as there were times when individuals needed to be healed and others when individuals needed interventions that treated more than a physical wound. There was discussion about the different models of practice among PPs, and also the use of labels.

PPs discussed the use of the word patient versus client and how this was perceived. The meaning of the word patient is distinct and links to the medical model and professional perceptions. Oxford (2018a) reported that a patient is a person involved in medical treatment.

> "Origin Middle English: from Old French, from Latin patient- 'suffering', from the verb pati)" (para 3).

Neuberger (1999) saw 'patient' as a word that objectifies a person who is passively involved in care treatment. With this definition, a power differential was assumed between the individual and their physician/doctor. NHS (2012) suggested some individuals were reluctant to be labelled as patients because of the association with suffering.

Some medical professionals maintained there was a clear need for set boundaries. One way to accomplish this was to maintain the boundary of referring to 'patients' and not to 'clients.' Conti (2008) was a physician who clarified that the physician's role was to treat the sick and he maintained that the boundary was clear and physicians should only refer to those whom they treated as patients. It was Conti who suggested this term patient should replace the term client in the medical discipline because of reimbursement issues. NHS (2012) recommended that alternatives to the word patient would empower the user by changing the "relationship with illness, society and the medical profession" (para 1.). Similarly, Neuberger (1999) argued that not all medical focus was to treat the illness, but rather some was for lifestyle 'fertility or cosmetic surgery' (p. 1756). He deemed the term patient as not fitting in the medical field. Then again, Tallis (1999) contended both sides and decided to keep 'patient' in the medical vocabulary,

> "The distinctiveness of patients reminds us of the vulnerabilities of the ill person and the often harrowing responsibility of the doctor or nurse…so while the term patient may be steeped in the abuses of the past, is also captures what it positive about the special relationship between health workers and ill people." (p. 1757)

Professionals debated the merits and disadvantages of patient and client labels, although all agreed that boundaries were necessary in some capacity.

The data for this research maintained the perception of older people with clear boundaries with physicians and GPs. This impacted both OP decision-making and care. Chapter Four established that GPs were viewed to be experts and "godlike" but the 'the powers that be' references made by OP were not limited to only GPs. This reference was applied to other supports including spouses and other professionals. It was consistent with GST, as it was the conceptual construct assigned by OP themselves. Other researchers suggested more widespread research on individual opinions on preferences with doctor and treatment interactions and how this was referenced (such as patient versus. client label) (Tallis, 1999).

The meaning of the word client is more multi-disciplinary. It was used to empower individuals (Neuberger, 1999; NHS, 2012). Oxford (2018b) reported client was,

> "A person or organization using the services of a lawyer or other professional person or company…. A person being dealt with by social or medical services…. (in ancient Rome) a plebeian under the protection of a patrician…. Origin Late Middle English: from Latin cliens, client-, variant of cluens 'heeding', from cluere 'hear or obey'. The term originally denoted a person under the protection and patronage of another, hence a person 'protected' by a legal adviser." (p. 1)

The NHS (2012) reported that psychotherapists and psychologists preferred client to patient as it was reported to have fewer historical connotations. In the social work discipline, client vs. patient references were debated to often utilising clients or client systems. Kirst-Ashman and Hull (2012) explained that "a client system is any individual, family, group, organization or community that will ultimately benefit from generalist social work interventions" (p, 11). Many disciplines vary the terminology.

The debate for using patient versus client language and how this influenced older people's decisions and resource utilisation was intricate. The NHS (2012) reported that individuals asserted power and control by refusing to be labelled as patients. When individuals rejected the word patient, it indicated personal freedom, autonomy, and an insistence that "we don't need others" (p. 9). Some similarities in word usage were noted as there was an assumed power differential with each label. In this research, different specific models of care and practice have been established in how to assess, intervene, and refer to individuals. Some literature suggested this debate was about maintaining idealism, boundaries, and perceptions with the use of the term patient (Conti, 2008). Tallis (1999) suggested asking for individual preferences. The next step was to determine whether the NHS would fund research to examine more widespread opinions. In summary, most agreed that cultural and organisational change was complicated. Social work practice often asked individuals what they preferred to be called, and this settled the debate of 'patient' or 'client' on an individual basis. For some the word patient was a positive boundary, others perceived it as a barrier. This thesis mainly refers to individuals as clients.

Other barriers to older people's decision-making depended on the way the system was set up and the engrained thinking of the professionals in the care system. This was similar to Velzke (2017) about the conversion to SDS policy in practice. The various models appeared to have a slower transition in some areas to diversify and expand practice holistically despite the additional emerging models of care (Velzke, 2017). This included a person-centred approach and models such as the policy and practice of SDS that established empowerment and promoted independence.

However, in broader terms, the ease of the transition and change process was debated. PP #19's (Care Inspector) opinion was this would not change unless there was a big shift in thinking toward people with higher care needs who required services,

> "…Until there's a massive shift in the way that we actually see people [laughs] people generally and older people and stop seeing them as just patients [clients] which is a word that I hear all the time and I absolutely hate, well so you're not a person any more because you're in a care home then you become a patient [client] then that's not that likely to change but I think as well because the system of assessment is so focused on people with a higher level of need physically and psychologically that you know that we can't get away from that, you don't, I don't meet that many people in care homes who have full capacity any more…"

It was reported that it would be an effort to change thinking at the front lines in a more direct way; it was reported that action efforts were underway. Velzke (2017) reported on advocating for choice, and other efforts were made to support staff and agencies for trainings and person-centred care. However, looking at the broader implications, labels were important as were perceptions of individuals and professionals in the care arena.

Influences of Professional Opinions and Roles

A variety of professionals were reported to be held in high regard by OP and influenced by how they made decisions, adding a better understanding of Research Question one. OPs stated that some people made no care decisions until they first consulted with their GP. This also emerged in both PP and OP interviews. One example was OP #03 who was diagnosed with AD. He gave up driving as his GP recommended. He also started a journal early on that detailed memory incidences, also as recommended by the GP, which assisted in diagnosing his AD.

Similarly, OP #02 consulted with her GP in decision-making. She reported,

> "…I phone my doctor and ask to speak to the doctor. Again I'm loathe to call them out for the least thing you see but I quite often have to call a doctor out but I can talk to my doctor and ask for advice.…"

She was confident in seeking her GP's opinion about issues that were important to her. Her GP was someone she trusted and she looked to her GP for advice beyond medical issues. GPs often did house-calls and home visits for clients as this OP was not able to get out of her home and into the surgery.

Another example was OP #05 who reported getting a medication box from her GP,

> "Well I would be perfectly capable of doing it on my own but the powers that be [GP] decided I ought to have one of those medical boxes made up you know with what you take at different times of the day and for seven days a week and so one of the pharmacies in the village makes that up for me and I just poke the correct bubble and take what's inside."

OP #05 reported she thought she could do this on her own. However, since it was the GP that said she needed assistance, they complied. The language used "…the powers that be..." indicated established power and authority in a Godlike persona (Martin, 2017). This was a major way in which professional roles influenced decision-making.

PP opinion about OP perspectives was similar, "…I mean GPs are gods in their own right here…" (PP #19) and they discussed the power that GPs have with people with dementia. The power differential that GPs had between clients, and how credentials influenced people's decision-making because of this added stature, was evident. This opinion also extended to other professionals. For example, PP #20 said that this applied to those conducting assessments,

> "Although they still, there's still this kind of attitude with a lot of older people, not everybody but you know the consultant is God kind of thing."

There were those that were held in higher esteem because of the professional position they had, duties performed, and power to influence decisions. However, this was not true for everyone. The NHS (2012) reported that individual roles with doctors might have been a partnership or a co-production. The balance of knowledge, power, and responsibility was reported to be based on "personality, psychology, disease status (unknown, deteriorating, recovering, recovered, etc,) wealth, education, sex, and social status" (p. 5). Toze and Ray (2018) reported that, if individuals did not get their social problems or other needs met elsewhere, they likely solicited out GPs advice.

The role of the professional and how that prior experience fits into OP conceptual constructs were internalised differently based on each individual's learned experience and path of equifinality. Individuals had many paths of decision-making as GPs were not always the first support person they called when they utilised shared decision-making. Von Bertalanffy (1972) explained the effects intrinsic influence has on behaviour. This demonstrates how each individual works to navigate and maintain homeostasis. GST was utilised to trace how those processes worked through systems with QoL being raised and lowered. The GPs assisted with decision-making at times other times it was family, neighbours or carers. Here again, the wider systems issues of homeostasis linked to shared decision-making, support systems and networks that can be related to an individual's prior experiences and conceptual constructs (Von Bertalanffy, 1972) on prior experience that influenced an individual's actual behaviour. Solomon et al. (2010) reported that individual ratings of QoL were subjective and varied and they also suggested that temporary factors of functional status can influence QoL. Individuals may have called their paid carer if needing a bath and not a clergy member for this function, but if they wanted communion they would have called clergy and not a paid carer. Individual's categorised individuals according to their own preferences and needs based on their own experiences and how they constructed the relationships they had with others to get needs met.

Risk and Adverse Behaviours for People with Capacity

Choice was not always an option that was available to people deemed at risk by professionals and practitioners. At times, this might have applied to even those who were retaining capacity. There appeared to be specific times when rights appeared to be denied to older people by professionals who influenced the decision-making process. This was reported to happen more in the acute care settings.

For example, there were multiple reports of risks and adverse behaviours,

> "One of the other issues is risk averse behaviours from NHS staff, interestingly not the staff that work in community it's the staff that work in acute… The assumption that somebody needs twenty-four hour care because they have falls or they've got a slight cognitive impairment but actually the person's got the capacity to make their own decisions and they would rather fall at home so" (PP #20).

There were times when individuals had the right to make decisions that were different from the professional's recommendations. This was seen when OP #04 discussed that he was falling at home. Indeed, OP #02 fell and needed the ambulance to go to the hospital. Previous data reported that individuals are making different decisions to accommodate their needs in situations (such as) when falling to get MECS and adding additional services in the home as needs change over time.

PP explained that capacity was needed for older people to be able to legally make risky decisions for themselves. If they had capacity, and they had all the applicable information, legally they had the right to make risky choices (Brown, 2011). Practitioners appeared to struggle with this at times as what they wanted for the client conflicted with what the client wanted for themselves. It appeared that some professionals took choice away from individuals even though they knew, under the law, that the individual had the right to make risky decisions.

For example, Hicks et al., (2012) illustrated that older people's options and choices in decision-making were sometimes limited by what was offered and who made decisions. This was reported to be skewed at times by what recommendations were offered to individuals based on a professional's perceptions about backgrounds, levels of risks, and demographics (Hicks et al., 2012). This influenced implementation of policy in practice and professional presentation of services (Scourfield, 2015).

Accommodating Difference in Attitudes, Views and Opinions

Many professionals commented on the perceived "stubborn" attitudes of older people when making choices in the refusal of services, assistive technology or devices when these pertained to care and resource utilisation. This included those who did not wish any more treatment. PP reported that there were safeguards in place when prior wishes were known and older people were able to have that choice of declining services even if at risk.

One example was an older person, a frequent faller, who was described by a PP as 'stubborn'. Duty to inform was described as being at the forefront. In order for the professional or family member to assess the danger, many factors including capacity and impairment were considered. For example, one case was the older person, age 97, who had been a frequent faller in the last two years. She had a hip fracture, damaged head, skin tears in the scalp, and an overnight hospital stay. As a result, professionals re-arranged her room, put sensors on her bed and chair, and considered that to be more beneficial. In order to maintain independence, it was determined she needed to have sensors for safety. The GP became involved because it was a well-being issue. This is an example of PPs looking at the situation itself holistically, and considering wider systems issues for the individual. Assisting in shared decision-making and providing person-centred care enable adaptations for the individual to remain as independent as possible. PP explained that people have the choice to make 'bad decisions' meaning some professionals/disciplines may not have agreed with the safety aspects of this persons' decision to remain in place as a fall risk, and the individual has the right to make their decisions as long as there is capacity and they have all the required information.

Perceptions of Behaviours Resulting in a Reluctance to Complain

There was general thinking of PP that older people do not complain; however, one exception was offered by PP #20.

> "In hospital people don't like to complain because they feel vulnerable and they're kind of at the mercy of those that they're complaining about so they don't. They are not as afraid to complain about social work [laugh] interestingly enough."

In this particular case, individuals were empowered to speak up and discuss what they did not like about social work. They were able to be active in their care decisions in a safe environment, when not in agreement and wanting to complain and were not influenced by power differentials or institutional status. The general reluctance to complain in areas except social work indicated that people felt empowered (and safe) towards social work professionals. Researchers have indicated that power and relationships are indicators of older people's roles to engage, or not, in care decisions (Petriwskyj et al., 2014; Petriwskyj et al., 2015). The individual who complained was working toward maintaining homeostasis to take steps to get balance and stability back in place. Whereas, in other areas where there was that reluctance, there could be more serious issues prohibiting people from voicing opinions such as vulnerability, guilt, emotions or issues as previously discussed.

This had other implications regarding people's reluctance to complain. For example, how individuals stated their preferences or remained silent depended on whether it would be considered negative. Relationships could be another factor in the situation; the better the relationship, the more likely the individual would be to voice an opinion with the profession. These factors may have been present in the prior example with PP #20 when individuals are empowered to complain about social work. Client rights are encouraged by social workers and consequences for speaking may pose less of a threat to the individual because of the relationship and established rapport. This would be influenced by the individuals' conceptual constructs and their prior experiences.

The power differentials influence interactions between individuals and professionals, and the way individual care needs were met affected if future needs were appropriately met or not. Petriwskyj et al., (2014) suggested that the reason why older people did not complain was that they did not want to be seen as pushy or to be putting their needs above others. Wada (2015) reported one case of a person's refusal to complain as this person saw herself as not competent on her own. She felt she might go unheard and there was a risk of neglect involved in voicing an opinion. These would be examples of passive involvement in care decisions.

Additional reasons people did not complain varied. For example, Hicks et al. (2012) illustrated a situation where a participant became hopeless in the care process after being left out of decision-making. The participant was being placed in a facility where she did not want to be. Finally, she just accepted that others would plan her care; so, she adopted a fatalistic view on her role within the care system by letting others take control of her care without trying to change this and not having a say. Others reported, in care home settings, a reluctance to speak out and experienced limited choice because of community living and consideration for others (Wada, 2015). Those in individual settings did not complain as they did not want to appear ungrateful (Wada, 2015). There were many reasons people decided not to complain in various settings based on preferences and conceptual constructs.

One OP had vertigo. When she had incidences she did not always share them, or waited to tell her family about them as she did not wish to complain,

> "Well I'm independent, in fact my daughter she was on holiday at the time when I took this shakiness and had to hold on and when she was home and her daughter told her she says why did you no' phone me? She says my granny warned me I wasnae [was not] tae [to] tell you till you came home.
>
> [Interviewer] So that's when you were hanging your sheets out on the line
> and you got dizzy so you grabbed the rope so you didn't fall."
>
> [OP #12] "Hmm mmm."

This could also be classified under relationships and support networks as the OP had trust in the granddaughter not to tell the daughter until after she returned home from holiday. The OP was reluctant to complain to the daughter. The OP was also very independent. Many influencing factors came into play (as part of wider systems issues) and this also affected QoL, and decision-making options in day-to-day living. Asking for help related to how the individual perceived herself and her independence. Although she reached out to the granddaughter about the incident, when looking at the broader picture there are multiple issues involved in how decision-making takes place. This chapter has shown the many reasons why and how individuals' decisions are made on a personal level focusing on the influence of relationships, support networks, and perceptions on decision-making at the meso level. The complexities of OPs decision-making were influenced by wider systems issues of individual preferences, family and professionals.

Conclusion

This chapter has focused on the meso level and provided an insight into the process of why people made decisions about care based on perceptions and the roles of those who were deemed important to them, such as church ministers. Personal interactions and relationships both inhibited, and supported, decision-making. Relationships led to individual support networks and were significant ways in which QoL was improved. This was evidenced in individual relationships and group activities. Individuals' social systems were the most prominent theme from older people and most individuals had more than one support system which they relied on for support with decision-making. This included both formal and informal structures. For example, the majority of participants (67% of OP) indicated that family and carers had some influence on decisions and QoL. GPs and professionals also had strong influences on decision-making.

Power differentials influenced older adults' decision-making behaviours. The added expertise that professionals bring with education and experience was a positive benefit. Some older adults struggled with the loss of independence and relied on the family to help meet needs. Any role reversals experienced in families had far reaching implications and the loss of favourite activities, physical activities, and social events was revealed. The roles and labels of older adults, perceived by professionals and individuals themselves, were found to have implications in established power and control. Models of care and discipline specific indicators had an impact on how older adults were approached and these demonstrated how the wider implications of control as well as how this influenced how decisions and resource utilisation were employed. Perceived power and control also influenced whether or not individuals complained or remained quiet if something was wrong.

Individual self-advocacy, and the environmental factors that influenced what was perceived to be good care by older adults, were identified. Environmental factors such as relationships, social networks, and alternative social supports impacted on how individuals made decisions and utilised resources based on their circumstances. Environmental factors and the influence of those factors on decision-making for older adults were identified throughout the chapter.

The environmental factors also assisted in a better understanding of some of the influence of services on decision-making and this feeds into our understanding of Research Question Two. For instance, some older people used domestic help, paid carers, and MECS. Homeostasis was an influence on those who were not already in balance to return to stability. They did this by getting additional services and resources to meet their needs. Manifold paths of equifinality were demonstrated through relationships, support networks, formal and informal care, and resource utilisation as individuals sought to meet their needs. Chapters Four and Five have revealed these as the structures that individuals adopted in the unique pathways to decision-making. These were based on individual relationships, attitudes, behaviours, perceptions and experiences. This was consistent with the initial research question.

Furthermore, labels and roles influenced decision-making and changed behaviours. How individuals perceived themselves was an important factor. One example of this was whether people classified themselves as disabled or not. Overall, OP did not identify themselves as disabled and a better understanding of this was provided for the initial research question. When someone was defined by a label, it changed behaviour as was seen in the diagnosis of AD. Perceptions were prominent and when labels were utilised this had wider implications in many areas related to decision-making. Individuals are living longer and much is unknown at individual, group, and community levels.

Moreover, there was an impact on relationships as a result of perceptions by both professionals and older adults. The boundaries in relationships emerged because of labels such as patient vs. client, or being labelled as disabled, in ageing issues and the perceptions and implications that accompanied these labels. Professionals were influenced by their own understanding of ageing and this influenced how they supported older people to make choices. If ageing was perceived as a bio-medical issue, this resulted in professionals tending to take over decision-making and not fully including the older people or supporting their self-advocacy. This is further supported by some professionals being elevated to a “godlike” status by OPs. However, different disciplines were found to utilise different models of care which in turn influenced practice. This affected relationships and had a direct impact on the style of decision-making OP utilised and how involved shared decision-making was with professionals.

These wider perceptions of ageing were also often reflected in policy which will be discussed in more detail in Chapter Six.

Chapter Six Findings: Environment and Resources

Introduction

This chapter explores macro level issues of environments and resources. It discusses the support and behaviours that have enabled older people to remain at home as well as the behaviours and reasons why older people want to reside in care homes. It explains the resources that have supported independence in these residences of choice so that individuals were able to remain in place. Implications from Chapter Five on meso issued led to further questions on the macro level of systems discussed in this Chapter, and how these interact within policy as well as wider attitudes and perceptions of professionals. This Chapter will expand on the perceived idea of how money, power and control within these systems and relationships play out on a wider scale. Attitudes about thresholds of quality of care from multiple perspectives are discussed and the constraints that older adults encounter are revealed along with the impact and influence that these constraints have on decision-making. Moreover, the chapter examines the behaviours of individuals in crisis. This is impacted in situations of limited services. For example, an individual's behaviours and expectations would be different if only one service area was available. Hospital services were highlighted as the services had strong influence on support or inhibition for care and resource utilisation.

The research focus broadens throughout the project examining the research questions and explored emerging policy. Policy changes regularly and this can be a complicated factor in making sense of a system with the OP at the centre. It is not always obvious, (within each system) what difference policy may make as it can impinge on the individual at times and it is mediated by multiple factors and people within the system. GST supported efforts to understand multiple perspectives (see Chapter 3) and how these interacted within policy. Velzke (2017) suggested that SDS assists in older peoples' goals. In addition, the views of professionals were explored. This had a focus on the fifth and final research question in the bigger picture of Scotland's policy as it influences choices available to and/or made by older people. This resulted in this research revealing that SDS policy was set to launch in 2014 in the local authority area where the research was conducted. SDS allows opportunities for older adults to take charge of personal budgets or to allocate budgets back to the local authority. This allows opportunities for individuals to decide the level of control over care management.

Velzke and Baumann (2017) reported that OP vignette data and feedback were similar to what OP experienced. This chapter, therefore, explores two main issues. First, it reviews how environmental factors inhibit or support decision-making by older people. Secondly, it provides insight into the perception of resource utilisation in decision-making, and illuminates further understanding of what influences decision-making by older people about what services are used. QoL manifested in decisions such as where and why people selected specific residences. In addition, this led to adaptation and sustainability over time. Participants moved for multiple reasons including being near family, living with family, or needing higher levels of care. Data were explored in terms of how decisions were made either to live in care homes and or to remain at home.

Where Older People Want to Reside

The environment affected decision-making, as the location of the residence was a key influence. It was more than a geographic location or setting in a home or facility. For instance, the environment influenced independence. The data demonstrated that the environment was linked to community resources and caregiving preferences. The environmental factors were discussed in Chapters Four and Five. OPs chose to live in care homes or at home and they were able to make the decisions for themselves or to have decision-making assistance from the family.

OP reported having support and viewed QoL positively. They had assistive technology and devices Mobile Emergency Care Service (MECS) to support them and the other issues which influenced QoL can be seen in Tables 13 and 14. In the first research visit with OP, 44% of participants reported they were healthy and 33% reported good health at the second visit, but a few participants reported minor illnesses and problems. OP did not consider QoL negatively because they were living in the place they desired and had set supports and resources in place. This suggested that QoL was subjective to individual perceptions based on conceptual constructs of QoL and equifinality. The decisions to live in care homes or at home, impacts of the reablement programme-a care at home programme that supports independence, and implications of satisfaction levels are described in the following sections in relation to the influence on decision-making.

Reablement and Remaining in the Home

Reablement is a six to eight week programme designed to support independence in the home setting. This responded to the final research question and how current policy influenced choices of older people. Many programmes often come together to assist in the needs of OP, and as OP were released from hospital this started their care in the home and they often transitioned to another care package later if their care needs continued. It gives individuals added support when they are discharged from the hospital. Furthermore, it gave OP some choice and decision options within care at home. The programme addressed services in the areas people needed temporary assistance to maintain living at home, but also worked on skills to get back to independent living. Everyone was required to go through this reablement programme upon release from hospital if care was needed. Sometimes people only needed the programme for two weeks and went back to a regular routine. Others extended it beyond the six to eight weeks of the programme. If they still needed care after that time, then it transitioned to another package of care. At that point, SDS would start. The idea behind the model was to prevent hospital admissions and to assist in speedier discharge from hospital (OP #18, CH Manager).

In contrast, there was a split between the positive reports and the negative implications regarding the reablement model on older people. The main difference was the role of the OP as that appeared to influence the perspective of the service offered to the older person. The Care Inspectors and social workers were concerned with the lack of choice and the rigidity of the system. The concerns stemmed from not being able to meet individual needs. Alternatively, the higher level managers were pleased with the cost savings associated with rehabilitation. It kept people at home and out of the care home setting. This did align with the majority of the older peoples' wishes to remain at home for as long as possible. Although, being at home fit the majority of older people (although not all want to be at home) and complements SDS in the continuation of care.

Reablement did not suit all older people as it created a one size fits all models approach. It was a challenge for those who were not suited to go back to the home setting. For example, an older woman wanted to go to a care home, but she was not able to do so until she went through her time at home and was found to be unsuccessful to become independent. All older people were mandated to go through the programme regardless of their wishes. Once the six to eight weeks of reablement were concluded, it was more likely that they were able to transition to a care home or more appropriate setting for their needs. Overall, reablement benefited the majority of older people; although, there were some changes in reablement which were made to improve some of the features included in the programme. Those changes were to advance personal independence and choice. SDS options, at the conclusion of reablement, were helpful for those wishing to remain at home. SDS allowed the OP options in the decision-making arena for in home care, but only limited care home choice. This was a resource that many OP had in place when care at home started; however, most in home care in the project converted to a different package of care if this was not already in place.

How Decisions Were Made to Live in Care Homes

Some OP self-selected care homes in decision-making when they had multiple options for care choices. The majority of OP reported that they preferred the home setting. For example, OP #01 stated she had many options when she decided to move to a care home after being repeatedly in and out of hospital for a year.

> "Yes there's always somebody here [care home] you know if you need them through the night and I mean talking to one or two of my friends that I've made round about here and they all feel the same that it's comforting to know there's somebody available if you need them."

She could have gone to live with family, but decided to go to a care home for the support network, the services offered, and the style of living.

This same participant reported she was looking for independence and privacy in the geographic area. She described herself as a "townie" who took advantage of shopping and walks. She reported she never learned to drive; the facility bus was important for her outings. In addition, she preferred having control, independence, and privacy maintained for her,

> "And they make you feel important, they make you feel that you know
> that you matter but I'm still a very independent person..." (OP #01).

Some influencing factors for OP #01 were previous care experiences in the home. She reported that, when she lived at home, she had carers. However, there were certain things they were not allowed to do (depending on the care plan, if items were not listed they were not allowed to do them), which caused difficulties. She also shared it was a relief to her daughter when she moved to the care home because she was now in a clean and safe environment. All these factors influenced how she was able to maintain homeostasis by meeting goals. Similarly, OP #14 reported she moved from her own home into a care home. She stated she moved quite a distance to be near her daughter who assisted in shared decision-making to locate a facility. She confirmed that she had little difficulty doing things and little help when she moved. The choice was more about location than necessity. She was able to use Skype, to speak with her son who travelled frequently. These are two examples of different situations that meet the same goals of homeostasis and how they got to that end (equifinality).

OP #14 reported she was happy in the care home as she enjoyed the easy conversations and the privacy of her own room. She stated she was able to specify her preferences and need with the caregivers and that she enjoyed time reading, knitting, attending church, and watching television with other residents, and completing word searches and crosswords. Her decisions were influenced by wanting companionship or time to herself. She enjoyed time in the community room with others but was always able to go to her room, close the door, and have time to herself when needed. These were also ways this participant maintained homeostasis. The social isolation of being in the home was an issue for this participant. She also provided insight into the attitude and behaviours of her decision-making about care.

The choice to reside in the care home setting was influenced by relationships, support systems, the need for added support, and higher levels of care. The reported environmental macro factors were safety and security, geographic locations, transportation opportunities, and assistance with technology. For some OP, the preference was to be near family (geographic location) or to be near resources such as shopping. Others desired safety and security. Prior negative experiences in care influenced some choices and many influences of how and why individuals decided to move to care homes emerged. Some OP utilised shared decision-making strategies. Care home options allowed many to remain independent in the ways that mattered to them. Their needs were fulfilled and feelings were reported to be validated by their choices, achieving homeostasis.

How Decisions Were Made to Reside at Home

Through the vignette responses, many OP revealed they resided in their own homes. Velzke and Baumann (2017) suggested the themes of remaining at home, avoiding being a burden, maintaining privacy and dignity, and continuing independence. They examined examples of ways that made this possible. Part of this was through environmental factors such as informal care and family assistance in caregiving. OPs explained that they worked (to maintain homeostasis) to balance care to meet needs. Each participant explained their individual situation, needs for care, and how they met care requirements and their perceptions about care and resources utilisation were revealed. Moreover, OP disclosed behaviours and attitudes in decision-making. For example, OP #02 reported,

> "I was in a wee bungalow and she [daughter] was buying another house so she sold her flat. They were in a flat and I was in the bungalow and we sold the two of them and built the house we're in now. [reported it was for convenience 20 years ago]… But I know, well I couldn't be more fortunate in the help I have, couldn't be more fortunate, everybody they're caring people; it's unbelievable."

OP #07 also shared wanting to remain in the home setting,

> "Well I think she's quite right wanting to stay in her own home and keep her independence. I'm the same as I say when I ta'en the stroke I was working right up to I took the stroke, I took the stroke in the factory and I landed up in hospital for a year and everything was sorted in the house before I came hame and the carers in position and everything like that, social workers took care of all that."

OP #05 wanted to return home from hospital. She had her husband at home to assist with her informal care needs, and reablement for up to eight weeks to assist with working toward independence,

> [Interviewer] "OK and were you given the option to come home or to go to a care home or some other place?"
>
> [OP #05] "Well I think they accepted (my husband) as being a carer…So I was allowed to come home."
>
> [Interviewer] "And is that where you want to be?"
>
> [OP #05] "Oh definitely [laughs] yes."

OPs had many personal situations impacted by different factors, programmes and supports allowing them to remain at home.

Velzke and Baumann (2017), and these examples, illustrated vignettes in the research process that related to decisions about care and QoL. This supported the use of participatory methods resulting in vignettes for this research. In order to make residency choices, older adults relied on relationships, support networks, informal care, financial resources, and environmental factors. These environmental factors included policy that allowed for formal care support in the home, such as reablement. Shared decision-making was utilised for some. OP #07 utilised a network of professionals to assist in arranging his support at home and he had employed a status quo decision-making style. The importance of professionals was also vital in making a choice. For example, OP #05 reported she was allowed to come home, which implied that the power and control was not all hers evidencing power differentials of professionals and the roles they held as experts in relation to how decisions were made. Decision-making is complicated, fluid, and multi-faceted.

Implications of Decision-Making on Satisfaction Levels

OP were questioned on QoL issues relating to satisfaction levels for their personal abilities and living space. OPs were asked three questions in the WHOQOL BREF about their personal abilities (see also Table 10). When participants were asked how satisfied they were with daily living activities, participants reported a mean score of 3.4 on the Likert Scale (14 % transformed) at the first visit and 2.87 (8.67% transformed) at the second visit. (Likert Scale rankings included: Two was ranked dissatisfied, three was neither satisfied nor dissatisfied and four was satisfied unless otherwise noted). Table 10 listed WHOQOL BREF Likert Scores in these areas. Overall, OP averaged 3.135 on the Likert Scale as neither satisfied nor dissatisfied. This suggested OPs were not dissatisfied with daily living activities and ADLs (balance, strength and self-sufficiency). This implied that individuals were coping with their levels of independence because they were able to complete ADLs with basic needs in routine activities such as eating, bathing, dressing, toileting, ambulating, and continence.

This was consistent with how OP ranked mobility. The first visit revealed a mean score of 3.20 (13.33% transformed) and 2.87 (10.00 transformed), the second (two is ranked as poor and three is ranked as neither poor nor well). The average mean of both visits was 3.035, suggesting OP were in the middle and coping with how they got around.

WHOQOL Scores on Abilities and Living Space

OP were asked how satisfied they were with their living space. Even OP, who started out in homes with their family, said that they were happy to be in their residence of choice for added support. Overall, QoL was a factor for those living at home as OPs reported an overall positive well-being and contentment in doing that. For example, OP reported identical Likert Scores on the both first and second visits of 4.27 mean scores (four was satisfied and five was very satisfied, 22.66% transformed). The probability of having identical scores was unlikely, so mathematics were checked and verified for accuracy. Overall, OP appeared to be satisfied with living conditions and this was consistent with how OPs made decisions about where to live. Some individuals reported being happy, as they had established influencing factors that supported their decisions and QoL. Homeostasis was in balance as satisfaction was reported.

WHOQOL Scores on Abilities and Living Space

	How satisfied are you with your ability to perform your daily living activities?				**How satisfied are you with your abilities?**				**How well are you able to get around?**				**How satisfied are you with the conditions of your living space?**			
Index	Visit #1 Likert Ratings	Visit #2 Likert Ratings	Visit #1 Transformed %	Visit #2 Transformed %	Visit #1 Likert Ratings	Visit #2 Likert Ratings	Visit #1 Transformed %	Visit #2 Transformed %	Visit #1 Likert Ratings	Visit #2 Likert Ratings	Visit #1 Transformed %	Visit #2 Transformed %	Visit #1 Likert Ratings	Visit #2 Likert Ratings	Visit #1 Transformed %	Visit #2 Transformed %
1	4	4	20	20	4	3	20	10	4	4	20	20	5	5	30	30
2	2	3	0	10	3	2	10	0	2	1	0	-10	5	3	30	10
3	4	4	20	20	4	3	20	10	4	4	20	20	5	5	30	30
4	2	1	0	-10	2	3	0	10	2	2	0	0	5	5	30	30
5	2	2	0	0	4	2	20	0	2	3	0	10	5	5	30	30
6	4	4	20	20	4	5	20	30	4	3	20	10	5	5	30	30
7	4	2	20	0	3	2	10	0	4	2	20	0	5	5	30	30
8	3	2	10	0	2	1	0	-10	4	4	20	20	4	4	20	20
9	3	3	10	10	2	2	0	0	2	2	20	20	5	4	30	20
10	2	2	0	0	2	2	0	0	1	3	-10	10	4	5	20	30
11	5	2	30	0	3	1	10	-10	5	2	30	0	2	2	0	0
12	4	2	20	0	4	2	20	0	2	2	0	0	4	4	20	20
13	4	5	20	30	4	5	20	30	5	4	30	20	4	4	20	20
14	4	4	20	20	4	4	20	20	4	4	20	20	4	5	20	30
15	4	3	20	10	2	2	0	0	3	3	10	10	2	3	0	10
MEAN	**3.4**	**2.87**	**14.00**	**8.67**	**3.13**	**2.60**	**11.33**	**6.00**	**3.20**	**2.87**	**13.33**	**10.00**	**4.27**	**4.27**	**22.66**	**22.66**

Table 15. WHOQOL Scores on Abilities and Living Space

When asked how satisfied OP were with their abilities (Table 15, completed by the Researcher), OP reported a mean score of 3.13 on the Likert Scale (11.33% transformed) at the first visit and 2.60 (6.00% transformed) at the second visit. The overall average mean of both visits, 2.865, ranked dissatisfied. Overall, OP were dissatisfied with certain abilities which was consistent with the interview and visual findings in which OP identified things they were no longer able to do. Homeostasis was not in balance. Individuals were seen to make up for deficiencies in other ways by employing resources for a number of reasons. This can be seen in discussions for OP #01 wanting a care home for overnight care but still wanting privacy but wanting transportation into town. Similarly, OP #05 explained she was a hillwalker, and no longer able to do this and had lost that ability. She also focused on the importance of her gardens, and at the start of the project she was not able to be out in her garden nor able to do anything with it. This was changing at the end of the research as she was gaining some of her independence back as she healed. OP #04 also reported the importance of his garden although he was no longer able to care for it and he had someone do this for him. The view from his window was important to him as he had similar views in his photographs. OP #06 also reported not being able to go to the pub, and this was something he missed. Many individuals reported the loss of activity or QoL issues in things they were no longer able to do. Some hired gardeners to help or had family to assist and other losses were compensated by increasing other activities to make up for the diminished activities.

Overall, OP collectively averaged scores in the middle range except for abilities. The results indicated satisfaction with daily living activities with 3.135 on the Likert Scale as neither satisfied nor dissatisfied; satisfaction with Abilities and Living Space a bit higher scores of identical Likert Scores on the first and second visits of 4.27 mean scores (four was satisfied and five was very satisfied); satisfaction with their abilities 2.865, ranked dissatisfied; satisfaction with how they get around with an average mean of 3.035 that ranked neither poor nor well. OP were in a balanced state of homeostasis for daily living activities and abilities and living space.

The importance of taking multiple measurements was to assist in developing a better understanding of the complexities within the relationships in decisions-making about care, resource utilisation, and QoL. The Likert QoL measures confirmed satisfaction levels and homeostasis. This was one part in triangulation that revealed data on QoL. Photos gave added measures and evidence as did interviews for individual on how OP utilised resources and adapted to changes in independence. The wider systems issues were considered, weaving together multiple points of data to triangulate a larger picture of how data interacted to provide understanding of multiple perspectives. The macro environmental factors confirmed individuals QoL and preferences for options and choices of the lived experiences on multiple issues such as implications on living space so how and where they lived and also implications on their personal abilities which led to decision-making on care and resource utilisation.

Resources

Resources are currently scarce in the British economy; it was a challenge for older people to learn about available resources. Barker (2003) defined a resource as "any existing services or commodities that can be called on to help talk care of a need…" (p. 370). This was especially challenging in settings with tighter eligibility criteria because of smaller budgets and these settings offered limited services and resources (Velzke 2017). Often, people supplemented care services in other ways as they did not always have access to the services they wanted or needed. Alternatives surfaced when choice and decision-making was not possible or was limited and added options such as signposting were instilled. Signposting was one way of making up for scarce resources and OP making adjustments to get needs met.

The following section explores views about money and its influence on decision-making and how this could lead to constraints and absence of choice.

The Power and Influence of Money on Decisions

The majority of OPs mentioned money and funding directly; the others alluded to resources and money having an impact on care choices. Money was a driving factor (and self-payment for care) in having input into care choices. Individual perception was that those who lacked in options and decision-making for care choices were in that situation because of a lack of money. The influence of money was a means to an end for many individuals. Equifinality allowed ways to solve care issues by giving individuals access to services but it also disrupted homeostasis by denying services because of the barriers involving funding issues. Overall, money aligned within a GST framework (at times) and it helped improve interactions with other systems (Kirst-Ashman & Hull, 2012).

Money was discussed in Velzke (2017) as part of budgeting and narrowing of eligibility criteria for SDS and other programmes as part of the efficiency agenda. The elimination of programmes was reported as the adult daycare programme moved to the therapeutic adult daycare model. Moreover, individuals were signposted (referred) to area lunch clubs (OP reported) if possible. This was also seen in the restructuring of the local authority services and outsourcing. Velzke (2017) discussed additional signposting for all levels of care; not just those who received service eligibility.

Money related to self-perceptions, social standing, and affluence. OP reported, only in affluent areas, that they recognised the importance of self. They were also more likely to pay for their own care. Most people, unless highly educated, were reported to have lower expectations in the standards for care received. Decision-making was revealed to be influenced by how OP viewed themselves in this study. This was another area where perceptions were important.

One example was a PP discussion of money that allowed someone to go back home. She was able to self-fund some of her own care. PP #21 explained,

> "Yes I've got a couple who have arranged self-directed support and the lady that I returned home, the lady I was talking about earlier I managed to get direct payment for her and I mean that woman at home that has got a twenty-four hour care package for her costs for twenty-four care. Twenty-four hour care is approximately a thousand pounds a week but she's getting I think it was five hundred something from the direct payments but she's still having to fund the rest of it herself. She very well may have been paying nearly as much as that in a care home but her money will run out very soon and I'll be very interested to find out what's going to happen then."

When the personal money ran out, the individual's choice was less clear as to what options for future care were. She had options at that moment thanks to SDS and having her own money. Thus, she had the perception of having affluence and options. When the money was spent, it appeared that her options might be limited. It seemed most people had difficulties with navigating systems when change was needed. Support networks were influential in these circumstances. These wider systems issues of money, perceived affluence and SDS options were also in play while navigating systems.

Another example related to people who had no family or support. This caused problems as some people were not familiar with systems. PP #21 reported that

> "…Some people have still got their money under their bed. You know they've no' quite got the hang of the banking systems and I think for them they have to manage it. It's tough and then you have to think about people who if the local authority are the only people that's going to be the welfare guardians because if there's no family we have to do it, we don't do financial guardianship…"

Financial guardianship was reported only for those with higher amounts of money as PP #21 explained,

> "… [local authority] employed a solicitor to manage people's finances but it's only if they've got money to manage, a lot of money. If somebody's got a property the money is going to run out but it would cost more because the lawyer will charge you for doing you financial guardian."

There was a reported gap in care services for those who needed assistance in managing money, but who did not have the funds to hire a financial guardian. There were several breaches in services within the local authority service area and the study identified that were systems issues such as this one.

Overnight care was reported to be another gap in services. PP #31 reported,

> "And because it's overnight care as well they've had to find private money to pay because the council home care only come into your home up until ten o'clock at night or something..."

Professionals reported that money was an influencing factor on options for care for many people. Velzke (2017) stated that SDS was found to assist in helping with overnight care barriers for some individuals. This suggested that money, and the broader issue of policy, were influencing factors in decision-making.

The influence of money allowed many participants to remain at home. This allowed individuals to supplement care and assistance personalised to individual needs. OP #02 explained.

> "…I started paying privately for domestic help so I have two ladies who come nine hours a week. One comes for six hours, three on Monday and three on Friday and the other on a Wednesday and I pay that out of my own pocket….
> And the same with the garden I get that, I pay for that. But mainly my domestic I have to pay for…"

OP #02 also had a MECS that assisted her if she fell. She had needed to spend time in hospital due to broken bones (three months),

> "I had a fall in the hospital and various things happened so that's what this is round my neck [MECS] and it's a life thing, I can't do without it, I would be totally lost without it but I pay, I pay the council for that. It's not very much.
> It's something like it's over a pound a week but it's worth every penny and they're very efficient."

Although she paid for the MECS on her own, this assistive device was part of the reason she was able to remain at home. Assistive devices were established as part of the relationships between QoL and decision-making.

OP #07 explained about paying for a gardener,

> "Ah well we've a young lad that comes up and tidies it up and
> then the wife comes down but he tidies the garden up… We pay for the young lad coming in."

OP #10 spent money on housework,

> "I was just thinking about help. Well I've got a granddaughter that comes and helps me wi' housework and general duties about the house…I pay my granddaughter…"

Many of these areas intertwined into other areas of decision-making and were inter-related as would be expected when looking at the broader context of the issues. OP paid for services and supplemental help and care in the areas they were unable to complete on their own. These all supported ways in which individuals maintained homeostasis. Each individual pathway to equifinality was unique based on how OPs solved ways to meet care needs.

In some areas money was necessary in having care options. Those without money and resources had limited options and decisions (or none at times) when compared to those who had personal funds to spend on care. Those with support systems also had more choice than those without. Those with money secured added assistance, while those without were limited. Some personal resources and assets triggered resources for some, while those with fewer resources and the same needs where not eligible as they could not afford to pay for them. Some individuals were able to maintain homeostasis and some were not as a result of influences of money. The initial research question was added to in revealing more about perceptions and behaviours in how money is spent as well as how services were used in the second research question.

Constraints

Constraints were evidenced in systems that controlled people's choices and decisions at times and were part of wider systems issues with homeostasis of individual's perceptions and choices. This offered limited choice in matters seen in conflicts such as delayed hospital discharges. Other times, PP reported it was specific to local authorities as they worked in more than one. For example, PP #19 stated,

> "Local authority services tend to be, tend to struggle the most to meet the needs of people with dementia. What services tend not to be very good at is actually establishing what the views are of people with dementia even though that can be the main sort of client group that they've got."

Another issue identified was the way information was sometimes a barrier in distribution. PP #19 suggested improvement,

> "To provide information for somebody who has dementia in a way, in a format that they can access."

Information was necessary to make educated decisions (Velzke, 2016). Velzke (2017) highlighted the importance of how information was offered to people. It was mandated, in legislation, that the information was presented in an accessible way. The way in which local authorities conducted services influenced many decisions and options (consistent to Scourfield, 2015) on how policy in practice influenced decision-making. It also shaped the role of managers who oversaw the implementation of policy and those in direct practice.

For instance, policy in practice limitations emerged during a focus group discussion about care plans, as well as the time and roles of carers. A reconvened focus group participant reported,

> "But see I mean they get they were termed as well they were home helps eh and they used to go in and they'd maybe dae [do] an hoor [hour] and dae a wee tidy up."

The conversation continued,

> "They're no' allowed."

Another participant replied,

> "Yes and they're no' allowed tae [to] do that now."

A different participant reported,

> "Aye but they're only in and oot [out] again, ten minutes, I think it's a shame."

Additional conversation included,

> "…They get a care plan and I don't know who decides what the care plan should be. There's one person could get quarter of an hour just and the other person half an hour but they're no' getting the full quarter of an hour or half an hour, they're in and out."

Sometimes, there were reports from participants of no one monitoring the designated allotment of care. Although some reports from PP stated they had reviews, individuals involved in the care were not always involved in the meetings.

There was much concern from focus group participants related to individual, group, and systems levels quality of care. This finding was validated by data from all participants.

The nature of service was reported to be a barrier in that services that people needed were not available. For example,

> "…I'm noticing there's more and more people with ARBD, (alcohol related brain disease) coming through… very limited resources for these people" (PP #20).

Also, care homes were reported as not wanting to take people with bariatric needs as this required additional staff and equipment but they were not receiving any additional funding.

PP #19 stated that limited choices lowered standards. Residents were less likely to go back home (PP #20). The lack of service options was a theme that arose from the data. For example,

> "An observation from the major constraints that people are telling me about is actually the lack of services that are available to them. … The council's day care is there and that's now really the only day care service that's really available for people..." (PP #20).

This was a barrier to decision-making as OP only have the decision to utilise the one service or no service. They had no alternative options in some cases.

This was consistent with reports that some people took what they were able to get and did not challenge or complain about things. PP #19 commented on the quality of care issues,

> "It also means that people are waiting to get a place if they want to access a service and it, for me, it means that that service doesn't maybe have to work so hard, that's a council run service and again personal opinion (but) an observation is that council run services aren't generally as good as third sector or private providers..."

The overall system and lack of service influenced behaviours and decision-making.

Rural areas were reported to have issues with fewer in-person services offered in remote areas. For example,

> "[Name of the City] is such a big area (that) some of the rural areas are missed entirely especially for people with dementia. We don't have the resources in the town never mind the rural especially for people with dementia" (OP #21).

Other reports included limited services (PP #18, 26, 32), higher costs for services in rural areas (PP #32), and support for not paying for employees for mileage or travel time for home care (PP #18).

Many environmental factors were constraints. These were reported to inhibit decision-making for older adults from the cost of care to variability on the availability of care. The lack of resources, quality of care, and restrictions on caregivers were additional environmental factors. The lack of information available, and services not being appropriate for the population served, were also environmental factors that limited choice and decision-making. These all influenced how decisions were made and impacted the maintenance of homeostasis. These also had direct effects on older adult behaviours with care and resource utilisation.

Larger Systems Level Influences on Decision-Making

PP reported complaints about the narrow focus of assessments in how they were structured at the systems level. Velzke (2017) discussed the differences between assessment times and administrative times when social workers were the determining person for levels of need of services. Professionals in multiple disciplines conducted assessments and participants reported that different professionals saw identical issues differently depending on their backgrounds. This led to varied outcomes for the older person between nursing and social work assessment, further, they could also be differences between individuals from the same profession. Different models of care and discipline specific views were revealed. The importance of professional perceptions was highlighted. The data suggested some professionals, for example, PP #20, challenged the assessment process,

> "…Sometimes the assumption's still made by medical staff looking at things purely from a biomedical model that people should go to long term care and don't necessarily have a holistic view and talk to the client about what other options are out there."

Some professionals considered additional avenues such as community support systems, informal care, community resources, and other empowering ways to assist an individual to be successful at home and maintain homeostasis reflecting their recognition of the wider systems illuminated by GST.

Velzke (2017) reported that social workers tended to look at psychosocial issues of individuals and analysed family involvement, community support networks, and social networks. While social work reviewed this on a regular basis, other disciplines might not have assessed psychosocial issues. An example was offered from a social work perspective,

> "They [other disciplines] assume and tell us they need long term care but we do our own assessment [laughs] so which I would like to think's a lot more holistic."

PP #21 reported,

> "Yes and the cost of care homes are extortionate for people, I don't think the NHS actually get that either apart from when you're talking about very different models, we're looking at people individually really person-centred, we're looking at people to see if we can what do you want, can we help you to achieve that but the hospital I think thinks they know better than the person."

These presented different approaches based on each discipline. The choices and services offered to older people were, therefore, dependent on who completed the assessment.

This was consistent with PP #22. She reported a holistic assessment approach, even though the medical model was dominant. She also shared that she did not see a change in the medical model dominance unless there was a funding increase from health to social care. PP #17 reported the ageing population increase had not been taken into account. To get better care she suggested there needs to be a tax increase. Several participants made suggestions to promote more holistic approaches; training and encouraging individual independence were recommended. PP planned for population increases and what that meant for changing resources.

Training was one of many ways used to make a difference in supporting older people to make choices about their care. Training opportunities and ways LAs made training and making information available to professionals was discussed. PP #21 reported,

> "I think the medical model is how the nurse works, how they're trained. I think they don't seem to get, I was talking about the reablement that whole idea we have now of reabling people and I'm seeing it being done effectively in the community, I've never seen it done in hospital, I've never seen any encouragement for people to become or to remain as independent as they were, they seem to, people seem to lose something when they come into hospital they seem to they kind of revert back to be children or for someone actually doing things to them which we would be trying to move away from for a long time, it's not good."

Adapting a reabling framework, in the hospital setting prior to discharge, was another way to support older people's choices.

Velzke (2017) reported on a person-centred outcome focus and appeared the most consistent with SDS, national policy initiatives, and wide-ranging goals of older people. This considers a person's physical, emotional, and funding aspects of care as reported by PP #22. Velzke described multiple concepts within an outcome focus that promoted independence and person-centeredness. (PP# 20 & #29) and PP #30 added that it "sustains a quality of life comparable to what the client wants" (Velzke, 2017, p. 23). This was consistent to GST as one area influenced another for QoL, a person-centred outcome focus and independence. In addition, it promoted homeostasis for older adults as it promoted what they wanted.

Decision-Making in Crisis

PPs reported that people in crisis gratefully accepted any assistance, and options and choices at those times were often more limited. Low standards of care were readily accepted and not challenged. Considering the processes of decision-making during crises can enhance understanding of the attitudes and perceptions of older people and how decisions are made to fulfil needs. PP #19 reported,

> "Yes but my sense of what happens then [when people are in crisis] is that people tend to be so grateful and so guilt ridden that they then accept a standard of service that's not always what they should expect…"

Decision-making for people in crisis appeared to change as PPs reported that it tended to lower the overall expectations in care service. Sometimes care was provided out of necessity because of a health crisis such as stroke (OP #07), illness (OP #02 in hospital) or falls (OP #04). In a case like that, the carer had no understanding of what was expected of them (Nolan et al., 2003). Secondly, emotion played a large part in how people made decisions while in crisis. Those in crisis were not in balance with homeostasis; they were not looking for alternative ways to get assistance during a crisis. Knussen et al. (2008) reported that coping strategies for carers and participants were unique. Furthermore, as strategies to maintain a balance in life increased, this decreased distress.

Velzke (2017) suggested that it was best to get programmes such as SDS set up in advance of crisis situations. Having more options and advanced planning in place would offer more choices to people for planning situations to avoid a crisis or to deal better if a crisis did arise. Velzke (2016) suggested ways individuals were able to remain at home.

Thus, caregiver stress was reduced and they had additional ideas for respite care. Velzke also highlighted ways to minimise the burden of care, reduce burn out and avoid crisis as adult daycare, respite care, carer benefits, and support groups. These macro level services offer ways to avoid crisis.

How People Find Out About Information

Social workers often played an integral role in signposting by making referrals to other services for people to work to fill gaps and meet needs. Individuals also worked to meet needs by utilising informal care and other resources as individuals do struggle to meet goals. There were examples of equifinality when there were many pathways provided in examples of OP who had to solve issues and meet needs. For example, people who wanted added safety and security sought that need in many ways. Some OP moved to care homes; some remained at home and acquired MECS services. They had the same goals, but utilised different pathways to meet those goals. Velzke (2016) and Velzke (2017) highlighted the ways in which people found resources and information. For example, SDS had a policy that required that information was offered to individuals to assist in making informed choices and setting up contingency planning. There were many ways and a range of professionals that assisted OP in resource utilisation, decision-making, and meeting needs.

For example, OP #07 found out about services from professionals,

> "Oh just wi' [with] social workers, you get some social workers come in and they ken [know] aboot [about] this and they ken aboot that and they'll go and introduce you to them."

OP #12 reported that she got information from her daughter.

OP #10 stated someone came to her and explained services,

> "I think they came to me. I think somebody came you know somebody from the council."

OP#12 explained how they found out about what services were available,

> "Well sometimes you just hear it fae [from] the mouth when you're in company and you hear something. [Interviewer-you said you mentioned that you phone the health visitor] Hmm mmm."

Obtaining information and knowing the care system can be an asset in supporting decision-making when information is available or a barrier to service access without. Most OPs were reported to have assistance, support systems, and relationships to assist in choice and decision-making. Velzke (2017) discussed people's access to information. Overall, the majority of OP who had people assisting them did not know how care was funded. The family or person assisting them was more likely to manage the care details. In this study, most OP did know what care they had in place and were active in decision-making about what they wanted.

For instance, PP #21 reported that an older person utilised funding, but did not know why she got it or how to utilise it for her care services. She just knew that she obtained funding for some of her needs,

> "I do her shopping, I do her cleaning. You know she doesnae [does not] see that as something that should be. She sees it as money from the government because of her illness and it is because of her disabilities but she doesn't use it appropriately."

This was consistent with Bell et al. (2006) who explained how individuals group together care needs as "holistic and do not single out personal care as a specific separate category" (p. 1). Sometimes people did not compartmentalise their needs nor the funding, policies, or programmes that supported how their needs were met.

One example was the therapeutic day centre programme that one OP attended and PPs were involved with. A preventative focus was reported. Velzke (2017) described a therapeutic day programme with a falls prevention focus. OP were able to have hands-on learning about falls prevention. Another focus was a safety-oriented emphasis presented to older adults during the therapeutic day programme. They discussed prevention for home safety and fraud prevention. This gave OP more ideas on how to remain safe at home as they were recovering during the programme.

There were a variety of ways in which individuals gained information, resources, and care; e.g. from professionals, family members, and results from care utilised. This reinforced the importance of relationships and support networks. The care utilised was also important as SDS had a requirement to offer information to those who utilise services. In addition, those in the therapeutic day programme were offered additional safety information. Relationships and support networks were also important as individuals usually did not know how care was funded in specific categories. They acknowledged that their need was met (or not) and were less likely to identify the precise funding stream. Individuals focused more on the big picture and less on the details of how care was funded. This was consistent to receiving help to improve their situation, and maintaining homeostasis.

Prohibiting Decision-Making During Hospital Visits

Other examples demonstrated how older people were prevented from making decisions as a result of costs and hospital placements. This caused non-involvement in decision-making for older people. Conflicting opinions emerged about the reasons for hospital placements. One of the main reasons was it offered a cheap long term placement. This inhibited older people's decision-making and choice as it did not allow individual options. Policy in practice interfered with the spirit of the law by not allowing individuals the option to leave a hospital when possible.

Cost was an indicator as to why individuals remained in hospitals for long-term placements. However, there was debate on the cost of care in the hospital setting and PP perceptions conflicted. PP #33 and PP #32 had opposite opinions about a hospital as the cheapest options of care and the reason why individuals were in that placement. Some PP assumed it was to be the cheapest placement, even if it restricted choice. It was also acknowledged by PPs to be detrimental for older people in long-term placements in Scotland.

PP #32 reported delayed discharge as a financial inefficiency and acute hospital stays also reduced the ability to return home later in life,

> "If you're lying in bed for six weeks your balance, your strength, your self-sufficiency decreases."

The Personal Social Services Research Unit (2018) listed the cost of services for inpatient hospital for elderly clients and the costs for care home services in the NHS for 2014. These were used as that was the timeframe for the research and the debate of the cost of care (see Table 16, completed by the Researcher).

Unit Costs of Health and Social Care 2014			
Type	Daily Rates	Weekly Rate	Source
Hospital - Elderly Clients	£157	----	Personal Social Services Research Unit (2018) p. 111
LA Residential Care for Older People (Mean Cost)	£119	£839	Personal Social Services Research Unit (2018) p. 35
Nursing Homes for People with Dementia	£112	£781	Personal Social Services Research Unit (2018) p. 36
Private Sector Nursing Homes for Older People	£104	£729	Personal Social Services Research Unit (2018) p. 33

Table 16. The Cost of Care

As listed, the hospital costs were the highest. However, looking at the broader picture as reported by participants, the other non-monetary costs in the long run for individuals were much greater when in hospital for long-term placement. The consequences influenced individuals' abilities when linked to ADLs (balance, strength and self-sufficiency), which were reported to decrease as did overall health and wellbeing. The decline and diminished abilities increased even more with those with AD and dementia in hospital.

Other reports of barriers to going home included disturbed overnight behaviour and faecal incontinence as they were difficult to manage in the home setting (PP #33). There were many consequences of delayed discharge that negatively influenced choice, decision-making, and diminished QoL. Those far-reaching effects ranged from no decision-making, to allowing people to pursue the options of choice in the consequences of delayed hospital discharge, to full decision-making options.

The costs of hospital stays were not only about the financial costs, but also the toll that hospital admission took on older adults. This was reported to have physical influence on independence and a decline of ADLs. Many considerations in the broader issues of hospital stays, when making choices and decisions, have been discussed in relation to influences on choice and decision-making. Influence is seen from the top down in this model on resources.

Delayed Hospital Discharge

Bed blocking inhibits and influences decision-making for older adults. Bed blocking is a term used in the medical field defined by Longman (n.d.) as, “a situation in which someone stays in hospital because there is no other suitable place where they can go to be looked after. Bed blocking means that other people cannot go into hospital when they need to, because there is no bed for them” (Para. 1). Decision-making was typically removed from the individual in question during that time, while evaluations were carried out to evaluate a person’s capacity to make decisions. This also influenced other people’s decisions for those needing services but cannot access this. Decision-making was removed from people needing to get in hospital and removed from those who wanted out.

Bed blocking was often the case during the guardianship process as it is assumed there was no choice but to stay in hospital. PP #21 reports,

> “It’s hard. It’s really tough for the nurses. I think my concern is that nurses are so concerned wi’ people blocking beds that they forget that these people are still needing support and actually maybe they’re right, maybe they don't need support in this hospital because they’re not receiving nursing care as such, well not the people I’m allocated to because they’re already fit for discharge.”

This was an example of non-involvement. Guardianship has to go through the courts. During this process, it was determined whether an individual was deemed to no longer have the capacity to manage property, financial or personal welfare (including health decisions). At this time, an appointee was granted to safeguard these interests (Scottish Government, 2008a). This was reported for cases where no other options were available.

Clients were ready to be released, but were continually held until guardianship was resolved. Therefore, when a person was in a hospital, and capacity was questioned, issues with decision-making emerged. Once guardianship was initiated, no decision was made for placement or release until the guardianship result was finalised. This was a lengthy process (up to six months or longer).

There were several points to consider with older adults when bed blocking issues emerged. This delayed discharge was reported to put individuals at risk and was a major concern (Toze & Ray, 2018; Wada, 2015). Wada discussed the ‘psychological aspects of choice’ which explained oppression and abandonment in not allowing people to have a say in decisions that affected their lives. People were powerless and at the mercy of those on the ward and in the courts. There were no options and individuals were not offered choice and often out of balance with homeostasis.

A few participants explained that more choice and options were needed. OP #12 reported her spouse was only to be in the hospital for six weeks and he ended up in hospital for 1.5 years. She stated this was against their wishes. He was reported to need a higher level of care than could be offered in the home setting. There was much discussion about the delayed discharge of hospital clients and lack of choices in care. In this instance, decision-making was removed for care choices. The client's choice was to return to the home setting after the six week stay. This was denied (and clearly not an option) as the length of stay was well beyond six weeks in the delayed hospital discharge.

PP agreed that hospital was not a good place for older people and people with dementia to be for long-term placements. One PP referred to a hospital placement as "a waiting ward." For example, PP #21 reported,

> "… I think for older people, especially for people with cognitive impairment who need structure, who need a purpose I think to be getting on with their day and getting up and doing things I think that is really bad for them [when they do not have that]."

There appeared to be many factors that altered the choice and decision-making process for people. This was mainly viewed as unfavourable when in hospital for delayed discharge. These factors included the risk of contracting infections, depression, and decline in independence and institutionalisation of clients to the structures of their environments (Glasby & Lester, 2004). These added issues influenced how decisions were made. Delayed discharge was reported to be a systems issue within organisations in conducting assessment or arranging alternate care (Toze & Ray, 2018). The broader issues of confinement in a "waiting ward" included the emergence of other issues because of the lack of choice in decision-making. These related to declining health and declining mental capacity. Overall, the well-being of individuals diminished when homeostasis was out of balance. However, the next section explores the policy that allowed individuals to be released to a less restrictive setting.

Adults with Incapacity Act

The NHS had specific training on capacity and adult support and protection as did the local Care Inspectorate and other health professionals. Even so, PPs reported that many staff were still confused about when people should retain their own decision-making capabilities with capacity outlined in the Adults with Incapacity Act (2000) (Scottish Government, 2008a). If they do not make their own decisions there might not have been a clear interpretation of the law on the part of professionals, especially with regards to clients' discharge plans. For example,

> "I think that what you know has been done in terms of legislation in recent years has definitely helped and is definitely an improvement but even now I can't go into services and say you must have trained all of your staff in adult support and protection because they don't actually have to..."(PP #19, Care Inspector).

There were difficulties in the hospital or care settings when capacity was an issue and the process for guardianship began. Delayed discharge, especially in the hospital setting, was problematic. During the capacity review process, clients often remained in the hospital until guardianship status was finalised. This was sometimes for up to six months when the patient did not need hospital care.

One hospital doctor reported,

> "…It's taken me five years to be absolutely certain of what it says and the law, the ethos of it, is do the least restrictive thing for the individual and I think people forget that, so one is backed up by the law when you are doing the correct thing and not having somebody imprisoned in hospital. I think the sub-clause is 13ZA" (PP #33).

Section 13ZA of the Social Work (Scotland) Act 1968 was inserted by the Adult Support and Protection (Scotland) Act 2007 and outlined discharging clients who might have lacked capacity. It moved them to residential care in a less restrictive environment if all parties agreed (Scottish Government, 2008b).

Another PP explained,

> "There is a new part of the Adults with Incapacity legislation Section 13ZA inserted into the Social Work Scotland Act that means if all parties are in agreement including the person we can transfer them" (PP #21).

Under the law, if a person was undergoing capacity evaluation and guardianship appointments were discussed, and all parties agreed, then they could be legally transferred out of the hospital into another more appropriate setting of choice (Scottish Government, 2008b). Although reportedly new, this action was not something that was completed frequently at the time of the research. This enabled additional decision-making opportunities for many individuals. It allowed added choices and alternate settings to the hospital in the right circumstance. Velzke (2017) addressed this situation as there may have been a need to add training and organisational culture change to promote policy in practice alternatives for staff as well as clients.

There were multiple factors that influenced the process of delayed discharge from hospital. These occurred during the process for determining capacity and guardianship and included ignorance of the law on the part of professionals, and financial implications for the hospital placement being reported as the cheapest placement out of the options by some (PP #33) but not all (PP# 32). It also meant there were various interpretations of the Act. This had implications on how the policy in practice was implemented. Chapter Two reported discrepancies between agencies and practitioners. During the research, a number of variables that emerged, influenced and affected choice on how older adult make decisions about care and resources.

Challenges arose in care settings about the carers not obtaining consent from clients. This stemmed from not understanding the legalities of capacity; the challenges transpired from a lack of understanding of when people should retain decision-making capabilities and when they should not. It was suggested that Formal Capacity Assessments needed to be encouraged. The lack of knowledge of the legal framework needed to be addressed, and more work in helping people to make decisions was needed (PP #17). This was especially important with safeguarding, Power of Attorney (POA), guardianship, and getting paperwork completed by the GPs (PP #17). Staff education used in legal frameworks and formal capacity assessments assisted to promote individual choice and decision-making. Some areas in the local authority were working on additional training. Velzke (2017) explained the need to see improvement and for management support of the organisational culture with additional training for staff within the local authority when necessary.

Similarly, PPs stated that choice, control, and decision-making options were issues in hospitals but some hospitals were working to improve the situation. This was evidenced by PP #28,

> “They would always be asked and I keep saying to the staff and always when I’m doing training…. I train as well for Alzheimer Scotland and I always say [laughs] say about my person-centred care… it doesn’t matter if they always say they want a cup of tea in the morning, always give them the choice of tea or coffee because that makes them feel in control...”

This was another way in which people had options to exercise decision-making capabilities in what might, otherwise, have been a constrained environment. Both the options with the visual (showing a plate of each option) for food choices and the offer for tea were examples of equifinality. Person-centred training was offered across all disciplines as person-centred practice offers ways to focus more on individuals and less on their illnesses (Velzke, 2014). Tanner et al. (2018) explained that person-centred care is a support for individuals.

Lack of Choice and Control

In other instances, older people were not offered choices, or services were not explained to them in the hospital. This prohibited decisions, opportunities and choice. For example, PP #28 reported,

> "…But he said to me when he came out he said nobody ever asked me anything. Nobody ever asked or explained anything to me you know if they came to take his blood pressure they never… they presumed because he'd got a dementia… he wouldn't understand so they just did it. People came and took blood and never introduced themselves or explained what they were going to do."

There were times assumptions were made and decision-making opportunities were absent, for example when professionals made choices for older people. Consequently, homeostasis was out of balance for individuals as choices were removed. However, there were measures in place in the broader systems to work on this as was evidenced by the added training. The data also revealed, in some disciplines, efforts to change this by implementing training for person-centred care.

Conclusion

This chapter has established how environmental factors supported decision-making at the macro level. Relationships and support networks influence how people spent money and utilised resources. These factors influenced wider systems issues in support networks and relationships with homeostasis and formulated a better understanding of the lived experiences of older people and how GST assisted in tracing the pathways OPs navigated whilst working through care decisions based on actual behaviours.

This chapter has identified the constraints and barriers that inhibited the decision-making process which older people encounter for resource utilisation. It has provided some insight into behaviours and attitudes toward older people's decision-making processes. It has examined how they determined where they wanted to reside and how independence and choice were factored into that process. Some individuals needed overnight care, so they moved to care homes or moved in with family. Others had more informal support requirements and were able to utilise daycentres, paid support and church support to get these needs met at home. Reablement is part of empowering success at home as well as SDS being a key part of changing how care at home and at night may be utilised. Relationships and support networks were a key part of decisions as well as policy that enabled success to balance homeostasis.

Additional focus was on Research Question 4 which looked at the environmental factors of the geographic location in regard to resources and family. Family decision-making was part of where individuals decided to live and some individuals moved to be closer to their family. Financial resources were another layer in selecting a residence of choice and perceptions of money and services in care decisions. Some resources were only offered to people who could afford them. This offered these individuals more options and choices than others. QoL was one area that appeared to motivate many decisions of older people and behaviour and various opinions were given as reasons for improved well-being.

Crisis, and its impact on lowering expectations, was discussed. Perceptions and lack of choice were explored because there were some difficulties with policy in practice and models of practice that were discussed. This included the way policy was interpreted in offering individuals choice or restricted decisions while they were in hospitals. It focused on the final research question about how social policy influenced choices for older adults in Scotland.

Overall, power differentials, with money as part of an individual’s personal resources, emerged. Money constituted choice and enabled the involvement of some individuals in care decisions. Money allowed some individuals additional choice and options, whereas, others with a lack of resources and personal finances, but with identical needs, were without those options. Some options were not considered until high enough personal resources triggered consideration for self-pay options. As a result, those with less money had less power and control in decision-making. When an individual’s money ran out, often options and choice ran out as well. For example, one area to be considered was assistance with managing money; however, the lack of funds to hire a financial guardian was problematic as there were no options available for individuals who were poor. This was not in alignment with national policy initiatives, and some of the emerging policies of empowerment (such as SDS), added power and control in individual care decisions.

Broader implications of OP perceptions can be seen as a result of the research with QoL, assessment processes, professionals and resources. However, individuals voiced their story in a number of ways explaining what they viewed as being important for their QoL. The visual data reported that multiple participants had described subjects that appeared to be off topic or unrelated to the photographs during the discussions in the final visit. However, individuals told their story of how things influenced their own QoL, identifying what was important to them in decision-making. Consistent with GST, individuals' realities were not always a reflection of actual events that were real or tangible (Von Bertalanffy, 1972). How individuals relate their self-perceptions on health, disability and QoL will directly influence the care, support and resources they are allocated. This is especially important during the assessment process, and how older people are perceived by professionals. Velzke (2017) established that this remains important as eligibility guidelines continue to reflect shrinking budgetary diminutions.

Overall, Chapters Four to Six demonstrated examples of OP being active as well as excluded from decision-making. The next chapter draws together the main findings from a micro, meso and macro perspective across the thesis to present discussion and conclusions and to answer the Research Questions.

Chapter Seven Discussion and Conclusion

Introduction

This thesis has advanced the existing knowledge base by pulling together multiple parts of smaller issues (Reason, 2010) and by examining how older people make decisions based on actual behaviours in relation to micro meso and macro issues. A GST framework has highlighted that several factors need to be in place in order to support participation by older people in decision-making. This framework helps to explain and examine the wider systems and networks that influence decision-making and highlights the most important influences. Firstly, individuals need to have the capacity to make decisions (and OP needed to have the capacity to be research participants). They, then, need opportunity and finally, they need the information to make informed decisions. These were found to be key issues for individuals to be active participants in care decisions. Decision-making has multiple steps involved in the process but if one of these three areas ends up absent from the process, the ability to make an informed decision diminishes or is gone.

Multiple decision-making styles were identified; individual, group, family, community and society level decision-making styles as well as the status quo of making no decision or staying with the previous decision.

Decision-making is, therefore, a complex process and decisions are not made in isolation. For instance, when individuals needed assistance they relied on relationships and support networks and utilised a variety of decision-making styles. This had implications in terms of both participant involvement and exclusion from the decision-making process. Older adults were involved, and they either elected to maintain the status quo or at times were excluded from decision-making because of family and/or professional behaviours. Many people, including the older people themselves, had an impact on decision-making, both directly and indirectly, with their perceptions and behaviours.

Environmental factors were found to have influenced decision-making and were found to have raised or lowered QoL, as individuals strived to maintain a balance of homeostasis. A change in one area was seen to influence many other areas of individuals' lived experiences and QoL and understanding evolved further with the exploration of the five Research Questions. This exploration also led to a better understanding of individuals' lived experiences on the micro, meso and macro levels and how these levels interact to produce the wider networks that influence individuals' decision-making about care, support, and resource utilisation. The Research Questions are as follows:

- ✓ *What are the attitudes, behaviours and perceptions of older people as they set out to fulfil their needs for care and support?*
- ✓ *What influences older people's decision-making about which services they use?*
- ✓ *What is the relationship between quality of life, and the decision-making process?*
- ✓ *What environmental factors come into play?*
- ✓ *How does current policy in Scotland influence the choices available to/made by older people?*

As would be expected with the complex nature of decision-making and the use of a GST framework exploring multi-faceted issues such as QoL, the Research Questions interconnected at times. For example, the topic of ageing well is relevant in both Research Questions 1 and 5.

The same decision-making styles occurred on multiple levels - the micro, meso and macro levels - but these were not mutually exclusive in the decision-making process that older adults utilised and if they usually utilised one style this does not exclude them from using other styles; for example, OPs were able to be self advocates and take ownership in decisions (Samuelson & Zeckhauser, 1998) while deciding to retain the status quo (Sanfey et al., 2003) or to participate in shared decision-making (Bowes et al., 1997) with another individual, or in group decision-making such as family or society (Sanfey et al., 2003). OPs were able to switch to another decision-making style at a later time. Decisions were influenced by what was happening in the individual's circumstances and situations and were unique to individuals based on their pathways to achieve homeostasis. How OP made decisions was based on prior experiences, conceptual constructs and other environmental factors and influences.

There were multiple influences revealed within the equifinality process on decision-making and these were relationships, support networks, QoL, control, independence, choice, influences of professionals and environmental factors. There were many pathways revealed for decision-making and findings that were unique to individuals based on attitudes, behaviours and perceptions. These included inclusion in the decision-making process and exclusion and non-involvement from that process. Each of the research questions will be explored on the micro, meso and macro levels.

Research Question One: What are the attitudes, behaviours and perceptions of older people as they set out to fulfil their needs for care and support?

Looking at multiple data points in time, triangulating data, and evaluating the wider networks of older people using GST assisted in understanding how one small change could influence many other areas and illuminated a broader picture of decision-making, care and the research process. This overall picture helped to better understand the attitudes, behaviours, and perceptions of older adults as they set out to fulfil their needs for care and support. The ways individuals saw themselves and their conceptual constructs of the world were unique and different to how they may have been seen by others.

Micro: How Older Adults see Themselves

The reported illness and satisfaction levels of OP when looked at individually told a story of illness that was different from the collective data about older people's satisfaction with health and wellness. Research Question 1 investigated individual behaviours and perceptions but using GST to understand the wider system gives another interpretation e.g., the perceptions of older people and how they viewed themselves when ill. The data presented in Chapter Four suggested a sample of ill individuals who listed their specific illnesses but OP's perceptions became clearer when triangulating the data and examining the wider picture over time.

As reported, OP were *neither satisfied nor dissatisfied* with their health or wellness on a Likert WHOQOL Scale. The qualitative data showed a more nuanced picture with many older people demonstrating better QoL than expected. Health and wellness were about more than just the individual and included wider issues such as wider support systems and relationships. This is similar to Chapter Three which suggested that health and social care are only part of QoL (Thorton, 2000). For instance, how older people saw themselves was different from how they were viewed by others. However, there were many factors that contributed to this complex issue of how OP see themselves and how decisions were made.

Meso: Support Systems, Relationships and Crisis

The meso level explored in Chapter Five focused on the importance of relationships and support systems as these, when developed with individuals, heavily influenced decision-making and influenced QoL e.g., how older individuals reacted when things went wrong and how individuals navigated care systems. OP trust, relationships and support systems in times of crisis from both professionals and partners and some individuals had strong support systems with people to rely upon to support them when things went wrong and this assisted in maintaining homeostasis by providing options to individuals in times of crisis. Shared decision-making was a key part of how decisions were made. The majority of OPs turned to support networks of family and carers to assist them or identified professionals they would ask. Support systems were a strong influence on behaviours of OPs and assisted individuals to return to homeostasis.

Macro: Professional Views and Power Differentials

At times, there were differences in the decisions that individuals wanted to make and those that professionals suggested (Hicks et al., 2012). Refusal of services was not a new topic as choice has often been found to go against recommendations (Hicks et al., 2012). One major issue was whose perception within the decision-making process had the most weight (or was deemed the most important). OP #02 discussed a letter that included a suggestion from staff that she should go to a care home that she did not know about. She refused this service and self-advocated to be released from hospital to go back to her own home. The wider policy issues of practice within the health care setting where professionals assume power over individuals were at work.

Another example of professionals influencing OPs, and power differentials coming into play in how policy can empower decision-making can be seen when implementing policy in practice (Section 13ZA of the Social Work (Scotland) Act 1968, Scottish Government, 2008b). Power differentials were identified between professionals and older people similar to those described by Petriwskyj et al. (2015). These power differentials were revealed in the analysis of relationships, support networks, professionals’ education and training. Professionals’ interpretations of policy and rights were discussed and how this influenced choice and decision-making where individuals deferred to professional opinions and status. Professionals were held in a high status and standards by the OP in this study and most OP consulted and deferred to what was recommended by those in a position of power. Chapter Five explored defined boundaries, the roles of professionals, models of care, discipline specific practice, and perceptions of clients which was opposed to clients’ influences on decision-making. Key findings indicated that some individuals make no decisions until they have first consulted with professionals.

Professionals play a bigger role in influencing decision-making than is immediately visible. OPs often waited to make decisions until they had consulted with

GPs. The significance of professional status in older people's perceptions is reflected in this study when looking at the roles that individual experience plays in decision-making in conversations and power and influence as a result of institutional status. This can be seen, for example, by GPs being "godlike" in status and when GPs suggest decisions and OPs abide by them. This can also be seen in how social workers assess holistically and utilise person-centred practice, and OPs used existing arrangements thus allowing social workers to arrange care. Individuals may agree to a decision based on a professional's status, regardless of personal opinions (Hicks et al. 2012).

These relationship issues were highlighted by Toze and Ray (2018) who reported that GPs' care for older people could be complex and that some relationships were more complex than others. Power differential were visible in the hesitancy of many OP to complain. Chapter Five discussed personal perceptions and labels and how perceptions of both OP and professionals influenced choice and decision-making. A key finding was how OP saw themselves as having better health and wellbeing than the professionals' views, and this influenced whether OP waited to make decisions in shared decision-making. The framework of society and status on the decision-making of older adults at the macro level was evidenced by institutional status and the importance of professionals.

The overall attitudes and behaviours and perceptions involved in decision-making is complex. Previous experiences and conceptual constructs of the professional can add a layer of complexity on the part of the individual. OPs perceptions and constructs about professionals' institutional status, credentials, or role and the perceived power and control that comes with this influenced decision-making, add an additional complexity. The bio-medical models of ageing are promoted through the work and attitudes of professionals both directly and indirectly by institutional status and behaviours perceived by older adults as well as professional approaches to understanding care and implementing policy in practice having some influence on the treatment and decision making of older adults.

Macro: Societal Views on Ageing and How Older Adults See Themselves

The way older adults saw themselves was not always the way they were seen by others. This was illustrated in the case of OP #04 who considered he had a good QoL while others assumed he did not because of his physical state; he was bruised and battered following a fall.

This was seen in how individuals self-identified as disabled. Barker (2003) described a disability as “temporary or permanent reduction in function; the inability to perform some activities that most others can perform, usually as a result of a physical or mental condition or infirmary” (p. 121). Using this definition, all fifteen OP would have been categorised as disabled; however they did not consider themselves as such.

The research for Research Question 1 has revealed that perceptions of ageing well, QoL and other labels, such as disability, can be different, with multiple viewpoints and perceptions in play. This agrees with Toze and Ray (2018) who, when reporting on older adults’ attitudes on ageing well, explained that they (OP) did not consider themselves old by chronical age but that age corresponded to positive activity levels of remaining active and being involved with their communities. This is important if an individual is undergoing an assessment for resources, self-reports for eligibility, or if being assessed by a professional. This may mean that an individual may not get necessary resources and, for those who are setting up policy and eligibility guidelines, this may have significant impact.

There are several issues which need to be taken into account. Smith et al. (2019) discussed being healthy and ageing well by staying active and coping well with changes. Healthy ageing also means lifestyle changes with individuals, hopefully, living longer (WHO 2015b). Society’s views on ageing have changed to this healthier outlook and key findings indicated individuals were more active in decision-making with policies such as self-directed support (SDS) and reablement.

Individuals found many ways to adapt and to find resources. OPs did many things to remain successful and maintain QoL and homeostasis, and each found various pathways of equifinality to problem-solve and live life in a way that was fulfilling to them as their needs changed over time. However, these processes also related to how individuals self-identified (with labels such as disability), and how professionals identified and diagnosed multiple issues (Alzheimer’s disease and capacity). The ways labels influenced resource utilisation did not always align with individual and family expectations. This was particularly important when considering how labels defined criteria, stigma, self-perceptions and reporting to enable older people to get resources or to be in a place of choice such as a hospital or other setting when working out capacity and guardianship issues. How policy is implemented in practice is influenced by both individuals and professionals e.g., disability and those who did not self-identify as such, and how this may qualify individuals for services in the future. Labels influence macro issues and policy in practice as OP perceptions influence how individuals are answering questions on needs-based assessments and how aware OP are of policy implemented into practice.

Chapter Six discussed how other policies such as SDS are influenced by perceived definitions of labels and perceived stigmas. It, therefore, does matter who is asking the questions and how these are framed as some disciplines are more dynamic and when a person-centred practice and a holistic framework were used, individual goals were more likely to be met.

How older people made decisions was based on actual behaviours, looking at the micro, meso and macro levels. Individual perceptions were provided from professionals and older adults on how older adults in Scotland fulfilled needs for care and support. The wider societal views of ageing were found to promote views differently to how OP saw themselves. Policy which influenced the care of OP had strong implications on the roles of the professionals and the power of institutional status. This research also found that behaviours of relationships, support networks and person-centred care fulfilled needs for care, support and resource utilisation of older adults and therefore Research Question 1 was answered. The attitudes behaviours and perceptions of older adults as they fulfilled needs for care and support demonstrated shared decision-making and that OP see themselves as healthier than how they may be viewed by those around them.

Research Question Two: What influences Older People’s Decision-making about which Services they use?

Health and wellness are complex issues in which services were used through policies, programmes, assistive devices and technologies. QoL and what is important to individuals, involves more than just the individual. The data have provided many examples of the involvement of support networks, paid and unpaid care, service utilisation and relationships which were needed to maintain a state of homeostasis. Services involved more than paid care and were influenced by the unpaid care and support of individuals to meet homeostasis. The significance of family relationships and the importance of professionals were discussed in Chapter Five.

In response to Research Question 2, policy had many implications and SDS was one policy that influenced decision-making. Reablement was another policy which individuals utilised and this highlighted that decisions were not made in isolation and involved a fluid process with a wide range of individuals and programmes.

Assistive devices and technologies influenced individuals' decision-making about services in both individual and family decision-making styles. One example of these was Mobile Emergency Care Service (MECS) for individuals staying at home and giving peace of mind to both family and self. There are many ways individuals met these needs and worked on relationship dynamics with families in order to remain at home and stay safe. MECS, for example, brought peace of mind to many. Older people's goals included independence, choice and control (Craig, 2004).

Micro: Ways to Remain Independent

This section will discuss more about micro levels and the ways in which individuals remained independent. Independence was a driving motivation for decision-making and choice for services. Chapter Two discussed Barker's definition (2003) of independent living, and the programmes that individuals implemented for social and medical modifications to remain independent. The research found forty-seven types of assistive technologies and devices with OPs. Some implications of external factors, such as the assistive devices, suggested that environmental factors raised and lowered QoL and made it possible for individuals to remain independent in their places of choice, and influenced ageing well. Some individuals had wet rooms, stair lifts, wheelchairs and many other devices to support their success. These devices enabled older people to fulfil decision-making by meeting independence to remain at home, as without them they would have needed a higher level of care.

MECS were also used to give security to family members. Individuals used MECS for falls, when they were locked out of the home and when they thought there might be someone breaking in. Electronic call systems were also used in care homes, and this also brought a sense of independence and security to OP, who reported that they liked knowing there was someone on hand if they were needed. There were many uses for devices that assisted in maintaining independence for all the people involved with older people, not just the OP themselves.

Meso: Relationships

Relationships were key influences in the services that OP used and that assisted individuals to maintain homeostasis. For some, these were family carers who stayed overnight and for others it was family arranging care which contributed to maintain homeostasis. Individuals followed their own decision-making pathways assisted by family. Half of the OPs (seven) had difficulties walking 100 metres, and all fifteen OP reported difficulty in lifting weights over 10 pounds and doing work around the house and garden. This resulted in many OP hiring gardeners, domestic help and having family as informal caregivers around the house.

There were many ways in which relationships and services influenced decision-making and there are many different pathways to homeostasis to get needs met; some were at home and some were in other environments. Tanner et al. (2018) highlighted that environmental factors and relationships can be influential and important in securing care beyond monetary value. These relationships and multiple decision-making pathways were revealed to impact the decisions OP made. Relationships influenced the services that individuals utilised, which was in part was based on how their informal care networks were structured.

Macro: Support Networks

Support networks, both formal and informal, had implications on what services individuals utilised. At times less formal care was needed if the informal care support was able to meet the needs of the individual. However, for those who did not have a live-in carer, or had higher care needs, additional formal care support and resources were needed to look after them and maintain homeostasis. Care also was dependent on the residence of individuals as those who lived at home had higher needs and responsibilities than those who lived in care homes. They tended to need gardeners or housekeepers, and assistance in changing linen and bedding with more support networks with individuals whilst those in care homes had fewer needs and fewer support networks in those added areas as the paid staff were their support.

OPs lack of support networks was also an important finding and when these were absent there were negative implications in many areas. Chapters Five and Six discussed issues with lack of support networks and constraints that negatively influenced older people’s decisions and the many areas these had influence. This was seen in one instance in the absence of clergy and GST assisted with exploring the many other areas of influence affected such as spiritual, emotional and mental with lack of support.

In response to Research Question 2, this research has found multiple factors that enable independence: relationships and support networks that influenced which services OP used. This included paid and unpaid care, policy, assistive devices and technology, and environmental factors such as relationships and support networks. Therefore Research Question 2 is answered. The influences on decision making about the services used depend on relationships, support networks, paid and unpaid care, policy and assistive devices and technology.

Research Question Three: What is the Relationship between the Quality of Life, and the Decision-making Process?

Relationships between QoL and the decision-making process have been explored throughout the thesis. Many individuals reported on QoL and how this influenced decisions such as wanting to remain living in a residence of choice. The reasons for this included environmental factors, support systems, paid and unpaid care and assistive devices and technology. Many QoL influences such as geographic location, family support, location to doctor, shopping, and loss of independence were reported and how individuals worked to balance homeostasis. The decision-making options and choices for older adults were individually different and as QoL fell below what was desired, individuals worked to regain homeostasis and higher QoL meant less work to maintain homeostasis. This also varied if individuals were making decisions alone, or shared decision-making.

Micro: QoL and Stay at Home

Many individuals shared significant details about why it was important they remained at home. For some, it was sitting in their favourite chair to look out their favourite window. They discussed the passing of the seasons outside the window and the changes that happened. They also discussed the importance of their garden and property and the surrounding areas that were within their lived experiences, especially for those who were homebound and limited to a smaller area. There were influences and memories of why OP wanted to remain at home or be in the care home.

QoL influenced the lived experience, support networks, and relationships because, when these dropped out of balance, individuals needed to work more and to make decisions to get back into homeostasis. As QoL declines, decision making needs to increase to regain homeostasis. However, there were also some negative decision-making areas of QoL and these included lived experiences of loss of independence, disability, loss of relationships and support networks.

Individuals constructed their own QoL and perceptions, which may be different from how professionals view the same situation. This was seen in how individuals conceptualised disability, illness and how diagnoses such as Alzheimer’s disease influenced QoL and decision-making. How these were perceived influenced whether individuals stayed at home as was evidenced by OP being able to advocate for themselves, having a voice and professionals' ability to assess the lived experience holistically.

Micro: Loss of Independence

Some individuals struggled with the loss of independence as OP had discussed activities they were no longer able to carry out. OP reported on how they were able to function in daily life, where they lived and how they viewed the world. As OP lost independence they found other activities to assist with remaining successful such as assistive devices and technology.

A key point is the relationship between quality of life and loss of independence in order to reach homeostasis stemmed from multiple influences such as support systems. Individuals' levels of resources allowed them to compensate with relationships (formal and informal care), and support networks were used if individuals were not able to implement care and support on their own. OP had family and friends who assisted but when this was not enough to meet care needs, they had paid carers. In areas outside of care they hired domestic help, housekeepers or gardeners if the family could not offer this. This meant they needed personal resources to remain successful and depended on their own money and finances and lack of finances brought choices and options into question. QoL and decision-making also depended on assistive devices that enabled OP to increase QoL over time as independence diminished.

Meso: Residential Care

The levels of support OP received in care homes were a factor that influenced QoL and also promoted independence and control. They were able to be their own decision makers about their activities, maintain independence and to keep QoL at an acceptable level. Individuals were able to take the care home bus if they wanted to go into town or they were able to have meals with other residents in the dining area or alone in their room for privacy. Some of the locations of care homes and the communities they were in were reported to matter as they could be near other family for added choice and control. For participants living in care homes, negative care experiences at home were reported and this favoured the care home over remaining at home.

OP offered a number of reasons for moving to a care home to improve QoL; these included independence, control, and privacy. For example, there were reports that individuals were made to feel they mattered by staff, and overall OPs reported feeling valued in care homes. This was an important part of QoL for them and they reported being part of the decision-making process. Some individuals had no care needs and moved to a care home to be nearer family. Others moved because of diminished independence and wanted assistance with this, and the care home offered options and choices so that the individual could be part of making choices. Others had family decision-making styles and made joint decisions to move to the care home.

Meso: Loss of Independence and Relationships

Many individuals reported a loss of independence that resulted in changed relationships that, in turn, influenced QoL. Many OP reported the loss of many social activities such as bowling, going to the pub, church activities and being unable to shop, resulting in a loss of relationships. These many complex situations were involved with lived experiences and the loss of independence raised and lowered the complex and multi-faceted QoL.

As QoL decreased, other areas increased. Individuals who lost some of those social activities identified other areas of importance in QoL such as their garden. QoL was unique to individuals, as OP worked out changes through equifinality to regain homeostasis.

Macro: Professional Perceptions and QoL

Professionals may have had a different view from the older people themselves as individuals are often best placed to measure their own QoL as there may be bias from any other source, and doctors and families were not reported as being able to accurately report QoL (Slevin et al., 1988). This has more implications than just QoL measures and who best should be measuring this. This could have significant implications as a range of professionals are responsible for a wide range of issues with individuals from assessment to service and resource allocation, medical care, assessing for capacity and many other issues.

There are additional implications as data revealed that OP often waited to consult with professionals before making decisions. There are many OP who describe GPs as “godlike” and this was not limited to doctors but included therapists, social workers and the clergy. This relates to other issues such as power differentials in how OP changed decisions based on professional status. Professional Participants (PP) reported that older people’s decisions were altered in times of crisis and they accepted anything despite OP personal belief systems (Hicks et al. 2012). If professionals are not always accurate in judging individuals’ QoL, and professionals have significant status and influence in decision-making, this brings up additional questions as to the role of shared decision-making for professionals and how well placed professional roles are for the best interest of older adults as they make decisions about care and resource utilisation.

QoL is not a linear process and is complex. OP were working to have the best QoL to meet goals and when QoL was diminished, OP worked to maintain homeostasis. Some OPs reported they would not make decisions until they had consulted with professionals; indeed, those who consulted with GPs or had professionals active in that decision-making voiced satisfaction with talking things over with professionals prior to making those decisions as part of the homeostasis process. This research has found that individuals construct their own QoL according to their own perceptions and these may be different from those around them as they make decisions. Many OP reported how their own perspectives of QoL influenced decisions on QoL and how this took into account what to do. Furthermore, OP identified a range of supports that assisted in compensating for loss of independence which assisted in raising homeostasis as QoL was diminished and this included relationships, support systems and assistive devices. There were also residential supports that encouraged QoL for individuals to want to be in a care home such as proximity to town, transportation, and being made to feel they mattered. At home, individuals moved homes to be nearer or to live with family such as building homes together, or getting a home with a grannie flat so family could live together and have privacy. Professionals also had an important role in QoL as some OP would not make decisions until they had consulted with professionals. Therefore Research Question 3 is answered. The relationship between QoL and decision making is complex with a range of supports that help raise QoL when diminished.

Research Question Four: What Environmental Factors come into play?

Environmental factors such as where people live, MECS and assistive devices, as well as policy and support networks influenced decisions and were found to raise and lower QoL. These were found to be different for each OP.

Each OP had environmental factors that influenced their unique decision-making pathway of equifinality to maintain homeostasis. However, constraints also played an important role in how environmental factors influenced decision-making and resource utilisation. Environmental factors were seen in the attitudes, behaviours, and perceptions of the lived experiences that OP, PP and focus groups shared as they revealed how relationships and support networks were key parts within decision-making.

Micro: Individualised Environmental Factors

The extent to which older adults remained active in decision-making was a process that involved many variables. Environmental factors, such as relationships, where individuals resided, and assisted devices such as MECS, were found to affect QoL. These environmental factors were unique to individuals; how they lived life, how they viewed the world around them and how they set goals. This is in accordance with individuals' equifinality and conceptual constructs (Von Bertalanffy, 1972). OPs had a number of environmental factors that supported success and goals to remain at home. These included gardeners, family support, spouses to help and a range of assistive devices unique to their needs. These environmental factors were individualised to meet OPs needs and preferences to maintain homeostasis.

Meso: Obtaining Information through Relationships

Support networks and relationships are environmental factors that also have substantial implications on how individuals obtain information. This thesis has established that individuals uncover information primarily from professionals and similar support people. The importance of information in decision-making and the broader influences these have on an individual's decision-making about care highlight the importance of relationships, support systems and professional influences.

Macro: Constraints to Decision-Making for Older People

Excluding individuals from decision-making processes has led to multiple constraints within the process and to multiple environmental factors coming into play. Constraints were established in Chapter Six and these included environmental factors, including money, cost of care, and restrictions on paid carers which can inhibit choice and decisions. Chapter Six also outlined monetary constraints including social standing and perceptions of the idea that money was needed to have care options. Money allowed individuals to pay for care above and beyond what was provided by the local authority when higher levels of care were needed at home but when the money was gone, there was uncertainty about what would happen to individuals who were paying for their own care.

Constraints can also be seen in the quality of care, low expectations and past negative experiences which all inhibited decision-making. This chapter also confirmed that some older people were reluctant to complain. They were willing to complain to social workers and there may have been a safer feeling following the building of a therapeutic relationship. Ray et al. (2015) suggested having social work practice in place where a focus on justice, human rights and advocacy can assist in offsetting “institutional and commercial priorities” (p. 1307). This can be a complex issue trying to understand why individuals will not speak out and Chapter Six demonstrated the lack of service options. This constraint could be a result of policy, or practice issues such as lack of funding limiting services available.

Sometimes, environmental factors played a part and these included decisions being made by other people and not individuals themselves. One part of that involved professionals and determining capacity to get the proper services that OP had qualified for. It did seem that once capacity was diminished, all choice and concern for personal preferences seemed to disappear in decision-making. PPs stated they would like to see more capacity work with people with diminished capacity completed and it appeared much work needed to be completed with GPs and other professionals to allow additional options for decision-making and choices for older adults.

Environmental factors were multi-faceted and assisted in working to maintain homeostasis as QoL was lowered and raised for individuals. Constraints were a main part of how individuals used environmental factors to raise QoL. Therefore the answer to Research Question 4 is that this research has found environmental factors that influenced decision making by older people included professionals, relationships, support networks, policy, money and constraints.

Research Question Five: How does Current Policy in Scotland influence the Choices available to/made by older people?

The Community Care and Health Scotland Act (2002) enabled programmes and care at home. Self-Directed Support (SDS) was a policy set to launch in the local authority in 2014 (in the year after my fieldwork) and PP were working on implementing this infrastructure. Direct payments had already been in use for some time with OP, and SDS was designed to add additional choice and options in care (Rummery et al., 2012). It was found that, consistent with national policy initiatives, there was an increase in independence, control and choice at the local levels (Velzke, 2017). Reablement was also found to influence choices for OP and promoted independence in the home (Clotworthy et al., 2020). OP was also given more options by Alzheimer Scotland’s models of care and by gaining more services and support in the first year of diagnosis (Alzheimer’s Scotland, 2016). The Adults with Incapacity legislation Section 13ZA allowed individuals to move to a less restrictive environment than the hospital setting when working out guardianship

(Scottish Government, 2008b) which was something that professionals were in the process of learning. This section explores the final Research Question on how current policy influences choice available to older people and this includes findings on person-centred practice, the importance of support systems and national law and policy.

Micro: Person-Centred Practice

Analysis highlighted person-centred practice that was consistent with policy initiatives and this approach allows older adults to have more access to care choices and to make decisions for themselves about participating in activities. Person-centred practice also illuminated the second Research Question on the services which individuals use. Person-centred outcomes were utilised for increased independence, control, and choice and were found to be implemented at local levels. SDS is person-centred with an outcome focus that aims to be holistic supporting individual goals. The options of SDS allowed opportunities for older adults to take charge of their budget and to have the family assist in shared decision-making if desired as most OP had help in navigating systems of care or could ask the local authority for help. SDS also allows some assistance and support for the caregiver. If a better understanding of SDS is gained, this will contribute to improved services and professional confidence.

Meso: Support Systems and SDS

Support systems were found to be fundamental in decision-making about care by OP. It was suggested that SDS policy was to expand decision making and to give older people the ability to make a range of decisions. Tanner et al. (2018) reported this included disabled people advocating for independent living and personalisation. However, the analysis yielded results that indicated older adults needed a greater level of support than was anticipated to navigate SDS and personalisation. Other changes with SDS moved funding and control to recipients as opposed to being controlled by social workers and this self-funding was part of personalisation with ideologies of choice, control and managed care by their defined outcomes.

The researcher identified gaps in SDS research in areas such as SDS caregiver assessments and how the role of the social worker was being reduced, adding support to the argument of the importance of the role of social work in care services. This was because of their role in care services because of their specific skillset to manage multiple challenging issues and a “greater capacity to deliver sustainable support” by reducing admissions into higher levels of care, to assess and support the individual and their carers as well as an increase in implementing successful care packages (Ray et al, 2015). The literature also looked at the limited long term use of SDS and SDS specific programmes with caregivers and the need additional SDS long term studies, and studies inclusive of social work involvement.

Macro: National Law and Policy

Other areas of policy that emerged included the issues of older adults not being involved in decision-making, such as when they are in hospital awaiting guardianship or unable to be released from hospital for an extended period of time. This is changing with sub-clause 13ZA with individuals included in group decision-making to be moved to a less restrictive setting when all parties are in agreement.

Reablement is another area that has impacted decision-making and is seen by many as a way to reduce the costs of long term care at home for older adults to regain confidence, skills to improve functional ability for Activities of Daily Living (ADLs). These are meant to be person-centred, to promote physical independence at home and social involvement in the community, but at times the personal goals of older people can be overlooked. This can be linked back to how older adults can be empowered to be involved in care decisions and the relationships between professionals and older people as policy and practice are implemented.

When OP do not have an accurate diagnosis of Alzheimer’s disease (AD) at home, this is unlikely to trigger services. The AD diagnosis is needed to start services as reported by PPs and this is problematic. This research has revealed the perceptions of labels and diagnoses that can trigger services or not. One example that discussed is Alzheimer Scotland’s models of care (five pillars of support, eight pillars of support and advanced Dementia Models of Care), for those living with dementia. There is a one-year long post-diagnostics support programme to support those newly diagnosed to assist with staying at home; however, without the diagnosis, they do not receive that added level of support. When individuals have this diagnosis they are able to access this additional support; however, when in a facility, PP reported that individuals will receive person-centred care and so having a diagnosis in that setting has less impact on services provided.

Macro: Ageing Well

There are many ways to formally and informally judge whether an individual is ageing well or not. This includes individual and professional perceptions and this extends further into policy issues and understanding ageing issues.

These issues centre on how well individuals are ageing with measures of independence and whether a person is healthy or not. This thesis has suggested that many OP did not consider themselves disabled, although, most OP would qualify as disabled under more formal and professional definitions. How individuals perceive themselves was different from how they were perceived by others but ageing well is often limited by terminology. When individuals were discussing their lived experiences this was better from individuals themselves, from their lived experience perspective than from others such as family members and professionals

Instrumental Activities of Daily Living (IADLs) are levels of function used to measure or assess disability. IADLs are often used as a universal measure of function and are more useful than activities of daily living (ADL) as measure. All OPs had difficulties in one or more areas at various levels of function. However, this did not mean OPs did not consider themselves as ageing well when considering the overall picture.

QoL influences many aspects of an older person's life and, in turn, is influenced by policy, expenditures, legal definitions and individuals. Identifying those factors which defined policy and practice about what is best for older people and had the most power in decision-making was an important issue. Defining an acceptable level of QoL was challenging because of the changing attitudes that varied in accuracy.

> "If 70-year-olds today have the same health as 60-year-olds in the past, one conclusion that might be drawn is that today's 70-year-olds are better placed to fend for themselves and so there is less need for policy action to help them do this." (WHO, 2015b, p. 9)

Varying QoL from one individual to the next was one issue to consider. This thesis has revealed that older adults do not limit themselves to the confines of labels, as was evidenced by reports of health, disability, and QoL. This may vary drastically from the way professionals and lawmakers view older adults. Capturing what is healthy and determining a baseline of QoL may continue to be a challenge. Thus, there are hurdles in determining whose perspective is most valid, and how to measure QoL accurately and how to measure the lived experience (although this thesis recommends individuals perspectives if possible.

When determining ageing well, there was an interest in biological age first, and then an interest in professionals measuring genetic and environmental influences and, because biological age is not seen as a good indicator in ageing well, there are other elements to consider when measuring the impact of disability and QoL. McNeill (2006) suggested that we all perceive the world in our own unique way based on personal experiences, which is consistent with GST. Finding answers to questions such as those posed here would better prepare and plan for how individuals, groups, communities and societies will be ready to make ongoing decisions about care and resources collectively. Cutbacks happen in treatment decisions, rising costs in pharmaceuticals and resources in already tight environments which bring on additional challenges and this is particularly true with upcoming changes in older population growth and with the known changes in the ageing trends that are expected. WHO (2015b) reported that "this complexity in the health and functional states experienced by older people raises fundamental questions about what we mean by health in older age, how we measure it and how we might foster it…new concepts are needed" (p. 12). This will enable better plans to support older people in upcoming changes with people living longer.

Therefore in response to Research Question 5, the answer is that this research has found that policy in Scotland does influence choices of older people and can be seen in reablement programmes, person-centred practice, Adults with Incapacity legislation (especially Section 13ZA), SDS, and Alzheimer's Scotland models of care.

Recommendations for practice

This thesis has demonstrated how practitioners can interact with older adults to improve decision-making processes but also raises some areas for development One recommendation is the need for training to address the confusion that professionals appeared to express around assessing capacity. Training would assist in addressing some of the barriers that emerged and improve professionals' practice and ability to support older people to make decisions. Additional training would clarify, for professionals, when older adults were legally able to make unwise decisions as opposed to having restricted decision-making abilities because of unclear capacity issues. This would have implications for older adults' QoL as this would open up decision-making opportunities.

The thesis has indicated many restrictions on decision-making from professionals because of confusion over policy, procedures, and the law. Recommendations include additional education in the use of anti-psychotic medications and around adverse incidences and a culture shift to moving to a more holistic model of practice as participants discussed that assessing all of the client's needs and not just curative in nature considers the overall system that person-centred care promotes. There is a need for training to address the confusion that professionals appeared to express around person-centred care. Added training may lead to fewer restrictions on older adults' options and choices in care and would implement a more universal person-centred practice to empower more decision-making for older people.

Additional training is also suggested for professionals' interpersonal communication skills. A professional's ability to convey and receive information while working with clients was found to be challenging (especially with 'non-verbal clients') and services with individuals with dementia. Additional interpersonal communication training may assist in improved communication, building rapport and fostering long term relationships which will enable delivery of better care services to these populations.

Looking at a broader perspective, GPs have a large amount of power. Being "godlike" had impacts on staff practice that influenced decision options for older adults. The researcher examined how key people could bring service change, particularly with capacity issues, something of concern to the Care Inspectorate. Services needed clarity on the process for determining capacity. In addition, staff education for identification of those with AD and dementia was necessary. This was especially important for those in the home setting to clarify the care pathways for services and early diagnosis for AD to get services.

This thesis has identified that SDS may enable more choice, independence and options in decision-making. Opportunities for more power and control in care planning were discussed and the reduction in stigma of accepting services was reported with SDS. Direct practice suggestions include sharing practice experience, adding support when individuals are being transferred from one service to another, and using strategies for direct practice in the field to assist with the reduction of barriers.

Conclusion

This thesis has used the GST framework to answer each of the Research Questions across micro, meso and macro levels to increase understanding of each question and present the whole system within which older people make decisions. Equifinality was evident in the ways older individuals worked to get their needs met when taking different routes to achieve homeostasis. Decisions were not made in isolation; they were revealed to be a fluid process with many people involved. There were three main influencing factors on older adults' decision-making; these were relationships, support networks and environmental factors. Individuals, support networks and relationships all directly and indirectly have the power and influence to impact the decision-making of older adults which in turn influenced QoL.

Perceptions, attitudes and behaviours of older adults, families and professionals were found to have a profound effect on decision-making and the choices that older people made both directly and indirectly. The way older people viewed themselves and the ways they conceptualised things such as disability and illness were important. The perception and influence of money, the reality of constraints, as well as concepts such as capacity and risk, also heavily influenced the perceived ways decisions were available and made by older adults.

The relationship between QoL and decision-making is complex. The perception of QoL by older people and by others was also found to be influential in decision-making. Older people were reported to change their choices based on professional recommendations or on professional stature alone; however, according to the literature, not all professionals have an accurate perception of an individual's QoL. Professionals may make assumptions about need based on their view of the older person's QoL rather than the person's own view of their QoL. Individual OP constructs of QoL according to their own perceptions may be different from how they are viewed by others. The role of professionals is questioned at times as power differentials may influence decisions.

The relationship between QoL and decision-making was made clearer when the data were examined e.g., older adults reported that they wished to live as independently as possible, in a variety of settings. As individuals fell below minimum QoL, they worked harder to raise this to a higher QoL to get back to homeostasis.

OP also discussed a number of environmental factors. The factors that were identified as important for older people relating to how to make decisions included relationships, choice, control, safety, community supports, and professional roles. How policy was implemented in practice influenced decision-making. Person-centred environments may be more conducive to involving older people in the decision-making process as these are personalised to meet an individual's needs. Other environmental factors, such as, MECS, support networks, residences of choice and assistive devices and technology influenced behaviours and the choices of older adults as these were influences that helped individuals maintain homeostasis.

There are programmes and policies in Scotland with ideologies to promote choice and independence for older people themselves such as reablement and SDS, yet most individuals were found to need assistance in navigating systems and had help with shared decision-making and support networks. This highlighted the importance of relationships. OP consistently reported the importance of family and professionals in the role of decision-making for them in care, and in resource utilisation. Policies such as SDS and reablement were designed to add options and choices to promote independence for older adults and had further influence. However, most individuals had a support person in working though care decisions. Support networks and relationships supported homeostasis but were not always within the control of the older adult, as some decision-making was conducted without the knowledge of the older adult or they were excluded from the decision-making process.

Theodore Roosevelt once said, “In any moment of decision, the best thing you can do is the right thing, the next best thing is the wrong thing, and the worst thing you can do is nothing” (n.d.). However, the perception of what is the right thing may be different depending on whether you are the older person, the GP, the social worker, caregiver, the clergy or a family member. Perceptions, attitudes and behaviours were revealed to be important influences on decision-making and choices for older people across the spectrum of care options. Decision-making influenced individuals whether or not they were actively involved in the actual decision-making. Most individuals, most of the time, want to be active in the decision-making process and in choices that influence them. However, at times, individuals choose not to be involved. It is having the opportunity and option to decide that makes the difference between empowering or suppressing individuals.

References

Age Scotland (2012). *At home with Scotland's older people facts and figures 2011-2012*. Retrieved April 19, 2020 from, http://www.ageuk.org.uk/pagefiles/17830/2011%20at%20home%20with%20scotland's%20older%20people%20-%20%20web%20pdf%20hi-res.pdf

Alzheimer's Scotland. (2016). *The 8 pillars model of community support*. Retrieved May 12, 2020, from https://www.alzscot.org/our-work/campaigning-for-change/current-campaigns/8-pillars-model-of-community-support

Andersson, I., Pettersson, E., & Sidenvall, B. (2006). Daily life after moving into a care home- experiences from older people, relatives and contact persons. *Journal of Clinical Nursing*, 1712-1718. doi: 10.1111/j.1365-2702.2006.01703.x

Asnani, M. R., Lipps, G. R., Reid, M. E. (2009). Utility of WHOQOL-BREF in measuring quality of life in Sickle Cell Disease. *Bio Med Central*, *7*(75), 1-6. doi: 10.1186/1477.7525.7.75

Audet, J., & d'Amboise, G. (2001). The Multi-Site Study: An Innovative Research Methodology. *The Qualitative Report*, *6*(2), 1-18. Retrieved from http://nsuworks.nova.edu/tqr/vol6/iss2/2

Audit Scotland. (2008). *A review of free personal and nursing care*. Retrieved March 22, 2020, from http://www.audit-scotland.gov.uk/docs/health/2007/nr_080201_free_personal_care_km.pdf

Barker, R. L. (2003). *The social work dictionary*. Baltimore, MD: NASW Press.

Barnard, M. (2010). *National Centre for Social Research, What is framework*. Retrieved April 10, 2020, from https://www.youtube.com/watch?v=QNiy4_63EVY

Bell, D., & Bowes, A. (2008). *Free personal care-some recent developments*. Retrieved May 10, 2020 from https://www.jrf.org.uk/file/37283/download?token=mBEcNKeQ&filetype=findings

Bell, D., Bowes, A., & Dawson, A. (2007). *Free personal care in Scotland: Recent developments.* Retrieved May 20, 2020, https://www.jrf.org.uk/report/free-personal-care-scotland-recent-developments

Bell, D., Bowes, A., Dawson, A., & Roberts, E. (2006). *Establishing the evidence base for an evaluation of free personal care in Scotland.* Retrieved May 12, 2020, from http://www.scotland.gov.uk/Resource/Doc/133358/0031763.pdf

Bergold, J. & Thomas, S. (2012). Participatory research methods: A methodological approach in motion. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research, 13*(1), [110 paragraphs]. doi: http://dx.doi.org/10.17169/fqs-13.1.1801

Bernard, T. J., Paoline, E. A., & Pare, P. (2005). General systems theory and criminal justice. *Journal of Criminal Justice, 33*(3), 203-211. doi:10.1016/j.jcrimjus.2005.02.001

Bland, R. (1999). Independence, privacy and risk: Two contrasting approaches to residential care for older people. *Ageing & Society, 19,* 539-560.

Bohnsack, R. (2008). The interpretation of pictures and the documentary method. *Qualitative Social Research, 9*(3), 1-25. Retrieved from www.qualitative-research.net

Boissonnault, P. (2008). Look out! Here comes the boomers: Ageism and the apocalyptic demographic. *Transformation Dialogues: Teaching & Learning Journal, 1*(3), 1-9.

Bowers, H., Clark, A., Crosby, G., Easterbrook, L., Macadam, A., MacDonald, R., … Smith, C. (2009). *Older peoples vision for long-term care.* Retrieved May 2, 2020, from https://www.jrf.org.uk/report/older-peoples-vision-long-term-care

Bowes, A., Dar, N., & Sim, D. (1997). Life histories in housing research: The case of Pakistanis in Glasgow. *Quality & Quantity, 31*, 109-125.

Brown, H. (2011). The role of emotion in decision-making. *The Journal of Adult Protection, (13)*4, 194-202. doi: 10.1108/14668201111177932

Care Inspectorate. (2015).*Services for older people in Glasgow Report on a joint inspection of health and social care services.* Retrieved May 07, 2020 from http://www.careinspectorate.com/images/documents/2601/Services%20for%20older%20people%20in%20Glasgow.pdf

Carver, L. F., Buchanan, D. (2016). Successful aging: considering non-biomedical constructs. *Clinical Interventions in Aging, 11*, 1623-1630. doi: 10.2147/CIA.S117202

Centre for Policy on Ageing. (2011). *How can local authorities with less money support better outcomes for older people?* Retrieved March 22, 2020, from https://www.jrf.org.uk/report/how-can-local-authorities-less-money-support-better-outcomes-older-people

Chachamovich, E., Trentini, C., & Fleck, M. P. (2006). Assessment of the psychometric performance of the WHOOL-BREF instrument in a sample of Brazilian older adults. *International Psychogeriatrics, 19*(4), 635-646. doi: 10.1017/S1041610206003619

Chadwick, D., Mannan, H., Iriarte, E., McConkey, R., O' Brien, P., Finlay, F., Lawlor, A., & Harrington, G. (2013). Family voices: Life for family carers of people with intellectual disabilities in Ireland. *Journal of Applied Research in Intellectual Disabilities, 26,* 119-132. doi: 10.1111/jar.12003

Chan, K. S., Kasper, J. D., Brandt, J., & Pezzin, L. E. (2011). Measurement equivalence in ADL and IADL difficulty across international surveys of aging: Findings from the HRS, SHARE, and ELSA. *The Journal of Gerontology, Series B. Psychological Sciences and Social Sciences, 67*(1)121-132. doi: 10.1093/geronb/gbr133

Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango). *Social Science & Medicine, 44*(5), p. 681-692.

Cho, J. & Trent, A. (2006). Validity in qualitative research revisited. *Qualitative Research, 6*(3), 319-340. doi: 10.1177/1468794106065006

Chock, M. M., Lapid, M. I., Atherton, P. J., Kung, S., Sloan, J. A., Richardson, J.W.,…Rummans, T. A. (2013). Impact of a structured multidisciplinary intervention on quality of life of older adults with advanced cancer. *International Psychogeriatic Association,* 1-10. doi: 10.1017/S1041610213001452

Claassens, I., Widdershoven, G. A., Van Rhijn, S. C., Van New, F., Broese van Groenou, M. I.,… & Huisman, M. (2014). Perceived control in health care: A conceptual model based on experiences of frail older adults. *Journal of Aging Studies, 31,* 159-170.

Clotworthy, A., Kusumastuti, S., & Westendorp, R. G.J. (2020). Reablement through time and space: A scoping review of how the concept of 'reablement' for older people has been defined and operationalised. *BMC Geriatrics*, 1-38.

Clough R., Manthorpe, J., Green, B., Fox, D., Raymond, G., Wilson, P., … Hay, J. (2007). *The support older people want and the services they need.* Retrieved May 14, 2020, from https://www.jrf.org.uk/report/support-older-people-want-and-services-they-need

Collier, J., & Collier, M. (1996). *Visual anthropology: Photography as a research method. Albuquerque:* University of New Mexico Press.

Conti, R. (2008). Doctors are caregivers or providers? Patients are clients? *Clinical Cardiology, 31*(11), 505. doi: 10.1002/clc.20414

Corcoran, J., & Walsh, J. (2006). *Clinical assessment and diagnosis in social work practice*. New York: Oxford Univ. Press.

Cordingly, L., Hughes, J., & Challis, D. (2001). *Unmet need and older people. Towards a synthesis of user and provider views.* Retrieved May 14, 2020, from https://www.jrf.org.uk/report/unmet-need-and-older-people-towards-synthesis-user-and-provider-views

Couffinhal, A., & Paris, V. (2001). *Utilization fees imposed to public health care systems users in France*. Retrieved March 22, 2020, from http://www.irdes.fr/EspaceAnglais/Publications/OtherPubs/UtilisationFeesImposedFrance.pdf

Craig, G. (2004). Citizenship, exclusion and older people. *International Social Policy, 33*(1), 95-114. doi: 10.1017/S0047279403007207

Cranley, L., Slaughter, S., Caspar, S., Heisey, M., Haung, M., Killackey, T., & McGilton, K. (2020). Strategies to facilitate share decision making in long term care. *International Journal Older People Nursing*, 1-10. doi: 10.1111/opn.12314

Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches.* Thousand Oaks, Calif: SAGE Publications Inc.

Dawson, A., Bowes, A., Kelly, F., Velzke, K., & Ward, R. (2015). Evidence of what works to support and sustain care at home for people with dementia: A literature review with a systematic approach. *BioMed Central, 15*(59)1-17. doi:10.1186/s12877-015-0053-9

Dewing, J. (2007). Participatory research: A method for process consent with persons who have dementia. *Dementia, 6*(1), 11-26.

DiazOrdaz, K., Slowther, A. M., Potter, R., & Eldridge, S. (2013). Consent processes in cluster-randomised trials in residential facilities for older adults: A systematic review of reporting practices and proposed guidelines. *BMJ open, 3*(7), 1-7.

DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education, 40*, 314-321. doi: 10.1111/j.1365-2929.2006.02418.x

Drack, M., & Schwarz, G. (2010). Recent development in general systems theory. *Systems Research and Behavioral Science, 27*, 601-610. doi: 10.1002/sres.1013

Ebrahimipour, H., Vafaee-Najar, A., Kahanijajani, A., Pourtaleb, A., Saadati, Z., Molavi, Y. & Kaffashi, S. (2013). Customers' complaints and its determinants: The case of a training education hospital in Iran. *Health Policy and Management, 1*(4), 273-277. doi: 10.15171/ijhpm.2013.56

Edemekong, P.F,, Bomgaars, D.L,, & Sukumaran S, (2020) *Activities of daily living (ADLs)*. Retrieved March 14, 2020, from https://www.ncbi.nlm.nih.gov/books/NBK470404/

Edwards, W. (1954). The theory of decision making. *Psychological Bulletin, 51*(4), 380-417.

Elliott, J., McNeil, H., Ashbourne, J., Huson, K., Boscart, & V., Stolee, P (2016). Engaging older adults in health care decision making: A realist synthesis. *Patient, 9,* 383-393. doi: 10.1007/s40271-016-0168-x

Evans, R., Kotchetkova, I. (2009). Qualitative research and deliberative methods: Promise or peril? *Qualitative Research, 9*(5), 625-643. doi: 10.1177/1468794109343630

Fade, S. (2004). Using interpretative phenomenological analysis for public health nutrition and dietetic research: A practical guide. *Proceeding of the Nutrition Society, 63*, 647-653. doi: 10.1079/PNS2004398

Fazio, S., Pace, D., Flinner, J., & Kallmyer, B. (2018). The fundamentals of person-centered care for individuals with dementia. *The Gerontological Society of America, 58*(S1), S10-S19.

Fernandez-Ballesteros, R. (2011). Quality of life in old age: Problematic issues. *Applied Research Quality of Life, 6*, 21-40. doi: 10.1007/s11482-010-9110-x

Foster, J. (2010). Thinking on the front line: How creativity can improve self-directed support. *Journal of Social Work Practice, 24*(3), 283–299. doi:10.1080/02650533.2010.500125

Gibbs, G. J. (2011). *Coding in qualitative data analysis*. Retrieved May 14, 2018, from http://eprints.hud.ac.uk/id/eprint/22754/

Gill, T. M., & Feinstein, A. R. (1994). A critical appraisal of the quality of quality-of-life measurements. *JAMA, 272*(8), 619-626.

Glasby, J. & Lester, H. (2004). Delayed hospital discharge and mental health: The policy implications of recent research. *Social Policy & Administration, 38*(7), 744–757.

Glasser, W. (1975). *Reality therapy: A new approach to psychiatry*. New York, NY: Harper & Row, Publishers, Inc.

Glynn, M., Beresford, P., Bewley, C., Branfield, F., Butt, J., Croft, S., …Turner, M. (2008). *Person-centred support what service users and practitioners say*. Retrieved March 22, 2018, from http://www.jrf.org.uk/sites/files/jrf/2173-person-centred-support.pdf

Gotschi, E., Delve, R., & Freyer, B. (2009). Participatory photography as a qualitative approach to gain insights into farmer groups. *Field Methods, 21*(3), 290-308.

Guyatt, G., Feeny, D. H., & Patrick, D. L. (1993). Measuring health-related quality of life. *Annals of Internal Medicine, 118*(8), 622-629.

Harper, D. (2002). Talking about pictures: A case for photo elicitation. *Visual Studies, 17*, 13-26.

Harrison, T. M., Weintraub, S., Mesulam, M. M., & Rogalski, E. (2012). Superior memory and higher cortical volumes in unusually successful cognitive aging. *Journal of the International Neuropsychological Society, 18(6). 1081-1085.* doi: 10.1017/S1355617712000847

Hicks, E., Sims-Gould, J., Byrne, K., Khan, K. M., & Stole, P. (2012). “She was a little bit unrealistic”: Choice in healthcare decision making for older people. *Journal of Aging Studies, 26*, 140-148.

Howatt, W. A. (2001). The evolution of reality therapy to choice theory. *International Journal of Reality Therapy, 21*(1), 7-11.

Hughes, R., & Huby, M. (2002). The application of vignettes in social and nursing research. *Journal of Advanced Nursing, 37*(4), 382-386.

Irvin, R., & Stansbury, J. (2004). Citizen participation in decision making: Is it worth the effort? *Public Administration Review, 64*, 55-65. doi: 10.1111/j.1540-6210.2004.00346.x

Jamieson, A., & Victor, C. R. (Eds.) (2002). *Researching ageing and later life: The practice of social gerontology*. Buckingham, UK: Open University Press.

Katz, J., Holland, C. & Peace, S. (2013). Hearing the voices of people with higher support needs. *Journal of Aging Studies, 27,* 52-60. doi: 10.1016/j.jaging.2012.11.003

Kelley-Gillespie, N. (2009). An integrated conceptual model of quality of life for older adults based on a synthesis of the literature. *Applied Research Quality of Life, 4*, 259-282. doi:10.1007/s11482-009-9075-9

Kelley-Gillespie, N. (2011). A secondary analysis of perceptions of quality of life of older adults residing in nursing home and assisted living setting using an integrated conceptual model of measurement. *Applied Research Quality of Life*, 1-18. doi:10.1007/s11482-011-9154-6

Kelly, F. & Innes, A. (2012). Human rights, citizenship and dementia care nursing. *International Journal of Older People Nursing*, 1-9.

Kemp, C., Ball, M., & Perkins, M. (2013). Convoys of care: Theorizing intersections of formal and informal care. *Journal of Aging Studies, 27*, 15-29. doi: 10.1016/.jaging. 2012.10.002

Kidd, P. S., & Parshall, M. B. (2000). Getting the focus and the group: Enhancing analytical rigor in focus group research. *Qualitative Health Research, 10*(32012), 293-308.

Kim, S. K., & Park, M. (2017). Effectiveness of person-centered care on people with dementia: A systematic review and meta-analysis. *Clinical Interventions in Aging, 12*, 381-397.

Kirst-Ashman, K. K. (2014). *Human behaviour in the macro social environment: An empowerment approach to understanding communities, organizations, and groups.* Belmont, CA: Brooks/Cole.

Kirst-Ashman, K. K., & Hull, G. H. (2012). *Understanding generalist practice.* Belmont, CA: Brooks/Cole.

Kitzinger, J. (1994). The methodology of focus groups: the importance of interaction between research participants, *Sociology of Health and Illness, 16*(1), 103-121.

Kmetec, S., Stiglic, G, Lorber, M., Mikkonen, I., McCormack, B., Pajnkihar, M., & Fekonja, Z. (2020). Nurses perceptions of early person-centred palliative care: A cross sectional descriptive study. *Scandinavian Journal of Caring Science, 34*, 157-166.

Knussen, C., Tolson, D., Brogan, C. A., Swan, I. R. C., Stott, D. J., & Sullivan, F. (2008). Family caregivers of older relatives: Ways of coping and change in distress. *Psychology, Health & Medicine, 13*(3), 274-290. doi:10.1080/13548500701405483

Kolb, B. (2008). Involving, sharing, analysing-potential of the participatory photo interview. *Forum Qualitative Social Research, 9*(3), 1-26. Retrieved from http://www.qualitative-research.net/index.php/fqs/article/view/1155

Kus, E. (2003). *Can quantitative and qualitative methods be combined? A comparison of quantitative and qualitative interviews.* Retrieved July 22, 2017 from, https://www.linkedin.com/pulse/research-methodologies-comparison-quantitative-mixed-methods-gunnell

Kusumastuti, S., Derks, M., Tellier, S., Di Nucci, E., Lund, R., Lykke Mortensen, E. & Westendorp, R. (2016). Successful aging: A study of the literature using citation network analysis. *Maturitas, 93*, 4-12.

LaPlante, M. P. (2010). The classic measure of disability in activities of daily living is biased by age but an expanded IADL/ADL measure is not. *The Journal of Gerontology: Social Sciences, 65B*(6), 720-732.

Leadbeater, C., &. Lownsbrough, H. (2005). *Personalization and participation: The future of social care in Scotland*. Retrieved May 15, 2020, from https://www.scie-socialcareonline.org.uk/personalisation-and-participation-the-future-of-social-care-in-scotland-final-report/r/a11G000000182KzIAI

Leech, N. L., & Onwuegbuzie, A. J. (2007). An array of qualitative data analysis tools: A call for data analysis triangulation. *School Psychology Quarterly, 22*(4), 557-584.

LeLow, L. P. (2018). *Decision-making experiences and patterns in residential care homes for older residents, family members and care providers.* In D'Onofrio, G., Greco, A., & Sancarlo, D (Eds.) Gerontology (pp. 221-245). London IntechOpen.

Levine, C., Faden, R., Grady, C., Hammerschmidt, D., Eckenwiler, L., & Sugarman, J. (2004). The limitations of vulnerability as a protection for human research participants. *The American Journal of Bioethics*, *4*(3), 44-49. doi: 10.1080/15265160490497083

Lin, Y. (2005). *General systems theory: A mathematical approach*. New York: Kluwer Academic Publishers.

Lin, Y., Hu, Q. P., & Li, D. (1997). Some unsolved problems in general systems theory. *Cybernetics and Systems 28*, 287-303.

Lin, Y., & Wang, S. T. (1998). Developing a mathematical theory of computability which speaks the language of levels. *Mathematical and Computer Modelling, 27*(6), 23-32.

Lindley, E. Broom, S, Dellot, B, Norrism E, Rowson, J, Soopramanien, D., & Truch, E. (2012). *Improving decision-making in the care and support of older people.* Retrieved May 22, 2020 from, https://www.jrf.org.uk/report/improving-decision-making-care-and-support-older-people

Lloyd, L., Tanner, D., Milne, A., Ray, M., Richards, S., Sullivan, M. P., Beech, C., & and Phillips, J. (2014). Look after yourself: Active ageing, individual responsibility and the decline of social work with older people in the UK. *European Journal of Social Work, 17* (3), 322-335.

Longman (n.d.). *Bed blocking definition. Status quo definition.* Retrieved February 27, 2017, from http://www.ldoceonline.com/dictionary/bed-blocking and http://www.ldoceonline.com/dictionary/the-status-quo

MacGregor, A. & Sheehy, C. (2004). *Evaluation of Lothian Ageing Well*. Retrieved May 10, 2020, from http://www.healthscotland.com/documents/463.aspx

Manthorpe, J., Martineau, S., Ridley, J., Cornes, M., Rosengard, A., & Hunter, S. (2014). Embarking on self-directed support in Scotland: A focused scoping review of the literature. *European Journal of Social Work, 18*(1), 36–50. doi:10.1080/13691457.2014.885883

Marshall, P. (2002). *Research methods: How to design and conduct a successful project.* Mumbai: Jaico Pub. House.

Martin, G. (2017). *The meaning and origin of the expression: The powers that be.* Retrieved May 07, 2020, from http://www.phrases.org.uk/meanings/the-powers-that-be.html

Maslow, A. H. (1943). A theory of human motivation. *Psychological Review, 50*(4), 370–396. doi:10.1037/h0054346

Mason, P. (2005). Visual data in applied quantitative research: Lessons from experience. *Qualitative Research 5*(3), 325-346.

Mauthner, N. S., & Doucet, A. (1998). Reflections on a voice-centred relational method of data analysis: Analysing maternal and domestic voices, in Jane Ribbens and Rosalind Edwards (eds.), *Feminist Dilemmas in Qualitative Research: Private Lives and Public Texts*. London: Sage; p. 119-144.

McNeill, T. (2006). EBP in an age of relativism: A model for practice. *Social Work, 51*(2), 147-156.

Merriam Webster. (2018). *Definition of participate*. Retrieved March 1, 2020, from https://www.merriam-webster.com/dictionary/participate

Moore, L., Britten, N., Lydahl, D., Naldemirci, O., Elam, M., & Wolf, A. (2017). Barriers and facilitators to the implementation of person-centred care in different healthcare contexts. *Scandinavian Journal of Caring Sciences, 31*, 662-673.

Moore, T. F., & Hollett, J. (2003). Giving voice to persons living with dementia: The researcher's opportunities and challenges. *Nursing Science Quarterly, 16*, 163-167.

Moran-Ellis, J., Alexander, V. D., Cronin, A., Dickinson, M., Fielding, J., Sleney, J., & Thomas, H. (2006). Triangulation and integration: processes, claims and implications. *Qualitative Research 6(*1), 45-59. doi:10.1177/1468794106058870

Mulhern, B., Rowen, D., Brazier, J., Smith, S., Romeo, R., Tait, R., Watchurst, C., Chua, K. C., Loftus, V., Young, T., Lamping, D., Knapp, M., Howard, R., & Banerjee, S. (2013). Development of DEMQOL-U and DEMQOL-PROXY-U: Generation of preference-based indices from DEMQOL and DEMQOL-PROXY for use in economic evaluation. *Health Technology Assessment NHS National Institute of Health Research, 17*(5), 1-140.

National Association of Social Workers, (NASW). (2006). *Social work speaks: National Association of Social Workers policy statements, 2006-2009*. Washington, DC: NASW Press.

National Health System (NHS). (2012). *A Better NHS Exploring the relationship between doctors and patients and health policy. What's in a name? Patients, clients and consumers.* Retrieved May 13, 2020, from https://abetternhs.net/2012/04/09/whats-in-a-name/

National Health System (NHS) Health Scotland. (2005). *Ageing well in Scotland*. Retrieved March 14, 2020, from http://www.healthscotland.com/documents/1560.aspx

Neuberger, J. (1999). Do we need a new word for patients: Let's do away with "patients." *BMJ, 318*, 1756-1758.

Nind, M. (2011). Participatory data analysis: A step too far? *Qualitative Research, 11*, 349-363.

Nolan, M., Lundh, U., Grant, G., & Keady, J. (Eds.). (2003). *Partnerships in family care: Understanding the caregiving career.* Berkshire, England: Open University Press.

O'Brien, M. (2015). *Successful aging*. Concord, Calif: Biomed General.

Office of the Public Guardian (Scotland). (n.d.). *Definition of incapacity*. Retrieved April 9. 2020, from http://www.publicguardian-scotland.gov.uk/adults-with-incapacity-(scotland)-act/definition-of-incapacity

Oxford. (2015). *Disability.* Retrieved October 13, 2019, from http://www.oxforddictionaries.com/us/definition/american_english/disability

Oxford. (2018a). *Definition of patient in English*. Retrieved February 23, 2020, from https://en.oxforddictionaries.com/definition/patient

Oxford. (2018b). *Definition of client.* Retrieved February 23, 2020, from https://en.oxforddictionaries.com/definition/client

Personal Social Services Research Unit. (2018). *Unit Costs of Health and Social Care 2014*. Retrieved May 03, 2020, from https://www.pssru.ac.uk/project-pages/unit-costs/unit-costs-2014/

Petriwskyj, A., Gibson, A., & Webby, G. (2014). Participation and power in care: Exploring the "client" in client engagement. *Journal of Aging Studies, 31*, 119-131.

Petriwskyj, A., Gibson, A., & Webby, G. (2015). Staff members' negotiation of power in client engagement: Analysis of practice within and Australian aged care service. *Journal of Aging Studies, 33,* 37-46

Philip, L., Gilbert, A., Mauthner, N., & Phimister, E. (2003). *Scoping study of older people in rural Scotland.* Retrieved April 16, 2020, from http://www.scotland.gov.uk/Resource/Doc/47034/0030397.pdf

Phillips, J. (2007). *Care.* Cambridge, UK: Polity Press.

Plath, D. (2009). Independence in old age: The route for social exclusion? *British Journal of Social Work, 38*(7), 1353-1369.

Punch, S. (2017). Research with children: The same or different form research with adults? *Childhood, 9*(3) 321-341.

Prosser, J., & Loxley, A. (2008). *Introducing visual methods. ESRC National Centre for Research Methods Review Paper, NCRM Methods Review Papers*. Retrieved from http://eprints.ncrm.ac.uk/420/1/MethodsReviewPaperNCRM-010.pdf

Puhan, M. A., Ahuja, A., Van Natta, M. L., Ackatz, L. E., & Meinert, C. (2011). Interviewer versus self-administered health-related quality of life questionnaires-does it matter? *Health and Quality of Life Outcomes, 9*(30), 1-11. Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3100232/

Qureshi, H., Patmore, C., Nicholas, E., & Bamford, C. (1999). *Outcomes in community care practice number five overview outcomes of social care for older people and carers.* Retrieved May 14, 2020, from https://www.york.ac.uk/inst/spru/pubs/occp/occp5.pdf

Ray, M., Milne, A., Beech, C., Phillips, J. E., Richards, S., Sullivan, M. P., Tanner, D., & Lloyd, L. (2015). Gerontological social work: reflections on its role, purpose and value. *British Journal of Social Work, 45* (4), 1296-1312.

Reason, M. (2010). *Mind maps, presentational knowledge and the dissemination of qualitative research*. Retrieved May 9, 2020 from http://eprints.ncrm.ac.uk/1577/1/0910_mindmaps.pdf

Reed, J., Cook, G., Bolter, V. & Douglas, B. (2006). *Older people 'getting things done' involvement in policy and planning initiatives.* Retrieved March 28, 2020, from https://www.jrf.org.uk/report/older-people-getting-things-done-involvement-policy-and-planning-initiatives

Reid, T. R. (2009). *The healing of America: A global quest for better, cheaper, and fairer health care*. New York: Penguin Press.

Rhynas, S. J., Garrido, A. G., Burton, J. K., Logan, G., & MacArthur, J (2018). New care home admission following hospitalization. *International Journal Older People Nursing, 13*(3), 1-22. doi: 10.1111/opn.12192

Rieger, J. (1996) Photographing social change. *Visual Sociology, 11*(1), 5-49.

Rowe, J. (2015). *Health and social care – benefits of active participation.* Retrieved May 05, 2020 from http://freedomtoteach.collins.co.uk/health-and-social-care-benefits-of-active-participation/

Rubin, A., & Babbie, E. R. (2008). *Research methods for social work*. Belmont, CA: Thomson/Brooks/Cole.

Rubin, A., & Bellamy, J. (2012). *Practitioner's guide to using research for evidence-based practice*. Hoboken, N.J: Wiley.

Rummery, K., Bell, D., Bowes, A., Dawson, A., & Roberts, E. (2012). *Counting the cost of choice and control: Evidence for the costs of self-directed support in Scotland.* Retrieved May 18, 2020, from http://www.scotland.gov.uk/Resource/0038/00388624.pdf

Samuelson, W., & Zeckhauser, R. (1988). Status quo bias in decision making. *Journal of Risk and Uncertainty, 1,* 7-59.

Sanfey, A.G., Rilling, J.K., Aronson, J.A., Nystrom, L.E., & Cohen, J.D. (2003). The neural basis of economic decision-making in the ultimatum game. *Science, 300*, 1755-1758. doi: 10.1126/science.

Santana, M., Manalili, K., Joley, R., Zelinsky, S., Quan, H, & Lu, M. (2018). How to practice person centred care: A conceptual framework. *Health Expect, 21,* 429-440. doi:10.1111/hex12640

Scheibl, F., Farquhar, M., Buck, J., Barclay, S., Brayne, C, & Fleming, J. (2019). When frail older people relocate in very old age, who makes the decision? *The Gerontological Society of America*, *3*(4), 1-9. doi: 10.1093/geroni/igz030

Scottish Executive. (2005). *Delivering for health*. Retrieved March 14, 2020, from https://www.webarchive.org.uk/wayback/archive/20170701074158/http://www.gov.scot/Publications/2005/11/02102635/26389 Edinburgh: Scottish Executive.

Scottish Government. (n.d.*). Self-directed support act.* Retrieved March 6, 2020, from http://www.selfdirectedsupportscotland.org.uk/self-directed-support/self-directed-support-act

Scottish Government. (2008b). *Adults with Incapacity (Scotland) Act 2000: Code of Practice: For Local Authorities Exercising Functions under the 2000 Act; Annex1: CCD5/2007 Guidance for local authorities: provision of community care services to adults with incapacity (Subclause 13ZA)*. Retrieved May 13, 2020 from http://www.gov.scot/Publications/2008/03/20114619/12

Scottish Government. (n.d.). *Self-directed support act.* Retrieved March 6, 2020, from http://www.selfdirectedsupportscotland.org.uk/self-directed-support/self-directed-support-act

Scottish Government. (2003). *Self-directed support a national strategy for Scotland.* Retrieved March 12, 2020 https://www2.gov.scot/resource/doc/329971/0106962.pdf

Scourfield, P. (2015). Even further beyond street-level bureaucracy: The dispersal of discretion exercised in decisions made in older people's care home reviews. *British Journal of Social Work*, *45*, 914-931.

Silverman, D. (2011). *Interpreting qualitative data: A guide to the principles of qualitative research*. London: SAGE.

Sinding, C & Aronson, J. (2003), Exposing failures, unsettling accommodations: Tensions in interview practice. *Qualitative Research*, *3*(1), 95-117. doi: 10.1177/1468794103003001770

Slevin, M. L., Plant, H., Lynch, D., Drinkwater, J., & Gregory, W. M. (1988). Who should measure quality of life, the doctor or the patient? *British Journal of Cancer, 57*, 109-112.

Smith, M., Segal, J., & White, M. (2019). *Aging well the keys to healthy aging*. Retrieved March 14, 2020 from https://www.helpguide.org/articles/alzheimers-dementia-aging/staying-healthy-as-you-age.htm

Smith, S. C., Lamping, D. I., Banerjee, S., Harwood, R. H., Foley, B., Smith, P., Cook, J. C., Murray, J., Prince, M., Levin, E., Mann, A., & Knapp, M. (2007). Development of a new measure of health-related quality of life for people with dementia: DEMQOL. *Psychological Medicine, 37*, 737-746. doi:10.1017/S0033291706009469

Solomon, R., Kirwin, P., Van Ness, P., O' Leary, J., & Fried, T. (2010). Trajectories of quality of life in older persons with advanced illness. *Journal of American Geriatric Society, 58,* 837-843.

Stewart, A. (2012). *Supporting vulnerable adults: Citizenship, capacity, choice.* Edinburgh: Dunedin.

Tallis, R. (1999). Do we need a new word for patients? Commentary: Leave well enough alone. *BMJ*, 318, 1756-1758.

Tanner, D., Ward, L., & Ray, M. (2018). Paying your own way: Application of the capability approach to explore older people's experiences of self-funding social care. *Critical Social Policy, 38* (2), 262-282

Teddlie, C., & Tashakkori, A. (2006). A general typology of research design featuring mixed methods. *Research in the Schools, 13*(1), 12-28.

Theodore Roosevelt Center. (n.d.) *Theodore Roosevelt quotes*. Retrieved May 10, 2020, from https://www.theodorerooseveltcenter.org/Learn-About-TR/TR-Quotes/In%20any%20moment%20of%20decision%20%20the%20best%20thing%20you%20can%20do%20is%20the%20right%20thing%20%20the%20nex?from=https%3A%2F%2Fwww.theodorerooseveltcenter.org%2FSearch%3Fr%3D1%26searchTerms%3DIn%2520any%2520moment%2520of%2520decision%252C%2520the%2520thing%2520you%2520can%2520do%2520is%2520the%2520right%2520thing

Thomas, N. & O'Kane, C. (2006). The ethics of participatory research with children. *Children & Society, 12*(5), 336-348). doi: 10.1111/j.1099-0860.1998.tb00090.x

Thorton, P. (2000). *Older people speaking out developing opportunities for influence.* Retrieved May 14, 2020, from https://www.jrf.org.uk/report/older-people-speaking-out-developing-opportunities-influence

Toze, M., & Ray, M. (2018). *Creative ageing*. Discussion Paper. University of Lincoln.

Trigger, D., Forsey, M. & Meurk, C. (2012). Revelatory moments in field work. *Quantitative Research, 12*(5), 513-527. doi: 10.1177/1468794112446049

Truscott, D. J. (2000). Cross cultural ranking of IADL skills. *Ethnicity and Health, 5*(1), 67-78.

United Nations. (n.d.).*World population ageing 1950-2050*. Retrieved May 19, 2020, from https://www.un.org/en/development/desa/population/publications/pdf/ageing/WPA2015_Report.pdf

Vahdat, S., Hamzehgardeshi, L., Hessam, S., & Hamzehgardeshi, Z. (2014). Patient involvement in health care decision making: A review. *Iran Red Cres Med Journal. 16*(1), 1-7. doi: 10.5812/ircmj.12454

Velzke, K. (2014). Evaluation of a dementia care learning programme. *Nursing Older People, 26*(9), 21-27.

Velzke, K., (2017). Exploration of choice for older people with daily care needs: Scottish professionals' perspectives on self-directed support. *The Journal of Gerontological Social Work, 60(1), 7-31.* doi: 10.1080/01634372.2016.1267674

Velzke, K. (2016). What influences older people's decisions about care and support? *Spark Stirling International Journal of Postgraduate Research, 1*(3). 1-27.

Velzke, K., & Baumann, S. (2017). Including the voice of older adults in research. *Nursing Science Quarterly, 30*(1), 67-72.

Vestri, P. (2007). *Evaluation of free personal care*. Retrieved May 18, 2020, from http://www.scotland.gov.uk/Resource/Doc/167866/0046182.pdf

Von Bertalanffy, L. (1972). The history and status of general systems theory. *The Academy of Management Journal. 15*(4), 407-426.

Von Bertalanffy, L. (1934). Untersuchungen fiber die Gesetzlichkeit des Wachstums. I. Allgemeine Grundlagen der Theorie mathematische und physiologische Gesetzlichkeiten des Wachstums bei Wassertieren. *Roux Arch. Entwicklungsmech, 131*, 613-652.

Wada, Y. (2015). Older people's exercising of choice in long-term care: A comparative analysis of England and Japan. *Aging & Society, 36*, 1185-1210. doi: 10.1017/s0144686x150000264

Walsh, J. (2010). *Theories for direct social work practice*. Australia: Wadsworth Cengage Learning.

Ware, T., Matosevic, T., Hardy, B., Knapp, M., Kendall, J., & Forder, J. (2003). Commissioning care services for older people in England: the view from care managers, users and carers. *Ageing and Society 23*, 411-428. doi: 10.1017/SOI44686X02001137

Wibeck, V., Abrandt Dahlgren, M., & Oberg, G. (2007). Learning in focus groups: An analytical dimension for enhancing focus group research. *Qualitative Research, 7*(2), 249-267.

Wiles, R., Heath, S., Crow, G., & Charles, V. (2005*). Informed Consent in Social Research: A Literature Review.* ESRC National Centre for Research Methods. Retrieved May 16, 2020, from http://eprints.ncrm.ac.uk/85/1/MethodsReviewPaperNCRM-001.pdf

World Health Organization (WHO). (2002). *Active ageing: A policy framework.* Retrieved May 6, 2020, from https://www.who.int/ageing/publications/active_ageing/en/

World Health Organization (WHO). (1999). *Ageing exploding the myths*. Retrieved March 6, 2020, from https://www.who.int/ageing/publications/exploding_myths/en/

World Health Organization (WHO). (2015a). *Disabilities*. Retrieved May 13, 2020, from http://www.who.int/topics/disabilities/en/

World Health Organization (WHO). (2015b). *Summary world report on ageing and health*. Retrieved May 13, 2020, from https://apps.who.int/iris/bitstream/10665/186463/1/9789240694811_eng.pdf

WHOQOL [The World Health Organization Quality of Life Assessment] Group. (1995). The World Health Organization Quality of Life Assessment (WHOQOL): Position paper from the World Health Organization. *Social Science Medicine, 41*(10), 1403-1409.

Appendix A Vignettes

Vignette 1 Female

Mrs. Eva Wallace, age 72 lives by herself at home and her husband is deceased. Eva has three children who are married with families of their own and they all live at least one hour away or more. One year ago, Eva found she struggled with keeping up the garden and had difficulties with larger tasks indoors such as hoovering and changing her bed sheets. She was able to hire a gardener who took care of gardening and he also did handyman jobs as needed. Eva also hired a cleaner to come in and help her with her laundry and clean the floors in her home. Lately, Eva has been having difficulties with getting in and out of her shower and also her bed. She also forgets to take her medication and finds medication left over in her pill box that she should have taken the day before. Eva does not want to be a burden and ask her children for assistance, yet she wants to remain in her home for as long as possible.

Vignette 2 Male

Mr. Alistair McDonald, age 83 is a bachelor who lives alone and resides in his house in the country. His sister, Claire is in good health and is ten years younger than him. Claire is in contact with Alistair several times per week. Alistair's sight and hearing have been declining. After a second car accident within a one year period his GP recommended Alistair should no longer drive and after much debate-Alistair agreed. Claire helps Alistair look after his finances and takes him out twice a week to do his shopping and have lunch. Alistair had his third fall and recently broke his right shoulder as a result. He finds he is often dizzy since the last car accident and refuses to use a walking stick or a zimmer as he says he does not need them. Claire has also discovered that Alistair has been missing meals and has had to change his clothes a few times before leaving to go shopping as he did not make it to the toilet in time. Claire knows it is important to Alistair to stay in his home for as long as possible, but he will not accept help from anyone except her.

Vignette 3 Female

Mrs. Fiona Campbell, age 85 has lived in a care home in her local community for one year. Her husband, Callum died ten years ago and she has one daughter, Kirsty who lives about 25 minutes away from the care home. Fiona had several options when she decided to move out of her own home and into a care home. She could have moved in with Kirsty and her family but she decided she wanted to remain as independent as possible. She made the decision to move to the care home as she felt the care home offered her more options to remain independent and she wanted to stay active in her local community. She takes the care home bus at least once per week on scheduled outings.

Vignettes Used (one of 1-3)

- Vignette 1 Vignette 2 or Vignette 3

Lead in prompts

- Reactions?
- What are some options going forward?
- Recognize
- Surprise
- Similar
- Different

Appendix B Ethical Approval

UNIVERSITY OF
STIRLING

SCHOOL OF
APPLIED SOCIAL SCIENCE

Colin Bell Building
University of Stirling
Stirling FK9 4LA
Scotland UK

T: +44 (0) 1786 467719 or 473171
F: +44 (0) 1786 466299
E: SASSPGOffice@stir.ac.uk

MM/SW

6 December 2012

To: Kari Velzke

Dear Kari

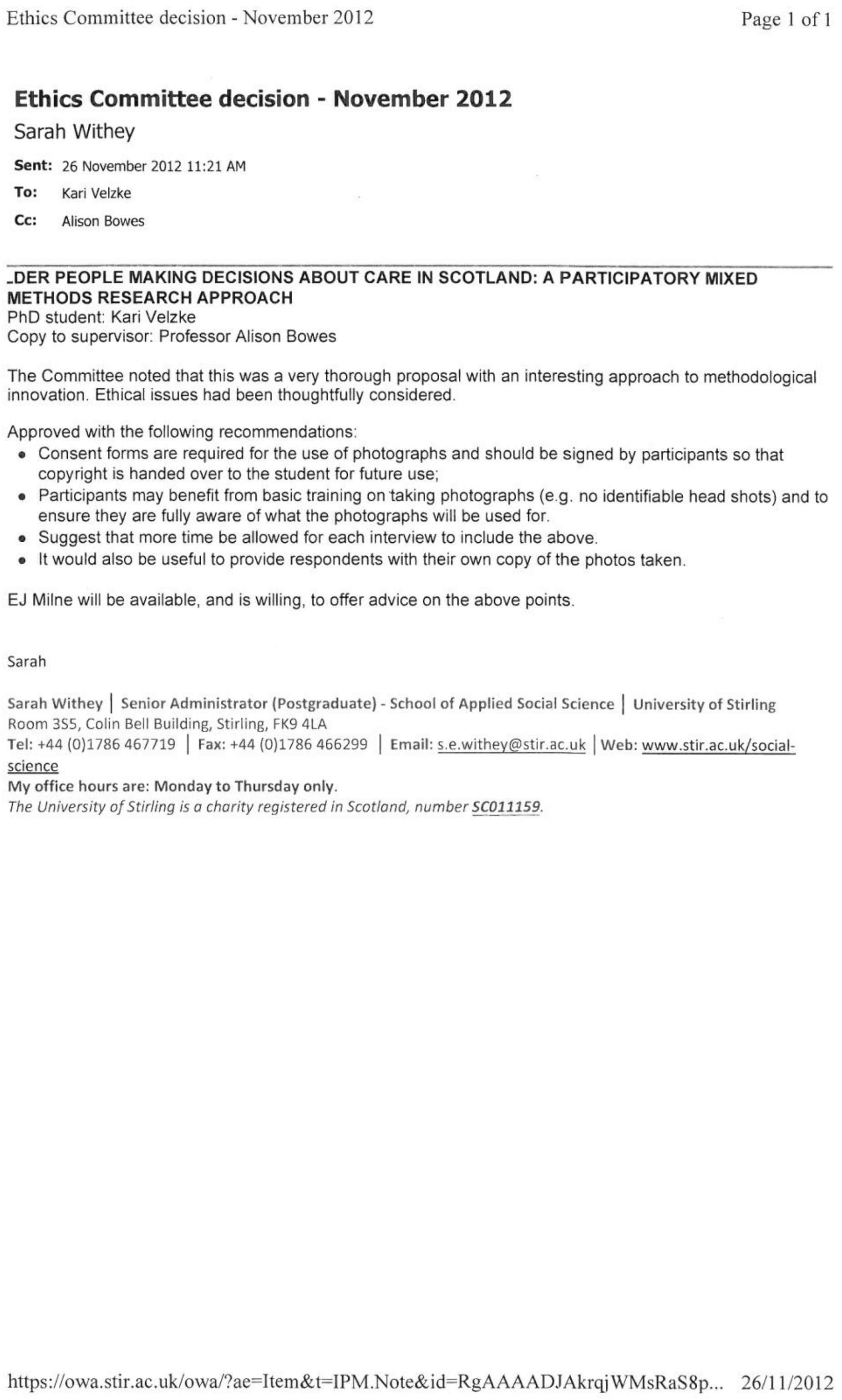
OLDER PEOPLE MAKING DECISIONS ABOUT CARE IN SCOTLAND: A PARTICIPATORY MIXED METHODS RESEARCH APPROACH

Thank you for your application to the School of Applied Social Science Ethics Committee for ethical scrutiny of your project. I am pleased to confirm that ethical approval has been granted with minor recommendations.

Yours sincerely

Sarah Withey

pp. Margaret Malloch
Chair, Ethics Committee



Ethics Committee decision - November 2012 Page 1 of 1

Ethics Committee decision - November 2012

Sarah Withey

Sent: 26 November 2012 11:21 AM
To: Kari Velzke
Cc: Alison Bowes

-DER PEOPLE MAKING DECISIONS ABOUT CARE IN SCOTLAND: A PARTICIPATORY MIXED METHODS RESEARCH APPROACH
PhD student: Kari Velzke
Copy to supervisor: Professor Alison Bowes

The Committee noted that this was a very thorough proposal with an interesting approach to methodological innovation. Ethical issues had been thoughtfully considered.

Approved with the following recommendations:

- Consent forms are required for the use of photographs and should be signed by participants so that copyright is handed over to the student for future use;
- Participants may benefit from basic training on taking photographs (e.g. no identifiable head shots) and to ensure they are fully aware of what the photographs will be used for.
- Suggest that more time be allowed for each interview to include the above.
- It would also be useful to provide respondents with their own copy of the photos taken.

EJ Milne will be available, and is willing, to offer advice on the above points.

Sarah

Sarah Withey | Senior Administrator (Postgraduate) - School of Applied Social Science | University of Stirling
Room 3S5, Colin Bell Building, Stirling, FK9 4LA
Tel: +44 (0)1786 467719 | **Fax:** +44 (0)1786 466299 | **Email:** s.e.withey@stir.ac.uk | **Web:** www.stir.ac.uk/social-science
My office hours are: Monday to Thursday only.
The University of Stirling is a charity registered in Scotland, number SC011159.

https://owa.stir.ac.uk/owa/?ae=Item&t=IPM.Note&id=RgAAAADJAkrqjWMsRaS8p... 26/11/2012

Appendix C Focus Group Agenda and Timeline Activity

Agenda-Focus Group with older people

10 am -Noon (2 hours)

Time	**Activity**
10:00-10:30	Coffee/Tea/Pastry Greetings, intro, informed consent
10:30-10:40	Overview of research project
10:40-10:50	Introduction to vignette's and you tube clip –story on care
10:50-10:55	Explain focus group task/directions of completing a timeline
10:55-11:00	Organise into groups of 2, hand-out timeline activity
11:00-11:10	Discussion of what types of things may be included on timeline
11:10-11:35	Work time-mingle with all groups; 'comfort' breaks as needed
11:35-11:50	Share results and group discussion of activity and findings
11:50-12:00	Review next step for follow up focus group in 6-12 months, thanks!

Timeline Activity

Your Name ________________________________ Date of Birth _________ Phone Number ___________

Person/People you are or were involved with care decisions (and your relationship to that person)

Please tell me about how the process of needing all help and when care started (using resources, formal care (F) paid and informal care (U) unpaid care) and how this progressed. Please detail how people recognised they needed help who they talked to, when they accepted help, and they type of help received.

How It Started	**Progress to Daily Care**	**Full Time 24/7 Care**
Example: hired a Gardner (F)		

How It Started	**Progress to Daily Care**	**Full Time 24/7 Care**

Other thoughts and observations:

Appendix D Older Participants Interview Schedule/Topic Guide

Topics	**Prompts**
QoL Decision-Making Processes	▪ **wishes in how you live your life; assistive devices or assistive technology**
Social Desirability Comparisons	▪ define QoL, what affects it, how affects decisions, relationships, top 3 affect QoL explain ▪ physical domain, psychological domain, level of independence, social relationships, environment, spirituality, religion, and personal beliefs
Day to Day Life	▪ have things changed/stayed same; how cope in difficulties; things enjoy, happiness, what keeps you going; how decide how spend time; **provide care for others**
Participation in groups	▪ feel part of any communities or groups, active citizen ▪ daily, weekly, monthly, social groups, volunteer, church
Care	▪ how know about available services; know which are free or have fees, how pay for care ▪ **goals, why/how pick services you have, different from interested in, have care want/need** ▪ **what choices offered, who informed of options, feel carers consider your wishes** ▪ what is important-in care and receiving care, relationships, **rank** ▪ **how/why decide services need- pay or not; how fulfil care and support, formal and informal care; roles family/spouse/friend/medical** ▪ has anyone said if get help family or friend limit other services ▪ expectations of care, assessment process; where prefer to receive care, tx need care, ▪ **do you use all services qualify for, feel need more and not qualify;** frustrations, constraints, restrictions with care; opportunities involvement in choice and decisions
Ageing Issues and perspective on complaints	▪ **what do when things not quite right or go wrong**/tell someone-who ▪ treated differently due to age, or need care; ageism, apocalyptic demography ▪ active ageing, person-centred care, self-directed care
Active Participant	▪ **how engaged in care decisions, actively involved** ▪ **what happens if your wishes differ from family, caregivers**
Decision-Making and **consent**	▪ **what is this research about/consent to,** ▪ **anyone help make care decisions, who/how, your wishes considered** ▪ **legally able to make all decisions, people need to help or do help** ▪ **how prefer care decision made, by whom; more or less control in decision-making**
Scotland	▪ **how older people viewed in Scotland**, your thoughts on Scotland's policy older people, public support programmes older people, ▪ **role of government programmes/policies in your care; systems consider your needs or rights** ▪ **do policy and services give you choice, independence, dignity, how/why**;

Appendix E Professional Participants Interview Schedule/Topic Guide

Topics	**Prompts**
Scottish Policy	▪ role of policy and programmes affect older people-choice, constraints, limits; informal care affect services; health and safety impacts; policy change in last 5 years 10 years, ▪ **Scotland's agenda with older people,** active aging, apocalyptic demography, ageism, constraints and facilitators for choice, examples of policy and programmes you see and fit with clients ▪ how Scotland compares to other countries-opportunities involvement in choice and decisions
Models of Care and Practice	▪ current models of care, practice; your agencies; see this changing; Scottish government role, support choice and decision-making older people; differences in agency models to other agencies ▪ role of older people in care decisions , family, spouse, caregiver; offering information, consent ▪ opportunities for active and contributing citizens; older people and passive, dependent, offered choice, person-centred (formal and informal care), how self-directed care used ▪ how Scotland compares to other countries- opportunities involvement in choice and decisions
Choice and Control	▪ view of client choice in agency, control, legislation to support policy in practice ▪ specific situations clients not offered choice, legal or other cognitive considerations, ▪ who helps clients make decisions if needed, how determined; role of carers, family, spouse, agency ▪ how older people request information, more choice, more control, sense of community, identity, make complaints
Caregiver Behaviours	▪ caregiver behaviors and policy, how know if older people unhappy if cannot will not report, check with family close friends, what if alone in world ▪ others people besides carers offering choice-who/how ▪ guidelines to safeguard older people; situations choice not offered
Restrictions	▪ risk assessments, person-centred support and care, person-centred care in practice, different than policy, themes in person-centred practice ▪ person-centred care and end of life, higher dependence and effects on independence, citizenship, autonomy
Findings from Older People	▪ how deal with people who refuse services "stubborn" ▪ describe the typical client you may come into contact with ▪ how much does assistive technology or assistive devices influence what you see

Appendix F Reconvened Focus Group Interview Schedule/ Topic Guide

Discussion Questions

1. Relationships were a key theme and most people who lived at home had help navigating systems and with informal care. Most people also reported they used shared decision-making. What do you think about older people using shared decision-making? Prompts: support networks, church and volunteer clubs, volunteer time (people with no one were more likely to be in a care home).

2. What do you think about situations when what the individual wanted was different to what the family or carer wanted?

3. Most of the time people adapted when they were no longer able to do routine things and used assistive devices, technology and assistance with informal and formal care to remain in the place of their choice. There were quite a few times were people were described as stubborn and refused to used Zimmer's or refused help with personal care or other services. There is an interesting debate about the health and safety and the legal right of people to make bad decision if they retain legal capacity to make decisions for themselves. Thoughts on that? Prompt about stigma of using services, use of technology and devices, idolizing GP's, stuck in hospital during the guardianship processes.

4. Quality of life varied for most people and some people that I would say had low QoL reported they had high QoL. People were generally happy if living at home even if housebound but seemed lonely for social activity. What do you think about changing quality of life as people get older, frailer and less able to do everyday activities and go out in the community? Prompt: Most people were regretful or upset about the things they could no longer do if they had mobility issues or could not go out and about and continue activities they previously enjoyed. Most everyone mentioned watching a lot of television and looked forward to having carers come in to visit with.

5. Have you heard of [Town Name] becoming a Dementia Friendly City?

6. Have you heard of the [Town Name] Care Village?

Main Themes for Older People

1. Care	• Relationships, Support Networks, Transportation • What is good care, How people perceive themselves in other viewpoints
2. How People Make Decisions	• Shared decision-making, Where people want to reside (fear of care homes), Options/choices in formal and informal care-find out about services • Independence-things no longer able to do, help when it goes wrong, GP and other professionals, Burden, complain and differences in what individual and family wants
3. Quality of Life	• Assistive devices and technology, Tasks able to do independently • Typical day and activities, things people enjoy, Community groups and activities, social isolation • Made to feel you matter, Hospital visits, Caregiving to others

1. Relationships were a key theme and most people who lived at home had help navigating systems and with informal care. Most people also reported they used shared decision-making. What do you think about older people using shared decision-making? Prompts: support networks, church and volunteer clubs, volunteer time (people with no one were more likely to be in a care home).