



Provided by the author(s) and University of Galway in accordance with publisher policies. Please cite the published version when available.

Title	Exploring the potential of social robots to support resilience in dementia
Author(s)	Whelan, Sally
Publication Date	2020-11-30
Publisher	NUI Galway
Item record	<a href="http://hdl.handle.net/10379/16578">http://hdl.handle.net/10379/16578</a>

Downloaded 2024-04-27T17:48:33Z

Some rights reserved. For more information, please see the item record link above.





**Title: Exploring the potential of social robots to support resilience in dementia.**

**Ph.D. Thesis by Publication**

**Candidate:** Sally Whelan MA; BA (Hons); RGN.

**Student Number:** 12230697

A thesis submitted to the College of Medicine, Nursing and Health Sciences, National University of Ireland Galway, in partial fulfilment of the requirements for the degree of Doctor of Philosophy in Nursing.

**Month of Submission:** November 2020

**Research Supervisor:** Professor Dympna Casey

**Graduate Research Committee**

Professor Declan Devane, Dr. Linda Beisty, Dr. Fionnuala Jordan

## Contents

Declaration .....	v
Abstract .....	vi
Introduction .....	vi
Methods .....	vi
Findings .....	vi
Conclusion .....	vii
Contribution to Knowledge .....	vii
List of Publications in this Thesis .....	vii
. Publications and Research Outputs related to the work of this Thesis. ....	x
Dedication .....	xii
Acknowledgments .....	xii
Funding .....	xii
Structure of the Dissertation .....	xii
List of Tables .....	xiii
List of Figures .....	xiii
List of Abbreviations .....	xiv
Chapter One. Background .....	1
1.1 Introduction .....	1
1.2.1. What are Social Robots? .....	2
1.3.1. Strength-based approaches to Care .....	6
1.4 Summary of key points in Chapter One. ....	8
1.5 Aim and Objectives of this Thesis .....	9
1.6. Chapter One. References .....	9
Chapter Two. Paper One .....	13
2.0. Prologue .....	13
2.1. Paper One: .....	13
2.1.1. Abstract .....	13
2.1.2. Introduction .....	13
2.1.3. Literature Search Methodology .....	14
2.1.4. Literature Review Results .....	14
2.1.5. Discussion and Future Research Directions .....	26
2.1.6. Conclusion .....	28
2.1.7. References .....	42
2.2. Chapter Two. Summary and Segue. ....	45

Chapter Three. Paper Two.....	47
3.0 Prologue.....	47
3.1 Paper Two.....	47
3.1.1. Abstract:.....	47
3.1.2. Introduction.....	48
3.1.3. Methods.....	49
3.1.4. Review Findings.....	50
3.1.5. Discussion.....	63
3.1.5.1. Implications for Future Research.....	66
3.1.5.2 Limitations.....	67
3.1.6. Summary.....	67
3.1.7. References.....	67
3. 2. Chapter Three. Summary and Segue.....	71
Chapter Four. Paper Three. Methodology.....	73
4.0 Prologue.....	73
4.1 Paper Three.....	73
4.1.1. Abstract.....	73
4.1.2. Introduction.....	73
4.1.3. Description of DESCARTE.....	74
4.1.4. Application of DESCARTE.....	74
4.1.5. Critical Appraisal of DESCARTE.....	80
4.1.6. Recommended Development to DESCARTE.....	81
4.1.7. Conclusion.....	81
4.1.8. References.....	82
4.2. Chapter Four. Summary and Segue.....	84
Chapter Five. Paper Four. Findings.....	85
5.0 Prologue.....	85
5.1. Paper Four.....	85
5.5.1. Abstract.....	85
5.1.2. Introduction.....	86
5.1.4. Findings.....	93
3.1. Theme: Resilience changes minute to minute.....	93
3.2. Theme: Initiating and Maintaining Readiness.....	95
3.3. Theme: Active Co-Creation of Meaningful Activity.....	96
3.4. Theme: Impact on Resilience.....	98
5.1.5. Discussion.....	100

5.1.6. Conclusion .....	103
5.1.7.References .....	103
5.2. Chapter Five. Summary and Segue .....	106
Chapter Six. Discussion .....	108
6.0 Introduction .....	108
6.1. Thesis scope and key findings .....	108
6.2. Discussion of Key Issues. ....	110
6.3. Implications for future research .....	114
6.5 Social robots in the context of COVID 19.....	115
6.6. Thesis Strengths .....	116
6.7. Thesis Limitations.....	117
6.8. Thesis Conclusion .....	117
6.9. Chapter Six. References .....	117
Appendix 1) Paper One: Search Strategy.....	122
Appendix 2) Paper One: Inclusion and Exclusion Criteria .....	123
Appendix 3) Paper One: PRISMA Flow Diagram. ....	124
Appendix 4) Paper Two: Quality Appraisal of Studies included in the review.....	125
Appendix 5) Paper Four: Copy of the letter granting ethical approval for the empirical study as part of the wider MARIO project. ....	141
Appendix 6) Paper Four: Ethical Distress Protocol .....	142
Appendix 7) Paper Four: Participant Information Sheets, Invitations to Participate and Consent Forms People with Dementia. ....	143
Appendix 8) Paper Four: Information Sheet and Consent Form for Formal Caregivers..	147
Appendix 9) Paper Four: Invitation Letter, Information Sheet and Consent Form for Relatives of People with Dementia.....	150
Appendix 10) Paper Four: Interview Guides for People with Dementia Pre and Post MARIO .....	157
Appendix 11) Paper Four: Interview Guide for Relatives of People with Dementia .....	162
Appendix 12) Paper Four: Interview Guide for Caregivers .....	164
Appendix 13) Paper Four: Example of Raw Quantitative Data obtained using Dementia Care Mapping.....	167
Appendix 14) Paper Four: Examples of Initial Coding of Data in NVIVO 12.....	168
Appendix 15) Paper Four: Example of Codes being Defined and the Hierarchical Structure of codes being developed.....	169
Appendix 16) Paper Four: The Coding Framework with associated files and references after coding data from all the cases.....	170
Appendix 17) Paper Four: Example of how the Data within each Case was Summarised in NVIVO.....	179

Appendix 18) Paper Four: An excerpt from the Matrix with summarised within case data. .....	180
Appendix 19) Paper Four: Example of a Memo written in NVIVO summarising all data from all cases, linked to the code Willingness and Intention to use MARIO. ....	181
Appendix 20) Paper Four: Example of an Analytical Memo .....	182
Appendix 21) Paper Four: Table showing the Coding Framework categories and the Final Themes.....	187
Appendix 22) Paper Four: Member checking of draft findings report – Caregiver participant.....	188
Appendix 23) Paper Four: Member checking of draft findings report - Relative participant .....	190
Appendix 24) Permission to Reproduce Published Material in this Thesis.....	191

## Declaration

I, Sally Whelan, certify that I have not obtained a degree in the National University of Ireland Galway, or elsewhere based on the work contained in this thesis. I am the author of this thesis and the principal author of the four included papers. The contributions of others to these papers are included under 'Contributions to research'.

Signature:



Date: 8<sup>th</sup> February 2021

## Abstract

### Introduction

Dementia is a debilitating progressive neurological syndrome that causes stress to people with the condition and their families. Most people with dementia want to be independent and with support, many people with dementia can maintain a level of independence. Robotics devices are being developed to support the independence of people with dementia but currently, there is limited empirical evidence concerning how they should be developed and deployed. There has also been little attempt to date to underpin the research into robotic technologies for people with dementia with substantive theory. Resilience is a substantive theory and a strength-based approach to dementia care. This approach focuses on a person with dementia's existing abilities and it employs person-centred strategies that empower and support a person's sense of personal identity. This doctoral thesis aims to explore the potential of social robots to support the resilience of people with dementia. In doing so, it applies the theory of resilience to the study of social robots for the first time.

### Methods

This thesis contains four papers. The first two papers report literature reviews that identify the current evidence base. The first review was conducted to determine what robots need to be like, in terms of their form and function, for people with dementia to find them acceptable and to engage with them. This review focused on identifying the key factors that impact the acceptability of social robots in the context of dementia. Then a second literature review was undertaken to determine how social robots could potentially be used to support the resilience of people with dementia. This review focused on identifying the content, structure, and effectiveness of psychosocial interventions that have aimed to support the resilience of people with dementia. The review also aimed to identify how the concept of resilience had been defined and operationalised in previous research. The literature reviews revealed that an empirical study was needed to provide an in-depth examination of a social robot within the real-world context of a dementia care setting. It was also important that the robot facilitated a person-centred approach and that the investigation captured the perceptions and experiences of people with dementia. Case study methodology was chosen for the empirical study and the third paper included in the thesis reports a critical appraisal of the DESCARTE model (DESIGN of CASE Research in healThcarE). This appraisal was conducted to determine the model's suitability to guide case study investigations that involve social robots for resilience in dementia care settings. The fourth paper reports a multiple case study that was designed using the DESCARTE model. This study examined the effect of the social robot MARIO on the resilience of people with dementia (n=10) in a residential care setting.

### Findings

The first literature review (paper one), which included forty-four studies, found that multiple factors impact the acceptability of social robots for people with dementia. Acceptance can be increased through robots using human-like communication and if they are personalised in response to the needs of individual users. However, many studies had been conducted in a laboratory rather than in real-world settings. The exploration of the literature on psychosocial interventions for resilience (paper two) included three studies that had investigated five interventions that aimed to support resilience in dementia. This review revealed that the interventions supported people with dementia by enabling reciprocal social interactions and meaningful activities, but that further interventions were needed to support people with dementia who lack family caregivers and/or have more advanced dementia. The review also identified that resilience had been defined as a process of adapting to stress that operates at multiple interacting levels of the individual, community, and society. The critical appraisal of the DESCARTE model (paper three) found that the model could usefully guide



the design and conduct of the MARIO case study investigation. DESCARTE provided a useful framework to enhance the quality of case study research by requiring the researcher to focus on philosophical cohesiveness, ethical considerations, reflexivity, and data analysis. However, recommendations were made to improve DESCARTE's utility by adding a task list and providing researchers with additional guiding questions. The empirical study (paper four) found that MARIO could provide an embodied presence and personalised stimulus that engaged people with dementia, with the support of a facilitator. Whilst using MARIO, eight out of ten people with dementia were empowered to co-create meaningful activity. This supported resilience by increasing their positive sense of self-identity because, whilst people with dementia were engaged with MARIO, they were 'doing okay' despite the limitations of living with dementia.

### Conclusion

Based on the literature and the empirical study, this body of work reveals that social robots have the potential to support the resilience of people with dementia. To support resilience robots need to facilitate people with dementia to maintain a positive sense of self-identity, through enhancing their ability to co-create meaningful activity and reciprocal social relationships. However, future social robots need to have a greater technical capacity to react to human emotions and communicate in a more human-like way, if they are to support the resilience of people with dementia, independent of human facilitators. These conclusions are based on a relatively small body of existing literature and an empirical study that used a small sample size and investigated only one residential care setting. Nevertheless, this thesis is underpinned by recognised theories of technology acceptance and resilience, and it is derived from comprehensive literature reviews and an empirical study that used robust methodology and provided an in-depth inquiry in a real-world clinical context.

### Contribution to Knowledge

This thesis contributes significantly to knowledge through identifying key factors that impact the usage and effect of social robots on resilience and by illustrating how case study methodology can be used to investigate social robots to support resilience. Through focusing on resilience, this body of research contributes to the state of the art by identifying how the principles of strength-based care can guide the development of social robots and their usage by people with dementia. The thesis addresses a gap in the literature by applying the theory of resilience to the study of social robots for the first time. In doing so, the thesis provides the rapidly expanding field of social robotics, with valuable knowledge that is relevant to current dominant discourses in gerontology and dementia. This knowledge can inform and guide the engineering developers of social robots, care providers, managers, educators, and policymakers on how social robots can be used to enhance the wellbeing of people with dementia. In particular, it contributes to knowledge by using a person-centred approach that ensures the voices and the needs of people with dementia impacts the future deployment of social robots.

### List of Publications in this Thesis

Three of the four papers have been published and one paper has been accepted for publication, in peer reviewed international journals.

#### Paper One.

The first paper is a literature review.

Citation: Whelan, S., Murphy, K., Barrett, E., Krusche, C., Santorelli, A. & Casey, D. (2018). Factors affecting the acceptability of social robots by older adults including people with dementia or cognitive impairment: a literature review. *International Journal of Social Robotics*, 10(5), pp.643-668.

Impact Factor of the International Journal of Social Robotics 3.168 (2019 Five year impact).  
Number of article citations to date: Twenty Five (Google Scholar accessed 27<sup>th</sup> October 2020.)

#### Author Contributions

The study was conceived and planned by SW in conjunction with DC and KM. An initial literature search was conducted by a librarian. The literature search strategy was updated and revised by SW. SW conducted the search, screened the literature for eligibility, conducted the data extraction, and interpreted the literature. SW wrote the manuscript and EB, CK, AS, DC critically reviewed the drafts and final paper. SW led the authors responses to the reviewer's feedback, collated the response and redrafted the final manuscript, which was approved by EB, CK, AS and DC.

#### **Paper Two.**

The second paper is a narrative literature review.

Citation: Whelan, S., Teahan, Á., & Casey, D. (2020). Fostering the Resilience of People with Dementia: A Narrative Literature Review. *Frontiers in Medicine*, 7, 45.

Impact Factor of *Frontiers in Medicine* 3.421 (2019).

This article has not to date been cited, but it has (8<sup>th</sup> February 2021) achieved over 2,559 views <https://www.frontiersin.org/articles/10.3389/fmed.2020.00045/full>. It has also been recommended by Charlotte Stoner, an expert in resilience in dementia [http://www.researchgate.net/profile/Sally\\_Whelan](http://www.researchgate.net/profile/Sally_Whelan).

#### Author Contributions

SW conceived, planned, and conducted all aspects of the review including writing the manuscript, leading, and collating the author responses to the reviewers' feedback and redrafting the manuscript for publication. ÁT conducted critical appraisal of the included papers, reviewed the drafts, and the final paper. DC provided guidance, critically reviewed drafts, and the final paper.

#### **Paper Three.**

The third paper is a methodology paper.

Citation: Whelan, S., & Casey, S. (Accepted for Publication) 'Applying the DESCARTE model: an example of case study research practice. *Research in Gerontological Nursing*.

Impact Factor of *Research in Gerontological Nursing* 1.140 (2019-2020).

#### Author Contributions

SW conceived, planned, and conducted all aspects of this research, including writing the manuscript, leading, and collating the author's responses to the reviewers' feedback, and redrafted the manuscript. DC provided guidance and critically reviewed drafts and the final paper.

#### **Paper Four.**

The fourth paper is an empirical study.

Citation: Whelan, S., Burke, M., Barrett, E., Mannion, A., Kovacic, T., Santorelli, T., Luz Oliveira, B., Gannon, L., Shiel, E., & Casey, D. (2020). The effects of MARIO, a social robot, on the resilience of people with dementia: A multiple case study. *Gerontechnology*, 20(0), 1-16.

Impact Factor of *Gerontechnology Journal* 0.7.

This article has not yet been cited.

### Author Contributions

SW was the Ph.D. student on the EU funded MARIO research project ([www.mario-project.eu](http://www.mario-project.eu)) and a member of the team of researchers and engineers that designed, developed, and tested the social robot, MARIO. MARIO was designed to increase the social connectedness and psychological wellbeing of people with dementia, using a user-led approach that involved people with dementia and caregivers. A picture of MARIO being used by a person with dementia is provided below in Figure 1.2 of this thesis.

As part of the wider MARIO project team SW conceived, planned, designed, and conducted all aspects of the empirical study presented in paper four. This included liaising with engineers and advising them about the requirements and needs of people with dementia during the iterative phases of the software development for the social robot MARIO's applications (these applications are described in Table 5.1 on page 88). SW also conducted trials alongside the engineers to test the software to obtain feedback on the robot's developments from people with dementia and their caregivers. In addition, throughout this research SW orientated the research assistants who participated in the research and trained them regarding communication with people with dementia. SW also liaised with the caregivers and managers at the research site, contributed to writing the participant information sheets, selected the dementia care mapping and resilience data collection tools, pilot-tested all the data collection tools, designed the interview guides, conducted the participant recruitment, administered the data collection tools, and analysed the data. SW wrote the manuscript and led the author's responses to the reviewers' feedback, collated the responses, and redrafted the manuscript. DC was the principle investigator on the MARIO project and provided guidance throughout the research, critically reviewed the drafts and the final paper. MG contributed to data collection. AS and BO provided technical support with the robot and contributed to data collection. LG and ES were relative and caregiver participants in the research who contributed data and critically reviewed the findings and the manuscript. EB and TK provided managerial and administrative support to the study and critically reviewed the drafts and final paper.

## Publications and Research Outputs related to the work of this Thesis.

### Oral Presentations and Conference Papers

- Whelan, S. & Casey, D. (2020) Fostering the Resilience of People with Dementia with Psychosocial Interventions. Engaging Dementia 12<sup>th</sup> Virtual International Dementia Conference, Transforming Care and Communities, Zoom Webinar hosted in Dublin, Ireland, 2<sup>nd</sup> November, 2020.
- Whelan, S., & Casey, D. (2019) Evaluating the impact of the Social Robot MARIO on the resilience of people living with dementia in residential care. Technology and Ageing Special Interest Group Symposium; Technology, resilience, and ageing; critical perspectives British Society of Gerontology Conference, Liverpool, UK, 10<sup>th</sup>-12<sup>th</sup> July 2019.
- Whelan, S., Murphy, K., Barrett, E., Krusche, C., Santorelli, A., & Casey, D. (2017) Factors affecting the acceptability of Social Robots by Older Adults, People with Dementia and Older Adults with Cognitive Impairment: A Literature Review. 9<sup>th</sup> International Dementia Conference, Dublin, Ireland, 15<sup>th</sup> May 2017.
- Whelan, S., Kouroupetroglou, C., Raciti, M., Barrett, E., Santorelli, A., & Casey, D. (2017) Investigating the effect of social robot embodiment. Advancement of Assistive Technology in Europe (AAATE) Conference, Sheffield, UK, 8<sup>th</sup> October 2017.

### Poster Presentations

- Whelan, S., and Casey, D. (2019) Resilience in the Context of Dementia: A literature Review. (Poster) 12<sup>th</sup> International Dementia Conference, Dublin, 1st April 2019.
- Whelan, S., Kovacic, T., Burke, M., & Casey, D. (2018) Exploring the Perceptions of Resilience in Nursing Home Residents. (Poster) 10<sup>th</sup> International Dementia Conference, Dublin, 16<sup>th</sup> April 2018.
- Whelan, S., Barrett, E & Casey D. (2018) Using Dementia Care Mapping to Evaluate the Impact of MARIO, a Social Robot. (Poster) 11<sup>th</sup> Annual Conference Irish Research Nurses Network, Dublin, 7<sup>th</sup> -8<sup>th</sup> November.

MARIO project Publications and Research Outputs related to the Thesis  
The Ph.D. candidate co-authored the following publications:

#### Journal Articles

- Mannion, A., Summerville, S., Barrett, E., Burke, M., Santorelli, A., Kruschke, C., ... & Whelan, S. (2019). Introducing the Social Robot MARIO to People Living with Dementia in Long Term Residential Care: Reflections. *International Journal of Social Robotics*, 1-13.
- Barrett, E., Burke, M., Whelan, S., Santorelli, A., Oliveira, B. L., Cavallo, F., ... & Mountain, G. (2019). Evaluation of a Companion Robot for Individuals with Dementia: Quantitative Findings of the MARIO Project in an Irish Residential Care Setting. *Journal of Gerontological Nursing*, 45(7), 36-45.
- D'Onofrio, G., Sancarolo, D., Raciti, M., Burke, M., Teare, A., Kovacic, T., ... & Dolan, A. (2019). MARIO Project: Validation and Evidence of Service Robots for Older People with Dementia. *Journal of Alzheimer's Disease*, 1-15.
- Casey, D., Barrett, E., Murphy, K., Adamantios K., Daniele S., R., Santorelli, A., Kovaic, T., Gallagher, N., & Whelan, S. (2020). The perceptions of people with dementia and key stakeholders regarding the use and impact of the social robot MARIO. *International Journal of Environmental Research and Public Health*. 17, 8621, 1-19.

#### Oral Presentations and Conference Papers

- Casey, D., Felzmann, H., Pegman, G., Kouroupetroglou, C., Murphy, K., Koumpis, A., & Whelan, S. (2016, July). What people with dementia want: designing MARIO an acceptable robot companion. In *International Conference on Computers Helping People with Special Needs* (pp. 318-325). Springer, Cham.
- Kouroupetroglou, C; Casey, D; Raciti, M; Barrett, E; D'Onofrio, G; Ricciardi, F; Giuliani, F; Greco, A; Sancarolo, D; Mannion, A; Whelan, S.; Pegman, G; Koumpis, A; Reforgiato Recupero, D; Kouroupetroglou, A. & Santorelli, A. (2017) 'Interacting with Dementia: The MARIO Approach'. *Studies In Health Technology And Informatics*, 242: Harnessing the Power of Technology to Improve Lives. Advancement of Assistive Technology in Europe (AAATE) Conference, Sheffield, UK; 8<sup>th</sup> October 2017.

#### Poster Conference Presentations

- Mannion, A., Whelan, S., Burke, M., Barrett, E., Santorelli, A., & Casey, D. (2018) Introducing MARIO, a social robot to people living with dementia in long term residential care: Reflections. (Poster) 10<sup>th</sup> International Dementia Conference, Dublin, 16<sup>th</sup> April 2018.
- Casey, D., Whelan, S., Barrett, E., Murphy, K., Santorelli, A., Burke, M., & Kovacic, K. (2018) The impact of a companion robot in combatting loneliness in people living with dementia in residential care: The MARIO Project. (Poster) 66<sup>th</sup> Annual scientific meeting Irish Gerontology Society, Cavan, 27<sup>th</sup>-29<sup>th</sup> September.
- Kovacic, T., Felzmann, H., Mannion, A., Summerville, S., Barrett, E., Burke, M., Santorelli, A., Whelan, S., Murphy, K., & Casey, D. (2018) Value sensitive design: Evaluating the usefulness of the MARIO ethical framework. (Poster) 10<sup>th</sup> International Dementia Conference, Dublin 16<sup>th</sup> April 2018.
- Burke, M., Whelan, S., Kovacic, T., Santorelli, A., Oliveira, B., & Casey, D. (2018) Evaluating the impact of MARIO on people with Dementia in a nursing home setting. (Poster) 10<sup>th</sup> International Dementia Conference, Dublin 16<sup>th</sup> April 2018.

## **Dedication**

To my parents, Alice, and Ron Whelan.

Alice is a lifelong advocate for education. She has enhanced the lives of generations of children, by going above and beyond to ensure that every child had the opportunity to participate. Not afraid to break the rules, Alice has dodged real gunfire and survived life's metaphorical bullets.

Ron Whelan (b. 1930 d. 1989) is a sorely missed ardent supporter and provider for his family. Ron was a humanist and a social soul who had a great memory. A competitive bridge player, athlete, an expert mime artist, and a singer of humorous songs.

## **Acknowledgments**

- I would like to thank the people living with dementia, their relatives, and caregivers who gave their time, humanity, and humour in contributing to this research. You have taught me about dementia, life, and resilience.
- A huge thank you to Professor Dympna Casey for giving me immeasurable support throughout my Ph.D. Thank you for your expertise, patience, and thoughtful feedback.
- Thank you to Professor Declan Devane, Dr. Linda Biesty, and Dr. Fionnula Jordan for their guidance during my general research council annual meetings.
- I would also like to thank the College of Medicine, Nursing and Health Sciences, National University of Ireland, for providing me with four years of scholarship funding. It is a necessity and privilege to receive funding for a postgraduate degree.
- I am also indebted to my colleagues on the MARIO project team: Eva Barratt, Megan Burke, Tanya Kovacic, Arlene Mannion, Barbara Luz Oliveira, and Adam Santorelli. It has been a pleasure and an honour to work with you.
- To my extended family, especially Brendan, Siobhan, and Joe, I could not have completed this work without you.
- Thank you to my friends at the Galway Ukers, Sonke Choir, and the Galway Jam Circle for sustaining me with music and craic.

## **Funding**

The wider MARIO project was funded through the European Union Horizons 2020—the Framework Programme for Research and Innovation (2014–2020) under Grant Agreement 643808 Project MARIO ‘Managing active and healthy aging with use of caring service robots’. The work presented in this thesis was also supported through a four year competitive scholarship grant awarded by the College of Medicine, Nursing and Health Sciences, National University of Ireland Galway.

## **Structure of the Dissertation**

There are six chapters in this dissertation. Chapter one provides background information and introduces the thesis. Chapters two-five contain the papers in which the research is presented. Chapters two-five also contain a prologue and segue, in which the individual papers are introduced, and relevant additional research is discussed. The central thesis of this dissertation is then discussed in chapter six. This argues that social robots have the potential to support the resilience of people with dementia if they are used according to the principles of strength-based care to create meaningful activities that enhance a sense of positive self-identity.

## **List of Tables**

Chapter Two

Table 2.1 Almere Model Constructs.

Table 2.2. Characteristics of Studies investigating acceptance of Social Robots.

Chapter Three

Table 3.1. Search Terms.

Table 3.2. Key Features of the Studies.

Table 3.3. The Impact of Interventions applied to the Resilience Process (Windle, 2011) and Framework (Windle & Bennett, 2012).

Chapter Four

Table 4. 1 Overview of the DESCARTE Model (Adapted from Carolan, 2016).

Table 4.2. The Inclusion and Exclusion criteria.

Table 4.3. Recruitment Strategy.

Table 4.4. Summary of the Data Collection Methods.

Table 4.5. Stages of Data Analysis (Derived from Gale et al., 2013).

Chapter Five

Table 5.1. Description of MARIO's Applications.

Table 5.2. The Inclusion and Exclusion criteria for Participant Eligibility.

Table 5.3. The Eight Stages of Framework Analysis used during the Data Analysis (Derived from Gale et al., 2013).

Table 5.4. The Participant Details.

Table 5.5. Change in Resilience due to using MARIO.

## **List of Figures**

Chapter One

Figure 1.1 Pictures of Social Robots.

Figure 1.2 Picture of a person with dementia using the social robot MARIO.

Chapter Three

Figure 3.1. PRISMA flow diagram describing the Identification, Screening, Eligibility, and Inclusion Criteria of the studies identified under the Scope of this Review.

Chapter Four

Figure 4.1. The DESCARTE model.

Chapter Five

Figure 5.1 Picture of Participant with Dementia interacting with MARIO

Figure 5.2. This Graph shows the Percentage of Time Participants with Dementia spent at levels of Mood and Engagement before and after using MARIO.

Figure 5.3. The Adaptivity-Wellbeing Continuum and Response to MARIO.

### **List of Abbreviations**

CINAHL	Cumulative Index of Nursing and Allied Health Literature.
CORTE	COnsent, maximizing Responses, Telling the story, and Ending on a high
DESCARTE	DESign of CAse Research in healThcarE
DOH	Department of Health
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
ICT	Information Communication Technology
MARIO	Managing Active and healthy aging with use of caRIng social rObots
MEDLINE	MEDLINE is the online counterpart to MEDLARS MEDical Literature Analysis and Retrieval System
NICE	National Institute of Clinical Excellence
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCT	Randomised Controlled Trial
SD	Standard Deviation
WHO	World Health Organisation



## Chapter One. Background.

### 1.1. Introduction

This chapter presents background contextual information and key concepts that are relevant to this thesis. In the chapter, dementia is defined and the impact of this condition both for individuals and society are described and situated within discourses about dementia. Then, current knowledge about the usage and effects of social robots in gerontology are discussed. Following this, strength-based approaches to care are discussed and the concept of resilience is introduced, and rationale is provided as to why resilience theory can usefully guide research on social robots. Then, the gaps in current knowledge concerning the potential of social robots to foster resilience in people with dementia are identified. Finally, the chapter is summarised, and the aims and an outline of this thesis are presented.

#### 1.1.1. What is Dementia?

Dementia is an umbrella term that describes a group of neurodegenerative disorders that can cause memory loss, personality, mood, and sensory challenges, difficulties with reasoning, communication, and carrying out daily activities (Prince, 2016).

#### 1.1.2. The Incidence and Impact of Dementia

The incidence of dementia increases as more people attain old age, and between the years 2015 to 2050, the proportion of the world's population that is over 60 years old is expected to increase from 12% – 22% (WHO, 2018). Consequently, the number of people with dementia is expected to double every 20 years to 66 million by 2030 and 115 million by 2050 (Prince et al., 2013). This is problematic for individuals with dementia, their families, and society because globally the societal economic impact of dementia costs over one trillion US dollars per year, and care provision is supplied by 40 million full-time workers (Wimo et al., 2018).

People who have dementia experience different rates of disease progression and their symptoms vary according to the type of dementia. Symptoms also vary day to day (Bryden, 2005; Rockwood et al., 2014). On good days individuals can have improved global cognition which results in better humour, more interest in life, and improved ability to perform daily living activities. In contrast, on bad days cognition and memory can be poor. This can result in increased verbal repetition, anxiety, and poor performance of activities. The experience of dementia also impacts individuals and families according to the stage of life that they are affected, and if they also experience other disadvantages due to disability, ethnicity, gender, age, socio-economic factors, and stigma (O'Shea, 2017; Sabat, 2018).

Currently, people with dementia can have fewer social interactions and lower levels of participation in communities than other people (Holtzman et al., 2004; Dobbs et al., 2005; Kruger et al., 2009) and people with dementia can find navigating social and environmental systems problematic (Kaspar et al., 2015). Consequently, it is twice as common for people with dementia, in comparison to the general population (20%: 10%), to experience loneliness (Victor et al., 2015). Social isolation is not necessarily reduced when people with dementia live alongside others in residential care (Cooney et al., 2014). One study that involved care homes (n=12) found that people with dementia can experience just two minutes of meaningful social interaction each day (Brooker, 2008). People living in residential care can also feel bored and under-stimulated due to a lack of opportunity to be engaged in an appropriate meaningful activity (Perrin, 1997; Ballard et al., 2001; Aggarwal et al., 2003; Train et al., 2005; Clare et al., 2008).

### 1.1.3. Approaches to Dementia, and Care Provision

Historical views of a person with dementia as a 'non-person' to be managed throughout their decline, were challenged by Kitwood (1997). He advocated that the care of people with dementia should be person-centred according to the needs and preferences of individuals, based on the concept of personhood. Personhood was defined by Kitwood as being 'a standing or a status that is bestowed on one human being by another, in the context of relationship and social being' (Kitwood, 1997, p 8). More recently, a qualitative evidence synthesis (n=20) was conducted that investigated personhood in dementia care from the perspective of people with dementia (Hennelly, et al., 2019). This review found that people with dementia experience personhood as a sense of self that changes greatly due to the progression of dementia and through the person's experience of care in multiple care settings. The review concluded that continuity and affirmation of self can be enhanced through interactions with other people and by people with dementia having opportunities to engage in social and occupational roles. This implies that people with dementia are active and have agency as co-producers of their health outcomes (Rahman & Swaffer, 2018). Agency has also been revealed by people with dementia who have written about their experiences of living with dementia (Bryden, 2005, 2016; Swaffer, 2018). Through this work, it is understood that people with dementia do not experience a 'loss of self' (Bryden, 2016) and that personal strengths, core values, and the potential to adapt and learn can be maintained whilst the disease progresses. This view of dementia means dementia can be regarded as a chronic disease, and there is potential for its impact to be modified (James & Bennett, 2019). Increasingly, there have been calls for the rights of people with dementia as citizens to be acknowledged and supported (Rahman & Swaffer, 2018). A human-rights based approach has been advocated by the World Health Organisation for people with dementia ([www.who.int/mental\\_health](http://www.who.int/mental_health)) and the Alzheimer Societies of Ireland and Scotland ([www.alzheimer.ie/](http://www.alzheimer.ie/), [www.alzscot.org/](http://www.alzscot.org/)) have published charters that state the rights of people with dementia.

Most people with dementia want to live in their own homes for as long as possible and they want autonomy, choice, and connectivity (O'Shea et al., 2019). Currently, international policy trends, within high-income countries, aim to enable people with dementia to be healthy and independent for as long as possible in their homes (DOH, 2014; HIQA, 2016; NICE, 2018). Policies also emphasise that non-pharmacological, environmental, and psychosocial interventions (PSIs) should be used to ameliorate problems experienced by people with dementia (NICE, 2018). Indeed, evaluation of PSIs, such as reminiscence therapy, cognitive stimulation, and rehabilitation therapy, has been deemed a priority (DOH, 2014). Recently, robotic technologies are being developed that aim to enhance the mental health and psychosocial well-being of older adults and people with dementia. A definition of social robots and an overview of their potential uses, and some examples of robots will now be described.

#### 1.2.1. What are Social Robots?

Social robots are artificial intelligence systems that are designed to interact with humans using social behaviours and rules that are appropriate to their role (Jensen, 2019). They possess skills that enable them to interact with people in a socially acceptable manner (Dautenhahn et al., 2005). Robots differ from other assistive technologies because they can be embodied, and they have the potential to be mobile and to act autonomously. Social robots can be distinguished from non-social assistive robots in terms of their function. Typically, non-social assistive robots are designed to assist users in performing specific physical tasks (Huter et al., 2020).

### 1.2.2. An overview of Social Robots in Gerontology

People with dementia and their caregivers are receptive to the idea of using social robots (Casey et al., 2016). This was revealed in a descriptive qualitative study that involved people with dementia (n=22) and their caregivers (n=49) and relatives (n=6). More recently, Hirt et al., (2019) synthesised the results of studies (n=24), fourteen of which included people with dementia to ascertain the needs and expectations of people with dementia and caregivers regarding assistive technologies. This scoping review found that people with dementia and caregivers want robots that can facilitate communication with family and friends, answer repetitive questions, and motivate people with dementia to participate in activities. However, people with dementia and caregivers sometimes expressed different needs and expectations (Hirt et al., 2019).

There are numerous robotic devices currently being developed that are marketed as devices that can support the health and wellbeing of older adults. Wellbeing is a concept that is related to quality of life. It concerns a person's subjective feelings of vitality, zest for life and their experience of a meaningful life (Muhli & Svensson, 2017). Some devices are available for commercial use. For example, Jibo ([www.jibo.com](http://www.jibo.com)) is an artificially intelligent and friendly device with voice and facial recognition that can answer questions and play music entertainment, connect with smart home environments, and the internet to facilitate communication with other people. ElliQ ([www.elliq.com](http://www.elliq.com)) is 8.5" by 5" by 5" in size and has similar functions and a tablet charging station attached so that communication can be via a touch screen in addition to voice control. Two other robotic devices have been developed with additional healthcare components. Mabu functions as a personal healthcare companion ([www.cataliahealth.com](http://www.cataliahealth.com)) and is designed to be a friendly robot with touch screen and voice communication that can coach the user to comply with healthy behaviours. It also provides a means for health professionals to communicate with the patients and to receive data on their health. Pillo is also designed to be a companion that aims to support compliance with healthy activities particularly medication as it stores and dispenses tablets ([www.pillohealth.com](http://www.pillohealth.com)). All these robots are relatively small and designed to be immobile, portable, tabletop devices.

The robotic devices described above have not yet been tested with people with dementia but other devices have been designed specifically for people with dementia. These robots are intended for multiple purposes: to provide comfort and enjoyment, to stimulate cognitive functioning, to increase the ability of people with dementia to be engaged, to assist with activities, and to facilitate communication with other people. Several zoomorphic robots have been developed that aim to build upon the success of animal therapy. These devices have the advantage of being more hygienic, hypoallergenic, and they require less attention than real animals. For example, PARO ([www.parorobots.com](http://www.parorobots.com)), which is designed to appear as a baby harp seal, has been used and tested most extensively in dementia (Huter et al., 2020; Shibata, 2012). Other zoomorphic robots are shaped like dogs, cats, dinosaurs, and bears. Babyloid, ([www.inhabitat.com](http://www.inhabitat.com)) is a robot shaped like a doll that was designed for use in doll therapy. This has a moveable mouth, arms, and eyelids. The acceptability of Babyloid was rated highly by older adults (n=29) living in a nursing home in Japan, but the residents preferred PARO (Furuta et al., 2012). Robots can also be machine-like or humanoid in shape. For example, Giraff is a machine-like mobile telepresence robot that has internet connectivity and Skype ([www.telepresencerobots.com](http://www.telepresencerobots.com)). Whereas NAO is a humanoid robot that is 58cm tall and weighs 4.3kg, that can sing, talk, and dance ([www.softbankrobotics.com](http://www.softbankrobotics.com)). Pictures of these robots are provided in Figure 1.1. below and a picture of the social robot MARIO being used by a person with dementia is provided in Figure 1.2. People with dementia have been involved in studies that assess the effect of robots on their psychosocial wellbeing and quality

## Chapter One. Background

of life. Current knowledge about the ability of social robots to foster wellbeing in people with dementia will now be discussed.

Figure 1.1 Pictures of Social Robots.

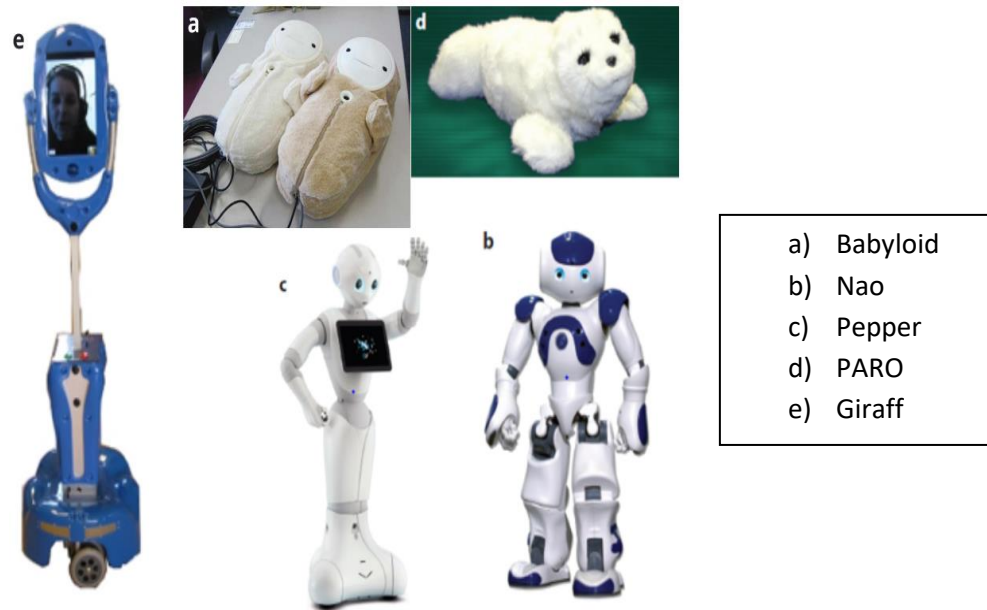


Figure 1.2 Picture of a person with dementia using the social robot MARIO.



### 1.2.3. Can social robots enhance the wellbeing of people with dementia?

The research to date suggests that social robots can support the wellbeing of people with dementia. Numerous studies have found robots can successfully provide enjoyment, increase cognitive attention and improve the social interactions of people with dementia (Wada et al., 2009; Klein & Cook, 2012; Mordoch et al., 2012; Chang et al., 2013; Tapus & Vieru, 2013; Moyle et al., 2013a; Takayanagi et al., 2014; Sung et al., 2015). For example, Moyle et al. (2013a) report a pilot study that aimed to compare PARO's impact on the emotions of people with moderate to severe dementia living in residential care, in comparison to participation in an interactive reading group. Both interventions and control groups lasted for 45 minutes, three times a week with nine participants for five weeks. This was followed by a washout period of three weeks that involved usual care and no additional intervention. After this time, participants then commenced the other activity. The PARO intervention aimed to focus on discovery, engaging emotional response, and social interaction using PARO as the stimulus. Participants were encouraged to examine two PAROs and were asked if they would like to get to know it. The control reading group activity was conducted by a trained activity therapist, using a protocol manual which focused the session into areas involving introduction, emotion, social interaction, and closure. Here participants were encouraged by the facilitator to engage with reading activities and to read out loud. Data was collected on quality of life, anxiety levels, apathy, and depression, before and after the intervention sessions, after the first five-week intervention, and after the second five-week intervention group. Also, levels of mood during the sessions were measured. It was found that PARO had a moderate to large positive effect on the quality of life in comparison to the reading group. Caregivers also reported that PARO users had less anxiety than the control group and they experienced more pleasure. In another study, nursing home residents (n=28) felt less lonely and regarded PARO as a playmate (Wada & Shibata, 2007). Furthermore, a robot shaped like a dog has been found to encourage more social interaction in people with dementia living in residential care than a real dog (Kramer et al., 2009). Social connectivity between people with dementia and their family and friends has also been successfully increased using Giraff (Moyle et al., 2013b). This study assessed the feasibility of Giraff, with people with dementia - relative dyads (n=5) and it was found that participants exhibited positive emotions and high levels of engagement during calls.

Three recent reviews of the literature have synthesised evidence concerning the effectiveness of social robots to people with dementia. Kang et al., (2019) performed a systematic review that included randomised controlled studies (n=8) that involved PARO. This review found PARO can improve quality of life, increase positive emotions and social interaction, and reduce neuropsychiatric symptoms. Pu et al., (2019) also found that social robots appear to positively impact older adults through reducing agitation, anxiety, and improving quality of life. But, the meta-analysis that they performed on the findings of randomised controlled trials (n=11) found that these positive effects were not statistically significant. They also concluded that there was a lack of existing high-quality studies. Neal et al. (2019) also found conflicting results concerning the impact of technologies used to enhance the meaningful engagement of people with dementia. This review examined empirical peer-reviewed studies that included robotic studies (n=14) and multi-media computer programs (n=6). Four of the robotic studies measured the impact of robots on quality of life. Of these studies, Neal et al., (2019) reported that one study found quality of life increased; the second found increase only occurred in severe dementia; the third study found no impact, and the fourth determined that agitation increased. Other studies in the review focused on the frequency of positive behaviours, such as interactions, smiling or laughing and interaction between people. Neal et al., (2019) reported that the robots

generally increased positive behaviours, promoted interaction but that one study did not report positive impact.

Therefore there is some evidence that social robots can support the wellbeing of people with dementia. However, currently, the potential of social robots is poorly understood because the evidence base concerning robotic technologies in dementia is relatively small, and inconclusive. Studies to date have not examined in depth, the factors through which people with dementia can be positively impacted by social robots or explored how social robots need to be used to increase their efficacy.

Another significant gap in the literature exists because there has been no attempt to systematically examine the usage and effect of social robots on wellbeing, using a recognised theory-driven approach. Indeed, much of the development of social robots for older adults has been stimulated by commercial interests and engineers and roboticists. This means there is an urgent need to develop an empirical research base within social science and health and social care disciplines to ensure social robots can be developed and deployed to address the unmet needs of people with dementia in a way that is person-centred and empowering. One way in which the development of social robots can be made relevant to the needs of people with dementia is if research is informed by discourses about dementia and theoretical approaches to care that support the psychosocial wellbeing of people with dementia. Strength-based approaches to care in dementia align with current discourses about increasing wellbeing and social participation in dementia. These will now be described.

### 1.3.1. Strength-based approaches to Care

Strength-based approaches to care require caregivers and supporters of people with dementia to focus on the assets and abilities of people with dementia, rather than focusing on tasks and a person's deficiencies (Moyle et al., 2014). Focusing on strengths does not mean that problems are ignored, but rather that people with dementia are empowered through supportive relationships, to identify and use their strengths and resources to deal with the difficulties they experience (Pearson, 2013). Using these approaches can avoid damaging a person's self-esteem and increasing their disability by underestimating their capability (Sabat, 2017).

There are several strength-based theories and care approaches. These include using narrative to elucidate and reframe a situation; solution-focused therapy (Pattoni, 2012); capacity building through asset-based community development (Hirst et al., 2013); appreciative inquiry, in which clinicians or researchers explore a person's world with them, eliciting information about their experiences to facilitate changes (Moyle et al., 2010) and resilience. Resilience will now be described in more detail because this approach was used to underpin the research that is presented in this thesis.

### 1.3.2. Resilience

Resilience has been defined as patterns of positive adaptation and development in the context of significant threats (Wright, Masten & Narayan, 2013) and as the process of negotiating, adapting to, and managing stress (Windle, 2011). Resilience has two co-existing central concepts; the presence of adversity, which is a threat or risk to wellbeing, and evidence of positive adaptation to limit the effect of the threat to wellbeing (Leipold & Greve, 2009). The theory of resilience has been used widely in the discipline of positive psychology (Seligman & Csikszentmihaly, 2000).

Resilience is an important concept in dementia because it is linked to the quality of life (Harris, 2016) and it contributes to people living meaningful lives (Bailey, 2017). Bailey (2017) proposed a model of resilience in which people with dementia use resources to negotiate

living with dementia in an ongoing process of 'overcoming dementia'. This model was developed following a systematic review involving n=7 studies and a qualitative study that used grounded theory to analyse data from interviews with people with dementia (n=7). Bailey's model concurs with Matchar & Gwyther (2014) who argue that resilience in dementia involves continuing life whilst transforming to accept new circumstances and a 'new normal'. Factors that promote resilience have been regarded in terms of resource assets and protective factors that exist at individual, social, and environmental levels (Harris, 2010). Resilience is supported by having positive social relationships (Harris, 2010) and through attachments of people with dementia to people and places that reaffirm positive identity (Bailey et al., 2013) and that support wellbeing (Harris, 2016). Positive outcomes of resilience include maintaining a strong self-concept (Harris, 2008), being engaged with life, and experiencing positive emotions (Sabat, 2018), maintaining a good quality of life. These are positive psychosocial outcomes that align with those discussed above that can potentially be supported by social robots. For this reason and others that will now be described, it is appropriate to use resilience (a strength-based approach) to advance knowledge about social robots in dementia.

### 1.3.3. Why should resilience be used to research social robots and dementia?

Like other strength-based approaches, the concept of resilience is attractive because it 'evokes the promise of something good resulting from misfortune, hope embedded in adversity' (Dyer & McGuinness, 1996). The usage of resilience is also an opportunity to reframe negative societal discourse about aging and dementia (Harris & Keady, 2008). Indeed, resilience is particularly useful in the context of dementia because it has a strong theoretical basis which acknowledges that an adaptive positive response to adversity is possible for all people. In a seminal work on resilience, cited by over 9682 articles (Google Scholar accessed, 29/10/2020), Masten (2001) argued that the capacity of humans to exhibit resilience processes and adapt in the face of adversity is their 'ordinary magic'. Theoretical work on resilience also acknowledges that people can remain vulnerable even though they manage to exist and retain the potential to grow (Windle, 2011). This makes resilience particularly relevant in dementia where wellbeing gains may be valuable but small, and where strengths and frailties do not exist as a dichotomy (Ramsey & Blieszner, 2016). Furthermore, resilience does not focus exclusively on the individual, which can potentially invite victim-blaming (Wild et al., 2013). Instead, an individual's resilience can be impacted by their personality and psychological processes, and external factors, such as place, culture, policies, and relationships with other people (Windle, 2011; Windle & Bennett, 2012). It is useful to examine both personal and external factors that impact the adaptation of people with dementia because the adversity experienced by individuals and how they use interventions to support their wellbeing will be impacted by the actions of other people. Therefore, resilience can facilitate the examination of interventions (Williamson & Paslawski, 2016) and it might be able to advance understanding as to how and why social robots can be used to increase the wellbeing of people with dementia.

Examining social robots through a resilience lens is also advantageous because it can help address some of the ethical controversies that surround the use of robots for people with dementia. Concerns have been raised that human care could be replaced by robots (Vallor, 2011). It is feared that the wellbeing of people with dementia could be reduced and their social isolation increased if robots perform tasks without the benefit of interpersonal relationships (Sparrow & Sparrow, 2006; Vallor, 2011; Sorell & Draper, 2014). Other ethical concerns are that robots could potentially reduce the dignity of people with dementia through infantilisation (Sharkey & Sharkey, 2012; Sharkey, 2014) and that robots can cause deception because they are designed to appear as something more than machines (Turkle, 2001; Sparrow & Sparrow, 2006). Resilience in dementia is increased if a person has a positive

sense of identity (Newman et al., 2018), a sense of belonging, and good communication with other people (Matchar & Gwyther, 2014). Therefore, to support resilience, social robots must be designed to be respectful to people with dementia and their caregivers. And, rather than replace caregivers, robot development and deployment must aim to enhance relationships between people with dementia and caregivers.

### 1.3.4 Current gaps in knowledge about social robots and resilience

The current literature does not address why certain individuals are receptive to the idea of using robots and engage well with them, but other people with dementia engage less well or do not want to use them (Broadbent et al., 2015). To date, there has been little attempt to apply the theories of technology acceptance to the development and usage of social robots for people with dementia. Therefore, little is currently known about what social robots should be like and what can be done to increase the likelihood that people with dementia will interact with them and find them beneficial. Further research is needed to understand robot acceptability in the context of dementia. The acceptability of social robots is a theoretical foundation that could inform how social robots should be designed, developed, and examined in future research.

Although previous research suggests social robots can positively impact the quality of life of people with dementia, no research to date has examined the potential of social robots to support the wellbeing of people with dementia by using them to support resilience. It is currently unknown what effect social robots can have on resilience, how interventions that aim to support resilience need to be structured, or how social robots need to be used by people with dementia. It is also unclear how the concept of resilience should be operationalised or how research can be optimally designed to investigate social robots in the context of dementia.

### 1.4 Summary of key points in Chapter One

- Dementia is a prevalent condition associated with a substantial psychosocial and economic burden to the individual, families, and society.
- Currently, people with dementia have unmet psychosocial needs and social robots are being developed that aim to promote their wellbeing. There is evidence that social robots can enhance the psychosocial wellbeing of people with dementia. However, the evidence base is small, inconclusive, and poorly understood.
- Potentially social robots can be used to enhance the current support available to people with dementia by supporting resilience. Resilience is a valuable concept that aligns with current discourses about dementia that support the use of strength-based approaches to improve the wellbeing of people with dementia. Resilience is a theoretically substantiated strength-based approach that enables a focus on factors that impact individuals both internally and externally. In dementia, resilience concerns achieving positive self-identity and it is supported by having good relationships with other people.
- There is an urgent need for theory-driven empirical research to guide the design and usage of social robots in dementia. Research needs to deepen understanding of the psychosocial factors through which social robots can impact wellbeing and how robots can be optimally deployed to make them more acceptable and beneficial to people with dementia.
- Research is needed to explore if and how social robots can be used to support resilience. This requires a focus on the factors that impact the usage and effect of social robots and on examining how robotic PSIs that aim to support resilience can be investigated.



## Chapter One. Background

### 1.5 Aim and Objectives of this Thesis

The work in this thesis aims to explore the potential of social robots to support the resilience of people with dementia.

This doctoral thesis has the following objectives:

1.5.1. Objective 1: To identify the factors that impact the acceptability of social robots for people with dementia.

To address the gap in the literature regarding the optimal nature of social robots for people with dementia, it is necessary to establish what evidence is currently available regarding what makes social robots acceptable to people with dementia. This objective is addressed in chapter two through a peer-reviewed published paper that reports a literature review that identified the factors that impact the acceptability of social robots for people with dementia.

1.5.2. Objective 2: To identify the key components of PSIs that aim to support resilience and to clarify how the concept of resilience can be defined and operationalised.

A narrative literature review was conducted to build upon previous knowledge of PSIs and resilience in dementia to identify the key components of psychosocial interventions that aim to support resilience and to clarify how the concept of resilience can be defined and operationalised in the context of dementia. This objective is achieved in the second published peer-reviewed paper which is presented in chapter three.

1.5.3. Objective 3: To determine the most appropriate study design to investigate the use and effect of social robots to support resilience in dementia.

The use and effect of social robots to foster resilience had not previously been examined, therefore, the most appropriate research design for this novel research needed to be critically determined according to best research practice. This objective was achieved in the third published paper, presented in chapter four. This paper presents a critical review of the recently developed DESCARTE model (Carolan, 2016) that has been designed to guide the design, conduct, and reporting of case study research in health care settings. This critical appraisal was conducted to determine the suitability of DESCARTE to guide the design and conduct of the empirical study which investigated the use and effect of the social robot, MARIO, on the resilience of people with dementia.

1.5.4. Objective 4: To investigate how using MARIO affected the resilience of people with dementia by identifying the characteristics of resilience in this context, exploring how resilience changed as a result of using MARIO, and identifying how MARIO was used to impact resilience.

Currently, it is unknown if social robots can support the resilience of people with dementia and little is known about how social robots can be optimally used to increase resilience. To address this gap in knowledge an empirical study was needed. This objective is addressed in the fourth paper, presented in chapter five, which describes a multiple case study that investigated the effects of the social robot Mario on the resilience of people with dementia living in a residential care setting and how MARIO was used to impact resilience.

### 1.6. Chapter One. References

Aggarwal, N., Vass, A.A., Minardi, H.A., Ward, R., Garfield, C. & Cybyk, B. (2003). People with dementia and their relatives: personal experiences of Alzheimer's and of the provision of care. *Journal of psychiatric and mental health nursing*, 10(2), pp.187-197.

Bailey, G. H. (2017). 'This is my life and I'm going to live it': A grounded theory approach to conceptualising resilience in people with mild to moderate dementia. Edinburgh, Scotland.

Bailey, C., C.L., Gibb, C., Haining, S., Wilkinson, H. & Tiplady, S (2013). Risky and resilient life with dementia: Review of and reflections on the literature. *Health, risk & society*, 15(5), pp.390-401.

## Chapter One. Background

- Ballard, C., Fossey, J., Chithramohan, R., Howard, R., Burns, A., & Thompson, P., et al. (2001). Quality of care in private sector and NHS facilities for people with dementia: Cross-sectional survey. *British Medical Journal*, 323, 426–427.
- Clare, L., Rowlands, J., Bruce, E., Surr, C., & Downs, M. (2008). The experience of living with dementia in residential care: an interpretative phenomenological analysis. *The Gerontologist*, 48(6), 711-720.
- Cooney, A., Hunter, A., Murphy, K., Casey, D., Devane, D., Smyth, S., Dempsey, L., Murphy, E., Jordan, F. & O'Shea, E. (2014). 'Seeing me through my memories': a grounded theory study on using reminiscence with people with dementia living in long-term care. *Journal of Clinical Nursing*, 23(23-24), pp.3564-3574.
- Dautenhahn, K., Woods, S., Kaouri, C., Walters, M.L., Koay, K.L. & Werry, I. (2005, August). What is a robot companion-friend, assistant or butler?. In 2005 IEEE/RSJ international conference on intelligent robots and systems (pp. 1192-1197). IEEE., Edmonton, Canada.
- Department of Health. (2014). The Irish national dementia strategy. Dublin, Ireland. <https://assets.gov.ie/>
- Dyer, J.G. & McGuinness, T.M. (1996). Resilience: Analysis of the concept. *Archives of psychiatric nursing*, 10(5), pp.276-282.
- Furuta, Y., Kanoh, M., Shimizu, T., Shimizu, M., & Nakamura, T. (2012, 10-15th June ). Subjective evaluation of use of Babyloid for doll therapy. 2012 IEEE International Conference on Fuzzy Systems, Brisbane, Australia.
- Harris, P. B. (2010) Is Resilience a key to living a meaningful life with dementia? Factors that contribute to the resilience process in early stage dementia 63rd Annual Scientific Meeting of The Gerontological Society of America November 19th-23<sup>rd</sup>, New Orleans, LA.
- Harris, P. B., & Keady, J. (2008). *Wisdom, resilience and successful aging: Changing public discourses on living with dementia*. Sage Publications Sage UK. <https://doi.org/10.1177/1471301207085364>
- Harris, P. B. (2016). Resilience and living well with dementia. In *Positive psychology approaches to dementia* (pp. 133-151). C. Clarke & E. Wolverson (Eds) London, England: Kingsley.
- Health Information and Quality Authority (2016). National standards for residential care settings for older people in Ireland. Dublin, Ireland. [www.hiqa.ie](http://www.hiqa.ie)
- Hennelly, N., Cooney, A., Houghton, C., & O'Shea, E. (2019). Personhood and Dementia Care: A Qualitative Evidence Synthesis of the Perspectives of People with Dementia. *The Gerontologist*. doi:10.1093/geront/gnz159.
- Hirst, S. P., Lane, A., & Stares, R. (2013). Health promotion with older adults experiencing mental health challenges: A literature review of strength-based approaches. *Clinical Gerontologist*, 36(4), 329-355.
- Jensen, E. A., Smith, J., & Kovach, C. R. (2019). Social Robots, Robotic Assistants, and Home Health Monitoring Devices: A Gerontological Research Perspective. *Research in gerontological nursing*, 12(4), 163-166.
- Leipold, B. & Greve, W. (2009). Resilience: A conceptual bridge between coping and development. *European Psychologist*, 14(1), pp.40-50.
- Masten, A.S. (2001). Ordinary magic: Resilience processes in development. *American psychologist*, 56(3), pp.227-238.
- Matchar, B.G. & Gwyther, L.P. (2014). Resilience in early-stage dementia: Lessons learned from early-stage Alzheimer education and support groups. *Topics in Geriatric Rehabilitation*, 30(3), pp.170-175.
- Mitchell, G. & O'Donnell, H. (2013). The therapeutic use of doll therapy in dementia. *British Journal of Nursing*, 22(6), pp.329-334.
- Moyle, W., Clarke, C., Gracia, N., Reed, J., Cook, G., Klein, B., & Richardson, E. (2010). Older people maintaining mental health well-being through resilience: an appreciative inquiry study in four countries. *Journal of Nursing and Healthcare of Chronic Illness*, 2(2), 113-121.
- Moyle, W., Cooke, M., Beattie, E., Jones, C., Klein, B., Cook, G. & Gray, C. (2013a). Exploring the effect of companion robots on emotional expression in older adults with dementia: a pilot randomized controlled trial. *Journal of gerontological nursing*, 39(5), pp.46-53.
- Moyle, W., Jones, C., Cooke, M., O'Dwyer, S., Sung, B. & Drummond, S. (2013b, June 6<sup>th</sup>-8<sup>th</sup>). Social robots helping people with dementia: Assessing efficacy of social robots in the nursing home environment. In 2013 6<sup>th</sup> International Conference on Human System Interactions (HSI) (pp. 608-613). IEEE. Gandansk, Poland.
- Moyle, W., Parker, D., & Bramble, M. (2014). *Care of older adults: A strengths-based approach*: Cambridge University Press. Melbourne, Australia.

## Chapter One. Background

- Muhli, U. H., & Svensson, A. M. (2017). Well-being in Old Age: A Question of Both Continuity and Change. *Well-being and Quality of Life: Medical Perspective*, Sept 6<sup>th</sup>, p.147.
- Newman, A., Goulding, A., Davenport, B. & Windle, G. (2019). The role of the visual arts in the resilience of people living with dementia in care homes. *Ageing & Society*, 39(11), pp.2465-2482.
- NICE (2018) Dementia assessment management and support for people living with dementia and their carers. Technical Report. <https://www.nice.org.uk/guidance/ng97/resources/>
- O'Shea, E., Keogh, F., & Cooney, A. (2019) *The Continuum of Care for People Living with Dementia in Ireland*. Tullamore: National Dementia Office.
- O'Shea, E., Cahill, S., Pierce, M., Rees, G., Irving, K., Keogh, F., & Hennelly, N. (2017). Developing and implementing dementia policy in Ireland. NUI Galway and Centre for Economic and Social Research on Dementia. <https://www.atlanticphilanthropies.org/wp-content/uploads/2018/01/Developing-and-Implementing-Dementia-Policy-in-Ireland.pdf>
- Pattoni, L. (2012). Strengths-based approaches for working with individuals. IRISS. <https://www.iriss.org.uk/resources/insights/strengths-based-approaches-working-individuals>
- Pearson, G. S. (2013). Strengths-Based Nursing Care for Psychiatric Nurses. *Perspectives in psychiatric care*, 49(1), pp. 1-1.
- Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W. & Ferri, C.P. (2013). The global prevalence of dementia: a systematic review and metaanalysis. *Alzheimer's & dementia*, 9(1), pp.63-75.
- Rahman, S., & Swaffer, K. (2018). Assets-based approaches and dementia-friendly communities. *Dementia*, 17(2), pp. 131-137.
- Ramsey, J.L. & Blieszner, R. (2016). *Spiritual resiliency and aging: Hope, relationality, and the creative self*. Routledge, New York.
- Rockwood, K., Fay, S., Hamilton, L., Ross, E., & Moorhouse, P. (2014). Good days and bad days in dementia: a qualitative chart review of variable symptom expression. *International psychogeriatrics*, 26(8), pp. 1239-1246.
- Sabat, S.R. (2018). *Alzheimer's Disease and Dementia: What Everyone Needs to Know®*. Oxford University Press. New York.
- Sharkey, A. & Sharkey, N. (2012). Granny and the robots: ethical issues in robot care for the elderly. *Ethics and information technology*, 14(1), pp.27-40.
- Sharkey, A. (2014). Robots and human dignity: a consideration of the effects of robot care on the dignity of older people. *Ethics and Information Technology*, 16(1), pp.63-75.
- Csikszentmihalyi, M. & Seligman, M.E. (2000). Positive psychology: An introduction. *American Psychologist*, 55(1), pp.5-14.
- Shibata, T. (2012). Therapeutic Seal Robot as Biofeedback Medical Device: Qualitative and Quantitative Evaluations of Robot Therapy in Dementia Care. *Proceedings of the IEEE*, 100(8), 2527-2538. <https://doi.org/10.1109/JPROC.2012.2200559>
- Sorell, T. & Draper, H. (2014). Robot carers, ethics, and older people. *Ethics and Information Technology*, 16(3), pp.183-195.
- Sparrow, R. & Sparrow, L. (2006). In the hands of machines? The future of aged care. *Minds and Machines*, 16(2), pp.141-161.
- Sung, H.C., Chang, S.M., Chin, M.Y. & Lee, W.L. (2015). Robot-assisted therapy for improving social interactions and activity participation among institutionalized older adults: A pilot study. *Asia-Pacific Psychiatry*, 7(1), pp.1-6.
- Takayanagi, K., Kirita, T., & Shibata, T. (2014). Comparison of Verbal and Emotional Responses of Elderly People with Mild/Moderate Dementia and Those with Severe Dementia in Responses to Seal Robot, PARO [Original Research]. *Frontiers in Aging Neuroscience*, 6(257). <https://doi.org/10.3389/fnagi.2014.00257>
- Vallor, S. (2011). Carebots and caregivers: Sustaining the ethical ideal of care in the twenty-first century. *Philosophy & Technology*, 24(3), pp.251-268.
- Wada, K., Shibata, T. & Kawaguchi, Y. (2009, June). Long-term robot therapy in a health service facility for the aged-A case study for 5 years. In 2009 IEEE International Conference on Rehabilitation Robotics (pp. 930-933). IEEE.
- Wild, K., Wiles, J.L. & Allen, R.E. (2013). Resilience: thoughts on the value of the concept for critical gerontology. *Ageing & Society*, 33(1), pp.137-158.
- Williamson, T. & Paslawski, T. (2016). Resilience in dementia: Perspectives of those living with dementia. *Canadian Journal of Speech-Language Pathology and Audiology*, 40(1), pp.1-15.

## Chapter One. Background

Windle, G. (2011). What is resilience? A review and concept analysis. *Reviews in clinical gerontology, 21*(2), pp.152-169.

Windle, G. & Bennett, K.M. (2012). Caring relationships: How to promote resilience in challenging times. In *The social ecology of resilience* (pp. 219-231). Springer, New York, NY.

Wimo, A., Gauthier, S., & Prince, M. (2018). Global estimates of informal care. *Alzheimer's Disease International*. London. July. <https://www.alz.co.uk/adi/pdf/global-estimates-of-informal-care.pdf>

World Health Organisation (2018) Ageing and Health. 5<sup>th</sup> February 2018 <https://www.who.int/news-room/fact-sheets/detail/ageing-and-health> Accessed 8th May 2020

Wright, M.O.D., Masten, A.S. & Narayan, A.J. (2013). Resilience processes in development: Four waves of research on positive adaptation in the context of adversity. In *Handbook of resilience in children* (pp. 15-37). Springer, Boston, MA.

## Chapter Two. Paper One.

### 2.0. Prologue

Paper one is presented in this chapter. Paper one describes a review of the literature that identifies current knowledge about the factors that impact the willingness of people with dementia to interact with social robots. The study uses concepts from the theory of technology acceptability that can measure and explain a person's intention to use technology. Initial literature searches found that few studies had previously addressed acceptability issues with study populations of people with dementia. Therefore, the review also included studies that involved older adults and people with mild cognitive impairment aged over 65 years. The work of this review identifies what people with dementia require of social robots, to encourage and enable their usage, and what factors need to be considered in future research. Additional information about this study, including details about the literature search strategy, the inclusion and exclusion criteria, and the PRISMA flow diagram are available in Appendices 1), 2) and 3).

### 2.1. Paper One:

Title: Factors affecting the acceptability of Social Robots by older adults including people with dementia or cognitive impairment: A Literature Review.

Authors: Sally Whelan<sup>1</sup>, Kathy Murphy<sup>1</sup>, Eva Barrett<sup>1</sup>, Cheryl Kruschke<sup>2</sup>, Adam Santorelli<sup>1</sup>, and Dympna Casey<sup>1</sup>.

1. School of Nursing & Midwifery National University of Ireland Galway Ireland.
2. Loretto Heights School of Nursing, Regis University, Denver, Colorado.

#### 2.1.1. Abstract

Social robots are being developed to support care given to older adults (OA), people with dementia and OA with mild cognitive impairment (MCI) by facilitating their independence and well-being. The successful deployment of robots should be guided by knowledge of factors which affect acceptability. This paper critically reviews empirical studies which have explored how acceptability issues impact OA, people with dementia and OA with MCI. The aim is to identify the factors governing acceptability, to ascertain what is likely to improve acceptability and make recommendations for future research. A search of the literature published between 2005 and 2016 revealed a relatively small body of relevant work has been conducted focusing on the acceptability of robots by people with dementia or OA with MCI (n=21), and on acceptability for OA (n=23). The findings are presented using constructs from the Almere robot acceptance model. They reveal acceptance of robots is affected by multiple interacting factors, pertaining to the individual, significant others, and the wider society. Acceptability can be improved through robots using human-like communication, being personalised in response to individual users' needs and including issues of trust and control of the robot which relates to degrees of robot adaptivity. However, most studies are of short duration, have small sample sizes and some do not involve actual robot usage or are conducted in laboratories rather than in real world contexts. Larger randomised controlled studies, conducted in the context where robots will be deployed, are needed to investigate how acceptance factors are affected when humans use robots for longer periods of time and become habituated to them.

#### 2.1.2. Introduction

Dementia, which affects mainly people over age 65, is expected to affect 66 million people by 2030 and 115 million by 2050 [1]. This progressive degenerative syndrome can cause memory loss, mood and personality changes, communication problems and difficulty performing routine tasks [2]. Mild Cognitive Impairment (MCI) is estimated to affect between

five and twenty percent of people over 65 and is a condition where people have minor problems with memory or thinking. People with MCI do not have a diagnosis of dementia but are at increased risk of developing this condition [3]. Social robots are being developed to support the care given by human care givers to older adults (OA), people with dementia and MCI [4, 5]. These aim to reduce social isolation, improve quality of life and support people in their social interactions [5-9].

Social robots are defined as being useful, and possessing social intelligence and skills which enable them to interact with people in a socially acceptable manner [10]. This means they need to be able to communicate with the user and be perceived by the user as a social entity [11]. This definition includes companion-type robots, with a primary purpose to enhance mental health, and the psychological well-being of its users, and service-type robots which support people in undertaking daily living functions. Acceptability is defined as the 'robot being willingly incorporated into the older person's life' [12], which implies long term usage.

Acceptability of these robots to people with dementia, OA with MCI and OA is an important issue which depends on multiple variables [13, 14]. Future research and the design, development, and deployment of robots, in this rapidly expanding field, needs to be guided by knowledge of factors which affect acceptability. This paper critically reviews empirical studies which have explored how acceptability issues impact these groups of people. It aims to: (i) determine how this issue has been examined to date; (ii) identify the importance of particular factors; (iii) ascertain what is likely to improve acceptability; and, (iv) make recommendations for future research.

#### 2.1.3. Literature Search Methodology

Literature published between 2005 and 2016 was searched systematically by a librarian and SW in the following databases: Cochrane library, PubMed, Scopus, CINAHL, EMBASE, Web of Science Core Collection, PsychINFO, Compendex (El Village 2), using the terms: accept\*, dementia\*, Alzheimer\*, robot\*, "cognitive deficiency", elderly, old\*, technology accept\*, user accept\*, attitude, social robots, assistive technology, social commitment, social, therapeutic, relationship building, companionship, caring, mental health, entertainment, interactive autonomous, interactive engaging, mental commitment. The titles of 198 articles were read and 143 were discounted as they were not in English, lacked relevance, or were duplicates. Abstracts from the remaining 55 papers were then examined and 11 were excluded as they were not empirical studies or did not focus on people with dementia, OA with MCI, or OA. Therefore, in total 44 studies were identified for inclusion in this review. OAs were defined as being people over 65 years who do not have a diagnosis of dementia or cognitive impairment and people with dementia describes participants who have a diagnosis of dementia.

#### 2.1.4. Literature Review Results

This review uses the Almere theoretical model of technology acceptance [15] as a framework to present its findings. Constructs from this model, which was developed to test acceptance of assistive social agents by OA users, are defined in Table 2.1. below.

Table 2.1. Almere model constructs [16]

Construct	Definition
Anxiety	Evoking anxious or emotional reactions when using the robot.
Attitude towards	Positive or negative feelings about the appliance of the robot.
Intention to Use	The outspoken intention to use the robot over a longer period of time.
Perceived Usefulness	The extent to which a user thinks a robot will be helpful in their daily activities.
Perceived Ease of Use	The degree to which the user believes that using the robot would be free of effort.
Perceived Enjoyment	Feelings of joy or pleasure associated by the user with the use of the robot.
Social Presence	The experience of sensing a social entity when interacting with the robot.
Perceived Sociability	The perceived ability of the robot to perform sociable behaviour.
Trust	The belief that the robot performs with personal integrity and reliability.
Perceived Adaptability	The perceived ability of the robot to be adaptive to the changing needs of the user.
Facilitating Conditions	Factors in the environment that facilitate using the robot.
Social Influence	The user's perception of what other people think about them using the robot.

The review begins by introducing literature which explains how psychological factors affect acceptance by impacting users' anxiety levels and their attitude towards robots. These factors predispose a user to respond to a robot in a particular way, influencing the degree of acceptance likely at an initial robot-user encounter.

#### 2.1.4.1. Attitudes and Anxieties towards Technology

Before a person has their first direct experience of robots, users form a mental model about them which conditions their responses to the robot. Mental models are influenced by past personal experience and second-hand sources of information external to the individual, such as science fiction and the media [11, 17-19]. For example, zoomorphic robots, such as PARO, appearing as a baby harp seal, may stimulate users and connect with prior experiences, by evoking happy caring emotions, previously generated when interacting with pets [20].

Prior experiences and an individual's attitude towards a robot are affected by their expectations about what it can and cannot do. This is also linked to anthropomorphism and the human tendency to regard robotic and non-robotic objects as living entities with human-like capacities of mind. How this occurs is explored further below.

Attitudes to particular robots, and the degree of anxiety or emotional reaction that they evoke, are influenced by the degree to which a human perceives a robot to have an ability to feel (mind experience) and an ability to do things (mind agency). The latter includes perceptions about its capacity for self-control, memory, and morality [21]. Takayama (2011) suggests that a robot which is perceived to have a high level of mind agency, appears to have its own needs, desires and goals, i.e. it is perceived to possess human attributes [22]. Whereas, a robot perceived to have a middle level of perceived agency, does not have its own motivations and is regarded as a tool. Takayama (2011) distinguishes

between in-the-moment perceptions of agency and more reflective perceptions which result from considered thinking about a situation. Robots can be perceived as highly agentic entities in-the-moment, as people respond to them instinctively. This tendency may facilitate humans forming emotional bonds with a robot and eliciting social responses. It has been proposed that the tendency to anthropomorphise may increase if a person is lonely or feels gratitude towards a device which helps them [17].

Stafford et al. (2013) [21] investigated whether perceptions about mind can predict robot usage and how this affects attitudes towards robots. They studied attitudes towards Healthbot, which can respond to face recognition and touch-screen interaction and perform vital signs measurements. It also provided medication reminders, entertainment or telephone calling and had the ability to assess brain fitness, with self-selected OA participants (n=25) living independently in a residential unit. Having obtained baseline measurements, fourteen participants did not interact with the robot, four used it in their apartments, four used it in the residents' foyer, and three used it in both places. Participants who attributed more agency to the robot were more wary of it and used it less, but their attitudes improved when they became aware of the robots limited ability to think and remember.

It is possible that acceptability will be improved if robots are perceived to have a level of agency appropriate to their purpose and the context in which they are employed. Indeed, it has been speculated that robots perceived as having low agency but high experience (feelings) might make more acceptable companion robots [11]. PARO is a highly successful robot which conforms to this specification, appearing to have a lot of feelings but little agency.

The evidence regarding how gender, education, age and prior computer experience (CE) impacts anxiety and attitude towards robots presents a complex picture. Arras and Cerqui (2005) found that 34% of men had a more positive image of robotics compared to 9% of women and the latter were more sceptical on every aspect of robot technology. In addition, 39% of OA had a more positive image of robots compared to 22% of those under 18 years. OA believed robots could contribute to their personal happiness and quality of life, although they rejected the idea of robots replacing human social contact [24].

Heerink (2011) [16] explored the influence of gender, education, age and computer experience on acceptance by showing OA, who were living semi-independently in residential care (n=66, 43 female, 23 male, aged 65-92), a film of a RoboCare robot being used by an older adult. Authors describe this robot as a mobile cylinder with a female screen face which can act autonomously and connect to smart-home technology. Data collected using questionnaires suggested that participants with more education were less open to perceiving the robot as a social entity. In addition, people with more CE perceived it as easier to use (PEOU). Gender differences coincided with correlations of CE and PEOU, which suggested that males had more CE, and this increased their PEOU. However, this study also found that anxiety levels towards the robot were influential and correlated with age, CE and education levels (0.331,  $p < 0,005$ ; -0.356,  $p < 0,005$ ; -0.229,  $p < 0.25$ ).

The effect of age and anxiety towards robots was also investigated by Normura et al. (2012) [25] who conducted an online survey randomly selecting respondents from a Japanese survey company, based on age and gender (n=100; aged 20-70). They found that people in their twenties, who had experienced humanoid robots directly or in the media, reported higher anxiety levels toward robots than those aged 50-60. However, OA mistrusted technology significantly more than younger adults. The former also found technology more difficult to use and had less knowledge of its capabilities. Women were



more sceptical about using robots than men. Interestingly, the age groups used different strategies when learning how to use unfamiliar technologies: young people used trial and error, adults read instructions whereas OA preferred to ask for help. This research also found that more OA compared to younger adults preferred robots not to be freely mobile within the home (90% vs 28%) and only 8% of OA compared with 54% of younger adults reported that they would feel completely safe and comfortable to have a robot performing tasks in their house. Scopelliti, Giuliani et al. (2004) [19] supported the inference that OA may respond to technologies differently to younger people. Their pilot qualitative study, which involved three generations in six families (n=23), found that OA evaluated robotic technology positively. However, OA were concerned about the harmonious integration of robots into the home environment, whereas participants in other age groups expressed different priorities [19].

#### 2.1.4.2. Intention to Use (ITU)

The evidence suggests that factors impacting acceptance can change when a person uses a robot and becomes more familiar with it, rather than just hearing about it from a third party [26-28]. For this and other reasons described below, ITU as a measure of robot acceptability can provide less reliable and valid information than studies which examine actual robot usage over a prolonged period of time. For example, Stafford et al. (2010) recorded attitudes towards the robot *Cafero*, using a robot attitude scale, before and after staff (n=32) and OA residents (n=21) in a retirement village had 30 minutes to interact with it. Following the interaction, both participant groups had less negative attitudes towards the robots. A similar improvement in attitude was found by Gross and Schroeter et al. (2012), in their observational qualitative field trial conducted in a 'smart' house. They found some OA with MCI and their carer partners (n=4 dyads), were initially negative toward the *CompanionAble* robot and perceived it as frightening [27]. However, they started to appreciate its benefits and found it more acceptable after spending one day using it. Heerink (2010) [15] evaluated whether ITU predicted actual robot usage, with OA residents (n=30) who were introduced to *iCat*, played with it for 3 minutes and then had their ITU measured by completing a questionnaire. Afterwards, *iCat* was left in a residents lounge for participants to use if they wished when they were alone. This subsequent usage was video recorded. They found that ITU sometimes predicted actual usage but did not always do so.

In a subsequent experiment involving OA (n=30), usage of *Steffie*, a virtual screen character used to assist participants with online computer activities, was recorded. This program was installed in participants' home computers. Heerink (2010) found ITU is impacted by other acceptance factors and can be predicted by users' attitude and how much they perceive the robot to be useful.

Stafford (2013) [11] suggests that ITU can be problematic when researching robot acceptability with OA and people with dementia. This is because questions about intending to use robots in the future do not always make sense to participants when they know a robot is not going to be available to them after completion of a study.

In contrast to studies which have used ITU measures, those examining the impact of direct robot experience on robot acceptance over longer periods of time in the user's usual living situation [6, 7, 9, 26] have the potential to provide more useful information on acceptability. Pfadenhauer and Dukat (2015) [28] provide insight on the importance of exploring acceptability factors in context. They ethnographically examined the deployment of *PARO* in a German residential care setting for people with dementia, using participant observation and video-graphic documentation of approximately three group activity sessions per month, over one year. They found that *PARO* was used in a variety of ways: to facilitate communication, as a conversationalist, and as an observation instrument. They

concluded that the robots appearance and its deployment were interdependent, as through these, humans establish how (and if) a technology will be used and what it means to them. Such decisions are influenced by users' perceptions about their unmet needs and how well they think a particular robot will meet these needs.

#### 2.1.4.3. Perceived usefulness (PU)

Social robots need to be perceived by users as useful and relevant to their current unmet needs [15,21, 29-31]. De Graaf (2015) [26] explored acceptability with a rabbit-like health promotion robot, Karotz, placed in the homes of OA (n=6) during three ten day periods over six months. The robot was programmed to greet participants, provide a weather report, advise on activity levels, discuss daily activities and remind participants to weigh themselves. Interactions were videoed and semi structured interviews were conducted. Researchers found that, at each usage phase, participants talked most about whether or not the robot was useful to them.

This suggests that identifying needs accurately may improve robot acceptability. However, ascertaining perceived needs of OA and people with dementia can be difficult and is impacted by many factors. For instance, identifying unmet needs is complicated if OA have reduced awareness of their own needs due to habituation or if they are unwilling to acknowledge disability fearing stigmatisation or loss of independence [11]. Furthermore, people with dementia may not have the cognitive ability to identify or express their needs [31] or they might believe that social robots are not useful if their needs are currently being fulfilled by caregivers [32]. Indeed, several studies suggest that people with dementia and their carers can disagree as to the nature of their unmet needs and potential solutions provided by robots [12, 30, 33]. This fact impacts robot acceptability by individuals and is discussed further below with reference to social influences.

Due to the challenge involved in accurately assessing the unmet needs of people with dementia and OA, Stafford (2012) [29] recommends that robot designers consider this issue early and regularly during the robot design stage using data triangulation and 'open' methodologies, with participants who match the end target users.

#### 2.1.4.4. Perceived Ease of Use (PEOU)

This section examines research which has addressed issues of perceived practical utility, which includes usability and PEOU. It focuses on what can enhance usability and therefore potentially increase acceptability.

The impact of usability issues of social robots for people with dementia is illustrated by Kerssens, Kumar et al.'s (2015) study [34]. This tested the acceptability of Companion, a touch screen technology which delivers psychosocial interventions to assist in the management of neuropsychiatric symptoms of dementia and seeks to reduce carers' distress. People with dementia and carers (n=7 dyads) were studied in participants' own homes, interacting with Companion for three weeks. PEOU and utility issues were important as all participants had comorbidities and the majority experienced visual, hearing, or fine motor difficulties. Companion was personalised to individual people with dementia by uploading information such as photographs, videos and messages from trusted people, information from life story interviews including food preferences, important routines, positive life events, memories and interests. Carers selected problematic symptoms that they would like to be targeted as intervention goals. Baseline status of these goals were recorded along with measures of participants' expectations of the technology using Davis' (1989) [35] scales of PEOU and PU. Post intervention objective and subjective measures suggested that Companion was perceived as easy to use and it significantly facilitated meaningful positive engagement and simplified the carer's daily

lives. However, people with dementia (n=2) did not use Companion independently, due to their physical limitations, and others (n=2) ignored the robot's interventions, even when these were noticed. Notably, carers also enjoyed the reminiscence of their shared past afforded by Companion. Regarding the targeted goals for reducing symptomatic behaviour, in 50% of cases carers rated people with dementia status as improved.

Improving the acceptability and usability of robots requires robot design to be matched to user group (i.e. carer, people with dementia, OA), individual requirements and environmental considerations. This means that all social robots need to be easily cleaned [14]. Those for use in peoples' homes need to be robust, require little maintenance or troubleshooting, and to be able to navigate environments with dynamic and static obstacles, uneven floors and possibly stairs, in conditions in which lighting varies along with door thresholds. In residential care, different designs are possible due to wider hallways, possibly static floor plans and duplicate furnishings [31].

In the context of residential care, robots need to accommodate the needs of multiple users with different physical and cognitive limitations. Campbell (2011) [36] conducted an observational case study involving nursing home residents (n=5), some of whom had advanced dementia. She found that a robotic dog and cat enhanced communication and were enjoyed by residents, but the off switch on the abdomen of a robotic dog was too stiff for people with arthritic fingers. Saaskilahti, Kangaskorte et al. (2012) also found that having a microphone hanging around the neck or worn on the wrist of OA, helped participants (n=4) to use a Kompai robot skype call function, when it was difficult for them to bend over the device [37]. Participants in this study liked the intuitive skype-call feature with only two buttons and the capacity to adjust the touch screen, making it optimally sensitive for specific users. It was also useful having controls operated through touch and speech options, although touch was more reliable as operating the robot through voice-commands required extremely clear speech. Researchers also noted that users needed to learn to wait 3 seconds for the robots response and a participant suggested that the robot could say 'please wait a moment' to avoid the user giving it too many commands at the same time [37].

OA with reduced hearing, visual impairment or cognitive deficiency can find robots easier to use if they accommodate multiple interactive modalities [23, 38]. Khosala, Chu et al. (2012) [38] found that nursing home residents (n=34) with sensory impairments and short term memory loss used different modes of communication at different times during a card game of Hoy with a robot called Matilda. The robot's visual display helped participants remember and see the numbers which were called out verbally. However, it should be noted that although people want robots to communicate with them via acoustic and visual modalities, ultimately OA prefer robots to use direct speech [19].

PEOU may be rated higher with longer use, habituation and learning. Torta et al.'s (2014) [39] study tested acceptability of a small robot used as a communication interface with an integrated smart home system in a usability laboratory set up as real-life user apartments. OA (n=6) had two sessions during a two week period and (n=2) had eight sessions over three months. Participants found that the system became easier to use during later sessions, particularly commenting how over time they became more accustomed to the robot's speed and behaviour.

A small amount of work has examined how OA and people with dementia learn to use robot interfaces and what helps them to remember how to use these after a period of non-use. Some evidence is provided by Granata and Pino (2013) who found that people with MCI (n=11) completed tasks slower, learned slower and committed more errors than OA (n=11) when performing tasks using the agenda and shopping list function on the robot Kompai.

Prior computer experience influenced rates of learning but there were no differences based on age or educational levels. Some participants had difficulty understanding the navigation and the authors recommend that the use of more intuitive designs, which reduce the number of steps in a process and hide choice lists until 'parent' categories are selected by users [40].

In summary, it is important that robots are matched to the needs and capabilities of the end users. PEOU can be improved over time with practice and learning. However, the literature has identified the following as factors related to PEOU; audio and visual communication of robot, ease of use of buttons and adjustability of monitor. It is also noteworthy that no studies were identified to have explored PEOU in depth, concerning how psychological factors of people with dementia and OA impact their perceptions on how easy robots will be to use.

#### 2.1.4.5. Perceived Enjoyment (PE)

If people are able to use robots and have a choice about doing so in a voluntary domestic context, motivational factors such as PE come into play as acceptability increases if the robot is perceived to be fun and if it provides entertainment [15, 17, 41]. Heerink, Kroese et al. (2010) found that PE correlated significantly with intention to use (0.420  $p < 0.05$ ) and minutes of actual usage (0.625  $p < 0.01$ ) in an experiment with an iCat robot, made conversational using a hidden operator [42]. Participants consisted of semi-independent OA (n=30). Participants completed questionnaires on their experience of conversing with iCat, asking for information on weather, the TV schedule or for a joke.

However, de Graaf's (2015) [26] and Torta et al (2014) [39] found that PE reduced over six months and eight months respectively. This suggests that novelty effects may enhance PE initially but then decrease over time, potentially resulting in less robot acceptance in the longer term.

#### 2.1.4.6. Social Presence (SP)

Robots whose function is to motivate and stimulate users require a degree of social presence (SP) relevant to their purpose, because users need to perceive that they are in the company of a social entity. Indeed, robots' potential to possess SP appears to be their advantage over non-robotic technologies. SP can be optimised by using embodied robots which are physically rather than virtually present, sharing the same space as the user. Tapus and Tapus [43] explored a robot which was used as a tool to monitor and encourage cognitive activities for people with dementia, in an eight month study with people with dementia (n=9). The robot provided customised cognitive stimulation by playing music and games with the user. Researchers compared responses to a humanoid torso design on a mobile platform with a simulation on a large computer screen. They found that participants consistently preferred the embodied robot to the computer and concluded that embodiment facilitated users' engagement with the robot as they shared their context.

However, the size of the robot is also important, as SP can be sub-optimal if it is too small and users fail to notice it. Torta et al. (2014) [39] evaluated a 55cm tall socially assistive humanoid robot as a communication interface within a smart home environment, in a usability laboratory set up to mimic a real apartment. OA (n=8) tested robot acceptability with scenarios including; asking about weather conditions, listening to music, doing exercises, receiving environmental warnings, and calling a friend to make plans to meet up. Participants experienced 2-8 sessions over variable time periods lasting 2-12 weeks. They found that participants had low anxiety levels and enjoyed the robot, but its SP scored very low due to its small size.

It is also important that robots are not too large. Robinson, Macdonald et al. (2013) [44] tested the acceptability of two robots, Guide and PARO for people with dementia (n=10) living in an institution. Guide at 1.6m tall can facilitate making phone calls, provide access to websites, and offers games and music, whereas PARO is approximately 55 cm long. Over a one week period, five minute demonstrations of robots were provided to people with dementia residents (n=10), family members (n=11), and staff (n=5) and a one hour long interactive session with the robots was videoed, transcribed and analysed. Semi-structured interviews were also held with staff and relatives. The findings suggested that residents responded and talked to PARO (n=6) more often than Guide (n=2). All residents touched PARO whereas 40% (n=4) touched Guide. Staff and relatives were more enthusiastic about PARO compared to Guide. They thought that PARO would be more useful in their setting because it encouraged tactile contact and had beautiful eyes. However, some relatives (n=5) and staff (n=3) thought it was too bulky and recommended it be made smaller. The potential for Guide to facilitate activities and stimulate residents was acknowledged but most participants considered that people with dementia would be unable to use it alone. In particular, participants had mixed opinions about Guide's size. Some thought it was too big and intimidating, whilst others acknowledged that its size enabled people to interact socially around it and it was not likely to be overlooked. This finding is supported by the findings of other studies which suggest that large robots can induce feelings of intimidation, anxiety and feelings of being unsafe [45, 32].

Acceptance is likely to be enhanced if robots are customised regarding their size, to fit the context in which they are deployed [14] and their function. Larger robots could be useful for mobility aids [14], they may have more SP and are less likely to be overlooked by people with dementia or OA who may have poor eyesight [12]. The literature also reveals that it is paramount for people to feel comfortable during interactions with a robot [19] and this can be affected by perceived sociability.

#### 2.1.4.7. Perceived Sociability (PS)

Social presence and PS have been found to correlate (beta 0.540,  $t$  3.399,  $p < 0.005$ ) [15]. PS concerns a user's need to believe that the robot has social abilities which enables them to function as an assistive device. PS is impacted by aspects of robot appearance, behaviour and communication styles.

#### 2.1.4.8. Robot Appearance

Scopelliti et al. (2005) [19] found that people hold a variety of opinions about the materials that robots should be made from and their colour. Begum, Wang et al. (2013) [32] conducted an acceptability and feasibility study in a home simulation laboratory, for a 40 inch tall prototype robot (Ed), based on an iRobot Create platform, which can deliver speech prompts to assist people with dementia performing a domestic sequence of events such as making a cup of tea. Researchers videoed interactions and interviewed people with dementia and caregivers (n=5 dyads). They reported a lack of consensus regarding whether a robot's voice should be soft or authoritative, and the gender it should represent.

Other issues influencing robot design concern how realistic they should appear to be and user preferences for a human-like or mechanical-like appearance. These questions relate to the uncanny valley concept [46], which suggests that people find robots more acceptable as they become realistic and human-like but when they are almost human, people are uncomfortable with them. Perceived human likeness was associated with more anxiety and elevated heart rates in OA participants compared to their formal carers in the Stafford, Broadbent et al. (2010) study described above [23]. This suggests that the uncanny valley concept varies between individuals and groups and it may be linked to anxiety.

Pino et al. (2015) [30] found that people with dementia (n=10) preferred a mechanical human-like robot with anthropomorphic facial features and global mechanical looking design. These authors used a mixed methods approach which aimed to discover how the views of people with dementia, their carers (n=7) and OA (n=8) converge and diverge regarding robot applications, feelings about technology, ethical issues and barriers and facilitators to adoption. Twenty five participants completed a survey and 7 completed a focus group. Few people preferred the android robot, and no-one voted for the one which was human-like. Participants with dementia were moderately interested in a robot having realistic human-like features, but OA were less so. Arras and Cerqui (2005) [24] conducted a large survey with respondents who were attending an international Swiss Expo-02 robotics exhibition (n=2042; Male 56%, Female 44%; OA 11%). They found that only 10% of people aged over 65 prefer humanoid robots.

However, the impact of realism on acceptability may differ concerning zoomorphic robots. Heerink et al. (2013) [47] compared the acceptability of PARO with other zoomorphic robots a: baby seal, puppy, cat, dinosaur, and bear. They interviewed professional caregivers (n=36) and observed the responses of people with moderate dementia (n=15). In the hour long sessions, each person with dementia was presented with the various robots for one minute, and their responses were observed. The baby seal scored highest for its simplicity, softness and because it was lighter and more portable than PARO. The cat was preferred second as it was realistic. PLEO, the dinosaur scored lowest, being regarded as unfamiliar and reptilian.

However, degrees of realism may not be key as acceptance can increase if a robot has an 'undetermined design' which facilitates interpretive flexibility by allowing people to interact with it in a variety of ways to fulfil their needs [5]. Chang, Sabanovic et al. (2013) explored the social and behavioural mechanism behind PARO's therapeutic effects. They analysed participant behaviours in video recorded 8 weekly group interactions between people with dementia (n=10) living in a retirement facility, and therapists and found that PARO was used in a variety of ways, and it increased physical and verbal interactions between participants. Spiekman et al. (2011) [13] also found that realism did not increase preference for a robot when they conducted an experiment to determine which characteristics are most important for a robot to support OA living alone. They evaluated four robots (iCat, Nao, Ashley and Nabartag) on 'wizard of oz' settings where researchers controlled them, but they appeared autonomous to OA (n=29). Data was collected by questionnaire after interactions with the robots which involved a short scripted conversation, initiated by the robot. Three components were found to determine participants' evaluation of the robot: realism, intellectuality and friendliness. Realism was not the key to preference as the most unrealistic agent (Nabartag) scored as high as the most realistic (Ashley) in terms of which agent participants would prefer to have at home. However, realistic facial features were important as they increased acceptability by effecting levels of trust, and perceptions of social presence, enjoyment and sociability.

Research concerning facial features suggests that opinion varies as to which features are preferred and whether or not they should be human-like [32]. Broadbent, Tamagawa et al. (2009) [12] concluded that some OA prefer a robot without a face, whereas no significant preferences for male/female human or machinelike faces was reported by Stafford et al. (2014) [48] when they evaluated the responses of participants (n=20; over 55 years), recruited at a university, to six different face conditions presented on a computer screen in a randomised order. With each display condition, participants interacted with the robot for 5 minutes using a psychotherapy programme which provided a constant conversational platform. Similar work was completed by Disalvo (2002) [49], who explored which aspects of robot faces need to be present for them to be regarded as human-like. Disalvo (2002) collected images of 48 robots and OA (n=20) rated their degrees of humanness on a scale

of 1-5 in a paper survey. They found that specific facial features accounted for 62% of variance in perception of humanness, which is most increased by a nose, eyelids and mouth being present. Robots with the most facial features were regarded as more human-like. Disalvo (2002) concludes that humanoid heads should have wide heads and wide eyes; the brow line to the bottom of the mouth should dominate the face; less space should be afforded to the forehead, hair jaw, or chin, and detail is needed in the eyes. For a humanoid face, eyes need to include a shaped eyeball, iris, pupil and four or more other features, preferably a nose, mouth, eyelids and skin.

Some robot designers have explored acceptance of human-like robots with minimalistic design and facial features [45, 50]. Khosla, Nguyen et al. (2014) [45] describe successful field trials with Matilda, an emotionally engaging small social robot with a minimalistic baby face which has a facial expression recognition system and is able to incorporate user preferences and personalise its services. Trials were conducted over a six month period, in seven Australian households involving people with dementia (n=7) and their carers. Interviews were conducted and interactions video-recorded with data analysed for participants' emotional response and quality of robot experience. The findings suggest that people with dementia enjoyed one to one activity with Matilda. All participants agreed or strongly agreed to the question 'Matilda makes me smile', saying 'Matilda is a friend' and 'Matilda does not worry me'.

A minimalistic tele-operated android, Telenoid, has also been evaluated regarding its acceptability in a one day field trial involving people with dementia (n=10) [50]. Researchers asked participants how they perceived its appearance to be compared to a human and if they thought Telenoid could help them. Participants were told that Telenoid could be used like a telephone, although they could see the robot operator in the room. Researchers observed participants showing strong attachment to its child-like huggable design and were willing to converse with it. Some perceived it as a doll or a baby.

It is clear that there is a lack of consensus regarding the optimal appearance of social robots. However, a robots appearance does not affect acceptance in isolation, but users respond to a package which includes the robots expressions and communication behaviour. These are now discussed below.

#### 2.1.4.9. Robot Behaviour and Communication Styles

The way in which a robot communicates and behaves should be compatible with the social context in which it is deployed and should be consistent with users' perceptions of its status and role [28, 42]. Säskilähti (2012) [42] found that OA (n=6) felt safer when Kompai gave a short warning signal before it started to move and stopped a sufficient distance from them.

Walters and Dautenhahn (2006) [51] compared user stress responses and preferred stopping distances of the human size mechanical-like PeopleBot as it behaved 'ignorantly' and then in a socially acceptable human-like way. Participants, university staff and students (OA n=3, in a total sample of n=28) performed a prescribed task which was interrupted by the robot in a simulated living room. The ignorant robot (optimal from a robotics perspective) took the shortest path between two locations and made little change in its behaviour in relation to the human. The socially interactive robot modified its behaviour to not get too close to the person, especially if their backs were turned. It moved slowly when closer than 2 meters, took a circuitous route when necessary, and appeared to be alert and interested in what the human was doing by looking actively at them. It also anticipated, by interpreting the human's movements, and waited for an opportune moment to interrupt the person. Stress was measured using a handheld device, video observation and questionnaires. Reports from this study do not separate findings pertaining to OA from the

rest of the participants, but findings suggest the majority of participants disliked the robot moving behind them, blocking their path or moving on a collision course towards them, especially when it was nearer than 3 meters. Sixty percent preferred the robot to stop 0.45-3.6m from them and forty percent allowed it to 0.5m from them which is on the edge of the intimate zone for human-human contact. Ten percent were uncomfortable with the robot approaching closer than between 1.2 and 3.5m, reserved for conversations between human strangers. Walters and Dautenhahn (2006) acknowledge that longer term studies are needed to establish how becoming familiar with the robot over time affects these preferences.

Communicating in a human-like way may be particularly important for robots designed to stimulate people with dementia. Cohen-Mansfield et al. (2010) [52] found that people with dementia (n=163) living in a nursing home were significantly longer engaged, more attentive and positive towards 23 types of social stimulus compared to non-social stimulus. These stimuli included a doll, a real dog, a plush animal, a robotic animal, a squeeze ball, an expanding sphere, music and a magazine [52].

It has been suggested that robots need to develop 'robotiquette' [9]. This needs to include being experienced as warm, open, creative, calm, spontaneous, efficient, systematic, cooperative, polite and happy [14, 55]. Issues of robot and user personality are also important. Brandon (2012) [55] interviewed relatively fit and able OA (n=22) and conducted two experiments in a simulated home-like laboratory aiming to discover the effect of matching personalities of the user and robot, with a mobile robot able to provide agenda and medication reminders. They found that participants recognised different personalities designed into the robots and extrovert robots were perceived as having significantly higher sociability, social presence and PE compared to an introverted robot. Participants preferred robots with similar rather than complementary personalities to themselves. However, they were more anxious about the robot who had similar extraversion levels to themselves. Furthermore, personality and behaviours need to be consistent with robot function and the users' expectations of their role [11, 12, 56]. Amirabdollahain, Akker et al. (2013) [57] investigated OA (n=41) response to robots undertaking specific tasks and roles in the laboratory setting. They aimed to investigate if preferences for a robot depended on context and the stereotypical perceptions held by people about certain jobs. They found that the acceptance of robots was not increased by complimentary or similarity of personality between the user and the robot but through the robot having a personality which fits the users' expectation for the particular task and context.

Heerink, Kroese et al. (2006) [41] investigated which social features are necessary for robots to make effective social partners. The responses of cognitively able nursing home residents (OA; n=40) to iCat robots, manipulated to be socially or non-socially expressive were compared. The socially expressive iCat was designed to look at participants, be cooperative, nod and be smilingly pleasant, use participants' names and remember personal details about them and admit its own mistakes. The researchers concluded that participants were more comfortable with the more socially expressive robot and they communicated with it more extensively. Participants in Pino's (2015) study cited above also considered facial expressions were important as they represent emotional capabilities [30]. Sakai et al. (2012) [58] describe an autonomous virtual agent, capable of speech recognition, which can nod its head, providing verbal acknowledgment to users. Details of their evaluation experiment are not provided, but authors state that their participants with dementia were more engaged by the robot when it provided them with feedback.



Recent advances in technology is making possible robots which are more emotionally responsive to users and this may enable them to be perceived as more sociable. The robot Matilda, whose field trials are described above, can respond to users' emotions as it incorporates emotion measuring techniques which can recognise the user's facial expression. This facilitates more natural social interaction which can incorporate user preferences and personalised services [45]. Brian is another robot which can determine user engagement and activity states and uses this information to determine its own emotional assistive behaviours [59]. McColl et al. (2013) tested Brian's acceptability and ability to provide encouragement, prompts and orientating statements to people with dementia (n=40), living in long term care, during mealtimes and when playing a memory card game. Participants were observed interacting with Brian for an average of 12.6 minutes and 22 questionnaires were analysed. The robot was relatively successful in motivating and engaging participants: (n=33) engaged all the time, (n=7) engaged some of the time; (n=35) complied with Brian all the time, (n=4) some of the time, (n=1) didn't comply (the robot's voice interfered with his hearing aid); 82% smiled or laughed in response to Brian's emotions and some were successfully re-engaged on task by Brian.

#### 2.1.5.10. Trust and Perceived Adaptivity (PA)

This section reviews studies that explored the importance of trust, suggesting that it underlies and interacts with the need for perceived control of the robot and PA. It is argued that users need to trust the robot and be comfortable with a particular level of perceived control, but they also require socially savvy robots to have a degree of autonomy and adaptability [17]. An acceptable balance between these variables probably varies between individual users, with robot purpose and deployment context. However, further research is needed with larger samples to confirm these propositions.

Heerink (2010) evaluated the effects on acceptance of PA [15] using identical experimental conditions to those described above (Heerink, 2011 [16]), showing a film of an adaptive and less adaptive RoboCare version providing OA with medication reminders, fitness advice, health monitoring and help calling for assistance. Participants preferred the more adaptive robot and rated it higher in terms of ITU, perceived enjoyment and perceived usefulness. However, they felt more anxiety towards the robot, which the authors suspected was because they had less control over its actions.

Users have to trust that robots will be safe and reliable [19], and trust has to be earned [14]. Frennert, Efring et al. (2013) [14] conducted a series of workshops with OA living in their own homes who had moderate sensory and mobility impairments. Participants were asked to respond to sketches of different robots stating their preferences for an ideal robot. They also interviewed OA (n=5) and one couple who lived with polystyrene style foam mock-ups of these ideals for one week. They found that feelings of control were crucial and connected with issues of trust and privacy.

The determinants affecting user trust and ITU with assisted living robots has also been investigated using a survey questionnaire with OA (n=292) [60]. This study described to participants two emergency scenarios in which the robots would be available to help respondents in a fire and when they were very unwell. Unsurprisingly, respondents said that they would be highly motivated to use the robots in these situations and trust in the robot strongly related to ITU (0.51). Trust levels were also correlated with PEOU (0.49), PU (0.50), and expected reliability (0.63). Scopelliti (2005) [19] also found that trust in the capabilities of robots for use in a domestic situation influenced OA (n=37) responses concerning three dimensions; robot benefits, disadvantages, and mistrust of robots. Mistrust was shown by 85% of participants who did not want a robot to move freely in the house and 82% were afraid of potential damages.

Within the literature the question arises as to how predictable and controllable users want robots to be. De Graaf (2015) [26] found that participants wanted more control over Karotz. As time passed they felt that this would help maintain their privacy and help them cope when unexpected human events occurred. For example, it was problematic when Karotz continued to remind them about their health promotion activity schedule when guests were present. They wanted Karotz to adapt to their needs, have more sophisticated interaction capabilities and more conversation topics.

In addition, a need for adaptability may be influenced by user perceptions of the opinions of significant others. Heerink (2010) [15] found that users were more influenced by the opinions of significant others when robots had greater adaptive capability.

#### 2.1.5.11. Social Influences and Facilitating Conditions

Most studies identified here do not focus on examining the impact of social influences. However, the social influence of significant others was one of the strongest predictors of ITU home healthcare robots by patients and healthcare professionals (n=108; OA 11.15%; 18-33 years 77.7%) who all used a computer daily [61]. This online and paper survey which collected quantitative and qualitative data, also found PU, trust, privacy, ethical concerns and facilitating conditions to be important. Wu et al. (2014) [62] also found social influence to be important after OA with MCI (n=5) and OA (n=5) interacted with the Kompai robot in their living laboratory study.

Social influences also encompass broader cultural issues, but few studies identified in this review appear to take account of cultural factors, and none specified the cultural background of their samples. Two studies were conducted in more than one country. Klein and Cook (2012) [6] found participants in care homes in the U.K. and Germany accepted PARO and PLEO to similar degrees. Whereas Amirabdollahian, Akker et al. (2013) [56] noted that OA in the UK and France had greater concerns about the need for privacy when asked about robot design, than those in the Netherlands. The former did not want images from within their home shared with other parties.

Another cultural and societal issue which can reduce the acceptance of robots involves negative ageist stereotypes [62, 30, 63]. Neven (2010) [63] examined how images of OA shape technology development by observing researchers interviewing OA (n=6) and 30-60 minute interactions between them and an unnamed robot. They found that ageist assumptions influenced robot design and implementation and that OA may have different representations of what being older means. Furthermore, if potential robot use is associated by OA with being perceived as lonely, isolated and dependent, they can be reluctant to be associated with them. This may be because using the robot would be contrary to their self-image and the image that they want to project, which is that they are healthy and independent [11, 14, 63].

Acceptability is also impacted by stakeholder opinions concerning the ethics of robot usage. Wu, Fassert et al. (2012) [64] conducted three videotaped focus groups with OA (n=8) and OA with MCI (n=7) who held a variety of views about the appearance of 25 robots displayed on a screen but all participants discussed ethical issues, expressing concern about robots replacing or reducing human contact.

#### 2.1.5. Discussion and Future Research Directions

Findings from the studies reviewed here reveal the key factors affecting the acceptability of robots by OA, people with dementia and OA with MCI. The literature suggests that acceptance is influenced by the psychological variables of individual users [11, 21, 23, 47, 48] and their social and physical environment [62, 30, 32, 61, 65]. These variables interact with one another to influence acceptance in each context [16, 61, 65, 66]. This includes

being easy and enjoyable to use [42, 44, 26] and fulfilling their function [32, 34, 64]. To entice people to use and engage with robots, they have to be designed so that they are personalised and conform to user expectations and environmental considerations. The opinions of significant others and what OA anticipate these will be are important in determining whether or not a robot will be accepted [26, 57]. This may relate to OAs' need, as social beings, to be able to project their preferred self-image to other people, therefore maintaining their privacy [11, 14, 63]. It appears important for robot acceptability into OA lives that users are comfortable with the robots degree of adaptability and controllability [15, 26], as this will impact their relationships with other people. Indeed, it may be crucial for acceptability that robots can function balancing these variables.

The literature suggests that it is important that users are able to engage with the robot and this requires that they feel at ease when interacting with it. The possibility of psychological and emotional comfort is increased if a robot has a realistic human-like, expressive face, if its behaviour conforms to human social norms deemed appropriate to its robot role and function, and if it has the capacity to be emotionally responsive to the user [13, 15, 45, 30, 59, 67, 68]. This suggests that acceptability of human-like non-zoomorphic robots designed for social companionship will be enhanced by current and future technological developments regarding the capacity of the robot to read and respond to users' emotional needs.

However, the research identified here has limitations which reflect the relative youth of this developing field and suggests generalisation of findings should be done with caution. Only ten studies were identified to have focused on examining the interaction between variables concerning acceptability of robots [15, 16, 23, 26, 30, 41, 42, 60, 61, 65]. Studies conducted to date have employed a range of research designs (see Table ii), which frequently had sample sizes of less than ten [6, 9, 26, 27, 32, 34, 36, 43, 45, 50, 62]. Other potential biases in studies exist through the lack of blinding in observational studies and that selection bias is not addressed. The latter is problematic in acceptability work where the views of participants who find robots least acceptable may not be captured.

No randomised controlled trials were identified, and the studies include several pilot or feasibility trials [6, 9, 27, 32, 34, 50]. Many of the other studies were primarily aimed to determine robot user preferences and needs [12, 30, 40, 47, 56, 57, 69]. These did not always include all stakeholders who could impact eventual acceptance. Some studies which do involve a range of stakeholders, collect data using mixed stakeholder focus groups [30, 45, 57]. Focus groups can be used to gather information from people with dementia and OA with MCI [70] but it is important that the views of carers do not dominate people with cognitive impairment or dementia [71, 72] who may be less able to articulate their views [73, 74]. Indeed, these difficulties may be exacerbated when in unfamiliar study situations or feeling less powerful relative to other participants. Alternative methods of data collection such as combining observational data collection with individual interviews may improve research validity particularly if the dementia is severe [74-76].

It is noteworthy that most of the studies which had mixed populations of OA, people with dementia and/or OA with MCI, analyse and report their findings together, rather than separating the data and comparing them along group lines. As people in these groups differ in terms of their cognitive ability, future research involving comparative studies may help to determine how the degree of dementia or cognitive impairment impacts acceptability issues. Many studies identified have not involved direct interaction between participants and robots [19, 24, 25, 48, 49, 56, 60, 61, 64, 67] or base their findings on participant-robot

interactions which were less than one hour long [8, 12, 13, 15, 16, 23, 32, 36, 40-42, 44, 47, 55, 51, 63].

According to the Almere model, intention to use (ITU) results in actual robot usage depending on facilitating conditions and social influences [15]. Findings from this review suggest that ITU is not a reliable predictor of long term robot acceptability [15, 26, 27, 39, 51, 62] and that people interpret and make use of robots in their own context [66] and that variables such as attitudes, perceived ease of use and enjoyment change over time [26, 39, 62] as users become more familiar with a particular robot. Therefore, robot acceptability should ideally be examined over a long duration in the participants living situation. Most of the studies identified here which conform to this ideal [5-7, 9, 26, 45, 34, 51, 66] have involved PARO. Those which used university rooms or simulated living laboratories [13, 62, 51, 27, 32, 48, 55, 63, 65] provide helpful but tentative information about how factors affect robot acceptability.

There are many opportunities for future empirical investigation to confirm the findings of this review and to develop this field of study. The impact of acceptability variables needs further examination with larger samples, in real world situations, with a variety of robots, using longitudinal robust study designs which address the complexities of conducting research with people with dementia and OA. In particular, there is potential to explore how acceptability is affected by the manner in which OA and people with dementia are introduced to robots and supported in learning how to use this technology. Related to this topic, it would be valuable to know more about how psychological factors impact users' perceptions on how easy robots will be to use. It would also be useful to investigate if optimal levels between robot controllability and adaptability can be determined, if these vary between users, and if acceptability is increased by varying the adaptability of robot behaviour according to whether it is being used in a public or private situation. If robot behaviour is made more human-like in this regard, robot users may be able to present their preferred public personae whilst using the robot. This topic may be important as it links to users' needs as social beings and because it is the ability of robots to be autonomously adaptive which makes them different to traditional technologies and potentially more useful.

Future research needs to focus on the impact of stakeholders and significant others as facilitators or barriers to acceptance. It also needs to be conducted with different cultural groups, to explore the impact of cultural factors and cross-cultural differences within a user's social or physical environment and their impact on robot acceptability. In addition, research is needed to explore the impact on acceptance of macro societal level factors, such as power relationships, ageism, economics, the media, and legislation. These factors potentially influence every aspect of the arena in which individuals' research, develop, deploy, and experience robots and no studies concerning them were identified by this review.

#### 2.1.6. Conclusion

This paper adds to the state of the art as for the first time a body of literature has been analysed according to a validated theoretical acceptability model. The review found acceptability of robots for OA, people with dementia and OA with MCI is likely to be improved if robots use human-like communication and if they meet users' emotional, psychological, social, and environmental needs. Robots acceptability is impacted by factors which interact at the level of the individual user and robot. These are influenced by significant social others and other macro-societal level factors. Future work aiming to promote acceptability will need to address the facilitators and barriers to acceptance at the level of individual users, significant others, and society. Whilst valuable work has been

## Chapter Two. Paper One.

completed to date, exploration about robot acceptability for people with dementia and OA is in its infancy. There are numerous opportunities to explore and investigate this expanding field further.

Table 2.2. Characteristics of Studies investigating acceptance of Social Robots

Studies involving OA									
Study ID	Country	Robot	Aim	Design	Methods	Setting	Study Population	Duration of robot contact	Core Outcomes
Stafford [21]	Australia	Cafero	To ascertain if perceptions of mind agency and attitudes towards robots predict their usage	Pre-post intervention comparison	Attitudes and perceptions of mind measured at baseline and after demonstration videoed interactions with robot then measurements repeated	Retirement village	OA (n= 23) data completed and OA (n=11) used robot during trial	2 week trial	Amount mind agency/experience perceived predicted how much users ITU
Stafford [23]	Australia	Cafero	To assess whether or not people's robot attitudes changed on meeting robot and if could be predicted	Quantitative and Qualitative data pre-post intervention	Baseline measurements and attitudinal scales questionnaires	Retirement village	OA (n=21) Formal Carers (n=32)	30 mins.	Meeting robot resulted in reduction in anxiety and improved attitude
Spiekman [13]	Netherlands	iCat Nao Ashley and Nabartag	To investigate acceptability of various service type social agents for people with dementia	Experiment	Wizard of Oz operated controlled for voice and script. Questionnaires completed following interactions	Laboratory	OA (n=29)	Short	Evaluated agents according to facial realism, intellectual components and friendliness.
Heerink [41]	Netherlands	iCat	Examines the influence of the user perceptions of the robots' social abilities	Experiment	Interviewed re perceptions after interacting with iCats manipulated as more and less socially	Residential care	OA (n=40)	5mins. with each condition	More comfortable with socially communicative condition.

Chapter Two. Paper One.

					communicative in Wizard of Oz setting				
Heerink [42]	Netherlands	iCat	Explored concept of PE	Experiment	Test session, then questionnaire interview and long term observation	Residential care	OA (n=30)	1-5 mins. to max. of 16 up to 9 times	PE affects ITU ITU predicts actual usage
Heerink [15]	Netherlands	1, iCat 2. Video of RoboCare 3. Actual use of iCat – interacting through a touch screen interface 4. Actual use of Steffie, virtual screen character	Proposed Almere model. Describes development and testing of this.	4 experiments and longitudinal data collection	1. Manipulated expressiveness of robot 2 movie of 2 robots different adaptiveness 3.4. Robot used in public setting and screen agent in private homes. Steffie installed in computer of participants used to assist online activities	3. Elderly residence	1. OA (n=40) 2. OA (n=88) 3. OA (n=30) 4. OA (n=30) computer owning	3. one week	1. Socially expressive iCat evoked more social presence, more PE and Intention to use (ITU) 2. more adaptive was more PE, ITU and more anxiety 3. Actual use predicted by ITU 4. ITU predicted by PU and Attitude; PE predicted PEOU; Perceived sociability predicting PE
Stafford [48]	Australia	Peoplebot robot installed in psychotherapy programme	Assess acceptability of face displays	Cross sectional repeated measures study	Evaluated responses to six face conditions on computer screen	University room	OA (n=20)	Virtual contact	No significant preferences for robot faces
Torta [39]	Austria	Small humanoid robot integrated	Explored acceptance of this robot	Experiments	Tested using 5 real-world scenarios	Usability laboratory simulated	OA (n=8)	8 sessions over 3 months (n=2). 2 sessions	PE might reduce over time; it is possible to have an emotional trusted

Chapter Two. Paper One.

		with smart home				real apartment		over 2 weeks (n=6)	relationship with robot
Walters [51]	UK	Peoplebot	Explored preferred stopping distances and approach direction	Experiments	Measured preferred stopping distances.	University room furnished as a living room	OA (n=3) (11% of adults sample of (n=28)	Short	60% comfortable within personal social zones for human equal to friends acquaintances strangers
Brandon [55]	Netherlands	Florence Robot	Test effect of user robot personality matching on acceptance	Experiments	Interviewed and conducted 2 experiments with robot programmed with extrovert or introvert personalities	Laboratory home-like room	OA (n=22)	Short	PS and PE higher with extrovert robot. OA recognise robot personalities
Sung [7]	Taiwan	Seal-like robot	To evaluate the effect of a robot assisted therapy for OA in Taiwan in residential setting	Pilot study pre and post-test	Group robot assisted therapy with trained nurse facilitator  Communication and interactions skills assessed with activity participation scale. N.B.no control group	Residential setting	OA (n=12) who were not deaf and did not have social interaction problems	20 mins twice weekly for four weeks	Significantly improved communication and interaction skills and participation activity
Pfadenhauer [28]	Germany	PARO	To assess how PARO was being accepted and utilised	Ethnographic	Group interactions recorded	Residential Geriatric care setting	OA - details of residents not given in paper	1 year observation period – PARO used 3 times a month	What a robot is can only be decided when its deployed
Amirabdollahi an	ACCOMPANY EU Project Internation	Care-O-Bot 3	To identify user needs and explore	Qualitative methods	Focus groups with 4-10 participants discussed user		OA (n=41)  OA and carers	None	Highlights principles of autonomy,



Chapter Two. Paper One.

[56,57]	al Netherland s, UK, and France		expectations for robot roles		requirements in scenario presented robot fetching water. Other scenarios also developed.		informal (n=32)  formal carers (n=40)		independence, enablement, safety and privacy. Found tension between  privacy and autonomy over safety.
Heerink [16]	Netherland s	RoboCare	To explore the influence of gender education and age computer experience on acceptance	Qualitative	Showed video of OA using robot, participants completed questionnaire	Residential home	OA (n=66) residentially living partially independent	Short	Almere model constructs and reliable and correlate with anxiety.
Broadbent [12]	New Zealand	Multiple robots	To investigate tasks for robot assistance, attitudes and preferences	Cross sectional	Asked preferences and tasks they would like help with from diagrams, images and models of robots. Used positive and negative affect schedule and robot attitudes scale	Retirement Village	Residents OA (n=32)  Staff (n=15)	1 session	Preferred silver robot 1.25m height. Help with falls, turning off appliances, lifting, cleaning, medication reminders, making phone calls, monitoring location
De Graaf [26]	Netherland s	Karotz	To explore acceptance and continued use of social robots	Longitudinal	Robot installed in homes. Content analysis of interviews.	Homes	OA (n=6) 1st phase  (n=5) 2nd phase  (n=5) all 3 phases	10 days each 3 times	Talked most about usefulness of robot. PE important as was adaptivity. Trust more important than privacy

Chapter Two. Paper One.

Wing-Yue [77]	Canada	Brian 2.1	To investigate acceptance of Brian for OA	Not specified	Administered robot acceptance questionnaire during a robot demonstration session	At a seniors club but home living participants	OA (n=46)	Brief	Majority had positive attitudes towards it
Disalvo [49]	USA	Images of 48 humanoid robots	To understand how features and dimensions humanoid robot face contribute to perception of humanness	2 paper Surveys	No details provided on how or where survey administered	No details	OA (n=20)	None	Presence of certain feature, dimensions influences perception of humanness
Frennert [14]	Sweden	None specified	To report process of participatory design process	Several Qualitative methods	3 participatory workshops recorded; questionnaires and interviews  Mock-up of robots	In usability laboratory and in homes of OA	Workshops 1st OA (n=10) 2nd OA (n=8) 3rd OA (n=9) Questionnaires OA (n=36) Interviews OA (n=14) Mock up adults (n=5) and 1 couple OA	One week	Acceptance depends on multiple variables, personal evaluations, PU, environmental variables, and context important
Arras and Cerqui [24]	Switzerland	None specified	Explores views about sharing lives with robots	Survey	Questionnaire completed after seeing various robots	International Swiss Expo-02 robotics exhibition	OA (n=225) 11% of total sample of (n=2042)	None	Overall positive attitude towards potential
Alaiad [61]	USA	None specified	To understand determinants of home healthcare robots adoption. Tested a research model	Quantitative and qualitative	Survey – online and paper	Participants living at home	OA and healthcare professionals (n=108)	None	Social influence is the strongest predictor of ITU. PU, trust privacy ethical concerns and facilitating condition were important.

									Sociotechnical factors powerful.
Scopelliti [19]	Italy	Non specified	Compared attitudes to robots by people of different ages	Qualitative and Quantitative	1. Pilot study. Interviews 2. Questionnaire	At home	1. Three generations in six families (n=23) included OA 2. OA (n=39) in total sample of (n-118)	None	Generally positive evaluation. OA some mistrust, most fearful, preferred to limit autonomy
Steinke [60]	Germany	None specified	To explore trust in ambient assisted living devices	Survey	Scenarios introduced in survey and questionnaire completed	Varied locations	OA (n=292)	None	A strong relationship re trust and ITU devices; PEOU PU and expected reliability influence trust
Studies involving people with dementia									
Kerssens [34]	USA	Companion	To test the feasibility and adoption of touch screen technology the companion	Qualitative and Quantitative data collected pre-post intervention	Personalised intervention using life story and care needs interviewing; Used several standardised measures.	Own homes	Carer-people with dementia dyads (n=7)  Diagnosis of dementia with MMSE above 10	3 weeks	Technology easy to use, facilitate meaningful and positive engagement. Provided carer respite some people with dementia not able to use independently
Tapus [43]	France	Robot human-like alternates verbal messages with non-	To examine the role of socially interactive robot as tool for	1, Observational  Pilot	Pilot of interactive Robot model games at different levels	Living care facility	Cognitive impairment and/or alzheimers mild (n-1)	6 months after 2 months learning	People with dementia mild can sustain attention to music 20 mins;

		verbal feedback for cognitive stimulation	encouraging cognitive activity	2, Experimental			moderate (n=1) severe (n=7)		14 mins mod; 10 min severe  Enjoyed sessions. Robot part of narratives in lives. No adverse responses
Khosla [45]	Australia	Matilda human-like communication	To examine the acceptability of Matilda	Observational	Pilot of interactive robot multipurpose data through observation videos and robot experience survey	Own homes	People with dementia and carer dyads (n=7)	6 months	Can provide sensory enrichment and social connectivity, carer respite. Most respond positively
Gross [27]	Netherlands	Companion Able Robot	To evaluate the robot's function and acceptability	Qualitative field trial evaluation, Observational approach	Semi structured interview administered couple lived in smart home as if it were own home supported by robot	Smart Home project test house	Couples (n=4): 1 person early dementia or MCI and their partner in each couple	2 days for each couple	Liked cognitive training; became less anxious with exposure; liked it prompting them with tasks;
McColl [59]	Canada	Brian 2.1	To investigate acceptability of Brian	Observations of interactions and questionnaire	Preliminary study measured duration and engagement in interaction – card game and help feeding, acceptance and attitudes towards robot measured	Long term care facility	Mild Alzheimer's disease, mild cognitive impairments, and normal cognitive control group (n= 40)	2 days	Majority people with dementia engaged and complied with the robot's prompts. High scores high on attitudes PE, and perceived sociability

Chapter Two. Paper One.

Yamazaki [50]	Denmark	Telenoid teleoperated android minimalist	To evaluate the effectiveness of Telenoid	Observational and interviewing	Introduced robots and observed interaction	Own homes	OA (n=1) mild dementia (n=1) living alone	2 hours	Positively received
Begum [32]	Canada	Prototype robot Ed teleoperated assistive robot	To assess feasibility of a robot.	Experimental	Completed task of washing hands and making a cup of tea prompted by the robot then interviewed	iDAPT HomeLab at Toronto Rehabilitation Institute eldercare institution	People with dementia (n=5) living in own home MMSE scores 9,24,25,25,18 and carer partners	Brief	Almost all positive about it. Robot has to meet needs.
Moyle [9]	Australia	Giraff – telepresence robot	To assess the feasibility of using Giraff in long term care	Mixed Methods	Verbal and nonverbal behaviour observed during calls with relatives using Giraff and interviewed participants	Long term care	People with dementia (n=5) and families, how dementia diagnosed not specified	Weekly for 6 weeks	High level of engagement and minimal negative emotions. Enjoyed experience and opportunities to reduce social isolation
Cohen-Mansfield [52]	USA	Robotic animals included in stimuli	To examine the impact of different social stimuli on engagement of people with dementia	Quasi experimental . Comparisons made through observation	Impact of attributes of social stimuli Observational Measurement of Engagement (OME) (Cohen-Mansfield et al., 2009) [53]; 23 stimuli presented twice over a period of 3 weeks (4 daily)	7 different Nursing Homes	People with dementia (n=193) MMSE averaged 7.2 (SD: 6.3, range: 0–23)  ADL performance, Minimum Data Set (MDS; Morris et al., 1991) [54], averaged 3.6	Short	Significantly Longer engagement with social stimuli. Social attributes of stimuli are important for people with dementia

Chapter Two. Paper One.

Heerink [47]	Netherlands	Dinosaur Cat Seal Bear	To elicit and specify requirements of robot assisted therapy robot	Observational	Compared responses to robots;	Institutional living	Moderate dementia. No details given	Short	Difficulties observing responses of people with dementia. Individuals' preferences varied. Carers open to alternatives to PARO
Robinson [44]	New Zealand	Guide/PARO	To explore reactions to 2 robots and determine how could be made more useful	Qualitative Cross sectional	Encouraged interaction after demonstration. Videoed and thematically coded this. Interview with relatives and staff	Secure Dementia Unit	People with dementia (n=10) how diagnosed and severity not stated.  Relatives (n=11) Staff (n=5)	10 to 15 mins	PARO preferred to Guide. In this setting robots need to be simple easy to use, stimulating and entertaining.
Sabanovic [78]	USA	PARO	To evaluate PARO in behavioural therapy in nursing homes	Observational  Test retest	Therapist group sessions. Measured baseline then interaction levels after and during interventions	Nursing home	People with dementia (n=10), precise detail of severity is not given but describing quite severe debilitation	weekly session for 7 weeks	Indirect benefits: increased activity in modalities of social interaction, activity levels steady growth over study period. Interpretive flexibility
Takayanagi [8]	Japan	PARO	To compare the effectiveness of PARO to a stuffed lion	Experiment	Interacted with PARO or non-robotic toy, responses observed	Nursing care facility	People with dementia (n=19) mild-moderate 16.4	15 mins with robot and toy 3-	Both groups of people with dementia more

							Hasegawa's Dementia Scale (similar to MMSE)  people with dementia (n=11) severe 8.8	6 months later	responsive to robot
Campbell [36]	UK	Cat  Dog	To analyse the benefits and disadvantages of using robotic pets in residential care	2 Case Studies	Introduced and observed interactions with robots		People with dementia (n=4) severe  OA (n=1) diagnosis not specified	Short	Can be ignored or acknowledged by some people with dementia.
Klein [6]	1.England and 2.Germany	1.PARO  2.PLEO and PARO	1.To assess feasibility of using PARO to stimulate group discussions with people with dementia  2. Student education exploring acceptability of PLEO and PARO	1.Ethnography  2.6 health and social work university student projects	1. Group discussions observed and interviews with staff  2. Group and individual interventions	1.Care home  2. Residential care	1. People with dementia (n=5)  2. Not specified (n=62)	1 90 mins for 6 weeks 2. 3 sessions each project	1. All but 1 participant accepted and valued PARO and connected emotionally. Authors identified new quality of interaction  2. Similar outcomes for PLEO who was accepted by most participants
Studies including Participants with Mild Cognitive Impairment									
Wu [44]	France	Several Robots	To investigate how OA perceive robot's appearance	Qualitative methods	Three videotaped focus groups. OA shown pictures of 26 robots and discussed	Hospital setting	OA (n=8)  MCI (n=7)	None	Acceptance improved if appearance related to

Chapter Two. Paper One.

					opinions. Shown video clip of robot.				function. Ethical concerns.
Pino [45]	France	RobuLAB 10 a social assistive robot.  Pictures of other robots	Investigate the opinions and attitudes of three stakeholder groups towards a social assistance robot	Mixed Methods	Robot demonstration and scenarios presented. Focus group discussion and questionnaires administered	Community based, MCI and Carer participants recruited through a memory clinic.	OA (n=8) Carers (n=7)  OA with MCI (n=10) clinically diagnosed using European Consortium on Alzheimer's Disease Working Group on MCI	1.5 to 2 hour sessions	ITU higher in future than present. Carers and OA with MCI higher PU and ITU than Customisation is important Identified barriers to adoption also.
Granata [46]	France	Kompai	To ascertain the user skills, needs and preferences for an interface using user centred design processes.	Observational and Experimental	Goal to assess usability of 2 services shopping list and agenda SAR  Experimental tasks on PC tablet	Living at home	MCI (n=11) diagnosed according to Peterson et al criteria without sensory deficit, behavioural or psychiatric conditions OA (n=11) Volunteers recruited from memory clinic	Short task related	OA with MCI can use applications with adaptations
Wu [3]	France	Kompai	To provide recommendations regarding	Mixed Methods	Shown how to use robot then observed using it	Living Laboratory	OA with MCI (n=5) diagnosed	Once a week for 4 weeks	Both groups rated robot similarly able to



Chapter Two. Paper One.

			robot appearance.				with MCI, according to Petersen's criteria, and OA (n=5)		learn MCI took longer. Social influence found important to acceptance
Chang [47]	USA	PARO	To explore the social and behavioural mechanism behind therapeutic effects of PARO	Observational Study	Group meetings with therapist videoed therapist encouraged to interact with PARO	Nursing Home	Cognitive impairment mild to severe (n=10)	Met weekly for 8 weeks	PARO's presence encouraged physical activity and interaction
Wu [64]	France	No robot present	To explore OA needs and preferences for an assistive robot.	Not stated	Questionnaire administered via interview to investigate feasibility of an assistive robot to support elderly at home. Establish needs and preferences		Volunteers (n= 30) subjective memory complaints attending memory clinic	None	Needs not clearly identified. Cognitive stimulation programme most highly valued and fall detection, help call

### 2.1.7. References

1. Prince M, Guerchet M, Prina M. (2013) Policy Brief for Heads of Government: The Global Impact of Dementia 2013–2050. Alzheimer's disease International (ADI), London.
2. Wimo A, Prince M. (2010) World Alzheimer Report: The Global Economic Impact of Dementia. Alzheimer's Disease International (ADI), London.
3. Alzheimers Society (2015) What is Mild Cognitive Impairment, Factsheet 47. <https://www.alzheimers.org.uk>. Accessed 18<sup>th</sup> June 2017
4. Mordoch E, Osterreicher A, Guse L, Roger K, Thompson G. (2013) Use of social commitment robots in the care of elderly people with dementia: a literature review. *Maturitas* 74 (1):14-20. doi:10.1016/j.maturitas.2012.10.015
5. Chang W-L, Sabanovi S, Huber L. (2013) Use of Seal-like Robot PARO in Sensory Group Therapy for Older Adults with Dementia *IEEE Robotics & Automation Magazine*
6. Klein B, Cook G. (2012) Emotional Robotics in Elder Care – A Comparison of Findings in the UK and Germany. In: al. SSGe (ed) *Emotional Robotics in Elder Care*. Springer-Ver, Berlin Heidelberg, pp 108-116
7. Sung HC, Chang SM, Chin MY, Lee WL. (2015) Robot-assisted therapy for improving social interactions and activity participation among institutionalised older adults: a pilot study. *Asia Pac Psychiatry* 7 (1):1-6. doi:10.1111/appy.12131
8. Takayanagi K, Kirita T, Shibata T. (2014) Comparison of Verbal and Emotional Responses of Elderly People with Mild/Moderate Dementia and Those with Severe Dementia in Responses to Seal Robot, PARO. *Front Aging Neurosci* 6:257. doi:10.3389/fnagi.2014.00257
9. Moyle W, Cooke M, Jones C, O'Dwyer S, Sung B. (2013) Assistive technologies as a means of connecting people with dementia. *International Psychogeriatrics* 25:S21-22
10. Dautenhahn K. (2007) Socially intelligent robots: dimensions of human-robot interaction. *Philos Trans R Soc Lond B Biol Sci* 1480:679-704
11. Stafford R. (2013) The contribution of people's attitudes and perceptions to the acceptance of eldercare robots. The University of Auckland,
12. Broadbent E, Tamagawa R, Kerse N, Knock B, Patience A, MacDonal B. (2009) Retirement home staff and residents' preferences for healthcare robots. Paper presented at the 18th IEEE International Symposium on Robot and Human Interactive Communication Toyama Japan, 27<sup>th</sup> Oct
13. Spiekman, M. E., Haazebroek, P., & Neerincx, M. A. (2011, November). Requirements and platforms for social agents that alarm and support elderly living alone. In *International Conference on Social Robotics* (pp. 226-235). Springer, Berlin, Heidelberg.
14. Frennert S, Efring H, Östlund B. (2013) Older People's Involvement in the Development of a Social Assistive Robot, in: G. Herrmann, M.J. Pearson, A. Lenz, P. Bremner, A. Spiers, U. Leonards (Eds.) *Social Robotics: 5th International Conference, ICSR 2013, Bristol, UK, October 27-29, 2013, Proceedings*, Springer International Publishing, Cham, pp. 8-18.
15. Heerink M, Kroese B, Evers V, Wielinga B. (2010) Assessing Acceptance of Assistive Social Agent Technology by Older Adults: the Almere Model. *Int J Soc Robot* 2: 361-375.
16. Heerink M. (2011) Exploiting the influence of Age, Gender, Education and Computer Experience on Robot Acceptance by Older Adults. Paper presented at the HRI'11, Lausanne Switzerland, March 6-9<sup>th</sup>
17. Young J, Hawkins R, Sharlin E, Igarashi T. (2009) Toward Acceptable Domestic Robots: Applying Insights from Social Psychology. *Int J Soc Robot* 1:95-108
18. Flandorfer, P. (2012). Population ageing and socially assistive robots for elderly persons: the importance of sociodemographic factors for user acceptance. *International Journal of Population Research*, 2012, 1-13. doi:10.1155/2012/829835
19. Scopelliti M, Giuliani MV, Fornara F. (2004) Robots in a domestic setting: a psychological approach. *Univ Access Inf Soc* 4:146-155
20. Shibata T. (2012) Therapeutic Seal Robot as Biofeedback Medical Device. *Proceedings of the IEEE* 100 (8):2527-2538
21. Stafford R, MacDonald B, Jayawardena D, Wegner D, Broadbent E. (2013) Does the robot have a mind? Mind perception and attitudes towards robots predict use of an eldercare robot. *Int J of Soc Robot*, 6: 17-32
22. Takayama L. (2011) Perspectives on agency: Interacting with and through personal robots, In Zacarias, M. & Oliveira, J. V. (Eds.), *Human-Computer Interaction: The Agency Perspective* (pp. 195-214). Springer Berlin Heidelberg.

## Chapter Two. Paper 1.

23. Stafford R, Broadbent E, Jayawardena C, Unger U, Kuo I, Igic A, Wong R, Kerse N, Watson C, MacDonald B. (2010) Improved robot attitudes and emotions at a retirement home after meeting a robot. . Paper presented at the RO-MAN International Symposium on Robots and Human Interaction, Viareggio, Italy.
24. Arras K, Cerqui D. (2005) Do we want to share our lives and bodies with robots? A 2000-people survey. Technical Report Nr 0605-001 Autonomous Systems Lab Swiss Federal Institute of Technology, EPFL,
25. Nomura T, Sugimoto K, Syrdal DS, Dautenhahn K. (2012) Social Acceptance of Humanoid Robots in Japan: A Survey for Development of the Frankenstein Syndrome Questionnaire. Paper presented at the 12th IEEE\_RAS International Conference on Humanoid Robots, Osaka Japan, 29th-1st Dec
26. de Graaf MMA, Allouch SB, Klamer T. (2015) Sharing a life with Harvey: Exploring the acceptance of and relationship-building with a social robot. *Computers in Human Behaviour* 43:1-14. doi:http://dx.doi.org/10.1016/j.chb.2014.10.030
27. Gross H, Schroeter C, Mueller S, Bley A, Langner T, Volkhardt M, Einhorn E, Merten M, Huijnen C, Heuvel Hvd, Berlo AC. (2012) Further Progress towards a Home Robot Companion for People with Mild Cognitive Impairment. Paper presented at the IEEE International Conference on Systems, Man and Cybernetics, COEX Seoul Korea, 14-17th October
28. Pfadenhauer M, Dukat C. (2015) Robot Caregiver or Robot-Supported Caregiving? *International Journal of Social Robotics* 7 (3):393-406. doi:10.1007/s12369-015-0284-0
29. Stafford R, MacDonald B, Broadbent E. (2012) Identifying specific reasons behind unmet needs may inform more specific eldercare robot design. Paper presented at the 4th International Conference on Social Robotics ICSR
30. Pino M, Boulay M, Jouen F, Rigaud A-S. (2015) 'Are we ready for robots that care for us?' Attitudes and opinions of older adults toward socially assistive robots. *Frontiers in Aging Neuroscience* 7 (141):1-15
31. Mitzner TL, Chen TL, Kemp CC, Rogers WA. (2014) Identifying the Potential for Robotics to Assist Older Adults in Different Living Environments. *Int J Soc Robot* 6 (2):213-227. doi:10.1007/s12369-013-0218-7
32. Begum M, Wang R, Huq R, Mihailidis A. (2013) Performance of Daily Activities by Older Adults with Dementia: The Role of an Assistive Robot. Paper presented at the IEEE International Conference on Rehabilitation Robotics, Seattle, Washington, USA, June 24-26
33. Säskilähti K, Kangaskorte R, Pieska S, Jauhiainen J, Luimula M. (2012) Needs and User Acceptance of Older Adults For Mobile Service Robot. Paper presented at the IEEE RO-MAN: The 21st IEEE International Symposium on Robot and Human Interactive Communication, Paris, France, September 9th-13th
34. Keressens C, Kumar R, Adams A, Knott C, Metalenas L, Sanford J, Rogers W. (2015) Personalised Technology to Support Older Adults With and without Cognitive Impairment Living at Home. *American Journal Of Alzheimers Disease and Other Dementias* 30 (1):85-97
34. Davis F, Bagozzi R, Warshaw P. (1989) User Acceptance of Computer Technology. A Comparison of Two Theoretical Models, *Management Science* 35: 982-1003
35. Campbell A. (2011) Dementiacare: could animal robots benefit residents? *Nursing and Residential Care* 13 (12):602-606
36. Campbell A. (2011) Dementia care: could animal robots benefit residents? *Nursing and Residential Care* 13: 602-604
37. Säskilähti K, Kangaskorte R, Pieska S, Jauhiainen J, Luimula M. (2012) Needs and User Acceptance of Older Adults For Mobile Service Robot, in: IEEE RO-MAN: The 21st IEEE International Symposium on Robot and Human Interactive Communication, Paris, France
38. Khosla, R., Chu, M. T., Kachouie, R., Yamada, K., Yoshihiro, F., & Yamaguchi, T. (2012, October). Interactive multimodal social robot for improving quality of care of elderly in Australian nursing homes. In *Proceedings of the 20th ACM international conference on Multimedia* (pp. 1173-1176). ACM.
39. Torta E, Werner F, Johnson D, Juola J, Cuijpers R, Bazzani m, Oberzaucher J, Lemberger J, Lewy H, Bregman J. (2014) Evaluation of a Small Socially-Assistive Humanoid Robot in Intelligent Homes for the Care of the Elderly. *J Intell Robot Syst* 76:57-71
40. Granata C, Pino M, Legouverneur G, Vidal JS, Bidaud P, Rigaud AS. (2013) Robot services for elderly with cognitive impairment: testing usability of graphical user interfaces. *Technol Health Care* 21 (3):217-231. doi:10.3233/THC-130718

41. Heerink M, Kröse B, Evers V, Wielinga B. The influence of a robot's social abilities on acceptance by elderly users. In: RO-MAN 2006 - The 15th IEEE International Symposium on Robot and Human Interactive Communication, Hatfield, 2006. pp 521-526. doi:10.1109/ROMAN.2006.314442
42. Heerink M, Krose B, Wielinga B, Evers V. (2008) Enjoyment, Intention to Use And Actual Use of a Conversational Robot by Elderly People Paper presented at the HRI'08, Amsterdam Netherlands, March 12-15th
43. Tapus A, Tapus C, Mataric M. (2009) The Role of Physical Embodiment of a Therapist Robot for Individuals with Cognitive Impairments. Paper presented at the The 18th IEEE International Symposium on Robot and Human Interactive Communication, Toyama Japan, Sept. 27th - Oct. 2nd
44. Robinson H, MacDonald B, Kerse N, Broadbent E. (2013) Suitability of Healthcare Robots for a Dementia Unit and Suggested Improvements. *Journal of the American Medical Directors Association* 14 (1):23-40
45. Khosla R, Khanh N, Chu M-T. (2014) Assistive Robot Enabled Service Architecture to Support Home-Based Dementia Care. In: 2014 IEEE 7th International Conference on Service-Oriented Computing and Applications. IEEE International Conference on Service-Oriented Computing and Applications. pp 73-80. doi:10.1109/soca.2014.53
46. Mori M. (2012) The Uncanny Valley, *IEEE Robotics and Automation Magazine*, 19: 98-100.
47. Heerink M, Albo-Canals J, Valenti-Soler M, Martinez-Martin P, Zondag J, Smits C, Anisuzzaman S. (2013) Exploring Requirements and Alternative Pet Robots for Robot Assisted Therapy with Older Adults with Dementia, in: Herrmann G, Pearson MJ, Lenz A, Bremner P, Spiers A, Leonards U (Eds.) *Social Robotics, ICSR 2013*: 104-115.
48. Stafford R, MacDonald B, Broadbent E. (2014) Older people's prior robot attitudes influence evaluations of a conversational robot. *Int J Soc Robot* 6: 281-297.
49. DiSalvo C, Gemperle F, Forlizzi H, Kiesler S. (2002) All Robots Are Not Created Equal: The Design and Perception of Humanoid Robot Heads. *DIS*
50. Yamazaki R, Nishio S, Ishiguro H, Nørskov M, Ishiguro N, Balistreri G. (2014) Acceptability of a Teleoperated Android by Senior Citizens in Danish Society. *International Journal of Social Robotics* 6 (3):429-442. doi:10.1007/s12369-014-0247-x
51. Walters ML, Dautenhahn K, Woods SN, Koay KL, Boekhorst RT, Lee D. (2006) Exploratory studies on social spaces between humans and a mechanical-looking robot. *Connection Science* 18: 429-439.
52. Cohen-Mansfield J, Thein K, Dakheel-Ali M, Rigier N, Marx M. (2010) The Value of Social Attributes of Stimuli for Promoting Engagement in Persons With Dementia. *The Journal of Nervous and Mental Disease* 198 (8):586-592
53. Cohen-Mansfield J, Dakheel-Ali M, Marx MS. (2009) Engagement in persons with dementia: The concept and its measurement. *Am J Geriatr Psychiatry*. 17:299 –307.
54. Morris J, Hawes C, Murphy K, Nonemaker S, Phillips C, Fries B, Mor V. (1991) *MDS Resident Assessment*. Natick (MA): Eliot Press.
55. Brandon M. (2012) Effect of Robot-User Personality Matching on the Acceptance of Domestic Assistant Robots for Elderly. Masters, University of Twente,
56. Amirabdollahian F, Op Den Akker R, Bedaf S, Bormann R, Draper H, Evers V, Gelderblom GJ, Ruiz CG, Hewson D, Hu N, Iacono I, Koay KL, Krose B, Marti P, Michel H, Prevot-Huille H, Reiser U, Saunders J, Sorell T, Dautenhahn K. (2013) Accompany: Acceptable robotics COMPanions forAgeiNG Years - Multidimensional aspects of human-system interactions, in: 2013 6th International Conference on Human System Interactions, HSI 2013, June 6, 2013 - June 8, 2013, IEEE Computer Society, Gdansk, Sopot, Poland: 570-577.
57. Amirabdollahian F, Akker Rod, Bedaf S, Bormann R, Draper H, Evers V, Perez JG, Gelderblo GJ, Ruiz CG. (2013) Assistive technology design and development for acceptable robotics companions for ageing years. *PALADYN Journal of Behavioural Robotics* 4 (2):94-112
58. Sakai Y, Nonaka Y, Yasuda K, Nakano Y. (2012) Listener Agent for Elderly Peolpe with Dementia. Paper presented at the HRI'12, Boston Massachusetts USA, March 5-8th2012
59. McColl D, Wing-Yue, Louie G, Nejat G. (2013) Brian 2.1 A Socially Assistive Robot for the Elderly and Cognitively Impaired. *IEEE Robotics and Automation Magazine* (March):74-83
60. Steinke F, Bading N, Fritsch T, Simonsen S. (2014) Factors influencing trust in Ambient Assisted Living Technology: A scenario-based analysis. *Gerontechnology* 12 (2):81-100
61. Alaiad A, Zhou L. (2014) THE determinants of home healthcare robots adoption: An empirical investigation. *International Journal of Medical Informatics* 83:825-840

62. Wu Y-H, Wrobel J, Cornuet M, Kerherve H, Damnee S, Rigaud A-S. (2014) Acceptance of an assistive robot in older adults: a mixed-method study of human–robot interaction over a 1-month period in the living lab setting. *Clinical Interventions in Aging*:801-811
63. Neven L. (2010) 'But obviously not for me': Robots, laboratories and the defiant identity of elder test users. *Social Health Illn* 32 (2):335-347. doi:10.1111/j.1467-9566.2009.01218.x
64. Wu Y-H, Faucounau V, Boulay M. (2010) Robotic agents for supporting community-dwelling elderly people with memory complaints: Perceived needs and preferences. *Health Informatics Journal* 17 (1):33-40
65. Frennert S, Efring H, Ostlund B. (2013) Older People's Involvement in the Development of a Social Assistive Robot, in: Herrmann G, Pearson M, Lenz A, Bremner P, Spiers A, Leonards U, (Eds.) 5<sup>th</sup> International Conference, ICSR 2013, Springer, Bristol United Kingdom: 8-18.
66. Pfadenhauer M, Dukat C. (2015) Robot Caregiver or Robot-Supported Caregiving? The Performative Deployment of the Social Robot PARO in Dementia Care. *Int J of Soc Robots* 7: 393-406.
67. Khosla R, Chu MT, Kachouie R, Yamada K, Yoshihiro F, Yamaguchi T, (2012) Interactive multimodal social robot for improving quality of care of elderly in Australian nursing homes, in: 20th ACM International Conference on Multimedia, MM 2012, October 29, 2012 - November 2, 2012, Association for Computing Machinery, Nara, Japan :1173-1176.
68. Sakai Y, Nonaka Y, Yasuda K, Nakano YI. (2012) Listener agent for elderly people with dementia, in: 7th Annual ACM/IEEE International Conference on Human-Robot Interaction, HRI'12, March 5, 2012-March 8, 2012, Association for Computing Machinery, Boston, MA, United states : 199-200.
69. Wu YH, Faucounau V, Boulay M. (2010) Robotic agents for supporting community-dwelling elderly people with memory complaints: Perceived needs and preferences. *Health Informatics Journal* 17: 33-40.
70. Bamford C, Bruce E. (2000) Defining the outcomes of community care: the perspectives of older people with dementia and their carers. *Aging and Society* 20: 543-570.
71. McKillop J, Wilkinson H. (2004) Make it easy on yourself! Advice to researchers from someone with dementia on being interviewed. *Dementia* 3: 117-125.
72. Bartlett R. (2012) Modifying the diary interview method to research the lives of people with dementia. *Qualitative Health Research* 22: 1717-1726.
73. Lloyd V, Gatherer A, Kalsy S. (2006) Conducting qualitative interview research with people with expressive language difficulties. *Qualitative Health Research* 16: 1386-1404.
74. Hubbard G, Downs MG, Tester S. (2003) Including older people with dementia in research: Challenges and strategies. *Aging and Mental Health* 7: 351-362.
75. Murphy K, Jordan F, Hunter A, Cooney A, Casey D. (2015) Articulating the strategies for maximising the inclusion of people with dementia in qualitative research studies. *Dementia* 14 (6):800–824
76. Cowdell F. (2008) Engaging older people with dementia in research: myth or possibility. *International Journal of Older People Nursing* 3: 29-34.
77. Wing-Yue, Louise G, McColl D, Nejat G. (2014) Acceptance and Attitudes Toward a Human-like Socially assistive Robot by Older Adults. *Assistive Technology: The Official Journal Of RESNA* 26 (3):140-150.
78. Sabanovic S, Bennett C, Chang W-L, Huber L. (2013) PARO Robot Affects Diverse Interaction Modalities in Group Sensory Therapy for Older Adults with Dementia. Paper presented at the IEEE International Conference on Rehabilitation Robotics, Seattle, Washington, USA, 24-26 June 2013.

## 2.2. Chapter Two. Summary and Segue.

The research presented in this chapter aimed to identify the factors that impact the acceptability of social robots for people with dementia. This aim was achieved by conducting a comprehensive review of the literature. This review found that robot acceptability is impacted by factors that pertain to the individual user, their community, and wider society. It also found that robots are more likely to be acceptable to people with dementia if they are human-like, personalised to the needs of individual users and if users trust the robot and feel comfortable with how much it can adapt and be controlled. The limitations of the review, for this thesis, are that it included studies that involved older adults with and without mild cognitive impairment, who could have different acceptability issues to people with dementia. Nonetheless, this evidence revealed that social robots have the potential to be acceptable to

people with dementia and the review increased clarity about what is likely to improve the acceptability of social robots for people with dementia.

In addition, the findings of this literature review identified that the Almere model could provide theoretically endorsed concepts that were relevant to the examination of social robots for people with dementia and these concepts were applied to develop the framework used to analyse the data obtained during the empirical study that is reported in chapters four and five of this thesis.

None of the papers identified in this review addressed the concept of resilience. Therefore, further examination of the literature was necessary to inform this thesis and to identify the key components of psychosocial interventions that aim to support resilience and to clarify how the concept of resilience can be operationalised. The second literature review is described in chapter three.

### Chapter Three. Paper Two.

#### 3.0 Prologue

This chapter presents paper two. Paper two reports a narrative literature review that systematically examined and synthesised the findings of previous research that has investigated psychosocial interventions that aimed to support the resilience of people with dementia. This review focuses on how the concept of resilience had previously been defined and operationalised during investigations and it identifies the essential contents of the psychosocial interventions that aim to support resilience and the mechanisms through which resilience in dementia can be fostered. The results of the quality appraisal of studies reviewed in paper two are reported in Appendix 4).

#### 3.1 Paper Two

Title:

Fostering the Resilience of People with Dementia: A Narrative Literature Review.

Authors:

Sally Whelan<sup>1</sup>, Áine Teahan<sup>2</sup> and Dympna Casey<sup>2</sup>

1.School of Nursing and Midwifery, National University of Ireland Galway, Ireland.

2. Centre for Economic and Social Research, National University of Ireland Galway Ireland.

Keywords:

dementia, Alzheimer's, resilience, systematic review, aging, interventions

#### Acknowledgements

The authors would like to acknowledge the contribution of John Ivory and Michael Smalle for their advice on planning the literature search strategy and Dr. Catherine Houghton who provided advice regarding the use of the CASP qualitative check list.

#### 3.1.1. Abstract:

Background: Resilience is a process through which people use resources to adapt to adversity. Interventions aiming to support resilience in people with dementia have been developed. However, the optimal content, structure and impact of these interventions is unclear. This literature review explores the factors through which interventions foster resilience in people with dementia and examines their efficacy.

Methods: Eight databases were searched systematically, for literature published from 2000 to 2019. Following the removal of duplicate articles, the titles, and abstracts of 6,749 articles were screened. Articles were selected if they: reported empirical studies in English; focused on resilience; involved people with dementia and psychosocial interventions. The full text of 53 articles were examined and three studies, reported in six papers, were included in the final review. Data were systematically extracted, and two authors critiqued the studies using the Critical Appraisal Skills Programme check lists. The studies were examined to determine how resilience was defined and operationalised and their findings were synthesised using the theoretical resilience framework.

Results: Five interventions aiming to foster resilience were identified: Dementia Advisors; Peer Support Network Services; Visual Arts Enrichment Activities; Memory Makers; and Early-Stage and Beyond Community Activities. All studies defined resilience as a process and most involved people with mild dementia who had family carers. The interventions impacted resilience by reducing the adversity of stigma and social isolation; increasing personal and social resources, providing stigma-free space and reciprocal support. Interventions empowered people with dementia, increasing their self-esteem and self-worth. Resilience

can be fostered both during, and after interventions. However, the efficacy of interventions could not be determined because the research designs utilised did not measure efficacy.

Conclusions: Interventions need facilitators to ensure they are strength-based, person-centred and they enable reciprocal social interactions. Future research needs to develop interventions that aim to foster the resilience of people with dementia who lack family carers and/or have more advanced dementia through meaningful activities that are identified by people with dementia as important to their resilience. Robust methodologies, including randomized controlled trials should be used to measure effectiveness and explore the impact of interventions regarding the: interplay between individual and community resources; the importance of reciprocity; and temporal aspects of resilience.

### 3.1.2. Introduction

Dementia is a chronic progressive syndrome, which currently affects 50 million people worldwide (1). Having dementia can negatively impact the person's cognitive functioning, memory, thinking, orientation, language, and emotional control (1). Dementia can cause anxiety (2), and it may be linked to depression (3). Every year, as more people live into old age, there are 10 million people newly diagnosed with dementia (1). Consequently, it is increasingly important to develop strategies that facilitate and support people with dementia to remain independent and functioning well for as long as possible (4).

Resilience is important for people with dementia (5) because it can help with the challenges of living with the condition (6, 7). Resilience has been defined as a dynamic "process of effectively negotiating, adapting to, or managing significant sources of stress or trauma" [(8), p. 2]. Resilience has also been described in terms of a resilience framework (9) which draws upon the ecological systems theory (10). This framework regards resilience as occurring within a complex interacting multi-layered system, in the presence of a significant adversity, which can be acute or chronic in nature (8, 11). A person's response to adversity is facilitated by use of, and access to, resources that can be internal and/or external to the individual in their environment. There are a range of possible resilience outcomes, from vulnerability to flourishing (12). Outcomes of resilience can include maintaining normal development or competence in the presence of mental or physical health difficulties (9). Therefore, resilience can be present when a person with a chronic disease adapts to the condition and demonstrates processes that include acknowledging the condition, gaining a sense of control over it and integrating it into their life and lifestyle (13).

In the context of dementia, resilience is complex and multifaceted (4). It involves the use of resources to negotiate living with the challenges of dementia (14) and the compensatory practices of other people who are close to the individual with dementia (significant others), who act as a resource to support the person, as the dementia progresses (4). Resilience in dementia is strongly related to being socially connected with other people (15) and the participation of individual people with dementia in purposeful activity (16). Harris (17) applied the theoretical framework of resilience using in-depth case study methodology and the qualitative interviewing of people with dementia (n = 2) who were "doing okay" and managing to live well with their dementia. Harris (17) found that positive adaptation in dementia involved overcoming negative influences and having assets and protective factors that outweighed the risks and vulnerabilities experienced by individuals with dementia. They identified that in dementia assets included: having effective coping strategies; acceptance of the dementia diagnosis; accepting changes to life and the need to accept help from available support networks; a positive attitude; and productivity. Whereas, protective factors included: positive relationships with other people that supported personhood (18); and having positive role models. Other researchers have also emphasised the importance of acceptance (19) and of having positive thoughts and feelings (20). In addition, resilience in



dementia has been characterized as a process of continual adjustment through which people with dementia learn to live with progressive limitations in their lives (21, 22).

Core outcome sets (23) for resilience in dementia have not yet been established but there has been a small amount of research focusing on outcome measures. Stoner et al. (24, 25) developed and validated with people with dementia (n = 126), the Positive Psychology Outcome Measure (PPOM) which measures capacity for resilience, and hope. PPOM has to our knowledge yet to be utilised in research, but Stoner et al. (25) found that PPOM may assist with the future development of asset-based approaches and interventions for dementia. From this literature, and that described above, it can be determined that the capacity of people with dementia for resilience can be improved through the presence of protective factors and that outcomes for resilience in dementia include: having capacity for resilience and protective factors; having the ability to cope effectively and recover from stress; having the ability to adjust and adapt attitudes and behaviour to respond positively to dementia; and the ability to accept the challenges and limitations of life with dementia.

Psychosocial interventions aiming to support resilience in people with dementia need to be informed by factors that support and limit resilience (4). However, to date no published literature has examined the existing evidence concerning the content, structure and impact of interventions that aim to support resilience in people with dementia. This narrative literature review aims to explore the evidence concerning interventions that aim to foster resilience in people with dementia: to identify and examine how the concept of resilience is defined and operationalised in these investigations, the efficacy of interventions and the factors through which they impact resilience.

The objectives of this research were to:

- Identify and describe the psychosocial interventions designed to foster the resilience of people with dementia.
- Describe how the interventions were perceived and experienced by people with dementia.
- Critically appraise the methodologies used to design and investigate the interventions.
- Apply the empirical findings of the studies reviewed to the resilience process and framework.
- Describe the efficacy and impact of the interventions on the resilience process of people with dementia.
- Examine the factors that impacted the effectiveness of the interventions.

### 3.1.3. Methods

#### Search Strategy

A comprehensive and systematic search of the literature published from 2000 to 2019 was conducted with the guidance of an expert librarian. Eight databases: Scopus, Web of science, EBSCO-CINAHL, Ageline, PsycINFO, Cochrane, OpenGrey, and Proquest were utilised. Abstracts and titles were searched using keywords, MeSH terms and subject headings (Table 1), which were selected as they corresponded to the key characteristics of resilience in dementia that have been described above. In addition, the references of relevant papers were hand searched and their citations were examined using Google Scholar.

Table 3.1. Search Terms		
Population	Phenomenon of Interest	
Dementi* OR Alzheimer’s Disease OR Alzheimer* OR Lewy body OR (Korsakoff OR Creutzfeldt-Jakob) N2 (disease OR syndrome) OR “Creutzfeldt-Jakob Disease” OR Frontotemporal dementia OR Huntington’s Disease, (Mixed OR Vascular) N2 dementia OR Parkinson’s Disease	Resilien* OR Adapt* OR “Bounce back” OR accept* OR Cop* OR Adjust* OR “protective factors”	Intervention* OR Improve* OR enhance* OR increase* OR therap* OR promot* OR foster* OR program* OR support* OR treat* OR educ* OR mang* OR method* OR approach* OR strategy*
*All possible endings of this word were included in the search.		

#### Inclusion and Exclusion Criteria

Papers were screened for eligibility by SW, the lead author. To be included, items needed to report empirical studies that involved people with dementia with any type of dementia of any severity. Studies also needed to involve non-pharmacological psychosocial interventions that addressed resilience or where this was named as an outcome measure. Interventions were defined as any physical, cognitive, or social activities that aimed to maintain or improve “functioning, interpersonal relationships and well-being in people with dementia” (26). All comparators to the interventions were included: treatment as usual, no treatment control, comparison with other interventions, usual treatment/care as were all design methods. Studies were excluded if they involved non-psychological interpretations of resilience, such as resilience in relation to the physical health or the geographical environment, and if they involved people with mild cognitive impairment or involved pharmacological interventions. They were also excluded if the studies used proxy terms for resilience such as self-efficacy, sense of coherence, hardiness, or quality of life. This ensured that the review focused on interventions which explicitly aimed to foster resilience.

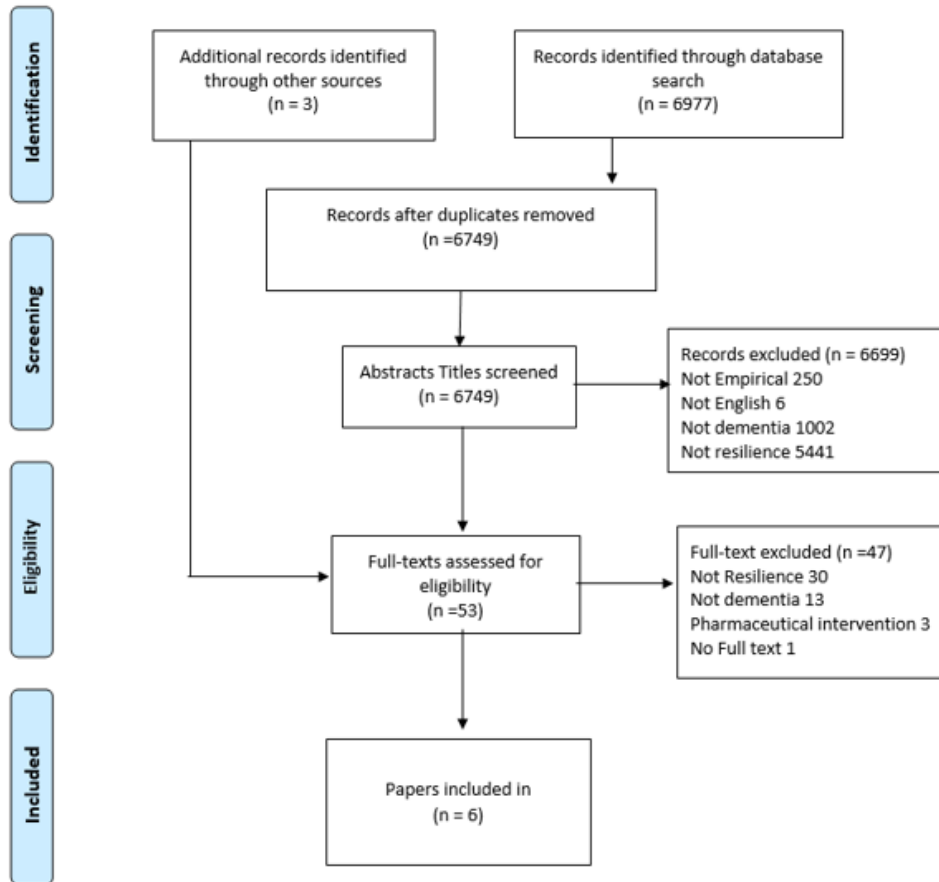
#### Data Extraction and Quality Assessment

Data from the selected papers were extracted systematically, by SW, using an extraction form relevant to the research objectives. This form captured the key features of the included studies (Table 2). As critical appraisal of studies has been strongly recommended when performing narrative reviews (33–35), the methodological strengths and limitations of the studies were assessed independently by two reviewers (SW, ÁT) using the Critical Appraisal Skills Programme (CASP-uk.net) qualitative checklist. The CASP checklist is a widely used tool for qualitative evidence synthesis and is recommended by World Health Organisation guidelines (36). No study was excluded as a result of this quality assessment.

#### 3.1.4. Review Findings

The PRISMA diagram in Figure 3.1. below summarises the selection and screening process (37). The initial search identified 6,977 items. After removing duplicates, the abstract and titles of 6,749 items were screened according to the inclusion and exclusion criteria. Three additional papers were identified through hand searching the reference lists of relevant studies. This resulted in 53 studies being retained for full-text review, against the inclusion criteria. The final review included six papers that reported five interventions (27–32). An overview of the studies and the interventions is provided below. Enough detail is provided in this overview to enable readers to make sense of studies’ context and findings (33), as has been strongly recommended in narrative literature reviews (34, 35). Following the overview, this review then focuses on how the concept of resilience was defined and operationalised within the included studies. After this, the findings of the studies are interpreted in relation to the resilience framework (9).

Figure 3.1. PRISMA flow diagram describing the identification, screening, eligibility, and inclusion criteria of the studies identified under the scope of this review.



### 3.1.4.1. Overview of the Studies and the Interventions for Resilience Dementia Advisors and Peer Support Network Services

Clarke et al. (27, 28) conducted a study which evaluated a national programme in the UK that aimed to compare the influence of dementia advisors (DA's) and peer support network (PSN) services on the well-being and resilience of people with dementia and their family carers, living in a community setting. The DA's provided information and an ongoing point of contact for service users. They aimed to provide information about dementia and signpost other services, such as social groups, legal or financial supports. The PSN provided emotional and social support to people with dementia and carers through Alzheimer Society support groups and dementia cafes. Both DA's and PSN facilitators were lay health workers, and many were volunteers (28). At the time of the Clarke et al.'s evaluation, the interventions had been operating for 10 years at 40 demonstration sites.

Clarke et al. used a mixed methods design which emphasised qualitative methodology (28). An organisational survey was conducted along with case studies of some demonstration sites (n = 8). People with dementia were interviewed, at their convenience, alone or with their family carers 1–3 times. These semi-structured interviews lasted up to 2 hours. At the time of interview, quantitative questionnaires were also administered. These included the adult social care outcomes toolkit (ASCOT) (38) which collected data on unmet needs and the DEMQoL(39), that recorded health related quality of life. In addition, staff and stakeholders (n = 82) were interviewed.

Participants were recruited through key staff working at the chosen demonstration sites and a sampling matrix was used to select a range of staff and stakeholders who had accessed the services. Participants included family carers (n = 54) and people with dementia (n = 47), the majority of whom were aged 65–85 years and had early stage (mild) dementia. The quantitative data were analysed using SPSS, to ascertain statistical representation of frequency and modal responses for each respondent and all people with dementia as a group. All the interview data was uploaded into NVIVO and descriptive content analysis was conducted on 25 of the interview transcripts from which the research team developed a coding framework which was used to analyse the remaining data into themes.

Clarke et al. identified three themes: addressing the needs of individual and communities; promoting choice, control and independence; and getting a life back. The findings included in the first theme revealed that both interventions operated through identifying and responding to the needs of their users. The DA and PSN were informed and shaped by the needs and expressed desires of the people with dementia and their carers. The carers wished to remain well and both the carer and person with dementia wished that the stigma surrounding dementia could be reduced. The data also revealed that the PSN and DA's responded to the needs of the people with dementia by providing a wider range of services than those offered by traditional providers, including for example, gardening clubs and music groups. Also, the PSN and DA facilitators raised awareness about dementia with the wider public through providing training and information. This was illustrated by a carer who said:

'I think people need a lot more training on it [dementia], because it's something that is not to be frightened of.' (Beth, daughter of couple who had accessed DA service) [(28), p. 389].

The second theme, incorporated findings concerning how the services promoted independence, through providing information directly and through signposting access to further support. As one care partner stated:

'It [the PSN] allows him to feel independent, and it allows me to be myself, or more myself.' (Nancy, care partner from PSN site) [(28),p. 390].

The third theme illustrated how the PSN and DA service users considered that they had been enabled to establish a new, improved life with dementia. Self-esteem and self-worth were increased, and participants commented that they had been able to replace the social life and activities that they had lost due to dementia. One participant said:

'It's [the PSN] been the best thing that's happened to me for a few years now. I've been going to an art class for Alzheimer's and meeting people. It's fantastic because we can all talk to each other.' (Lillian, person with dementia who had accessed PSN site) [(28), p. 391].

#### Visual Arts Enrichment Activities

The second study included in this review was conducted between 2013 and 2017 in the UK (29). This study aimed to evaluate the impact of visual arts enrichment activities (VAEA) on opportunities for the resilience of people with dementia. This study was part of a wider mixed methods study on dementia and imagination (30) that prioritised qualitative methodology. Papers reporting on the wider study were excluded from this review because they did not focus on resilience.

During the VAEA intervention, experienced participatory artists who had received training in dementia, used a person-centred approach to organise activities around the interests, abilities and energy of people with dementia (n=48), aged 70–99 years, living in care homes (n = 4). The Clinical Dementia Rating scale (40) was used to rate the severity of participants' dementia. This found that the participants' dementia was borderline normal (n = 6), mild (n = 18), moderate (n = 8) and severe (n = 16).

The VAEA sessions lasted 2 hours and were held weekly, for 3 months. The VAEA aimed to engage the senses of the participants in activities that could be, for example, individual collage painting or collective, film making, sculpture, or poetry. Participants also visited a contemporary arts centre and a celebratory event was held that included their family and carers. Data was captured at 3 time points: baseline, when the activity sessions finished and 3 months after their cessation. Data was collected from people with dementia (n = 3) and family carers (n = 3) who were interviewed separately and the participatory artists (n = 2) who completed structured notes after each session. In addition, sessions were videoed, and recordings were observed to verify the study's findings. The data was analysed in NVIVO, where multiple readings were used to identify emergent codes which were collated into themes.

This study found that the resilience of people with moderate and advanced dementia can be supported through VAEA. Newman et al. (29) found that VAEA provided a platform which facilitated creative expression; increased communication and self-esteem and that the intervention enhanced the relationships between participants with dementia, their carers and relatives. For example, collectively creating a poem relied upon participants expressing their emotional responses to their individual memories, of being at the sea. The first four lines of this poem were:

The Cruel Sea

The beautiful sea goddess

Godiva Pearl

Beautiful ruffles

The ripples [Poem Created by participants, (29), p. 8]

Creating the poem was facilitated by participants being of similar age and possessing compatible attitudes. Newman et al. (29) argue that in order to produce this adaptive response, participants drew on both personal and collective resources. These resources were cognitive, emotional, imaginative, and aspects of their social selves, including being able to perceive and interpret the thoughts and feelings of others in the group.

Participants were more resilient during the activity than they would have been without it. Newman et al. (29) describes how one person with dementia who was usually solitary and uncommunicative, was poised and passionate when painting. And, as a result of group singing, her interactions with others were observed to increase and be more socially engaging. Newman et al. (29) suggested that the VAEA increased her selfhood and therefore supported her resilience. A carer reported:

'It really did feel quite different to me all of the activities were bringing everybody together. . . .She was really connecting with other people in the group as well. Her whole body language seemed to be different.' [Care home Director, (29), p. 11].

Self-esteem of participants was also increased, through participants' mastery of the activity and their success being praised by other people. However, self-esteem could also be undermined if a person was not able to accomplish the task or participate within the group and if the person's attention was drawn to their lack of ability and they became frustrated. Yet, when this occurred, participants demonstrated their ability to adapt because they still found the sessions enjoyable and wanted to participate in them. One man was able to participate, despite his communication difficulties, because he had developed a good relationship with the facilitators. It was argued that his resilience was supported through the social context of the VAEA.

Researchers also found that VAEA supported resilience through promoting personhood. VAEA enabled people to attain their potential without being inhibited by the assumptions other people made about their capabilities. In addition, VAEA increased the knowledge of carers and family members about the capabilities of people with dementia. One care home director said:

'I loved hearing people read and was surprised how confident the readers were. I suppose I'd underestimated how capable people with dementia are and had assumed they would find this difficult. You underestimate people don't you, you think 'Oh they're not going to do that'. [Care home director, (29), p. 13].

Improving the knowledge of significant others of the individuals' personhood meant VAEA had the potential to increase resilience in a sustained way in future interactions. This potential was also increased through VAEA giving residents, carers and relatives, an opportunity to celebrate and enjoy the activities together, in an atmosphere of positive equal relationships:

'It just felt like any social occasion/party-friends enjoying themselves, no distinction between those who were experiencing dementia and carers, family and friends.' [Care home director, (29), p. 13].

#### Memory Makers

The fourth intervention, "Memory Makers," started in the USA in 2012 and was investigated in a study that aimed to explore its impact on resilience, using an observational descriptive study design (31, 32). This community-based intervention recruited people with dementia from memory clinics, medical practices and the Alzheimer's Association. To participate, people with dementia needed to be: in the early stage of their disease; aware of their diagnosis; able to discuss their feelings and experiences about dementia; have no behavioural psychiatric medical difficulties that would cause them to disrupt the group; have transport to the group and a care partner who was able to attend the majority of sessions. Participants included people with dementia ( $n = 35$ ), aged 56–93 and family carers ( $n = 35$ ).

"Memory Makers" provided structured education about dementia and psychosocial support in a group setting for people with dementia and their family carers. The groups were facilitated by master's educated social workers (two per group) who were trained with information from the Alzheimer's Association early stage group facilitators manual. Memory Maker sessions lasted 3 hours and were conducted weekly for 8 weeks. During each session, people with dementia and carers ( $n = 12$  dyads) were separated into two groups for 75 minutes, where they discussed different topics related to living with dementia. After this time, the groups joined. On the final session, the participants wrote a communal poem about their group bonding which aimed to capture the spirit of their resilience.

Data for the study was collected from consecutive groups ( $n = 4$ ), at the end of each group of sessions, via an emailed online evaluation survey. This recorded perceived outcomes anecdotally. This study's findings, which will be described after the fifth intervention is introduced, were also derived from the facilitators' observations. Details as to how data analysis was conducted is not provided by the authors.

#### Early-Stage and Beyond Community Activities

The fifth intervention was the Early-Stage and Beyond Community Activities (ESBCA) (31). This involved a range of activities (see Table 2) for people with dementia and family carers who were graduates from the Memory Maker program. ESBCA aimed to build resilience by developing community support. ESBCA was facilitated by trained social workers (31). Data was collected from family units ( $n = 1,799$ ), that included people with dementia ( $n = 166$ ),

aged 49–93 years, and family carers (n = 178). The authors do not provide details as to how data was collected or analysed.

The impact on resilience of the Memory Makers programme (32) and the ESBCA (31) will now be discussed together because the interventions involved similar participants and the findings of their investigations concur with one another. Matchar et al. (31) describes themes that were derived separately from people with dementia and their family carers. Here however, in keeping with the aims of this review only the themes identified for people with dementia will be reported. The eight themes identified were: acceptance; disclosure; significant others; sense of purpose; faith; routines, familiar environments, and memory aids; showing up/the value of a support group. The theme of acceptance relates to evidence in which participants described that they were resigned to having dementia, living with limitations and that they accepted this with a determination to make the best of life. One gentleman with dementia said:

‘There’s no changing it [having dementia]. I’m just rolling with it. . . .I want to find some strategy to best function. . . ’ [Person with dementia, (31), p. 273].

Participants also identified that disclosure to others about their dementia was important to them as a source of support. This allowed them to continue with activities that they enjoyed. For example, one lady continued playing golf as her friends kept score for her. The second theme recognised that the support of significant others was crucial to people with dementia. Participants also highlighted the importance of having a sense of purpose and taking opportunities to stay engaged and socially active. Several participants adapted their activities to accommodate the dementia. Sometimes adaptation to continue activities occurred facilitated by friendships developed through Memory Makers. This happened when one person who could no longer drive was facilitated to continue with voluntary work, delivering donated food, because a Memory Maker friend, who also had dementia, drove them.

The theme, routines, familiar environments, and memory aids revealed the ways in which participants benefitted from sharing strategies with one another. Doing so increased their knowledge and independence about managing daily life with dementia. Such strategies included keeping objects in the same place, keeping to the same routine including using the same shops or recreational facilities. The final theme clearly illustrated the beneficial impact of the Memory Makers group. Members valued attending the group. One person said it gave her “renewed meaning” in life [Person with dementia, Matchar et al. (31), p. 274]. Matchar et al. (31, 32) also reported that participants thoroughly enjoyed the “bubbly ambience” of Memory Maker, and ESBCA which were filled with fun, humour and laughter. One participant said:

‘It’s like a party. . . .Everyone’s laughing, and everyone is happy’ [Participant with Dementia, (31), p. 274].

The atmosphere of the groups meant that participants could relax, be themselves, focus on their strengths rather than losses (32), in an environment which was free from stigma and one in which they felt safe to make mistakes (32). In the activities offered by both these interventions, participants were treated with “acceptance, kindness, and respect” and the study authors argue that this helped participants to build and maintain their resilience (31). One participant illustrated these findings saying:

‘Everyone in the group ‘got it’ and that was a very liberating experience. . . . . I felt less like complaining and more inclined towards positive planning and living one day at a time’ [Person with dementia, (32), p. 174].

### Chapter Three. Paper Two.

Being a member of the group provided participants with a sense of belonging. One participant said they had gained a new family, and this empowered them as individuals. The power of the group and the bonds created within them was captured in a poem that participants created:

'You are not alone.

I felt the group was a life saver.

It brought a life, empowering us all' [(32), p. 173].

Key features of the studies and interventions are summarised in Table 2. Having provided an overview description of the studies, this paper now focuses on how the concept of resilience was defined and operationalised during the investigations.



Table 3.2. Key Features of the Studies								
Study ID Country	Aim	Intervention Name Target Population Facilitators	Intervention Description	Context Delivered, Duration, Frequency	Study Design and Methods	Study Population	Results	Conclusion
{Clarke et al., 2013, 2018) UK	To compare the influence of DA and PSN services to identify ways they contribute to well-being and resilience of people with dementia and family carers	1.DA 2.PSN  People with dementia and Carers/Families  Lay Health Workers	1. Signpost to other services and ongoing support.  Lay Health Worker  2. Psychosocial Support in Alzheimer Society support groups and dementia cafes.	Community  Ongoing	Mixed Methods  Qualitative semi-structured Interviews Thematic analysis  Well-being and QoL surveys using ASCOT and DEMQoL. Statistically analysed.	People with dementia (n=47) Early Dementia, family carers (n=54), staff and stakeholders (n=82).	Themes  -Addressing the needs of the individual and community - Promoting independence.  -Control and choice.  -Getting a life back.	Public health models of healthcare provision. Should be used to promote resilience.
(Newman et al., 2018; Windle et al., 2016) UK	To evaluate the impact of visual arts enrichment activities on opportunities for resilience.	Visual arts enrichment activities people with dementia.  Artists trained about dementia	Creative individual and collective activities	Care Home  Weekly, 2 hours for 3 months	Mixed Methods, (only Qualitative data focused on resilience) Interviews baseline, post intervention, and 3 months follow up with People with dementia, relatives and Carers.  Sessions Videoed  Facilitator Structured notes.	People with dementia (n=48) in care homes (n=4) aged 70 to 99, CDR scale – n=6 was 0.5 questionable; n=18 1 mild; n=8 2 moderate; n=16 3 severe, care staff, family (n=37)	Supported resilience through creative expression, increased communication, improved self-esteem and relationships with significant others.	Resilience can be supported by visual arts enrichment activities. The concept of respondent habitus may be useful.

Chapter Three. Paper Two.

<p>(Matchar et al., 2018) USA</p>	<p>(Not explicitly stated)</p>	<p>Early-Stage &amp; Beyond Community  Post Memory Makers  People with dementia and Family Carers  Four Masters level Social Workers trained by Alzheimer’s Association Early-Stage Group Facilitators Manual.</p>	<ol style="list-style-type: none"> <li>1.Lunch gatherings</li> <li>2.Museum tours, activities, lunch</li> <li>3.Support groups</li> <li>4. Workshop for partners</li> <li>5. Carer support groups</li> <li>6. Lecture series for carers</li> <li>7. Concerts, movies, education</li> </ol>	<p>Community</p> <ol style="list-style-type: none"> <li>1.Monthly</li> <li>2.Monthly</li> <li>3.Monthly</li> <li>4.4 monthly every 1-2 years</li> <li>5.Monthly</li> <li>6.Quarterly</li> <li>7.Random</li> </ol>	<p>Observational and Descriptive reported than using specific outcome measures.</p>	<p>Graduates from 16 Memory Makers support programme groups Family units (n=1799) with people early dementia (n=166; aged 49-93) and their care givers (n=178)</p>	<p>Resilience fostered through acceptance, disclosure, significant others, sense of purpose, routines and familiar environments and memory aids, showing up/value of a support group, faith.</p>	<p>Resilience is of critical importance to people with dementia regarding acceptance of diagnosis and adaptation to it and there is limited work completed to date as to how resilience can be strengthened.</p>
<p>(Matchar &amp; Gwyther, 2014) USA</p>	<p>To explore the impact on resilience of an Alzheimer education and support group</p>	<p>Memory Makers program  Structured Educational support group  people with dementia and Family Carers  2 Masters level Social Workers trained by Alzheimer’s Association Early-Stage Group Facilitators Manual.</p>	<p>Structured Educational support group; with carer-people with dementia 5-12 dyads. 75 minutes of discussion separately and then dyads together on different topics weekly.</p>	<p>Community</p> <p>3 hours weekly, for 8 weeks</p>	<p>Observational Descriptive</p> <p>Evidence from 4 groups.</p> <p>Open-ended evaluation surveys were emailed after intervention. Anecdotes from these combined with facilitator observations</p>	<p>People with early dementia and care partner dyads (n=35) spouse 86% adult daughter 14%</p>	<p>People with dementia expressed gratitude for care partner, perceived small victories sustained their resilience. Groups shared coping strategies, expressed hope, humour, living the best lives they could, reciprocal caring.</p>	<p>Resilience benefits from sense of belonging to peer group.</p>

#### 3.1.4.2. Definition and operationalisation of resilience

To address the aims of this review to fully examine and integrate the findings of the studies it is important to establish how resilience was defined and operationalised. This is because historically resilience has been defined in different ways (8). Newman et al. (29) and Matchar et al. (31, 32) state that they defined resilience as a dynamic process that encompasses positive adaptation in the presence of adversity. Although a definition of resilience is not expressly stated by Clarke et al. (28), the study's design supports the supposition that resilience was defined as a process. This is because resilience is reported to be an outcome of the DA and PSN interventions, and yet quantitative outcome measures of well-being and quality of life are used in the study, rather than scales that aim to measure the psychological capacity for resilience.

The studies identified in this review were informed by different research paradigms and theoretical backgrounds including, social constructivism and social disability (28); the ecological theory of human development and the ecological framework of resilience (29); and the social context perspective (31, 32). Newman et al. (29) explicitly stated that the ecological view of resilience underpins their investigation, but all the studies included in this review appear to endorse the view that the resilience of people with dementia is impacted by resources that are accessed at individual, social and community level (8). This supposition is supported because the interventions target both people with dementia and their family carers and the wider community.

Because resilience has been operationalised in this way it is appropriate to apply the resilience framework (9) to the studies' findings to facilitate a more in depth examination as to how the interventions impacted the resilience of people with dementia. This is relevant because resilience can potentially be supported through: reducing the adversity and via improving the provision or access to resources. In applying the framework in this review, community level resources that support resilience are defined as being people in direct contact with people with dementia (significant others) and societal level resources are defined as referring to people outside immediate contact with individual service users.

The results of applying the framework to the included studies are discussed below and summarised in Table 3.

#### 3.1.4.3. The impact of the five interventions on the resilience of people with dementia

##### DA and PSN Services (27, 28)

The DA and PSN services supported resilience by helping to identify the adversity and needs of people with dementia. This included identifying participants' needs and desires to have a wide range of activities to help them stay well. The adversity experienced by individuals through the stigma of dementia was also combated through DA facilitators providing education to groups of people (other than the participants) about dementia and the needs of people with dementia.

The interventions enabled access to resources that occurred at individual, community and societal levels. Individual resources included the activities that were applicable to people's individual strengths, needs and desires. Indeed, access to these was supported through the participants' increased independence and sense of control. One participant referred to how the services empowered her to make choices with her partner:

'It gave us the confidence to move in the directions we wanted to move in' (Jilly, care partner who had accessed DA service) [(27),p. 392].

At community level, the interventions impacted the resilience of the people with dementia through providing support to their carer and through providing participants with access to social peer support. Lillian, a participant with dementia said of the PNS:

'It's fantastic because we can all talk to each other' [(27), p. 391].

Having access to resources appeared to impact the outcomes of resilience. The theme, "getting a life back" speaks to participants having achieved a "new normal" and improved quality of life. One of the participants said:

'We've sort of got back some normality now. He's got quite a week of things happening most days.' (Carer) [(27), p. 391].

#### Memory Maker and ESBCA (31, 32)

The Memory Maker and ESBCA, did not use a specific tool to identify the needs of the people with dementia as part of the investigation. Never-the-less, it can be extrapolated from the study's data, that participants were experiencing adversity particularly regarding social isolation as a result of the dementia and stigma.

The interventions provided participants with time with others who shared their experiences as people with dementia and family carers. Having time to bond as a group was a resource for individuals and the community through which resilience could be supported and sustained (31).

The outcomes of these interventions for resilience, were improved communication between people with dementia and care partner dyads (32), increased capacity for empowerment, independence, and positivity going forward into the future. The data also suggested a more global outcome, that group membership helped move individuals toward a more normal life with dementia, which included being themselves and having a social life with friendships that reduced social isolation. In this regard, their lives with dementia were normalised and the dementia was reframed as being part of their lives. The findings further revealed that participants had more confidence to disclose their dementia to other people (31). This suggests that not only do these outcomes have the potential to be sustained within this community of participants, but outcomes could potentially develop as a result of individuals seeking and benefiting from the support of others outside this immediate peer group community. However, evidence that this occurred is not provided by Matchar et al. (31, 32).

#### VAEA (29)

In terms of reducing adversities, the VAEA intervention highlighted that participants had cognitive and communication difficulties, that were more severe than those experienced by participants in the other studies. The severity of difficulties was variable both in and between individuals (29). Newman et al. (29) also identified that the beliefs and actions of carers and relatives, regarding the person with dementia's capabilities, impacted how adversity was experienced by people with dementia. Newman et al. (29) found that seeing people with dementia involved in VAEA increased their awareness. This could potentially change the behaviour of carers and relatives resulting in them acting in way that supported resilience and did not cause excessive disability. However, no evidence of this change was reported by the study.

In contrast to the other studies, Newman et al. (29) argue that participating in the VAEA increased access to resources but these resources could not be separated into distinct individual and community categories. Instead, resources were used in a complex interplay which was enabled by VAEA. VAEA had no visible impact on resilience through wider societal issues but the impact was through individual, and community issues as described above.

### Chapter Three. Paper Two.

VAEA resulted in people doing better than would otherwise be expected and this can be regarded as an outcome of resilience, during the intervention. In addition, their communication and interaction with others increased in quality and their self-esteem improved.

The findings of this review are now discussed in relation to the wider literature and then recommendations for future research are proposed.

Table 3.3. The impact of interventions applied to the Resilience Process (Windle 2011) and Framework (Windle & Bennett, 2012)			
	Adversity	Resources	Outcomes for Individuals diagnosed
<p><b>PSN and DA Services</b> <b>(Clarke et al., 2013, 2018)</b></p>	<p>Identified and address a wide range of needs.</p>	<p><b>Individual</b></p> <ul style="list-style-type: none"> <li>-Provided resources relevant strengths and desires of individuals. e.g. people wanted to keep well, wide range of services and purposeful activities</li> <li>-Supported access to resources, through empowering participation, choice, independence, control.</li> </ul> <p><b>Community</b></p> <ul style="list-style-type: none"> <li>-Social contact with peers.</li> <li>-Supported significant others.</li> </ul> <p><b>Societal</b></p> <p>Education for others in society and advocated on behalf of people with dementia.</p>	<ul style="list-style-type: none"> <li>-Increase QoL, independence.</li> <li>-Achieved a 'new normal' living with dementia.</li> <li>-Recommended social life and purposeful activities.</li> <li>-Improved self-esteem, self-worth, improved self-identity,</li> <li>-confidence to disclose dementia to others.</li> </ul>
<p><b>Memory Maker and ESBCA</b> <b>(Matcher et al., 2014, 2018)</b></p>	<p>Identified Stigma Reduced Social Isolation</p>	<p><b>Individual</b></p> <ul style="list-style-type: none"> <li>-Access to information about successfully living with dementia</li> </ul> <p><b>Community</b></p> <ul style="list-style-type: none"> <li>-Opportunities to support and receive support from others.</li> <li>-Social contact with peers.</li> <li>-Opportunities for social life and environment without stigma.</li> </ul>	<ul style="list-style-type: none"> <li>-Improved independence, positivity, communication.</li> <li>- Adapted purposeful activities.</li> <li>-Empowered to seek further help through disclosure.</li> <li>-Reframed dementia normalising existence.</li> </ul>
<p><b>VAEA</b> <b>(Newman et al., 2018)</b></p>	<p>Variable cognitive and communication difficulties. Stigma Excessive Disability</p>	<ul style="list-style-type: none"> <li>-Access to group and individual creative activities</li> <li>-Access to context which supports personhood.</li> <li>-Access to and use of interplay of individual and social resources.</li> </ul>	<p>Did better than expected.</p> <p>Increased communication, self- esteem</p> <p>Improved relationships with others.</p>

### 3.1.5. Discussion

The studies reported the perceptions and experiences of people with dementia and the findings reveal that the interventions were well-received by participants who engaged with them voluntarily. Many people with dementia reported the interventions to be beneficial and their views concurred with the observations and opinions of significant others (27, 28, 31, 32). Newman et al. (29) reported the experiences of people with dementia using the intervention as being beneficial to their resilience but did so using the observations and verbal reports of significant others, rather than directly from people with dementia. This raises questions about the challenges involved in assessing the resilience of people with moderate and advanced dementia. As dementia progresses it is important to find ways to accurately capture the perspectives of people with dementia about their resilience. Not to do so is potentially problematic because the perspectives of people with dementia and carers can differ regarding perceptions of quality of life (41) and what makes activities meaningful (42).

One of the benefits of the interventions, was that they empowered people with dementia to disclose their diagnosis to other people (27, 28, 32). Disclosure of dementia diagnosis to friends and family is beneficial (43) and it is logical that informing significant others may be a gateway to the person gaining support from significant others. This finding was less pertinent in the study population living in residential care, but it is notable that involvement with VAEA also improved communication with other people (29). The latter could improve the possibility of compensatory support which may increase the resilience of people with dementia (4).

It is noticeable that only the study reporting VAEA described any weakness or disadvantages to the interventions. VAEA was reported as enjoyable despite some people with dementia experiencing frustration if they were unable to master certain activities.

The results of this review reveal that most studies to date have focused on people with dementia who are “doing okay” (44). Participants with dementia who were recruited for Memory Makers and ESBCA were relatively well-supported, and those accessing PSN and DA services had the capacity to reach out to the services and engage with them. Although participants involved with VAEA all had significant vulnerabilities, only people without severe communication difficulties were involved in the study. Clarke et al. (28) acknowledges that not accessing people with dementia who did not use the service, was a limitation of their investigation. In addition, except for some participants, involved with VAEA, most participants had early stage dementia. Therefore, the findings of the community-based studies reflect the impact of the interventions on the resilience of people with dementia who have a relatively high ability to access and use resources to support their resilience. This is a situation common to other studies conducted regarding resilience in people with dementia where participants were deemed to be “doing okay” (15, 44), living with people who were supportive and willing to participate in research (22, 45, 46), had contact with support groups (16, 47, 48), and were in receipt of support services (19). However, Harris (44) investigated the resilience of people with dementia including some who were not “doing okay” (n = 5). Therefore, it is possible to examine the resilience of people with dementia who are adapting less well to the challenges of living with dementia. Accessing and recruiting participants who are in the most need can be challenging (49). It may take more time to convince gatekeepers that such individuals would be able to participate and to gain participants’ consent (50). It may also be challenging to convince funders that recruitment time and study duration in the context of dementia research may need to be extended to facilitate the inclusion of individuals who are in most need.

This review identified that a small number of studies have examined interventions that aimed to support the resilience of people with dementia, who live in both community and residential care settings. The studies were undertaken within the last decade and three of the papers reporting their evaluations were published in 2018. This suggests that the investigation of interventions to support resilience in dementia is a relatively recent and developing field of research and practice. This novelty is reflected in the research designs used to evaluate the interventions. The assessment of the studies methodological strengths and weaknesses during this review found that all the studies produced valuable results in terms of their contribution to knowledge and regarding the aims of this review. However, only Clarke et al. (27, 28) and Newman et al. (29, 30) rated highly in terms of methodological quality. This result was obtained by the two reviewers whose independent assessments, which initially revealed a high degree of consensus, achieved full consensus through discussion.

The research designs of all the studies do not seek to measure change in well-being but instead seek to describe how the services were used and experienced by people with dementia and to identify what stakeholders perceived their impact to be. Matchar et al. (31, 32) and Newman et al. (29) focused on describing details of the perceived process and outcomes of the interventions. Their investigations infer that outcomes are as a result of the interventions, and there was no attempt to isolate variables and measure change. Newman et al. (29) did obtain data at multiple time points in relation to participation in VAEA, including data obtained 3 months after the intervention, but their findings concerning potential changes in well-being beyond the VAEA sessions were not reported. Without alternative study designs providing control group comparisons, it is impossible to ascertain effectiveness and whether participation was beneficial due to the components of each intervention per se, or due to them being offered in the absence of another viable activity. Therefore, it cannot be determined to what degree the social component of the group interventions were important. Never-the-less, it should be noted that the varied interventions examined here all supported resilience through socially related characteristics namely, their positive impact on stigma, social contact, and social support.

The stigma associated with dementia was highlighted as an adversity in that it contributed to excessive disability (29) and social isolation (28, 31, 32). This concurs with findings elsewhere, that the actions of other people in applying negative stereotypes increase the difficulties of living with dementia (43). It is therefore significant that the interventions reduced these adversities through providing stigma free, psychosocially safe platforms (29) in which people were free from the fear of potential embarrassment (43, 51).

Social contact and support from other people are also important for resilience (5, 15, 22), as is the quality of the relationships that people with dementia have with other people (52). It appears that the quality of relationships within all the group interventions were improved because they involved people who shared the experience of living with dementia. The interventions provided the opportunity for participants to interact and belong to a peer group and this was hugely valued by participants (28, 29, 31, 32). Belonging to a peer group is known to positively impact resilience in dementia (16, 19, 53) by empowering people, providing opportunities to share practical information strategies to increase their repertoire of adaptive coping strategies (54) and enhancing positivity, which is important for resilience (15, 55).

The quality of relationships between people with dementia and the interventions' facilitators were also important to the success of the interventions. It is notable that all the interventions involved facilitators who played key roles conducting and creating both the content of the interventions and their processes. The artists created the VAEA intervention, enabled



participation and ameliorated the impact on self-esteem for individuals who were not able to master the activity (29). The lay health advisors of the DA intervention had ongoing in-depth interactions with service users throughout their journeys with dementia and they shaped the service in response to needs (27, 28). In order to be effective, these facilitators had direct personal knowledge of dementia and intimate knowledge of communities (27) and had training in dementia care as social workers (31) or as researchers (29). This reveals that successful resilience building interventions requires skilled facilitation. In addition, as dementia progresses the way facilitators facilitate interventions is likely to differ and require additional skills.

The interventions also impact resilience through being supportive of the personhood (56) of individuals with dementia, by providing them with meaningful activities (29, 31). Meaningful activities are likely to contribute to the increased self-worth and self-esteem that resulted from the interventions (27–29). Indeed, the activities may support resilience through providing a sense of continuity in identity (55, 57) which can be balanced against the changing perceptions of identity that occur due to the dementia. Successfully managing this balance is important for resilience in dementia (53, 58). The proposition that the interventions may support this important “task” of resilience in dementia is supported by participants in the studies who said the interventions helped them adjust to dementia, to reframe and normalise living with the condition (27, 31, 32).

Another characteristic of the interventions is that they were strength-based in that they built upon the assets and resources that people with dementia already possessed. The interventions required participants to have and use personal and social skills in order to participate. For example, the group interventions required communication and cooperation skills and when participating in the VAEA interventions, participants used aspects of their personal and shared cultural, previous and present identities (29). This implies that people with dementia did not just receive the interventions, but they contributed of themselves, to the intervention and to other group members. Indeed, because their participation involved reciprocity, questions can be raised as to how the positive impact on the resilience of individuals might be increased through the interventions providing opportunities to contribute to communal resilience. People with dementia want to give support to others and contribute (16, 59, 60) and doing so provides them with opportunities for increased self-worth through reinforcing positive self-identity (43). It appears that when the interventions impacted as resources to support resilience, the lines between individual and community resources are blurred regarding reciprocity. Lines between these resource categories were also blurred because two out of three interventions aimed to support the resilience of both people with dementia and family carers. Indeed, carers can be regarded as a community support for people with dementia and family carers with greater well-being may have greater capacity to support the resilience of the people with dementia.

It is also noteworthy that Newman et al. (29) identified there was interplay between individual and community resources during VAEA.

The findings of the review revealed that resilience can be fostered “in the moment” during an intervention and/or sustained after the intervention has finished. “In the moment” increased adaptation was highlighted during VAEA, whereas the community-based interventions placed greater emphasis on supporting resilience with the goal of attaining sustainable outcomes (31), through increased independence and ongoing well-being (27, 28). However, fostering of resilience “in the moment” was implied during all the interventions through the reports of humour, joy, and release reported by participants. These positive emotions equate to what have been described as “good moments” (61) of happiness. It appears logical that interventions that create opportunities for small moments

of happiness are likely to increase positivity and hope which are very important for resilience in people with dementia (16, 19, 21).

The studies in this review provide some evidence that the effects of interventions on resilience can be sustained. Some people with dementia reported and recalled the effects of the interventions when data was obtained (27, 28) and after they had occurred (32) and effects of ESBCA were on-going (31). On-going sustained effect was not highlighted in the findings of VAEA, but the potential for this exists if carers were to act differently due to improvements in relationships and increased awareness concerning the capabilities of people with dementia. Potential for sustained effect on resilience also exists regarding the other interventions due to their empowerment effects and the potential for increased support from other people due to disclosure.

#### 3.1.5.1. Implications for Future Research

Applying the resilience process (8) and framework (9) to the interventions discussed in this review, facilitated in depth understanding as to how these interventions impacted resilience of people with dementia. Therefore, it would be useful for future research to include a resilience perspective using the framework. Doing so would be particularly beneficial to investigations concerning interventions that aim to support people with dementia in any purposeful activity. This is because purposeful activity, chosen by a person (57, 62) and compatible with their tacit norms (63), is important to the resilience of people with dementia (48, 55, 57, 63, 64). For example, spirituality can be an important resource for the resilience of many people with dementia (5, 19, 48, 51, 59, 65–67). But to date interventions targeting spirituality have not, to our knowledge, focused on resilience even through spirituality based interventions have been found to impact wellbeing (68–70). Applying the resilience process when examining such interventions may increase understanding of how they impact wellbeing.

This review also found that although supporting resilience was beneficial to people with dementia, only a limited number of interventions have been developed and these have been assessed predominantly with people in early dementia in community settings who are currently “doing okay.” Future research should focus on interventions that have the potential to support resilience through facilitating communication opportunities for people with more advanced dementia to interact with other people (58, 71, 72). Indeed, touchscreen technology has been found to enhance personhood of people with dementia (73) and robotic technologies can positively impact quality of life (74, 75) and improve mood (76). The potential of these interventions to support resilience could be investigated. Indeed, focusing on people with moderate dementia and those not “doing okay” might reveal the need to target different areas and develop different strategies to support their resilience.

This review highlights gaps in current knowledge concerning how interventions support the resilience of people with dementia and their carers differently, similarly, and jointly. This warrants further investigation, as joint interventions may not suit all dyads and could even harm the resilience of either party. Furthermore, if it is found that the resilience of people with dementia can be enhanced by interventions that also support family carers, then the potential for interventions that jointly target the resilience of people with dementia and professional carers should be investigated in residential care settings.

The findings of this review suggest that resilience can be supported “in the moment” and/or sustained after interventions. This suggests that resilience in relation to time needs further examination. Further investigation is also warranted concerning the interplay between individual and community resources(29), particularly regarding reciprocity and how reciprocity can be used in interventions to support resilience in people with dementia.

It is difficult to assess the impact of interventions that occur in clinical environments (77), particularly when investigating them in the context of dementia, which is a progressive disease and where the symptoms of the disease and the adversity caused vary within and between individuals (29). Therefore, in order to potentially influence policy and practice, future research ideally needs to use methodologies that elucidate changes that occur both during and as a result of interventions. Furthermore, tools such as Dementia Care Mapping (78) and the Observational Measurement of Engagement (79), may be needed to accurately capture behavioural responses to stimuli and measure changes in resilience. In addition, because the resilience of individuals is impacted by significant others, it is important that future investigations examine the social context into which interventions are introduced and their impact on resilience in the light of this.

#### 3.1.5.2 Limitations

This review has limitations and its findings should be considered in the light of these. The search was limited to items published in English and in order to focus on resilience, it excluded proxy terms for resilience. Therefore, intervention investigations reported in different languages and those that explored alternative well-being outcomes, which may have impacted resilience, were omitted. In addition, the search process and data extraction were conducted by one reviewer therefore some relevant articles might have been erroneously excluded. However, the review utilised a theoretically informed systematic approach and the included studies were subjected to in-depth analysis applying resilience theoretical constructs.

#### 3.1.6. Summary

This review used a systematic approach to identify and examine research that investigated psychosocial interventions that aimed to support the resilience of people with dementia. The findings revealed a variety of interventions conducted in both residential care and community living settings. The interventions were found to impact all the components of the resilience process (8) and sometimes there was interplay between the individual and social resource components of resilience. The findings reveal that interventions can support resilience, both during and after the intervention sessions, although evidence of their effectiveness is limited because studies are descriptive and do not measure change. This review found there is a need for further research in this developing field. However, interventions that successfully build resilience in people with dementia need skilled facilitators to ensure that they are supportive of personhood and that they enable reciprocal social interactions to occur. It is also important that interventions are provided within a stigma free context.

#### 3.1.7. References

1. World Health Organisation. Dementia Factsheet. (2019). Available online at: <https://www.who.int/news-room/fact-sheets/detail/dementia> (accessed March 4, 2019).
2. Porter VR, Buxton WG, Fairbanks LA, Strickland T, O'Connor SM, Rosenberg-Thompson S, et al. Frequency and characteristics of anxiety among patients with Alzheimer's disease and related dementias. *J Neuropsychiatry Clin Neurosci.* (2003) 15:180–6. doi: 10.1176/jnp.15.2.180
3. Ganguli M. Depression, cognitive impairment and dementia: why should clinicians care about the web of causation? *Indian J Psychiatry.*(2009) 51:529–34.
4. Clare L, Kinsella GJ, Logsdon R, Whitlatch C, Zarit SH. Building resilience in mild cognitive impairment and early-stage dementia: innovative approaches to intervention and outcome evaluation. In: Resnick B, Gwyther L, Roberto K, editors. *Resilience in Aging.* New York, NY: Springer (2011). p. 245–60. doi: 10.1007/978-1-4419-0232-0\_16
5. Harris PB, Keady J. Wisdom, resilience and successful aging: changing public discourses on living with dementia. *Dementia.* (2008) 7:5–8. doi: 10.1177/1471301207085364
6. Angus J, Bowen-Osborne S. A self-narrative of life-long disability: a reflection on resilience and living with dementia. *Dementia.* (2014) 13:147–59. doi: 10.1177/1471301212455121

## Chapter Three. Paper Two.

7. Harris P. Is resilience a key to living a meaningful life with dementia? Factors that contribute to the resilience process in early stage dementia. In: The 63th Annual Scientific Meeting of the Gerontological Society of America. New Orleans, LA (2010).
8. Windle G. What is resilience? A review and concept analysis. *Rev Clin Gerontol.* (2011) 21:152–69. doi: 10.1017/S0959259810000420
9. Windle G, Bennett KM. Caring relationships: how to promote resilience in challenging times. In: Ungar M, editor. *The Social Ecology of Resilience: A Handbook of Theory and Practice.* New York, NY: Springer (2012). p. 219–31. doi: 10.1007/978-1-4614-0586-3\_18
10. Bronfenbrenner U. Ecological models of human development. *Int Encyclopedia Educ.* (1994) 3:37–43.
11. Gillespie BM, Chaboyer W, Wallis M. Development of a theoretically derived model of resilience through concept analysis. *Contemp Nurse.* (2007) 25:124–35. doi: 10.5172/conu.2007.25.1-2.124
12. Windle G. The contribution of resilience to healthy ageing. *Perspect Public Health.* (2012) 132:159–60. doi: 10.1177/1757913912449572
13. Garcia-Dia MJ, Dinapoli JM, Garcia-Ona L, Jakubowski R, O’Flaherty D. Concept analysis: resilience. *Arch Psychiatr Nurs.* (2013) 27:264–70. doi: 10.1016/j.apnu.2013.07.003
14. Bailey C, Clarke C, Gibb C, Haining S, Wilkinson H, Tiplady S. Risky and resilient life with dementia: review of and reflections on the literature. *Health Risk Soc.* (2013) 15:390–401. doi: 10.1080/13698575.2013.821460
15. Bailey GH. “This is my life and I’m going to live it”: a grounded theory approach to conceptualising resilience in people with mild to moderate dementia (Doctoral dissertation). The University of Edinburgh, Edinburgh, Scotland (2017).
16. Casey D, Murphy K. People with dementia’s perceptions of resilience and the factors that strengthen resilience. In: *Gerontological Society of America 2014 Annual Scientific Meeting.* Washington, DC (2014).
17. Harris, PB. Another wrinkle in the debate about successful aging: the undervalued concept of resilience and the lived experience of dementia. *Int J Aging Hum Dev.* (2008) 67:43–61. doi: 10.2190/AG.67.1.c
18. Kitwood TM. *Dementia Reconsidered: The Person Comes First.* Buckingham. Open University Press (1997).
19. Pilon-Young FE, Lee KM, Jones F, Guss R. I’m not all gone, I can still speak: the experiences of younger people with dementia. An action research study. *Dementia Int J Soc Res Pract.* (2012) 11:597–616. doi: 10.1177/1471301211421087
20. Preston L, Marshall A, Bucks RS. Investigating the ways that older people cope with dementia: a qualitative study. *Aging Ment Health.* (2007) 11:131–43. doi: 10.1080/13607860600844572
21. Werezak L, Stewart N. Learning to live with early dementia. *Can J Nurs Res.* (2009) 41:366–84.
22. Van Dijkhuizen M, Clare L, Pearce A. Striving for connection: appraisal and coping among women with early-stage Alzheimer’s disease. *Dementia.* (2006) 5:73–94. doi: 10.1177/1471301206059756
23. Williamson PR, Altman DG, Blazeby, JM. Developing core outcome sets for clinical trials: issues to consider. *Trials.* (2012) 13:132. doi: 10.1186/1745-6215-13-132
24. Stoner CR, Orrell M, Long M, Csipke E, Spector, A. The development and preliminary psychometric properties of two positive psychology outcome measures for people with dementia: the PPOM and the EID-Q. *BMC Geriatr.* (2017) 17: 72. doi: 10.1186/s12877-017-0468-6
25. Stoner CR, Orrell M, Spector A. The Positive Psychology Outcome Measure (PPOM) for people with dementia: psychometric properties and factor structure. *Arch Gerontol Geriatr.* (2018) 76:182–7. doi: 10.1016/j.archger.2018.03.001
26. Moniz-Cook E, Vernooij-Dassen M, Woods R, Orrell M, Interdem Network. Psychosocial interventions in dementia care research: the INTERDEM manifesto. *Aging Ment Health.* (2011) 15:283–90. doi: 10.1080/13607863.2010.543665
27. Clarke C, Keyes S, Wilkinson H, Alesjuk J, Wilcockson J, Robinson L, et al. Healthbridge: The National Evaluation of Peer Support Networks and Dementia Advisers in Implementation of the National Dementia Strategy for England. (Ref: 025/058). Department of Health Policy Research Programme Project (2013).
28. Clarke C, Keyes S, Wilkinson H, Alesjuk J, Wilcockson J, Robinson L, et al. ‘I just want to get on with my life’: a mixed-methods study of active management of quality of life in living with dementia. *Ageing Soc.* (2018) 38:378–402. doi: 10.1017/S0144686X16001069

## Chapter Three. Paper Two.

29. Newman A, Goulding A, Davenport B, Windle G. The role of the visual arts in the resilience of people living with dementia in care homes. *Ageing Soc.* (2018) 39:2465–82. doi: 10.1017/S0144686X18000594
30. Windle G, Newman A, Burholt V, Woods B, O'Brien D, Baber M, et al. Dementia and Imagination: a mixed-methods protocol for arts and science research. *BMJ.* (2016) 6:e011634. doi: 10.1136/bmjopen2016-011634
31. Matchar BG, Gwyther LP, Galik E, Resnick B. Building resilience in persons with early-stage dementia and their family carers. In: Resnick B, Gwyther L, Roberto K, editors. *Resilience in Aging*. New York, NY: Springer (2018). p. 261–79. doi: 10.1007/978-3-030-04555-5\_14
32. Matchar BG, Gwyther LP. Resilience in early-stage dementia. *Top Geriatr Rehabil.* (2014) 30:170–5. doi: 10.1097/TGR.000000000000020
33. Baumieister R, Leary M. Writing narrative literature reviews. *Rev Gen Psychol.* (1997) 1:311–20. doi: 10.1037/1089-2680.1.3.311
34. Green B, Johnson C, Adams A. Writing narrative literature reviews for peer reviewed journals: secrets of the trade. *J Chiropr Med.* (2006) 5:101–14. doi: 10.1016/S0899-3467(07)60142-6
35. Ferrari R. Writing narrative style literature reviews. *MedWrit.* (2015) 24:230–5. doi: 10.1179/2047480615Z.000000000329
36. Noyes J, Booth A, Flemming K, Garside R, Hardent A, Lewins S, et al. Cochrane qualitative and implementation methods group guidance series— Paper Three: methods for assessing methodological limitations, data extraction and synthesis, and confidence in synthesised qualitative findings. *J Clin Epidemiol.* (2018) 97:49–58. doi: 10.1016/j.jclinepi.2017.06.020
37. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Ann Intern Med.* (2009) 151:264–9. doi: 10.7326/0003-4819-151-4-200908180-00135
38. Office of National Statistics. *Measuring Outcomes for Public Service Users (MOPSU) Project. Final Report.* London: Office of National Statistics (2010).
39. Banerjee SS, Smith SC, Lamping DL, Harwood RH, Foley BB, Smith PP, et al. Quality of life in dementia: more than just cognition. An analysis of associations with quality of life in dementia. *J Neurol Neurosurg Psychiatry.* (2006) 77:146–8. doi: 10.1136/jnnp.2005.072983
40. Hughes CP, Berg L, Danziger, W, Coben LA, Martin RL. A new clinical scale for the staging of dementia. *Br J Psychiatry.* (1982) 140: 566–72. doi: 10.1192/bjp.140.6.566
41. Spector A, Orrell M. Quality of life (QoL) in dementia: a comparison of the perceptions of people with dementia and care staff in residential homes. *Alzheimer Dis Assoc Disord.* (2006) 20:160–5. doi: 10.1097/00002093-200607000-00007
42. Harmer BJ, Orrell M. What is meaningful activity for people with dementia living in care homes? A comparison of the views of older people with dementia, staff and family carers. *Aging Ment Health.* (2008) 12:548–58. doi: 10.1080/13607860802343019
43. Sabat SR. *Alzheimer's Disease and Dementia: What Everyone Needs to Know.* New York, NY: Oxford University Press (2018).
44. Harris PB. Resilience and living well with dementia. In: Clarke C, Wolverson E, editors. *Positive Psychology Approaches to Dementia.* London: Kingsley (2016). p. 133–51.45.
45. Sørensen L, Waldorff F, Waldemar G. Coping with mild Alzheimer's disease. *Dementia.* (2008) 7:287–99. doi: 10.1177/1471301208093285
46. Pearce A, Clare L, Pistrang N. Managing sense of self: coping in the early stages of Alzheimer's disease. *Dementia.* (2002) 1:173–92. doi: 10.1177/147130120200100205
47. Ditta G. *Resilience and Wellbeing in People Living With Dementia in Relation to Perceived Attitudes in Their Communities.* Alzheimer Scotland (2015).
48. Beard RL, Knauss J, Moyer D. Managing disability and enjoying life: how we reframe dementia through personal narratives. *J Aging Stud.* (2009) 23:227–35. doi: 10.1016/j.jaging.2008.01.002
49. Watson JL, Ryan L, Silverberg N, Cahan V, Bernard MA. Obstacles and opportunities in Alzheimer's clinical trial recruitment. *Health Aff.* (2014) 33:574–9. doi: 10.1377/hlthaff.2013.1314
50. Beuscher L, Grando VT. Challenges in conducting qualitative research with individuals with dementia. *Res Gerontol Nurs.* (2009) 2:6–11. doi: 10.3928/19404921-20090101-04
51. Bryden C. A spiritual journey into the I-Thou relationship: a personal reflection on living with dementia. *J Relig Spiritual Aging.* (2016) 28:7–14. doi: 10.1080/15528030.2015.1047294

52. Donnellan WJ, Bennett KM, Soulsby LK. What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study. *Aging Ment Health.* (2015) 19:932–9. doi: 10.1080/13607863.2014.977771
53. McDermott O, Charlesworth G, Hogervorst E, Stoner C, Moniz-Cook E, Spector A, et al. Psychosocial interventions for people with dementia: a synthesis of systematic reviews. *Aging Ment Health.* (2019) 23:393–403. doi: 10.1080/13607863.2017.1423031
54. Stocker KB. Personal experience of coping with brain disease: neglected area of research (Doctoral dissertation). University of Massachusetts, Boston, MA, United States (2001).
55. Schmidt T. Resilience in dementia: Perspectives of those living with dementia (Master's thesis). University of Alberta, Edmonton, AB, Canada (2014).
56. Kitwood T, Bredin K. Towards a theory of dementia care: personhood and well-being. *Ageing Soc.* (1992) 12:269–87. doi: 10.1017/S0144686X0000502X
57. Smith D, Smith D. Our journey with Alzheimer's disease. *N Z J Occup Ther.* (2012) 59:5.
58. Astell AJ, Savundranayagam MY, Kelson E, Purves B, Phinney A. Fostering resilience in dementia through narratives: contributions of multimedia technologies. In: Resnick B, Gwyther L, Roberto K, editors. *Resilience in Aging.* New York, NY: Springer (2018). p. 245–60. doi: 10.1007/978-3-030-04555\_5\_13
59. Bryden C. *Dancing With Dementia: My Story of Living Positively With Dementia.* London: Jessica Kingsley Publishers (2005).
60. Suwa S, Otani S, Tsujimura M, Nogawa K, Shiya Y. The diary of a nonagenarian-centenarian woman with dementia: memory loss, life changes, and community care in Japan. *Int J Nurs Pract.* (2018) 24:e12655. doi: 10.1111/ijn.12655
61. Sabat SR. Existential phenomenology and the quality of life of carers and are recipients: a case study. *Dementia.* (2009) 8:163–6. doi: 10.1177/1471301209103247
62. Friedell M. Awareness: a personal memoir on the declining quality of life in Alzheimer's. *Dementia.* (2002) 1:359–66. doi: 10.1177/147130120200100307
63. Cerderall Y, Torres S, Åberg AC. Maintaining well-being and selfhood through physical activity: experiences of people with mild Alzheimer's disease. *Aging Ment Health.* (2015) 19:679–88. doi: 10.1080/13607863.2014.962004
64. Olsson A, Lampic C, Skovdahl K, Engstrom M. Persons with early stage dementia reflect on being outdoors: a repeated interview study. *Aging Ment Health.* (2013) 17:793–800. doi: 10.1080/13607863.2013.801065
65. Beuscher LM. Exploring the role of spirituality in coping with early stage Alzheimer's disease (Doctoral dissertation). University of Arkansas for Medical Sciences, Little Rock, AR, United States (2007).
66. Agli O, Bailly N, Martinent G. Spirituality, quality of life, and depression in older people with dementia. *J Relig Spirituality Aging.* (2018) 30:268–78. doi: 10.1080/15528030.2018.1452832
67. Ramsey JL, Blieszner R. *Spiritual Resiliency and Aging: Hope, Relationality, and the Creative Self.* New York, NY: Routledge (2016). doi: 10.4324/9781315230979
68. McGee JS, Myers D. Sacred relationships, strengthened by community, can help people with mild or early-stage Alzheimer's. *Generations.* (2014) 38:61–7.
69. Wu LF, Koo M. Randomized controlled trial of a six-week spiritual reminiscence intervention on hope, life satisfaction, and spiritual well-being in elderly with mild and moderate dementia. *Int J Geriatr Psychiatry.* (2016) 31:120–7. doi: 10.1002/gps.4300
70. Mackinley E. Resistance, resilience, and change: the person and dementia. *J Relig Spirituality Aging.* (2012) 24:80–92. doi: 10.1080/15528030.2012.633048
71. Subramaniam P, Woods B, Whitaker C. Life review and life story books for people with mild to moderate dementia: a randomised controlled trial. *Aging Ment Health.* (2014) 18:363–75. doi: 10.1080/13607863.2013.837144
72. Subramaniam P, Woods B. Digital life storybooks for people with dementia living in care homes: an evaluation. *Clin Interv Aging.* (2016) 11:1263–76. doi: 10.2147/CIA.S111097
73. Evans SB, Bray J, Evans SC. The iPad project: introducing iPads into care homes in the UK to support digital inclusion. *Gerontechnology.* (2017) 16:91–100. doi: 10.4017/gt.2017.16.2.004.00
74. Barrett E, Burke M, Whelan S, Santorelli A, Oliveira BL, Cavallo F, et al. Evaluation of a companion robot for individuals with dementia: quantitative findings of the MARIO project in an Irish residential care setting. *J Gerontol Nurs.* (2019) 45:36–45. doi: 10.3928/00989134-20190531-01

## Chapter Three. Paper Two.

75. Moyle W, Jones C, Cooke M, O' Dwyer S, Sung B, Drummond S. Social robots helping people with dementia: assessing efficacy of social robots in the nursing home environment. In: Proceedings of the 6th International Conference on Human System Interactions (HSI). Sopot: IEEE (2013). p. 608–13. doi: 10.1109/HSI.2013.6577887
76. Lane GW, Noronha D, Rivera A, Craig K, Yee C, Mills B, et al. Effectiveness of a social robot "PARO," in a VA long-term care setting. *Psychol Serv.* (2016) 13:292–9. doi: 10.1037/ser0000080
77. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Medical research council: developing and evaluating complex interventions: new guidance. *BMJ.* (2008) 337:a1655. doi: 10.1136/bmj.a1655
78. Bradford UO. DCM 8 User's Manual. Bradford: School of Dementia Studies; University of Bradford (2016).
79. Cohen-Mansfield J, Dakheel-Ali M, Marx MS. Engagement in persons with dementia: the concept and its measurement. *Am J Geriatr Psychiatry.* (2009) 17:299–307. doi: 10.1097/JGP.0b013e31818f3a52

### 3. 2. Chapter Three. Summary and Segue

Chapter three reported a narrative review that applied resilience theory to examine and synthesise the findings of psychosocial interventions that aimed to support the resilience of people with dementia. The findings of the review informed the work of this thesis by identifying how resilience had been applied in previous research and the key components of existing psychosocial interventions designed to promote resilience. The review found that the resilience of people with dementia can be supported by increasing access to beneficial resources and reducing the impact of adversity, including stigma and excessive disability. Furthermore, a detailed examination of resilience was achieved by defining resilience as a process and applying the resilience framework to the examination of these studies. The review also revealed a gap in the literature and the need for further psychosocial interventions to support the resilience of people with dementia who are arguably in most need and relatively unable to access existing services, including people with more advanced dementia.

The findings of this second review informed the design of MARIO's psychosocial intervention and how the intervention using MARIO was delivered and perceived during the robot's empirical evaluation which is reported in the fourth paper in this thesis. This literature review identified that for MARIO to impact resilience, the robot's psychosocial intervention needed to engage its users in purposive activities that supported personhood, by facilitating communication to produce reciprocal social interactions. MARIO's applications needed to enable its user to participate in creative activities that supported identity. This meant that games, pictures, music, and reminiscence were likely to be important. The review also identified that facilitators in previous psychosocial interventions for resilience were important and this finding suggested that facilitators might also play a role in the intervention involving MARIO.

The findings of both reviews presented in chapters two and three informed how the research to investigate the potential of social robots to support resilience should be designed. The reviews revealed that the usage and effect of social robots on resilience would be likely to involve processes and that both social robots and resilience are impacted by interacting factors that exist at an individual, community, and societal levels. These findings indicated that social robots and resilience needed to be investigated in a real-life, rather than simulated conditions, and using a methodology that could provide an in-depth examination and acknowledge the complex interplay between multiple factors. Therefore, case study research (CSR) was one methodology that could be used to explore the potential of social robots to support resilience.

### Chapter Three. Paper Two.

CSR can facilitate the in-depth examination of contemporary phenomena in real-life settings (Yin, 2014) and it is useful to examine processes, interventions, or techniques when they seek to understand the intentions and implications of actions (Stake, 2006). Furthermore, CSR is helpful when there is an indistinct boundary between the phenomena that is under investigation and its surrounding context (Yin, 2014) and when investigating complex interventions that have several interacting components and where the outcomes of interventions are unknown (Abma, 2005). Paper three presented in the next chapter discusses how the optimal case study design was selected and applied to the empirical study which examined the effect of MARIO on the resilience of people with dementia living in residential care.

Abma, T. A. (2005) Responsive evaluation in health promotion: its value for ambiguous contexts. *Health Promotion International*, 20, 391-397.

Stake, E. (2006) *Multiple case study analysis*. New York: Guilford Press.

Yin, R. K. (2014) *Case study research: Design and methods (Fifth)*: London, UK: SAGE Publications Ltd.



### **Chapter Four. Paper Three. Methodology.**

#### 4.0 Prologue

This chapter presents paper three, the methodology paper within this thesis. The work presented in this paper advances the development of DESCARTE, a theoretical model that has been proposed to guide the design and application of case study methodology. The paper presents a critical appraisal of this theoretical model. It also provides an in-depth analysis and rationale for how case study methodology was applied to examine the effect of the robot MARIO on the resilience of people with dementia. The paper provides guidance to future researchers on the use of DESCARTE and on the design and conduct of case study research using the best research practice in the context of dementia.

#### 4.1 Paper Three.

Title: Examining the utility of the DESCARTE model for case study research

Authors: Sally Whelan School of Nursing and Midwifery, National University of Ireland, Galway Ireland.

Dympna Casey School of Nursing and Midwifery, National University of Ireland, Galway Ireland.

Keywords:

Case study, methodology, healthcare, DESCARTE, research design

##### 4.1.1. Abstract

The DESCARTE model aims to guide healthcare researchers on the design, conduct, and reporting of case studies. This article critically appraises the utility of the model and provides an example of its application to a multiple case study that examined the effect of MARIO, a social robot, on the resilience of people with dementia. The DESCARTE model is explained, its strengths and the challenges encountered during its application are discussed. DESCARTE provides a structured framework that promotes quality in case study research by requiring the researcher to articulate philosophical cohesiveness, ethical considerations, reflexivity, and the strategies used during data integration and throughout data analysis. However, the model does not prompt the development of research questions, or methods to promote rigor and reflexivity throughout the case study. A task list and additional guiding questions are provided to address these deficits and to improve the utility of the DESCARTE model.

##### 4.1.2. Introduction

Case studies are intensive, holistic descriptions, and analysis of contemporary phenomena (Merriam, 1988), within their real-life context (Yin, 2009). Case study research (CSR) is particularly useful for examining processes and interventions in healthcare settings (Brogan, 2019). It has been used in gerontological research to investigate resilience in older adult caregivers (Ewen et al., 2015), aging with mobility impairment (Harrison et al., 2013), and palliative care delivery (Sussman et al., 2011). Previous reviews have found that researchers need guidance to design quality case studies (Hyett et al., 2014; Brogan, 2019). The DESign of CAsE Research in healThcarE (DESCARTE) model aims to guide healthcare researchers on the design, conduct, and reporting of case studies (Carolan, 2016). DESCARTE particularly aims to provide guidance on the integration of quantitative and qualitative data in CSR that uses mixed methods. A detailed account of DESCARTE's application to healthcare research (Žulec, 2019) has not to date been reported, and DESCARTE's development followed a relatively small rapid review of case studies (n=20) (Carolan, 2016). Therefore, a critical appraisal of this model is needed to inform future users of the model by describing its application to research practice, and critically examining its utility.

This paper critically appraises the utility of DESCARTE. It provides an example of DESCARTE's application to the design and conduct of a case study that investigated the effect of MARIO, a social robot, on the resilience of people with dementia. This study was part of a wider research project that developed MARIO to increase the social connectedness of people with dementia ([www.mario-project.eu](http://www.mario-project.eu)).

Herein, the DESCARTE model will be described and applied to the exemplar case study the strengths of DESCARTE and the challenges experienced during the model's application are discussed and recommendations are made to improve the utility of the model.

#### 4.1.3. Description of DESCARTE

The DESCARTE model has three stages that are applied in sequence: 1. Situating the research and the researcher; 2. Determining the components of the case study; 3. Data analysis, adopting the three stances. Design decisions made during stage one concern all aspects of the study because stages two and three are embedded in stage one (Figure 1). Table 1 provides an overview of DESCARTE, summarising the tasks researchers are required to undertake when applying DESCARTE. Table 1 also lists twelve questions provided by Carolan (2016) to guide and structure DESCARTE's application. During stage one, the researcher uses critical reflection to identify the research paradigm and considers how their assumptions, preferences, and clinical, educational, or management roles, may potentially bias the research. The researcher also considers and plans how to address the study's ethical dimensions.

During DESCARTE's second stage, the researcher designs the interdependent components of the CS including the: case in its context, research purpose, and the study's conceptual/theoretical framework. The case-purpose dyad is centrally important. Research questions are derived from this dyad, mediated by the study's conceptual theoretical framework (Carolan, 2016). Defining the case includes determining if the case is a phenomenon or an entity, and temporal dimensions of the case context should be considered to determine if the CS should be longitudinal, retrospective, or cross-sectional (Carolan 2016). Then, the researcher selects the sampling approach and data collection methods in relation to the case-purpose dyad and conceptual framework.

In stage three, the researcher concurrently considers three overlapping stances concerning the data analysis: philosophical, strategic, and integrative. The researcher must justify how: their positioning of self impacts the analysis, when specific strategies will be applied, and the timing and purpose of data integration. The model will now be applied to the exemplar case study using Carolan's (2016) twelve guiding questions.

#### 4.1.4. Application of DESCARTE

##### **What is my Philosophical Approach?**

The constructivist paradigm underpinned the MARIO CS. Constructivism supports the existence of multiple realities focusing on the production of shared meanings and the meaning placed on knowledge (Kelly et al., 2018). These characteristics were pertinent because the resilience of people with dementia is impacted by meaning created from life-experiences (Kitwood, 1993), and technology use is influenced by what the technology means to individuals (Chang et al., 2013). Merriam's qualitative approach to CSR is compatible with constructivism (Merriam, 1988, 1998), therefore this approach underpinned the deployment of methods in this CS.

How do I Situate my ‘Self’ in this Research?

The lead author (SW: herein referred to as the author) used journaling (Johns, 2017) to identify that she held views consistent with constructivism. The author believed that people with dementia had a right to participate in research that involved technologies and that technologies should supplement rather than replace contact with people. The author realised that using person-centred principles (Kitwood, 1993) and the CORTE framework (Murphy, 2014), would facilitate people with dementia to participate in the research.

The author identified her training needs, guided by a researcher experienced in dementia research, and she received supervisory support and training in conducting questionnaires with people with dementia and dementia care mapping (Bradford, 2016). SW was a nurse, experienced in the care of people with dementia, and familiar with nursing home environments. These factors might facilitate developing rapport with participants, but she needed awareness of alternative perspectives about the care context. Also, as an immigrant, the author identified herself as an ‘outsider’ to the dominant culture within the research setting. Therefore, her potential to notice cultural nuances increased. However, the author needed to build rapport with participants to avoid assuming she correctly understood the meaning of expressions and behaviours.

**Table 4.1** Overview of the DESCARTE Model (Adapted from Carolan, 2016).

Model Stage	Researcher Tasks when Applying DESCARTE	Guiding Questions
1. Situating the Research and the Researcher	<p>Articulate the paradigm that guides the study and consider what this means for other components of the study.</p> <p>Identify how the researcher positions ‘self’ and the impact that their views, attitudes, and role will have on the study.</p> <p>Identify the study’s ethical dimensions and plan how they will be addressed.</p>	<p>1. What is my philosophical approach?</p> <p>2. What are the ethical dimensions of this research?</p> <p>3. How do I situate my ‘self’ in this research?</p> <p>Questions 1-3 are not addressed in any prescriptive order.</p>
2. Determining the components of the case study design	<p>Define the case.</p> <p>Determine if the case is a phenomenon or an entity.</p> <p>Identify the context and consider the temporal dimensions.</p> <p>Identify the study’s purpose and if a deductive, inductive, abductive approach is appropriate.</p> <p>Identify the theoretical framework.</p> <p>Identify a sampling approach.</p> <p>Determine data sources and provide a rationale for these.</p>	<p>4. How is the case defined?</p> <p>5. How is the context defined?</p> <p>6. What is the purpose of the case study?</p> <p>7. What is the conceptual/ theoretical framework for the case study?</p> <p>8. What is my sampling approach?</p> <p>9. What is the rationale for my choice of data sources?</p> <p>Questions 4-7 are addressed in an order that is appropriate for study. Then questions 8 and 9 are addressed in relation to the previous questions.</p>
3. Data Analysis-adopting the three stances	<p>Articulate how the data analysis method is congruent with the adopted philosophical approach.</p> <p>Plan how the researcher will work reflexively during analysis.</p> <p>Articulate and justify the strategic approaches to data analysis.</p> <p>Consider the implications of using these strategies</p> <p>State in detail how data will be integrated, including the timing and purpose of data integration.</p> <p>Consider if the types of data are transformed and the implications of any transformation.</p>	<p>10. Is data analysis congruent with the philosophical approach?</p> <p>11. Is my analysis adopting a case-based or a variable analysis-based approach?</p> <p>12. How and why is data integrated during data analysis and interpretation?</p> <p>Questions 10-12 are addressed concurrently.</p>

**Figure 1** The DESCARTE Model.

(Figure redacted due to publisher restrictions – See Carolan et al., (2016) for original Diagram).

**What are the Ethical Dimensions of this Research?**

Experienced dementia researchers led discussions to determine how to address recruitment, consent, participant wellbeing, confidentiality, and data storage. Also, before MARIO's arrival, the nursing home manager completed a risk assessment of the environment. A distress protocol was written advising that in the event of a participant becoming distressed, the author would assess the situation and react to address the source of the distress seeking caregiver advise and ceasing research activity if necessary. Computer-based data was encrypted using <https://www.axcrypt.net/> and pseudonyms provided participants with anonymity. The National University of Ireland Galway Research Ethics Committee granted ethical approval.

**What is the Purpose of the Case Study?**

This study investigated MARIO’s capacity to support resilience and built upon resilience theory and knowledge about robot usage. It required both deductive and abductive approaches, as explained below.

**What is the Conceptual/Theoretical Framework for the Case Study?**

Windle (2011) identified that resilience is a process of adapting to stress that operates at multiple interacting levels that are reflective of the human ecology framework described in ecological systems theory (Bronfenbrenner, 1994). A resilience framework drawing on this theory has conceptualized resilience in people with dementia (Newman et al., 2018) and older adults (Bennett et al., 2016; Thetford et al., 2015). The resilience framework considers that resilience occurs in the presence of adversity, such as living with dementia. Resilience outcomes in dementia include ‘doing okay’ (Harris, 2008, p.59), positive mood, and quality of life (Sabat, 2018). Outcomes are impacted by resources that interact occurring at the individual, community, and societal levels. Resilience resources include having a sense of purpose, good social relationships, and supportive institutional policies (Harris & Keady, 2008; Williamson & Paslawski, 2016).

**How is the Case Defined?**

The case was the resilience of a person with dementia who used MARIO. To address the CS purpose, the case was bound through ensuring the people with dementia met relevant inclusion/exclusion criteria (Table 2). In addition to people with dementia, relatives, and caregivers were relevant informants, and they contributed to the eco-social factors that impacted both resilience and MARIO’s usage. Therefore, each case included embedded units involving a person with dementia, two caregivers, and a relative of the person with dementia.

**Table 4.2.**

The Inclusion and Exclusion Criteria

Type of Participant	Inclusion	Exclusion
People with Dementia	Living in the care setting for at least one month before the study. Have either a formal diagnosis of dementia of any severity and/or it was stated that they have dementia in the medical records.	Not likely to continue living in the care setting for the study’s duration. Not have a significant sensory impairment or acute illness which caregivers considered would impair their ability to participate.
Caregivers	Have provided care to the person with dementia during the preceding month.	Not likely to continue to provide care to the participant.
Relatives	Will be visiting with the person with dementia during the study period.	

**How is the Context Defined?**

The context was the social-cultural environment within the nursing home and investigating how resilience changed due to using MARIO used a diachronic pre-during-post intervention design.

**What is my Sampling Approach?**

Ten cases were examined simultaneously, rather than sequentially. The case selection strategy also addressed important ethical considerations concerning the recruitment and wellbeing of participants with cognitive and communication difficulties (Table 3).

**Table 4.3.**

The Information in this Table Describes the Recruitment Strategy

Recruitment Stages	Description of Activity
1	People with dementia who met the inclusion/exclusion criteria were asked by a senior nurse, whom they knew well if they wanted to meet the researcher. If they agreed, the nurse introduced the author, who spent considerable time with the person with dementia, building rapport, explaining the study, and what being a participant would involve. During the discussions, the author read with the person a participant information leaflet (PIL) designed for people with dementia. Also, if they wished, the person with dementia met MARIO.
2	After seven days, the author returned, reintroduced herself and the study to the person with dementia, and again took time to build rapport and answer questions using the PIL. After these discussions, if the person with dementia wanted to participate, their consent was recorded in writing. Also, before every episode of their involvement in the study, ongoing consent was obtained (Dewing, 2007).
3	When people with dementia had consented to participate, relatives and caregivers received information about the study. If they fitted the inclusion/exclusion criteria, they received a PIL, and their consent to participate was sought after further discussion a week later.

Conversations during recruitment took place when the people with dementia were ready to process information (Mayo & Wallhagen, 2009), guided by information from caregivers who knew the person with dementia well (Hubbard et al. 2003) and facilitated by reducing distractions, speaking clearly, and giving the person time to think and react. Capacity to consent used the British psychological society guidelines (Herbert, 2019).

**What is the Rationale for my Choice of Data Sources?**

Using multiple sources of data is typical in CSR (Merriam & Tisdell, 2016). This CS used quantitative and qualitative data (Table 4) to facilitate understanding patterns of resilience that vary between contexts and cultures (Ungar, 2011). Audiotaped, semi-structured interviews used with a supportive, flexible approach guided by the CORTE framework (Murphy, 2014), provided rich data (Yin, 2014) about how MARIO was perceived and impacted resilience. Questionnaires were deployed that investigated the capacity for resilience and quality of life as resilience outcomes, and their administration was guided by the authors' questionnaire instruction manuals and the result of pilot testing in the nursing home. Dementia care mapping (DCM) (Bradford, 2016) captured data about the social and environmental factors impacting resilience and the impact of MARIO on the mood and engagement of people with dementia. DCM is a semi-structured, non-participant observation technique that involves trained mappers quantitatively recording the activities, mood, and engagement levels of people with dementia at 5-minute time intervals and recording notes describing social interactions and contextual details. The Observational Measure of Engagement (OME) (Cohen-Mansfield et al., 2009) captured participants' engagement and activity levels while they used MARIO. MARIO was offered to participants, facilitated by a

researcher, three times a week for 12 sessions, in which they engaged with MARIO and used the robot’s personalised applications. Applications included photographs to support reminiscence based conversations, favourite music, calendars, news, and games. Data were collected before MARIO’s introduction (Pre-MARIO), during sessions with the robot and after their completion (Post-MARIO). Also, each questionnaire and interview were administered on different days to minimise participants’ fatigue.

**Table 4.4.**

This Table Summarises the Data Collection Methods

Study Stage	Demographic Data	DCM	Questionnaires	OME	Semi-Structured Interviews
Pre MARIO	✓	✓	✓		People with dementia
During MARIO				✓	
Post MARIO	✓	✓	✓		People with dementia, caregivers, and relatives
<b>Demographic data</b> included: Mini Mental State Examination (Folstein & McHugh, 1975) and Cornell Scale for Depression in Dementia (Alexopoulos, et al., 1988). <b>Questionnaires:</b> The Resilience Scale (RS-14)(Wagnild & Young 1993); Quality of Life in Alzheimer’s Disease Scale (QOLAD) (Logsdon et al., 1999).					

**Is Data Analysis Congruent with the Philosophical Approach?**

Consistent with Merriam’s CS approach, data analysis aimed to provide a holistic understanding of the cases using robust, theoretically endorsed procedures (Merriam & Tisdell, 2016). Through reflective journaling, the author identified that the data analysis strategy needed to mitigate aspects of her personality according to the Enneagram (a model of the human psyche and its nine interconnected personality types) (Riso & Hudson, 1999) that emphasised creative synthesis. Therefore, the analysis was conducted being aware of how meaning within the data was being interpreted, and with the intention to keep ideas tentative and consider alternative meanings until the ideas were corroborated by the data. It was also beneficial to guide the analysis using a theoretically informed structured approach because the author was a researcher conducting CS analysis for the first time. Therefore, framework analysis, using a qualitative content analysis approach (Heish & Shannon, 2005), was deployed using eight iterative steps (Gale et al., 2013) (Table 5).

**Is my Analysis Adopting a Case-based or a Variable Analysis-based Approach?**

The analysis used case rather than variable based strategies. Within-case analysis started by analysing the quantitative DCM data according to the DCM procedures (Bradford, 2016), and the OME and questionnaire data were analysed using SPSS version 24 (<https://spss.en.softonic.com>). On the advice of a researcher experienced in quantitative methods, the cross-case analysis used descriptive statistics, and the Wilcoxon signed-rank test ( $\alpha = 0.05$ ) to assess mean rank differences between the group questionnaire results. All the qualitative data was imported into NVIVO 12 (<http://www.qsrinternational.com>) and reviewed to ‘revisit the phenomenon’ (Timmermanns & Tavory, 2012, p.175) that was under investigation. Then, the constant comparative method (Lincoln & Guba, 1985) was used whilst reading the transcripts of four cases, line by line, to code segments of data according to their meaning. This coding involved abductive reasoning and creative inference, examining the interplay between the data and the existing theory (Timmerman & Tavory, 2012). Following this, a formal coding framework was developed using the codes already created and deductive reasoning to deduce ‘statements’ derived from the theory (Bergdahl & Bertero, 2014) on robot acceptability and resilience in dementia. This coding framework was then used to code data from the remaining six cases and additional codes were added if new ideas presented in the data. Then, both qualitative and quantitative data were entered into a matrix, created with codes in columns, cases in rows, and data in the matrix cells.

**Table 4.5.**

The Stages of Data Analysis (derived from Gale et al., 2013)

Stage Number	Summary of Activity
1	Transcription (interview data was professionally transcribed).
2	Familiarisation with data.
3	Coding of data from 4 cases in NVIVO 12.
4	Developing a coding framework.
5	Framework implemented, coding the remaining data.
6	Charting data into a matrix.
7	Interpreting and abstracting the data into themes.
8	Themes were finalised in a written report.

The data in the cells were summarised in ‘memos’ (Bonello & Meehan, 2019). The summaries were then systematically reviewed, and case summaries were written. Cross-case analysis was conducted, comparing similarities and differences in the data across all the cases to identify themes and deviant cases. These themes were reviewed and developed by writing analytical memos (Bonello & Meehan, 2019) that facilitated building abstractions and an in-depth understanding of what was important in the data (Merriam & Tisdell, 2016). Then, using critical thinking, the analytical memos were synthesised to define the final themes.

**How and why is Data Integrated during Data Analysis and Interpretation?**

The integration strategy involved concurrent analysis of the quantitative and qualitative data, separately, and then both types of data were integrated before developing the themes. Quantitative data was placed in the matrix according to where it was most meaningful in relation to the codes and categories derived from the qualitative data. For example, the quantitative OME results that concerned the participant’s attitude towards MARIO were integrated with qualitative data in the matrix under codes that concerned the participant’s willingness to use MARIO. Using these integration techniques meant that the numbers and words within the data types were preserved (Sandelowski, 2000) and they corroborated the thematic findings (Yin, 2014).

**4.1.5. Critical Appraisal of DESCARTE.**

**The Strengths of DESCARTE**

DESCARTE focused the researcher’s attention on the selection and application of a research paradigm. This ensured the CS was cohesively, theoretically underpinned. Through prioritising the positioning of self and ethical considerations, the model improved the research quality by facilitating the researcher to mitigate their impact on reflexivity and ensuring that potential ethical problems were proactively addressed.

DESCARTE guides the CS researcher to critically consider data analysis and integration strategies. This guidance addresses an underdeveloped area in CS literature (Yin, 2009). This guidance enables multiple data sources to be deployed using theoretically robust strategies.

Using DESCARTE avoided the necessity to pigeon-hole the exemplar study into a CS taxonomy (Carolan, 2016). Instead, the researcher had to identify whether the study required deductive, inductive, or abductive approaches. Doing so, was more useful because it facilitated the selection of strategies for data collection and analysis. In comparison, determining whether the exemplar study was exploratory and/or evaluative, as outlined by Yin (2014), seemed to have little practical value.



The model is logically structured, generic, and flexible. Through these factors DESCARTE guides the researcher to accomplish tasks required in the design and conduct of CSR in the most appropriate way for the individual study. For example, although embedded units were not considered helpful by Carolan (2016), they were used because they were meaningful in the exemplar study.

#### Challenges using the DESCARTE model

Traditionally during CS design, components are derived from the research questions (Stake, 1995; Yin, 2014; Merriam & Tisdell, 2016). Indeed, having 'how' and 'why' questions are reasons for choosing CSR (Yin, 2014). Using the case-purpose dyad and not prompting researchers to identify the research questions, did not prevent DESCARTE being applied to the exemplar CS. But consideration of research questions might have more quickly determined the study's strategic direction and its specific objectives. Furthermore, not focusing on research questions might be more problematic to post-positivist case studies. In case studies using this paradigm, researchers are required to identify propositions from the research questions and data is linked to these propositions during data analysis (Yin, 2014).

The promotion of rigor is inherent when using DESCARTE. However, the researcher is not prompted to identify specific methods to address rigor and to demonstrate the trustworthiness of findings. For example, the exemplar used strategies that align with constructivism: credibility, confirmability, data dependability, and transferability, and the plausibility of the findings were reaffirmed using 'member checking' (Merriam & Tisdell, 2016).

The model assumes that the researcher has prior knowledge of research philosophy and CSR. This means that some steps commonly taken in CS design are not highlighted in the model's guidance provided by Carolan (2016). The guidance is particularly limited when the researcher is directed to identify if the case is a phenomenon or a person (Carolan, 2016). This limited categorisation of a case does not acknowledge complexities that a case is a 'bounded system' (Merriam, 1998; Stake, 1995; Yin, 2014) and that the case is important because of what it represents or reveals about a phenomenon (Merriam, 1998; Stake, 1995). Or, indeed that the case is required to be 'something of' a phenomenon, which could be an aspect of a person (Thomas, 2015). The current guidance on DESCARTE also understates the need to deploy specific strategies for reflective practice to enhance reflexivity throughout the study.

#### 4.1.6. Recommended Development to DESCARTE

For reasons stated above, two additional prompt questions are proposed to facilitate future applications of DESCARTE: 1. What are the research question(s)/aims? 2. What strategies and methods are used to address rigor in this research? Ideally, the research question(s)/aims should be addressed after determining the CS purpose and its conceptual framework. Consideration of methods to promote rigor can take place after determining the data sources. Also, DESCARTE users should identify strategies to facilitate reflection and incorporate reflexive practice throughout the study, and the requirement to determine if the case is a phenomenon or an entity should be removed.

#### 4.1.7. Conclusion

The DESCARTE model provides a useful framework to enhance CS quality by requiring the researcher to focus on philosophical cohesiveness, ethical considerations, reflexivity, and data analysis. However, its use requires knowledge of research philosophy and CSR and it does not prompt the identification of research questions, specific strategies, and methods to promote rigor and reflexive practices throughout the research. Additional guidance and guiding questions were recommended to improve the model's utility.

#### 4.1.8. References

- Alexopoulos, G. S., Abrams, R. C., Young, R. C., & Shamoian, C. A. (1988). Cornell scale for depression in dementia. *Biological psychiatry*, 23(3), 271-284. [http://dx.doi.org/10.1016/0006-3223\(88\)90038-8](http://dx.doi.org/10.1016/0006-3223(88)90038-8)
- Bennett K, Reyes-Rodriguez M, Altamar P and Soulsby L. (2016) Resilience amongst older Colombians living in poverty: an ecological approach. *Journal of Cross-cultural Gerontology* 31, 385–407.
- Bergdahl, E., & Berterö, C. M. (2015). The myth of induction in qualitative nursing research. *Nursing Philosophy*, 16(2), 110-120. <http://dx.doi.org/10.1111/nup.12073>
- Bonello, M., & Meehan, B. (2019). Transparency and Coherence in a Doctoral Study Case Analysis: Reflecting on the Use of NVivo within a 'Framework' Approach. *The Qualitative Report*, 24(3), 483-498. <https://nsuworks.nova.edu/tqr/vol24/iss3/4>
- DCM 8 User's Manual. Bradford, UK: School of Dementia Studies, University of Bradford.
- Brogan, P., Hasson, F., & McIlfratrick, S. (2019). Lessons learnt: examining the use of case study methodology for nursing research in the context of palliative care. *Journal of Research in Nursing*, 24(6), 446-459. <http://dx.doi.org/10.1177/1744987119867737>
- Bronfenbrenner, U. (1994). Ecological models of human development. In T. Husen, & T. N. Postlewaite (Eds.), *International encyclopedia of education* (pp. 1643–1647). Elsevier.
- Carolan, C. M., Forbat, L., & Smith, A. (2016). Developing the DESCARTE model: The design of case study research in health care. *Qualitative health research*, 26(5), 626-639. <http://dx.doi.org/10.1177/1049732315602488>
- Chang, W. L., Sabanovic, S., & Huber, L. (2013). Situated Analysis of Interactions between Cognitively Impaired Older Adults and the Therapeutic Robot PARO. In G. Herrmann, M. J. Pearson, A. Lenz, P. Bremner, A. Spiers, & U. Leonards (Eds.), *Social Robotics, ICSR 2013* (Vol. 8239, pp. 371-380). Springer-Verlag Berlin [http://dx.doi.org/10.1007/978-3-319-02675-6\\_37](http://dx.doi.org/10.1007/978-3-319-02675-6_37)
- Cohen-Mansfield, J., Dakheel-Ali, M., & Marx, M. S. (2009). Engagement in persons with dementia: the concept and its measurement. *The American journal of geriatric psychiatry*, 17(4), 299-307. <http://dx.doi.org/10.1097/JGP.0b013e31818f3a52>
- Dewing, J. (2007). Participatory research: a method for process consent with persons who have dementia. *Dementia*, 6(1), 11-25. <http://dx.doi.org/10.1177/1471301207075625>
- Ewen, H. H., Chahal, J. K., & Fenster, E. S. (2015). A portrait of resilience in caregiving. *Research in Gerontological Nursing*, 8(1), 29-38. <https://doi.org/10.3928/19404921-20141111-01>
- Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state": a practical method for grading the cognitive state of patients for the clinician. *Journal of psychiatric research*, 12(3), 189-198.
- Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC medical research methodology*, 13(1), 1-8. <http://dx.doi.org/10.1186/1471-2288-13-117>
- Harris, P. B. (2008). Another wrinkle in the debate about successful aging: The undervalued concept of resilience and the lived experience of dementia. *The International Journal of Aging and Human Development*, 67(1), 43-61. doi: 10.2190/AG.67.1.c
- Harrison, T., Taylor, J., Fredland, N., Stuifbergen, A., Walker, J., & Choban, R. (2013). A Qualitative Analysis of Life Course Adjustment to Multiple Morbidity and Disability. *Research in Gerontological Nursing*, 6(1), 57–69. DOI 10.3928/19404921-20121107-01.
- Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative health research*, 15(9), 1277-1288. DOI: 10.1177/1049732305276687
- Herbert, C., Gray G., Poate-Joyner, A., Ferry, S., Betteridge, S., Hill S., Macpherson, G., Joyce, T., Soeterik, S., Campber Reay, A., Parker, Gaby., Todd, N., Mackenzie, Brechin, D. (2019) What makes a good assessment of capacity? The British Psychological Society. <https://www.bps.org.uk/news-and-policy/what-makes-good-assessment-capacity>
- Hubbard, G., Downs, M. G., & Tester, S. (2003). Including older people with dementia in research: challenges and strategies. *Aging & Mental Health*, 7(5), 351-362. <http://dx.doi.org/10.1080/1360786031000150685>
- Hyett, N., Kenny, A., & Dickson-Swift, V. (2014). Methodology or method? A critical review of qualitative case study reports. *International journal of qualitative studies on health and well-being*, 9(1), 23606. <http://dx.doi.org/10.3402/qhw.v9.23606>
- Johns, C. (2017). *Becoming a reflective practitioner*. John Wiley & Sons.
- Kelly, M., Dowling, M., & Millar, M. (2018). The search for understanding: The role of paradigms. *Nurse researcher*, 25(4), 9-13. <http://dx.doi.org/10.7748/nr.2018.e1499>

- Kitwood, T. (1993). Discover the person, not the disease. *Journal of Dementia Care*, 1(1), 16-17.
- Lincoln, Y. S. & Guba, E. G. (1985). *Naturalistic inquiry*, Sage.
- Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (1999). Quality of life in Alzheimer's disease: patient and caregiver reports. *Journal of Mental health and Aging*, 5, 21-32.
- Mayo, A. M., & Wallhagen, M. I. (2009). Considerations of informed consent and decision-making competence in older adults with cognitive impairment. *Research in gerontological nursing*, 2(2), 103-111. <http://dx.doi.org/10.3928/19404921-20090401-08>
- Merriam, S. B. (1988). *Case study research in education: A qualitative approach*. Jossey-Bass.
- Merriam, S. B. (1998). *Qualitative Research and Case Study Applications in Education*. Revised and Expanded from "Case Study Research in Education." ERIC.
- Merriam, S. B., & Tisdell, E. J. (2016). *Qualitative research: A guide to design and implementation*. John Wiley & Sons.
- Murphy, K., Jordan, F., Hunter, A., Cooney, A., & Casey, D. (2015). Articulating the strategies for maximising the inclusion of people with dementia in qualitative research studies. *Dementia*, 14(6), 800-824. <http://dx.doi.org/10.1177/1471301213512489>
- Newman, A., Goulding, A., Davenport, B., & Windle, G. (2019). The role of the visual arts in the resilience of people living with dementia in care homes. *Ageing & Society*, 39(11), 2465-2482. <http://dx.doi.org/10.1017/S0144686X18000594>
- Riso, D. R., & Hudson, R. (1999). *The wisdom of the Enneagram: The complete guide to psychological and spiritual growth for the nine personality types*. Bantam.
- Sabat, S. R. (2018). *Alzheimer's Disease and Dementia: What Everyone Needs to Know®*. Oxford University Press.
- Sandelowski, M. (2000). Combining qualitative and quantitative sampling, data collection, and analysis techniques in mixed-method studies. *Research in nursing & health*, 23(3), 246-255. [http://dx.doi.org/10.1002/1098-240X\(200006\)23:3%3C246::AID-NUR9%3E3.0.CO;2-H](http://dx.doi.org/10.1002/1098-240X(200006)23:3%3C246::AID-NUR9%3E3.0.CO;2-H)
- Sussman J, Barbera L, Bainbridge D, et al. (2011) Health system characteristics and quality of care delivery: A comparative case-study examination of palliative care for cancer patients in four regions in Ontario, Canada. *Palliative Medicine* 26(4): 322–335. <http://dx.doi.org/10.1177/02692163111416697>
- Stake, R. E. (1995). *The art of case study research*. Sage.
- Thomas, G. (2015). *How to do your case study*. Sage.
- Thetford, C., Bennett, K. M., Hodge, S., Knox, P. C., & Robinson, J. (2015). Resilience and vision impairment in older people. *Journal of Aging Studies*, 35, 37-8. <http://dx.doi.org/10.1016/j.jaging.2015.07.007>
- Timmermans, S., & Tavory, I. (2012). Theory construction in qualitative research: From grounded theory to abductive analysis. *Sociological theory*, 30(3), 167-186. <http://dx.doi.org/10.1177/0735275112457914>
- Ungar, M. (2011). The social ecology of resilience: Addressing contextual and cultural ambiguity of a nascent construct. *American journal of orthopsychiatry*, 81(1), 1. <http://dx.doi.org/10.1111/j.1939-0025.2010.01067.x>
- Wagnild, G. M., & Young, H. M. (1993). Development and psychometric and psychometric evaluation of the Resilience Scale. *Journal of nursing measurement*, 1(2), 165-17847.
- Williamson, T., & Paslawski, T. (2016). Resilience in dementia: Perspectives of those living with dementia. *Canadian Journal of Speech-Language Pathology and Audiology*, 40, 1-15.
- Windle, G. (2011). What is resilience? A review and concept analysis. *Reviews in clinical gerontology*, 21(2), 152. <http://dx.doi.org/10.1017/S0959259810000420>
- Yin, R. K. (2009). *Case study research: Design and methods* 4th edition. Yin, R. K. (2009). *Case study research: Design and methods (Applied social research method)*. Sage.
- Yin, R. K. (2014). *Case Study Research: Design and Methods (Applied Social Research Methods)*. California: Sage.
- Žulec, M., Rotar-Pavlič, D., Puharić, Z., & Žulec, A. (2019). "Wounds Home Alone"—Why and How Venous Leg Ulcer Patients Self-Treat Their Ulcer: A Qualitative Content Study. *International journal of environmental research and public health*, 16(4), 559. <http://dx.doi.org/10.3390/ijerph16040559>

#### 4.2. Chapter Four. Summary and Segue

Paper three presented the first critical appraisal of the DESCARTE model that had been proposed as a framework to promote the quality of case study research in healthcare settings. This paper contributes to the literature and it advances knowledge by analysing and applying DESCARTE thereby demonstrating the robustness as a model and its usefulness as a framework. In addition, the paper recommended developments for the model, potentially increasing its utility.

The following additional information about the conduct of the empirical study to examine the effect of MARIO on resilience is available in the Appendices 5) - 12). The information includes the letter granting ethical approval, the ethical distress protocol, participant information sheets, and consent forms, and the interview guides.

Chapter five reports the findings of the empirical study that investigated how MARIO, a social robot, effected the resilience of people with dementia.

## Chapter Five. Paper Four. Findings.

### 5.0 Prologue

This chapter presents Paper Four. Paper Four reports the findings of the multiple case study that examined the effect of MARIO on the resilience of people living with dementia in a long-term care setting. This is the first study that has investigated the effect of a robotic psychosocial intervention on resilience and it focuses on the effect of MARIO on resilience and how social robots can be used to increase resilience.

### 5.1. Paper Four

#### Title:

The effects of MARIO, a social robot, on the resilience of people with dementia: A multiple case study.

#### Authors:

Whelan, S.,<sup>1</sup> Burke, M.,<sup>1</sup> Barrett, E., Mannion, A.,<sup>1</sup> Kovacic, K.,<sup>2</sup> Santorelli, A.,<sup>3</sup> Luz Oliveira, B.,<sup>3</sup> Gannon, L.,<sup>1</sup> Shiel, E.,<sup>4</sup> & Casey, D.<sup>1</sup>

#### Authors Address Details

1. School of Nursing & Midwifery, National University of Ireland Galway, Ireland.
2. School of Political Science and Sociology, National University of Ireland Galway, Ireland.
3. Translational Medical Device Lab, National University of Ireland, Galway Ireland.
4. St. Brendan's Community Nursing Unit, Loughrea, Co. Galway Ireland.

### 5.5.1. Abstract

#### Background

Resilience is a process of adapting to stress. For people with dementia, resilience is enhanced through having positive social relationships. Social robots, such as MARIO, can facilitate social engagement. However, the effect of social robots on resilience has not yet been determined.

#### Research Aim

To investigate how MARIO, a social robot, affects the resilience of people with dementia.

#### Methods

Multiple case study methodology was used to explore the resilience of people with dementia during and after they used MARIO in 12 facilitated sessions. Data collection was conducted using dementia care mapping; semi-structured interviews with people with dementia (n=10), caregivers (n=6) and relatives (n=7); and questionnaires including the Quality of Life in Alzheimer's disease and The Resilience Scale. During sessions, data was collected using the Observational Measure of Engagement. Data analysis was guided by framework analysis. Qualitative and quantitative data were analysed in NVIVO 12 and SPSS, respectively. Then, all data was triangulated in a matrix, analysed for similarities and differences within and across cases and themes were developed.

#### Findings

The cross case analysis produced four themes: Resilience changes minute to minute; Initiating and maintaining readiness; Active co-creation of meaningful activity; Impact on resilience. The findings revealed that people with dementia required skilled facilitation to use MARIO. During interactions with MARIO, the resilience of eight out of ten people was supported. Sessions with MARIO increased the wellbeing of people with dementia through providing meaningful activity that re-enforced their positive self-concept.

### Conclusion.

Social robots need to have greater capability to interpret and respond to the emotional needs of users if they are to benefit the resilience of people with dementia without the presence of a supportive facilitator. Future research should explore how strength-based strategies can empower people with dementia to create meaningful activity using social robots.

Keywords: Dementia, Alzheimer's, Resilience, Case Study, Social Robots.

### 5.1.2. Introduction

Dementia is a syndrome that causes stress to people with dementia and their families (Prince, 2016). Stress can result from the symptoms of dementia that include cognitive, communication, emotional, and sensory difficulties (WHO, 2020), which makes performing everyday activities challenging (Prince, 2016). Stress can also be caused by poor relationships with other people and environmental factors (Beard, 2009), such as moving into residential care (Sury et al., 2013) and stigma (Bryden, 2018). However, people with dementia can demonstrate resilience (Newman et al., 2018) and be regarded as 'doing okay' (Harris, 2008) or doing better than expected (Bailey, 2017) whilst living with the limitations of dementia.

Resilience has been defined as a process of negotiating and adapting to stress that occurs in the presence of adversity (Windle, 2011). Resilience is impacted by a person's ability to access the resources that are available to them at individual, community, and societal levels (Windle & Bennett, 2012). However, people need to be motivated to use resources, and motivation is increased if people consider that resources are meaningful to them (Ungar, 2008).

For people with dementia, the goal of resilience is to achieve a degree of wellbeing that includes having: a positive self-concept (Harris & Keady, 2008), a positive mood, and being engaged with life (Sabat, 2018). To achieve wellbeing, people with dementia need to accept: support from other people, that they have dementia, and that this necessitates changes to their lives (Pipon-Young et al., 2012). The ability of people with dementia to achieve a good level of wellbeing is enhanced through the availability of protective assets and resources (Harris & Keady, 2008). All people have personal resilience repertoires (Ottmann & Margoudaki, 2015). These include the practical and psychological strategies that people use to cope with difficulties in life. Casey and Murphy (2016a) interviewed people with dementia (n=6) and found that their resilience repertoires included spirituality, being determined, having a fighting spirit, a positive attitude, and a sense of gratitude. Williamson and Paslawski (2016) examined the perspectives on the resilience of people with dementia (n=7) and their care partners (n=5). They identified that resilience is supported by having a sense of purpose in life and being involved in meaningful activity. Resilience is also supported by resources that are available at the community level, by having positive relationships with other people (Harris, 2010). Harris (2010) interviewed people with dementia (n=6) to examine how resilience can facilitate people with dementia to have a more meaningful life. They found that resilience can be fostered through having a social environment that promotes dignity, respect, and attainable independence. Societal level resources that can support resilience concern the social, economic, and institutional policies (Windle, 2011) that underpin the practices used to care for people with dementia.

Previous research has revealed that social robots have the potential to support constituents of resilience in people with dementia. Kang et al. (2019) systematically reviewed randomised controlled trials (n= 8). They found that PARO, a zoomorphic robot, which appears as a baby harp seal, can improve social interactions. People with dementia (n=5) and caregivers (n=12) have also reported a sense of social connection and positive emotions when using the telepresence robot, Giraff (Moyle et al., 2019). Higher levels of engagement during robot-

assisted psychomotor therapy and increased emotional positivity were also found when people with dementia (n=9) used NAO, a humanoid robot (Rouaix et al., 2017). Feng et al. (2019) also found the communication and engagement of people with dementia (n=9) were enhanced when they evaluated an interactive system, LiveNature, involving a robotic sheep and an ambient wall display unit, which provides pictures of nature. However, a recent review of randomised controlled trials (n=11) and meta-analysis on the effectiveness of social robots on quality of life and psychological outcomes, found that their impact was not statistically significant (Pu, et al., 2019). Researchers have also speculated that the initial improvements in wellbeing, due to the novelty of robots, may not be sustained in the long-term (Moyle et al., 2017).

While the research described above has revealed that social robots can beneficially impact constituents of resilience, research has not yet been conducted that focuses on the effects of social robots on resilience. Research is also lacking regarding how social robots can be used to support the resilience of people with dementia through stimulating human to human contact (Jøranson et al., 2016) and promoting engagement in meaningful activities (Neal et al., 2019).

The current study aimed to investigate how using MARIO, a social robot, effected the resilience of people with dementia. Its objectives were to: (i) identify the key characteristics of resilience in this context, (ii) explore how resilience changed due to using MARIO and (iii) identify how MARIO was used to impact the resilience of people with dementia. This study was part of a wider EU project (<http://www.mario-project.eu>) that developed MARIO, to increase the social connectedness of people with dementia. MARIO uses a mobile Kompai robotic platform ([www.kompairobotics.com](http://www.kompairobotics.com)). The robot has a camera and sensors to enable indoor navigation and obstacle avoidance (D'Onofrio et al., 2019). MARIO is capable of 2-way voice communication via a microphone and speakers (Barrett et al., 2019). The robot's eyes are animated and move when it speaks and MARIO has a range of applications that can be personalised to the interests of individual users: My Music, My Memories, My Games, My Calendar, and My News. These applications were developed in response to the feedback provided by people with dementia and caregivers (Casey et al., 2016b). Users can operate MARIO's applications using speech and/or touchscreen commands, responding to MARIO's voice and/or written instructions. A description of MARIO's applications is provided in Table 1 and a picture of a participant with dementia interacting with MARIO is provided in Figure 5.1. below.

Figure 5.1 Picture of Participant with Dementia interacting with MARIO

N.B. Permission to publish this photograph was obtained from the person with dementia and their family during the wider MARIO Project.



Table 5.1. Description of MARIO's applications.	
My Music	Allows people with dementia to enjoy, remember, and talk about their favourite music or songs. The user can select the music, move between the music tracks, and alter the volume using touchscreen controls or verbal commands.
My Memories	Uses principles of reminiscence therapy to encourage communication and recall of experiences and memories. MARIO displays pictures of the person's life and engages the user in conversation reminding the user about the content of the pictures and using prompt questions.
My Games	Provides entertainment and cognitive stimulation. Users can select, play, and move between their favourite activities e.g. painting, games of golf and darts, card games, chess.
My News	Provides news from web feeds of online news sites that conforms to the user's interests. MARIO reads the headlines and provides the text on the touchscreen. MARIO invites the user to indicate if they want to hear/see more about any item of news. e.g. MARIO reads the headlines from Manchester United football club then the user asks to hear more news about a specific player.
My Calendar	Facilitates participation in society and temporal orientation. Reminds users about the day and time and provides information about daily activities and forthcoming events e.g. appointments, religious ceremonies, birthdays.

### 5.1.3. Methodology

The study used Case Study Methodology (CSM). CSM is useful for in-depth investigations of contemporary phenomena in real-world settings, where the phenomenon of interest interacts with the context that surrounds it (Yin, 2014). The examination of a 'case' within its context is central to CSM. In this study, the case was defined as, the resilience of a person living with dementia who uses MARIO. The context, surrounding each case, was the residential care setting, and the phenomenon of interest was change in the resilience of each person with dementia. To facilitate a focused, in-depth inquiry, and to obtain relevant data, each case contained three embedded units of analysis: 1) The perceptions of the person with



dementia about their resilience and usage of MARIO. 2) The perceptions of relatives and caregivers about the resilience of the person with dementia and their usage of MARIO. 3) The psychosocial factors that impact the resilience of the person with dementia and their usage of MARIO. A multiple case study design (n=10) was chosen in which the cases were the resilience of ten people with dementia who lived in a residential care setting. This design was chosen because the phenomenon of interest in the study was broader than that contained in a single case (Stake, 1995) and because examining multiple cases provided greater opportunity to address the study's aims, through comparing and contrasting the findings from multiple cases.

The concept of resilience was operationalised through drawing on the resilience framework (Windle & Bennett, 2012) and adapting this to accommodate key components of adversity, resources for resilience and outcomes of resilience in the context of dementia, that were identified from the literature on resilience in dementia that has been described above. Therefore, adversity was investigated through focusing on the challenges experienced by people with dementia. Resources for resilience were examined through identifying resilience repertoires, meaningful activities, and focusing on social relationships and cultural care practices. Change in the outcomes of resilience was assessed through examining the wellbeing of the people with dementia, regarding their levels of mood and engagement, quality of life, capacity for resilience, and the degree to which they could be regarded as 'doing okay'.

#### Sampling and Recruitment

The case selection strategy used purposive sampling, according to inclusion and exclusion criteria (Table 2). Each case required the selection of one person with dementia, two formal caregivers, and a relative. The recruitment strategy was designed to accommodate the cognitive and communication difficulties of people with dementia and to achieve their informed consent to participate in the study. A senior nurse, who knew the residents well, asked people with dementia, who fulfilled the inclusion criteria if they would like to meet the researcher. If the person with dementia agreed, the researchers, who were trained by experienced dementia researchers, spent considerable time talking with them, building rapport, explaining the study and reading with them the participant information leaflet, which was designed for people with dementia. In addition, before deciding to participate, the person was given the opportunity to meet MARIO. Conversations about consent used a person-centred approach (Mayo & Wallhagen, 2009) in which researchers took time to get to know the views of the person, to check their understanding, and assess their capacity to consent using the Psychological Society (Herbert, 2019) guidelines. Conversations were facilitated by the researcher taking the advice of caregivers (Hubbard et al., 2003) and they occurred when the person was not tired and was most likely to be able to process information (Mayo & Wallhagen, 2009). After initial conversations took place, researchers allowed potential participants the time and opportunity to discuss participation with their relatives and caregivers. Researchers then returned seven days later. On returning, researchers explained the study once more, reading the consent form which had been designed for people with dementia, with the person and answered any questions. Following this, if the person wanted to be included in the research, their consent was recorded by the researcher in writing. In addition, on every occasion that participants were involved in the study, researchers took the time to reintroduce themselves, remind participants about the project, confirm their understanding of this, and their ongoing verbal consent (Dewing, 2007). After the person with dementia had consented to participate, their relatives and caregivers were approached, told about the study, and given opportunities to ask questions. If relatives and caregivers met the inclusion/exclusion criteria they were given a patient information leaflet and their written consent was sought seven days later.

Table 5.2. The inclusion and exclusion criteria for participant eligibility.	
Inclusion	Exclusion
<b>People with Dementia</b>	
Had to be living in the care setting for at least one month prior to the study because moving into residential care requires significant adaptive efforts (Aminzadeh, et al., 2009). Therefore, if MARIO was introduced during the first month, it would be difficult to determine whether resilience processes were being impacted by MARIO or adapting to living in residential care.	Not be likely to continue living in the care setting for the study's duration.
Have either a formal diagnosis of dementia of any severity and/or it was stated that they have dementia in the medical records because it was recognised that not all people with dementia might have a formal diagnosis (Cahill et al., 2012).	Not have a significant sensory impairment or acute illness which caregivers considered would impair their ability to participate.
<b>Caregivers</b>	
Have provided care to the person with dementia during the preceding month.	Are not likely to continue to provide care to the participant.
<b>Relatives</b>	
Will be visiting with the person with dementia during the study period.	

### The Intervention

MARIO was offered to participants with dementia (PWD) for up to 12 individual sessions, 3 times a week, during a 5 week period. This was comparable to the other studies that have tested robotic devices in similar contexts (Gustafsson et al., 2015; Moyle et al., 2015; Joshi et al., 2019). Sessions were conducted between 10 am and 4 pm, avoiding mealtimes, in places that were convenient to the PWD, including bedrooms, dayrooms, and corridors. One researcher facilitated the sessions and another researcher recorded observations.

Before each interaction, the researcher opened the individual user's personalised folder on MARIO. At the beginning of sessions, MARIO introduced himself to the user addressing the user by name. Then, MARIO used verbal and visual prompts inviting the user to engage. MARIO reminded the user what activities it could provide and how the user could choose an activity by saying a keyword or using the touchscreen. When the user had selected an application, MARIO then reminded the user how to use the application and prompted them, as necessary. Sessions ended when PWD indicated to researchers that they had used MARIO for long enough.

### Data collection

Multiple methods were used to collect the data, which were piloted with people with dementia in the research site who were not involved in the study. Data were collected in three phases before MARIO was introduced (Pre-MARIO), during 12 sessions with MARIO, and after the 12 sessions had been completed (Post-MARIO).

### Data Collection Pre-MARIO

Pre-MARIO, data collected included the participants' demographic information, screening for depression using the Cornell Scale for Depression in Dementia (Alexopoulos et al., 1988), and cognitive function was assessed using the mini-mental state examination (MMSE) (Folstein et al., 1975). Then, Dementia Care Mapping (DCM) (Bradford, 2016) was used by the lead author (SW, a registered nurse with training in dementia and DCM) to capture data about the activities, social relationships, care practices, and mood and engagement levels (ME) and the wellbeing of PWD. DCM is a semi-structured non-participant observation technique that involves a trained mapper recording the activities and the ME levels of people with dementia every 5-minutes throughout the observation period, using DCM codes and values. The resulting ME levels are used to calculate wellbeing scores. In addition, qualitative notes are

recorded throughout the observation period. DCM has been successfully used to determine the effect of interventions on people with dementia (Hsu et al., 2015; Kontos et al., 2016). Each person with dementia was 'mapped', on a typical day, between 10.00 am-12.00 pm and 1.00 pm-4.00 pm.

Also Pre-MARIO, semi-structured audio-recorded interviews were undertaken by SW, with PWD, using a flexible supportive approach necessary for people with dementia (Beuscher & Grando, 2009). And, the following questionnaires were administered: The Resilience Scale (RS-14) (Wagnild & Young 1993) which measures capacity for resilience and The Quality of Life in Alzheimer's Disease Scale (QOL-AD) (Logsdon et al., 1999). The RS-14 and QOL-AD are valid and reliable for older adults (Wagnild, 2009) and people with dementia (Logsdon et al., 2002). The questionnaires were administered by researchers who received training on how to administer the measures from an experienced dementia researcher with a Ph.D. and Registered Nurse Tutor qualification, and each questionnaire was administered on a different day to avoid participant fatigue.

#### Data Collection during 12 sessions with MARIO

The semi-structured Observational Measure of Engagement (OME) (Cohen-Mansfield et al., 2009) was used to capture data during interactions with the robot. The OME enables the measurement of variables of engagement with a stimulus: duration, refusal, attention, and attitude. The OME has been used to assess the response of people with dementia to robotic devices (Cohen-Mansfield et al., 2011; Feng et al., 2019). In addition, contextual details surrounding the sessions and what the PWD said during sessions were recorded.

#### Data Collection Post MARIO

A second DCM mapping period of two hours was undertaken immediately after participants had engaged with MARIO for approximately the sixth time. And, after the 12 sessions were undertaken with MARIO, the same researchers re-administered the RS-14 and QOL-AD, and the interviews with PWD were repeated. In addition, caregivers, and relatives of the PWD were also interviewed.

#### Data Organisation and Analysis

Data was stored throughout the study in accordance with the General Data Protection Regulations (Crowhurst, Bergin, & Wells, 2019). Initial data analysis commenced during data collection, as recommended in CSM (Merriam & Tisdell, 2016). This involved summarising observational notes and listening to interview recordings.

Quantitative DCM data were analysed according to DCM procedures using a DCM excel template (Bradford, 2016). The quantitative OME and questionnaire data were entered into SPSS and analysed using descriptive statistics of percentage, standard deviation, mode and mean. Then, the Wilcoxon signed-rank test ( $\alpha = 0.05$ ) was used to assess mean rank differences between the group questionnaire results, and changes to mood and engagement levels as a result of using MARIO. Qualitative data was uploaded into a database in NVIVO 12 (<http://www.qsrinternational.com>). Then, framework analysis (Ritchie & Lewis, 2003; Gale et al., 2013) was used to code and analyse the data, in eight iterative phases which are described in Table 3. Data analysis included creating a matrix that had the case study cases in rows, codes in their categories in the columns, and the cells containing the data. The matrix was used to examine all the data from all the data sources, within and across the cases to develop themes that provided a holistic explanation of the cases (Merriam & Tisdell, 2016; Gale et al., 2013).

Table 5.3. The eight stages of framework analysis used during the data analysis (Derived from Gale et al., 2013).		
Phase	Key Feature	Description
1	Transcription	Interview data was professionally transcribed.
2	Familiarisation with data.	Transcripts were reviewed for errors, for familiarisation with the data, and uploaded into NVIVO 12.
3	Coding of data from 4 cases.	The transcripts from four cases were read line by line and segments of the data were copied into codes. After codes had been created they were examined and judged according to their meaning in relation to one another. During this process, some codes that contained data of similar meanings were amalgamated and renamed.
4	Developing a coding framework.	A formal coding framework was then developed through reviewing the codes that had already been created, in light of the literature concerning resilience and robot acceptability in the context of dementia.
5	Framework implemented, coding the remaining data.	Data from the remaining six cases were then read line by line and coded according to the framework whilst also remaining open to creating new codes from the data.
6	Charting data into a matrix.	A matrix was created, and all quantitative and qualitative data was copied into relevant cells. Following this, the data in each case were systematically examined and case summaries were written. Across case analysis was then conducted, by comparing and contrasting the coded data in all the cases, and themes were identified.
7	Interpreting and abstracting the data.	The data and the themes were reviewed and analytical memos (Bonello & Meehan, 2019) were written.
8	Themes were finalised in a written report.	The final themes were defined, and the analytical memos were synthesised into a cohesive report.

#### Rigour

Strategies based on Lincoln and Guba (1985) were adopted during the study to ensure rigour and demonstrate the trustworthiness of the findings, through concepts that align with constructivism: credibility, confirmability, and data dependability and transferability. Credibility was enhanced by the collection of both qualitative and quantitative data, the inclusion of multiple stakeholders (PWD, relatives, caregivers), and member checking of the findings (Miriam & Tisdell, 2016). Dependability and confirmability were enhanced through using NVIVO 12 because this software stores the raw data and records all stages of the data analysis so processes can be audited (Bonello and Meehan, 2019). Decisions about transferability were aided through the final study report containing thick descriptions, including direct quotations and examples of observational data (Houghton et al., 2013).

#### Ethical issues

The study was granted ethical approval from the National University of Ireland Galway research committee, as part of the wider EU MARIO project. Before MARIO's arrival, the residential care home managers completed a risk assessment, and Health Service Executive health and safety procedures were followed throughout the research. In addition, researchers were guided by an ethical distress protocol whereby in the event of a person with dementia becoming distressed, the researcher would talk with the person to ascertain what the issue might be and then if necessary, the advice of the participant's carer would be sought, MARIO would be removed, and the research activity discontinued.

The findings of the cross-case analysis are presented in the next section. To protect their anonymity, PWD have been given pseudonyms and their caregivers and relatives are not individually identified.

#### 5.1.4. Findings

The participants included people with dementia (n=10), caregivers (n=6) and relatives (n=7) (Table 4). All PWD experienced short term memory loss, physical and/or mental ill-health in addition to dementia. The majority were unable to walk without assistance, some were physically frail, and many had communication difficulties.

A total of ninety-six sessions with MARIO were completed: Seven PWD completed twelve sessions; Brendan completed seven sessions before he moved away to another residential care home; Clare completed one session before deciding that she did not want to use MARIO again; Cheryl completed four sessions and then withdrew from the study, for reasons explained below.

Sessions with MARIO lasted from five to sixty minutes with a mean duration of twenty four minutes. Six PWD increased their usage duration over the course of sessions, but for four PWD, the typical duration for did not change. The data analysis resulted in four themes being identified: Resilience changes minute to minute; Initiating and maintaining readiness; Active co-creation of meaningful activity; Impact on resilience.

#### 3.1. Theme: Resilience changes minute to minute

This theme describes how PWD experienced and responded to adversity with fluctuating degrees of adaptation and wellbeing, which impacted how they used MARIO.

Table 5.4. The participant details.					
Participant Type	Gender	Age (Years)	Highest Educational Level	Mini-Mental State Examination	
People with Dementia	Female (n=7) Male (n=3)	Mean Age 83; SD 10.1	Primary school (n=1) Secondary School n=6 Third level (n=3)	Mild dementia (MMSE 21 to 30) (n=2) Moderate dementia (MMSE 11 to 20) (n=6) Severe dementia (MMSE 0 to 10) (n=2)	
Nursing caregivers	Female (n=4) Male (n=2)	Age Groups 20-29 (n=2) 30-39 (n=1) 40-49 (n=1) 50-59 (n=2)	Secondary School (n=2) Third Level (n=2), Higher Diploma (n=2), Masters (n=1),	Training in Dementia or Care of Older Adults	Grade of Caregiver
				Yes (n=3) No (n=3)	Registered Nurse (n=4) Healthcare Attendant (n=2)
Relatives	Female (n=7)	40-49 (n=7)	Secondary School (n=2) Third Level (n=3) Masters (n=2)	Yes (n=2) No (n=5)	N/A

Adversity for PWD was caused by memory loss, difficulty concentrating on tasks, disorientation, and having experienced loss. The degree of adversity experienced by PWD could change from moment to moment, due to fatigue and degrees of lucidity. For example, Emily stated:

‘One minute I'd know it [whatever she is thinking about] and again I'd say no, I don't know.’ (Interview Emily)

Sometimes PWD might not recall participating in activities that they found meaningful. For example, Lucy was observed during Pre-MARIO DCM playing cards with friends during the afternoon. However, she had no recollection that this had occurred when interviewed later that day when she voiced regret that she could no longer enjoy playing cards with her friends. In addition, PWD had difficulty initiating activities and maintaining their concentration. This meant PWD were dependent on caregivers, who may or may not be available, to help them participate in meaningful activities. For example, Peter was observed to stop engaging with a sensory activity board that was designed to promote stimulation and interaction, when the caregiver supporting him started to talk with another caregiver.

All PWD had experienced losses: through bereavement, and of their independence, and through not being able to participate in activities that were meaningful to them. It was evident that individuals became upset when they remembered these losses. Indeed, recalling good memories for PWD could be followed by feelings of loss when PWD remembered that they were bereft. For example, when Sarah described a memory she said:

'She [Margaret] was the oldest sister and she'd always say to me, 'Sarah won't you housekeep for me, while I go away for a few days', I'd say, 'I will Margaret, I'll be delighted to'.....I loved her. That's why I miss her so much.' (Interview Sarah Post-MARIO).

The behaviour and verbalisations of the PWD revealed that their mood fluctuated. For example, a carer described how Jack was 'on and off' and his relative said:

'Sometimes you go in and he's in great form and he talks and there's other days ...he's not in any humour to talk about anything' (Interview Relative).

When PWD exhibited low adaptability to their life with dementia they also exhibited low levels of wellbeing through expressing negative thoughts and emotions. Negativity could be linked to episodes of anxiety, or feeling fatigued with life:

'You get sick in some too much trying..... I am too old.' (Interview Jack).

'I'm anxious to get home now.' (Interview Sarah).

Intermittent unhappiness was expressed by all PWD, but the Cornell Scale for Depression scores ranged from 1-9 with a group Mean/SD of 4.50/2.77. This suggested PWD had no significant symptoms of depression. However, two participants, more frequently than other PWD, exhibited low adaptability and lower levels of wellbeing; Sarah was frequently preoccupied with events surrounding her husband's death, and Brendan, expressed his unhappiness through resistance and refusing care:

'He could wake one day and refuse his drugs, refuse his insulin, refuse, refuse' (Interview Carer).

However, at times, all PWD demonstrated positive adaptation and relative wellbeing by being accepting and having positive thoughts and feelings. 'Doing okay' was illustrated when participants said they felt 'alright' but also when they possessed the motivation to be proactive and do what they wanted to satisfy their desires, for example, reaching out for food, drink, contact with others, entertainment or to perform acts of self-care. Even the most physically and cognitively debilitated participants could be observed to be 'doing okay' despite living with the limitations of dementia whilst they were completely absorbed by simple activities. For example:

Jack stares at his cup and takes the lid off the cup to drink without the lid... then he endeavours to put the lid back on and this takes studied concentration for almost 2 minutes. (Post-MARIO DCM Jack).

However, 'doing okay' also involved PWD doing their best whilst accepting that life was not ideal:

'Well, I play [live] the best I can.' (Interview Jack).

Sometimes this involved stoicism and putting up with circumstances PWD found difficult. For example, it was observed that good social etiquette at mealtimes was important to Sarah and yet she continued eating stoically, despite being aware of the lack of etiquette during a mealtime in the dementia unit dayroom:

A carer stopped another resident from taking food from Sarah's plate ....One resident reaches across the table and takes a spoon from Sarah, the carer intervenes .....Sarah continues eating quietly and slowly, eyes down. (Pre-MARIO DCM Sarah).

In responding to the adversity, PWD described a range of coping strategies, which had been learned from parents or previous experience. Strategies included: accepting the past, having good relationships with other people, doing something to change the problem, trying hard, acknowledging that life has difficulties, appreciating what you have, particularly children and family, valuing small things, and not asking too much. For example,

'If you have a building for yourself, your wife, and your family...you come out of life fairly handy enough' (Interview Peter).

Spirituality and religious practices were also an important part of the current and previous lives of eight participants, who used these to help them cope with problems:

'You'd be telling God about it and that would be strengthening yourself.' (Interview Emily).

'I don't know does it make you stronger but you, well you pray to God, it helps you to accept it.' (Interview Sarah).

Some PWD placed value on being helpful to others, being mobile, and busy.

However, coping strategies were discussed during interviews when PWD were 'doing okay' whilst interacting with the researcher. In contrast, when PWD were experiencing poor levels of wellbeing, there was no data that suggested their coping strategies were effective, without the support of other people.

### 3.2. Theme: Initiating and Maintaining Readiness

This theme describes what needed to be addressed before and throughout each interaction with MARIO, to enable PWD to use MARIO. It concerns PWD's attitudes towards MARIO, their willingness and ability to use MARIO, and the support PWD required from facilitators to enable them to access and engage with MARIO.

There were no PWD who demonstrated fear of the robot and only one participant (Clare) did not like MARIO and subsequently, she withdrew from the study. The OME data revealed that no PWD was distressed or disruptive during sessions with MARIO. A 7-point scale was used in the OME to measure the PWD's attitude when using MARIO: 1 (very negative), 2 (negative), 3 (somewhat negative), 4 (neutral), 5 (somewhat positive), 6 (positive) to 7 (very positive). The results showed that the PWD had a positive mood with mean attitudes, most of the time

that ranged from 4.92-6.33 ( $M=5.52$ ,  $SD=.55$ ) and that the highest recorded levels of mood in sessions ranged from 6.75-6.86 ( $M=6.29$ ,  $SD=.43$ ).

MARIO was refused by Brendan twice on days when he refused everything that was offered to him, and Peter refused the robot once, saying he was too busy. Most PWD were very willing to use MARIO. However, some PWD could initially be hesitant, expressing tiredness, or low confidence in their ability to use MARIO or they were preoccupied when MARIO was offered. For example, Emily welcomed MARIO and the facilitator at the start of one session but her primary concern was that someone had been in her house without her permission. The facilitator talked with Emily for a few minutes, then she became calmer and was ready to engage with MARIO.

A few PWD were independently able to use the touchscreen to move through MARIO's applications but all participants had some degree of difficulty. Difficulties included manipulating the stylus, reaching the screen with their hands, or their arms getting tired. Some participants pressed too hard, used multiple taps, or tapped in the wrong part of the screen. PWD also had difficulty maintaining their concentration and levels of distraction varied between having no distraction in sessions to PWD being distracted for most of the time. In addition, three sessions were temporarily disrupted due to technical problems. However, with facilitation, all the PWD were able to use the touchscreen.

Before sessions, facilitators improved PWD's readiness to use MARIO by preparing MARIO, so PWD could access their pre-personalised files without delay. They also reduced potential distractions. For example, as Peter was often walking in the corridor he needed to be encouraged to walk to a quieter place to use MARIO.

The facilitator responded to the needs of individual PWD by giving explanations, reminding, prompting, modelling, encouraging, advising, reassuring, trouble-shooting, and occasionally stepping in to manipulate the touchscreen. For example, the following observation was recorded:

Sarah is telling the facilitator about the people in the picture and Sarah is touching the photo – this causes the photo to move right on the screen and the researcher moves it back. Sarah talks about her granddaughter's wedding, a positive memory. ....Sarah is deep in thought, reminiscing, then loses track and needs reminding to press next photo. (OME Sarah Session 7).

Facilitators particularly supported conversation, stimulated by MARIO, when PWD had difficulty initiating and/or maintaining this and, if necessary, they helped PWD recover a positive mood. For example:

[Emily went from] happy to sad talking about her husband and her sadness after he died. ...talked with the researcher and then moved to the next photo spontaneously. (OME Emily Session 9).

### 3.3. Theme: Active Co-Creation of Meaningful Activity

This theme describes how sessions with MARIO provided PWD with increased opportunities for meaningful activity. It also describes how PWD were active in responding to MARIO and worked in partnership with facilitators to actively create how MARIO was used for meaningful activity.

All PWD expressed the desire to once again experience activities that they had previously enjoyed and could no longer undertake. In addition, the Pre-MARIO DCM data revealed that



PWD spent large amounts of time being passively watchful or cool and disengaged (19% and 17% of the time respectively), without access to meaningful activities. PWD who were able to walk independently walked to obtain interaction with others, but immobile people were frequently observed to be watching and waiting for people to interact with them.

The DCM observations and interview data revealed that caregivers prioritised addressing the physical medical needs of PWD, rather than their psychosocial needs. Indeed, some caregivers acknowledged that they found it difficult to address the PWD's need for meaningful activity. It was observed that the PWD's psychosocial needs were predominantly addressed through brief interactions that took place, whilst caregivers were bringing food or drink to the person or moving them to attend to toilet needs. For example:

A caregiver enters with a tray before dinner and helps her with her drink. Asking if that is better. Inaudible reply from Margaret. The caregiver then says, 'Say your prayers so' and leaves again (1 min interaction total) (Pre-MARIO DCM Margaret).

Caregivers and relatives noted that MARIO provided more opportunity than was normally available for the PWD to have individualised meaningful activity. These views concurred with findings from the OME that revealed PWD were solitary and unoccupied at the beginning of 28% of sessions. Furthermore, only 21% of sessions with MARIO were interrupted, mostly by caregivers performing brief task-based activities.

MARIO particularly provided opportunities for meaningful interaction, through acting as a stimulus for conversational topics that supported feelings of positive self-concept. PWD spoke to the facilitator in 95% of sessions and during 56% and 23% of these sessions, PWD spoke for some of the time or most of the time, respectively. PWD mostly talked about themselves, their family, and memories:

Emily is speaking about photos of her wedding day 'It was a lovely day, I was happy ....He was lovely wasn't he.... (OME Emily Session 9).

They also talked about their interests. For example, Louise enjoyed talking about plants and Brendan talked about music from the 1970s and his involvement in that era's music scene:

Brendan 'Do you remember this one?....That base is really great....This is where you'd be jumping up and down'. Brendan talked about shows and concerts. 'I went to all of them.' (OME Brendan Session 3).

During the sessions, when PWD were not talking, they non-verbally responded to MARIO's applications through singing, clapping, dancing, tapping feet, and listening.

PWD responded to MARIO, as they would typically respond to other stimuli. Their responses were influenced by their mood, personal desires, and preferences. For example, caregivers and relatives confirmed that Jack's responses to MARIO were typically muted and somewhat positive when he said MARIO was 'alright'. Peter also illustrated typical behaviour when initially he examined the robot in detail and in later sessions he used MARIO to paint with the facilitator's support. Peter had a technical degree and his relative reported that he had always enjoyed working creatively alongside other people. In addition, the PWD who were observed and reported to enjoy being sociable and altruistic, preferred to share MARIO using the robot with other residents. Also many PWD who had enjoyed music throughout their lives did so using MARIO.

PWD personified MARIO in terms of their personal history, their dementia, and what they found meaningful when using the robot. Only Brendan referred to the robot as 'MARIO'. For

example, Sarah called MARIO: 'the gadget', 'it', and on several occasions 'he' was 'a great singer'. For Louise, MARIO was: 'she', and 'a tolerant teacher' but on other occasions 'he' was referred to as being 'well trained' and 'a younger thing'. All participants responded verbally to MARIO's personalised greeting. However, MARIO's social presence and communication skills were not strong enough to maintain the attention of the PWD who, OME data revealed, mostly ignored MARIO's verbal prompts and preferred to talk with the facilitator.

For PWD to respond to MARIO and use the robot according to their desires, the facilitators created an atmosphere in which PWD felt empowered. Sometimes PWD needed reminding that MARIO was there for them to use as they wished but mostly PWD used MARIO assertively. For example:

Emily 'I'll draw a box' choosing painting (OME Emily Session 7).

For PWD, sessions with MARIO were sociable occasions with partnership and rapport between them and the facilitators. Most PWD asked facilitators about their families and they enquired about facilitators who were absent. Facilitators and PWD jointly celebrated the efficacy of PWD using MARIO and moments of shared delight were observed. Facilitators also followed the lead of PWD in choosing the content of sessions. This enabled MARIO's applications to be further personalised for future sessions in response to the preferences that individuals revealed. For example:

The facilitator and Margaret were chatting through the photographs then Margaret chose the music application.

Margaret 'It's very good', looking at MARIO's face while the music is playing for 1 minute and then she says, 'I would like to get home'.

Facilitator 'Yes. Does the music remind you of something?'

Margaret 'I would like to do that myself..... the same as other people'

Facilitator 'You'd like to be more independent?'

Margaret 'Yes (pause)... Do you like the music?'

Facilitator 'Yes, it's lovely.....does it remind you of something?'

Margaret 'Jeanie of the light brown hair'.

Facilitator 'Is that a song?'

Margaret 'Yes'

Facilitator 'Would you like MARIO to play it?' (OME Margaret Session 10).

### 3.4. Theme: Impact on Resilience

This theme describes the positive impact on resilience that occurred during sessions with MARIO. It also includes questions as to whether the impact was sustained after the sessions were over.

The resilience of Clare and Cheryl was not positively impacted by MARIO. After having one session with MARIO, Clare said that she did not like the robot and chose not to use it again. Whereas, Cheryl discontinued involvement with the research because she suffered from paranoia. This condition was stable when the research started, but for reasons unrelated to MARIO, as determined by the medical team, the paranoia deteriorated, during the research period.

For the remaining eight PWD the sessions with MARIO provided enjoyment, engagement, increased levels of positive mood and a sense of satisfaction:

Emily 'He'd [MARIO] make you good.' (Interview Emily).

The OME measured engagement with MARIO on a 7-point scale: 1 (very disruptive), 2 (disruptive), 3 (somewhat disruptive), 4 (not attentive), 5 (somewhat attentive), 6 (attentive) to 7 (very attentive). The results recorded that the mean attention scores for each PWD ranged from 5.00-6.43 (M=5.70, SD=.53) and the highest level of engagement during sessions showed that PWD were very attentive at points during the sessions with scores that ranged from 6-7 (M=6.44, SD=.35).

Relatives and caregivers commented that some PWD were more stimulated and alert during sessions. For example, one carer considered that MARIO had maintained Peter's interest more than would otherwise be possible saying:

'He was actually doing it [painting]. Whereas, if it were you or I asking him to sit down and asking him to draw a square, it wouldn't happen.' (Interview Carer).

If PWD had a low mood at the beginning of sessions this tended to be lifted. For example:

[Sarah] Was praying before the session started for all people [she had] known and lost. She tells the facilitator about these people.... the facilitator listens, then asks if she would like to listen to a song..... Immediately the music starts [Sarah] is tapping her hand on the bed and singing happily. (OME Sarah Session 5).

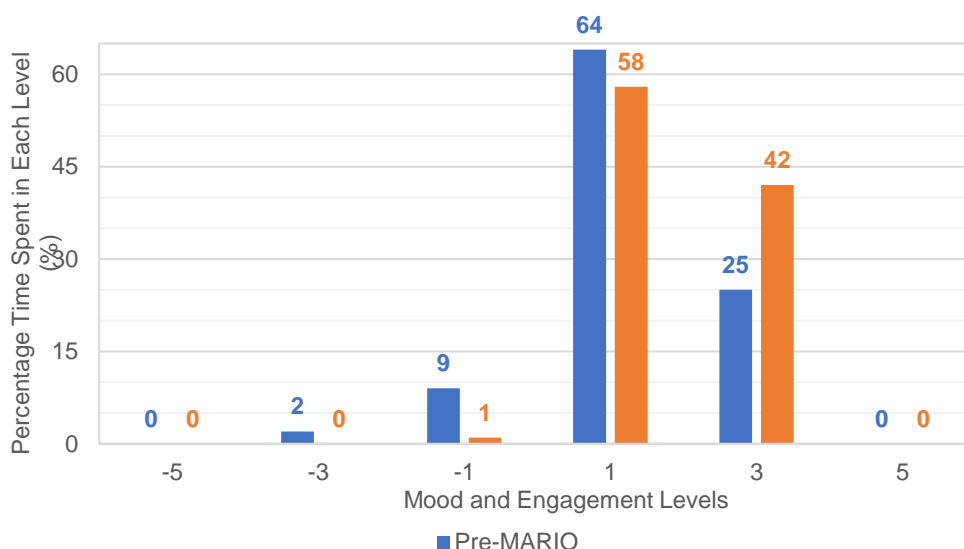
A few caregivers considered that the value of MARIO was contingent on PWD being able to remember the robot after the sessions. PWD had a memory of MARIO or the researchers at the beginning of 64% of sessions. They had no memory in 23% of sessions and there were missing data on this question for 13% of sessions. Post-MARIO, most participants remembered MARIO when prompted by the researcher showing them a picture of MARIO. Then, they remembered details about the sessions with variable accuracy:

'I don't know what or how or not, but I got on with it [MARIO]' (Interview Emily).

Only once did a participant with dementia, unprompted, mention material he had seen on MARIO to his relative. However, a memory of the sessions could be kept 'alive' by caregivers and relatives prompting PWD. For example, caregivers put a painting completed by Peter on MARIO on his bedroom wall, and the following day Peter spontaneously showed this to researchers.

The quantitative DCM data revealed that there were positive changes in the level of mood and engagement (ME) after using MARIO. For 2 hours after using MARIO, 58% and 42% of the time, PWD had ME levels of +1 and +3, respectively. This meant that PWD showed signs of considerable positive mood and engagement for 17% more time after using MARIO than they did Pre-MARIO. PWD also showed fewer signs of negative ME, as scores of -1 and -3 improved by 10% on Pre-MARIO levels. Figure 5.2 shows the percentage of time that participants spent at different ME levels in the first DCM period Pre-MARIO, in comparison with after using the robot.

Figure 5.2. This graph shows the percentage of time participants with dementia spent at levels of mood and engagement before and after using MARIO. The ME Levels range from: -5 Very great signs of negative mood; -3 Considerable negative mood; -1 Small signs of negative mood withdrawn/out of contact; +1 No overt signs of positive or negative mood. Brief, intermittent engagement; +3 Considerable positive mood concentrating but distractible; +5 High Positive mood, deeply engaged. (Bradford, 2016).



Multiple data sources revealed that there were no long term changes to resilience:

‘Once that’s over [using MARIO], she [Sarah] is back into listening to the radio again’. (Interview Caregiver).

‘Once he [MARIO] was gone he was gone.’ (Interview Emily).

‘I think it’s [MARIO’s] helped my mother.... temporarily anyway’ (Interview Relative).

Furthermore, as reported in Table 5, there were no statistically significant changes in resilience Post-MARIO in comparison with Pre-MARIO levels, measured through the quality of life and capacity for resilience questionnaires and the well and ill-being (WIB) scores. All PWD had a more positive WIB score after using MARIO in comparison to their Pre MARIO levels, except for Jack, whose score was unchanged.

Outcomes	Mean (Standard Deviation)		P Value
	Pre-MARIO	Post-MARIO	
Quality of Life: QOL-AD	32.13 (4.73)	32.25 (6.54)	0.61
Capacity for Resilience: RS-14	84.50 (13.92)	83.12 (11.66)	0.93
Wellbeing: WIB	1.03 (0.44)	1.99 (0.58)	0.81

There was a small amount of potential for ongoing impact on resilience, as a few caregivers and relatives said they intended to change their behaviour as a result of witnessing sessions with MARIO and learning more about the preferences and abilities of individual PWD. For example, Sarah’s carer learned the type of music Sarah liked and said she would help Sarah access appropriate music in the future. Caregivers and relatives also expressed changed opinions about Peter:

‘Before seeing Peter using MARIO I would have been saying that Peter has no attention.’ (Interview Carer).

#### 5.1.5. Discussion

This study aimed to investigate how using MARIO affected the resilience of people with dementia by identifying the characteristics of resilience in this context, exploring how resilience changed as a result of using MARIO and identifying how MARIO was used to impact resilience.

The findings revealed that the resilience of people with dementia can be envisaged as existing along an adaptivity-wellbeing continuum. People with dementia moved between experiencing moments of positive adaptation which resulted in them doing okay despite living with limitations, and moments when they exhibited low levels of adaptability and poor wellbeing. These findings are consistent with those of previous studies, that the symptoms and impact of dementia can fluctuate (Rockwood et al., 2014; Bradshaw et al., 2004). Indeed, resilience may be impacted by the increased emotional volatility that is experienced by people with dementia (Bryden, 2005; 2018). The findings also revealed no evidence that people with dementia in this context could effectively deploy their resilience repertoires without the support of other people when they were situated at the negative end of the adaptability-wellbeing continuum.

One person with moderate dementia chose not to use the robot and another person with dementia had to withdraw from the study due to her deteriorating health. Other studies have also found that robots are not acceptable to all people with dementia (Demange et al., 2018; Hebesberger et al., 2017), and conducting research is complicated by people with dementia having co-morbidities (Fox, et al., 2014).

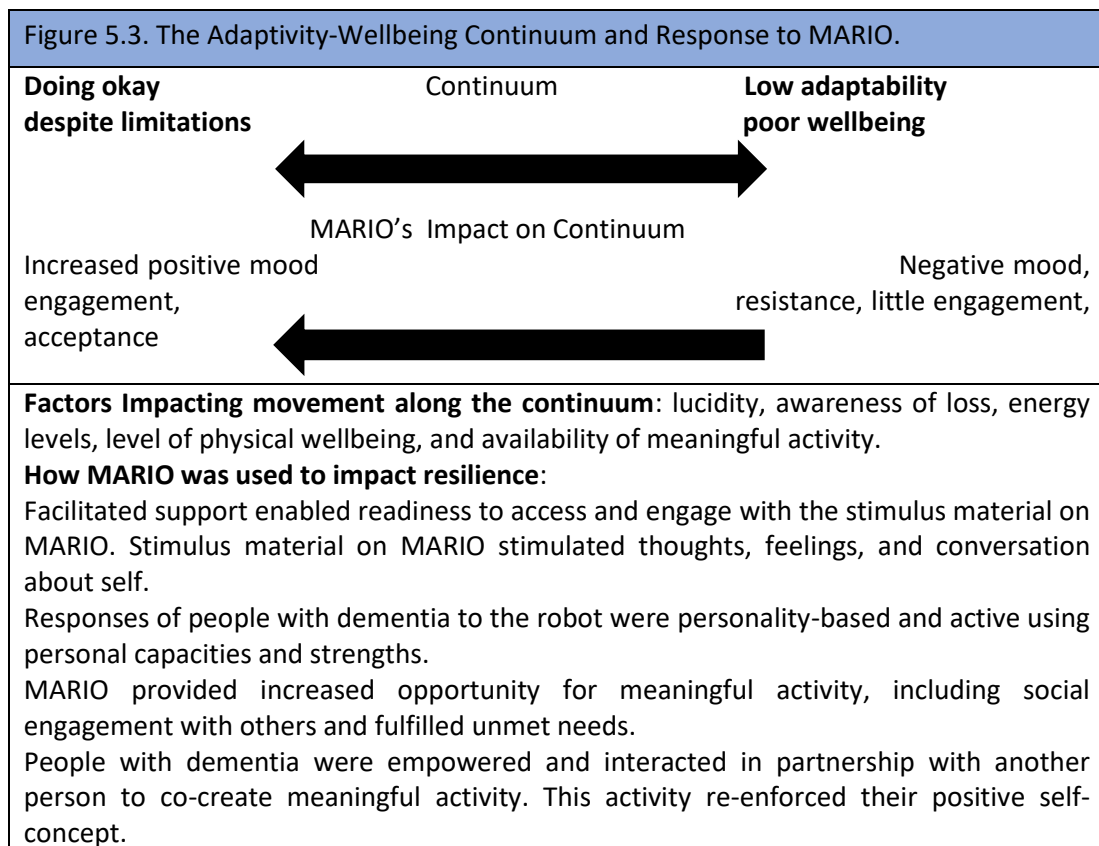
Using MARIO appeared to positively impact the resilience of eight people with dementia. because when they engaged with MARIO and the facilitator, they moved towards the positive end of the adaptation-wellbeing continuum and were more positive in attitude, engaged and they could be said to be 'doing okay' (Figure 5.3.). There was some evidence that increased resilience outcomes could be maintained for up to two hours after sessions. But, differences in mood and engagement levels were not statistically significant and there was no difference in resilience outcomes after two hours.

The sessions with MARIO enhanced the resilience of people with dementia because they served as a resource for resilience which addressed people's unmet need for meaningful activity. Opportunities for meaningful activities were lacking in this context, as they can be in other residential care settings (Harmer & Orrell, 2008; Clare et al., 2008). Through meaningful activity, the sessions improved resilience and provided stimulation and opportunities for enjoyment and interaction with other people which increased positivity and engagement. It is also possible that people with dementia achieved a more positive sense of self-concept because the conversation, stimulated by MARIO, focused on their positive memories and topics about which the individuals retained knowledge and held a passionate interest. These personal interests corresponded to the strengths and positive attributes of individuals with dementia (Sabat, 2018). Therefore, MARIO was impactful through being a strength-based platform for meaningful activity. In addition, people with dementia were active in their interpretation and usage of MARIO. Through their active responses and creation of activity, people with dementia illustrated they had, throughout their dementia, maintained intact the personalities and interests that had informed their lives prior to having dementia (Bailey, 2017).

People with dementia in this residential care setting required support and encouragement to access and engage with MARIO. MARIO was unable to independently provide this support because the robot lacked the technical capacity to assess and respond to the variable and complex physical and psychological needs of the people with dementia. Therefore, the presence of a skilled facilitator was essential to enable the interactions between MARIO and the people with dementia to be sufficiently meaningful to support their resilience. Facilitators have also been important in other interventions that aimed to foster resilience in the context of dementia (Newman et al., 2018; Clarke et al., 2018; Macher et al., 2018) and during studies that involved social robots (Feng et al., 2019; Chang, Sabaovic, & Huber, 2013). For robots, including MARIO, to support successful interactions without a facilitator, they will

need to be developed to possess more sophisticated human-like communication skills that include the capacity to assess and respond to the complex needs of people with dementia.

In this study, MARIO encouraged engagement through being an embodied presence that provided personalised stimulus material. The facilitators acted in concert with MARIO to support the robot’s interactions by enabling people with dementia to prepare for and maintain in-depth meaningful activity. The concept of readiness, that encompassed the attitude and ability of people with dementia to engage with MARIO, was useful in this study, as it has been in other contexts concerning the support of people with chronic health conditions (Dalton and Gottlieb, 2003). Indeed, it is apparent that facilitators needed skills to move people into a state of readiness through ‘scaffolding’ (Sharma, 2007) their support according to the individual’s needs that fluctuated during sessions. The facilitators’ responses were based on their knowledge of dementia, active listening, observation, and empathy. The facilitator also enabled access through creating rapport and a human relationship with the person with dementia that was based on reciprocity and partnership. This required the facilitators to have a flexible agenda that focused on enjoyable joint discovery and responded to what the person with dementia revealed was meaningful to them during the interactions. The equality and rapport created during these sessions may be important for the successful usage of social robots for resilience because they emphasise similar qualities to peer relationships, and aspects of positive human relationships that are supportive of resilience (Matcher et al., 2018).



Future Research

Future investigations need to focus on exploring strategies to facilitate people with dementia being empowered to co-create meaningful activities whilst using social robots alongside other people. Studies need to emphasise that people with dementia are active recipients of interventions (Beard et al., 2009). In addition, investigations need to address the cultural factors that impact the sustainability of resilience after it has been supported through robotic interventions.

### Strengths and Weaknesses of the Research

The literature to date indicates that this is the first study to examine how social robots can affect the resilience of people with dementia. The usage and impact of MARIO were examined over a relatively long period and in a real-world clinical context, using multiple sources of data and robust frameworks for data analysis. The use of case study methodology facilitated an in-depth examination of the personal, relational, and contextual factors which affected MARIO's impact on resilience. This study is limited because it involved a relatively small number of people with dementia and there was no control group or blinding of the researcher to the intervention. Nonetheless, involving this number of participants in the study enabled an in-depth investigation and understanding of resilience and the effect of MARIO. Furthermore, this sample size is typical of investigations that examine the effects of social robots in people with dementia (Moyle et al., 2019; Rouaix et al., 2017; Feng et al., 2019).

### 5.1.6. Conclusion

To conclude, social robots need to have greater capability to interpret and respond to the emotional needs of users if they are to benefit the resilience of people with dementia without the presence of a supportive facilitator. However, with a skilled facilitator, people with dementia were able to access stimulating material on the robot. This was used by the people with dementia to co-create meaningful activity that supported resilience through fostering a positive sense of self-concept.

### 5.1.7. References

- Alexopoulos, G. S., Abrams, R. C., Young, R. C., & Shamoian, C. A. (1988). Cornell scale for depression in dementia. *Biological psychiatry*, 23(3), 271-284.
- Aminzadeh, F., Dalziel, W. B., Molnar, F. J., & Garcia, L. J. (2009). Symbolic meaning of relocation to a residential care facility for persons with dementia. *Aging and Mental Health*, 13(3), 487-496.
- Bailey, G. H. (2017). 'This is my life and I'm going to live it': A grounded theory approach to conceptualising resilience in people with mild to moderate dementia. University of Edinburgh. Doctoral Thesis Clinical Psychology. Scotland.
- Barrett, E., Burke, M., Whelan, S., Santorelli, A., Oliveira, B. L., Cavallo, F., Casey, D. (2019). Evaluation of a companion robot for individuals with dementia: Quantitative findings of the MARIO project in an Irish residential care setting. *Journal of Gerontological Nursing*, 47(7), 36-45.
- Beard, R. L., Knauss, J., & Moyer, D. (2009). Managing disability and enjoying life: How we reframe dementia through personal narratives. *Journal of Aging Studies*, 23(4), 227-235.
- Beuscher, L., & Grando, V. T. (2009). Challenges in conducting qualitative research with individuals with dementia. *Research in Gerontological Nursing*, 2(1), 6-11.
- Bonello, M., & Meehan, B. (2019). Transparency and coherence in a doctoral case study analysis: Reflecting on the use of NVivo within a 'Framework' approach. *The Qualitative Report*, 24(3), 483-498.
- Bradford, U. O. (2016). DCM 8 User's Manual. Bradford, UK: School of Dementia Studies, University of Bradford. England.
- Bradshaw, J., Saling, M., Hopwood, M., Anderson, V., & Brodtmann, A. (2004). Fluctuating cognition in dementia with Lewy bodies and Alzheimer's disease is qualitatively distinct. *Journal of Neurology, Neurosurgery & Psychiatry*, 75(3), 382-387.
- Bryden, C. (2018). *Will I Still be Me?: Finding a Continuing Sense of Self in the Lived Experience of Dementia*. Jessica Kingsley Publishers. London UK.
- Bryden, C. (2005). *Dancing with dementia: My story of living positively with dementia*. Jessica Kingsley Publishers. London UK
- Cahill, S., O'Shea, E. & Pierce, M. (2012). *Creating excellence in dementia care: a research review for Ireland's National Dementia Strategy*. [http://dementia.ie/images/uploads/site-images/creating\\_excellence\\_in\\_dementia\\_care\\_2012.pdf](http://dementia.ie/images/uploads/site-images/creating_excellence_in_dementia_care_2012.pdf)
- Casey, D., & Murphy, K. (2016a). Factors governing the development of resilience in older people with dementia and caregivers. In C. Clarke, M. Schwannauer, J. Taylor, & S. Rhynas (Eds.), *Risk and resilience: Global learning across the age span* (pp. 46-61). Dunedin Academic.

- Casey, D., Felzmann, H., Pegman, G., Kouroupetroglou, C., Murphy, K., Koumpis, A., & Whelan, S. (2016b). What people with dementia want: designing Mario an acceptable robot companion? In International Conference on Computers Helping People with Special Needs (pp. 318-325). Springer, Cham.
- Chang, W.-L., Sabaovic, S., & Huber, L. (2013). Situated Analysis of Interactions between Cognitively Impaired Older Adults and the Therapeutic Robot PARO in G. H. e. al., (Ed.), ICSR 2013 LNAI 8239 (pp. 371-380). Switzerland: Springer International Publishing.
- Clare, L., Rowlands, J., Bruce, E., Surr, C., & Downs, M. (2008). The experience of living with dementia in residential care: an interpretative phenomenological analysis. *The Gerontologist*, 48(6), 711-720.
- Clarke, C. L., Keyes, S. E., Wilkinson, H., Alexjuk, E. J., Wilcockson, J., Robinson, L., & Cattan, M. (2018). 'I just want to get on with my life': a mixed-methods study of active management of quality of life in living with dementia. *Ageing & Society*, 38(2), 378-402.
- Cohen-Mansfield, J., Dakheel-Ali, M. & Marx, M. S. (2009). Engagement in persons with dementia: the concept and its measurement. *The American journal of geriatric psychiatry*, 17, 299-307.
- Cohen-Mansfield, J., Marx, M. S., Freedman, L. S., Murad, H., Regier, N. G., Thein, K., Dakheel-Ali, M. (2011). The comprehensive process model of engagement. *American Journal of Geriatric Psychiatry*, 19(10), 859-870. doi:10.1097/JGP.0b013e318202bf5b
- Crowhurst, N., Bergin, M., & Wells, J. (2019). Implications for nursing and healthcare research of the general data protection regulation and retrospective reviews of patients' data. *Nurse Researcher*, 27(1).
- Dalton, C. C., & Gottlieb, L. N. (2003). The concept of readiness to change. *Journal of advanced nursing*, 42(2), 108-117.
- Demange, M., Lenoir, H., Pino, M., Cantegreil-Kallen, I., Rigaud, A. S., & Cristancho-Lacroix, V. (2018). Improving well-being in patients with major neurodegenerative disorders: differential efficacy of brief social robot-based intervention for 3 neuropsychiatric profiles. *Clinical interventions in aging*, 13, 1303-1311.
- D'Onofrio, G., Sancarolo, D., Raciti, M., Burke, M., Teare, A., Kovacic, T., Greco, A. (2019). MARIO Project: Validation and Evidence of Service Robots for Older People with Dementia. *Journal of Alzheimers Disease*, 68(4), 1587-1601. doi:10.3233/jad-181165
- Dewing, J. (2007). Participatory research: a method for process consent with persons who have dementia. *Dementia*, 6 (1), 11-25.
- Feng, Y., Yu, S., Van De Mortel, D., Barakova, E., Hu, J., & Rauterberg, M. (2019). LiveNature: Ambient display and social robot-facilitated multi-sensory engagement for people with dementia. Paper presented at the DIS 2019 - Proceedings of the 2019 ACM Designing Interactive Systems Conference.
- Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state": a practical method for grading the cognitive state of patients for the clinician. *Journal of psychiatric research*, 12(3), 189-198.
- Fox, C., Smith, T., Maidment, I., Hebding, J., Madzima, T., Cheater, F., & Young, J. (2014). The importance of detecting and managing comorbidities in people with dementia? *Age and ageing*, 43(6), 741-743.
- Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC medical research methodology*, 13(1), 117.
- Gustafsson, C., Svanberg, C., & Müllersdorf, M. (2015). Using a robotic cat in dementia care: a pilot study. *Journal of gerontological nursing*, 41(10), 46-56.
- Harmer, B. J., & Orrell, M. (2008). What is meaningful activity for people with dementia living in care homes? A comparison of the views of older people with dementia, staff and family carers. *Ageing and Mental Health*, 12, 548-558.
- Harris, P. (2010). Is resilience a key to living a meaningful life with dementia? Factors that contribute to the resilience process in people with early stage dementia. *Gerontologist*, 50, 231-231.
- Harris, P. B., & Keady, J. (2008). *Wisdom, resilience and successful aging: Changing public discourses on living with dementia*: Sage Publications Sage UK: London, England.
- Hebesberger, D., Koertner, T., Gisinger, C. Pripfl, J. (2017). A Long-Term Autonomous Robot at a Care Hospital: A Mixed Methods Study on Social Acceptance and Experiences of Staff and Older Adults. *International Journal of Social Robotics*, 9, 417-429.
- Herbert, C., Gray G., Poate-Joyner, A., Ferry, S., Betteridge, S., Hill S., Macpherson, G., Joyce, T., Soeterik, S., Campber Reay, A., Parker, Gaby., Todd, N., Mackenzie, Brechin, D. (2019) What makes a good assessment of capacity? The British Psychological Society. May.



- Houghton, C., Casey, D., Shaw, D., & Murphy, K. (2013). Rigour in qualitative case-study research. *Nurse Researcher*, 20(4), 12-17.
- Hubbard, G., Downs, M. G., & Tester, S. (2003). Including older people with dementia in research: challenges and strategies. *Aging & mental health*, 7(5), 351-362.
- Hsu, M. H., Flowerdew, R., Parker, M., Fachner, J., & Odell-Miller, H. (2015). Individual music therapy for managing neuropsychiatric symptoms for people with dementia and their carers: a cluster randomised controlled feasibility study. *BMC Geriatrics*, 15(1), 84.
- Jøranson, N., Pedersen, I., Rokstad, A. M. M., Aamodt, G., Olsen, C., & Ihlebæk, C. (2016). Group activity with PARO in nursing homes: systematic investigation of behaviours in participants. *International psychogeriatrics*, 28(8), 1345-1354.
- Joshi, S., & Šabanović, S. (2019, March). Robots for inter-generational interactions: implications for nonfamilial community settings. In 2019 14th ACM/IEEE International Conference on Human-Robot Interaction (HRI) (pp. 478-486). IEEE. New York.
- Kang, H. S., Makimoto, K., Konno, R., & Koh, I. S. (2019). Review of outcome measures in PARO robot intervention studies for dementia care. *Geriatric Nursing*. <https://doi.org/10.1016/j.gerinurse.2019.09.003>
- Kontos, P., Miller, K. L., Colobong, R., Lazgare, P., Luis, I., Binns, M., . . . Naglie, G. (2016). Elder-clowning in long-term dementia care: Results of a pilot study. *Journal of the American Geriatrics Society*, 64(2), 347-353.
- Lincoln, Y. S. & Guba, E. G. (1985). *Naturalistic inquiry*, Sage.
- Logsdon, R.G., Gibbons, L.E., McCurry, S.M. and Teri, L. (1999). Quality of life in Alzheimer's disease: patient and caregiver reports. *Journal of Mental health and Aging*, 5, pp.21-32.
- Logsdon, R.G., Gibbons, L.E., McCurry, S.M. & Teri, L. (2002). Assessing quality of life in older adults with cognitive impairment. *Psychosomatic Medicine*, 64, 510-519.
- Mayo, A. M., & Wallhagen, M. I. (2009). Considerations of informed consent and decision-making competence in older adults with cognitive impairment. *Research in Gerontological nursing*, 2(2), 103-111.
- Merriam, S., & Tisdell, E. (2016). *Qualitative Research: A Guide to Design and Implementation* (Vol. 4th). San Francisco, CA: John Wiley and Sons.
- Moyle, W., Beattie, E., Draper, B., Shum, D., Thalib, L., Jones, C., Mervin, C. (2015). Effect of an interactive therapeutic robotic animal on engagement, mood states, agitation and psychotropic drug use in people with dementia: a cluster-randomised controlled trial protocol. *BMJ open*, 5(8), e009097.
- Moyle, W., Jones, C. J., Murfield, J. E., Thalib, L., Beattie, E. R., Shum, D. K., Draper, B. M. (2017). Use of a robotic seal as a therapeutic tool to improve dementia symptoms: A cluster-randomized controlled trial. *Journal of the American Medical Directors Association*, 18(9), 766-773.
- Moyle, W., Jones, C., Dwan, T., Ownsworth, T., & Sung, B. (2019) Using telepresence for social connection: views of older people with dementia, families, and health professionals from a mixed methods pilot study. *Aging & Mental Health*, 6th July DOI: 10.1080/13607863.2018.1509297
- Neal, I., du Toit, S. H., & Lovarini, M. (2019). The use of technology to promote meaningful engagement for adults with dementia in residential aged care: a scoping review. *International psychogeriatrics*, 1-23.
- Newman, A., Goulding, A., Davenport, B. & Windle, G. (2018). The role of the visual arts in the resilience of people living with dementia in care homes. *Ageing and Society*, 1-18.
- Ottmann, G., & Maragoudaki, M. (2015). Fostering resilience later in life: a narrative approach involving people facing disabling circumstances, carers and members of minority groups. *Ageing & Society*, 35(10), 2071-2099.
- Pipon-Young, F. E., Lee, K. M., Jones, F., & Guss, R. (2012). I'm not all gone, I can still speak: the experiences of younger people with dementia. An action research study. *Dementia*, 11(5), 597-616.
- Prince, M., Comas-Herrera, A., Knapp, M., Guerchet, M., & Karagiannidou, M. (2016). *World Alzheimer report 2016: Improving healthcare for people living with dementia: coverage, quality and costs now and in the future*. Alzheimer's Disease International (ADI): London, UK.
- Pu, L. H., Moyle, W., Jones, C., & Todorovic, M. (2019). The Effectiveness of Social Robots for Older Adults: A Systematic Review and Meta-Analysis of Randomized Controlled Studies. *Gerontologist*, 59(1), E37-E51. doi:10.1093/geront/gny046
- Ritchie J., Lewis J. (2003) *Qualitative research practice: a guide for social science students and researchers*. London: Sage.

- Rockwood, K., Fay, S., Hamilton, L., Ross, E., & Moorhouse, P. (2014). Good days and bad days in dementia: A qualitative chart review of variable symptom expression. *International psychogeriatrics*, 26(8), 1239-1246.
- Rouaix, N., Retru-Chavastel, L., Rigaud, A.-S., Monnet, C., Lenoir, H., & Pino, M. (2017). Affective and Engagement Issues in the Conception and Assessment of a Robot-Assisted Psychomotor Therapy for Persons with Dementia. *Frontiers in psychology*, 8, 950. doi:10.3389/fpsyg.2017.00950
- Sabat, S. R. (2018). *Alzheimer's Disease and Dementia: What Everyone Needs to Know®*. Oxford University Press.
- Scott, I. and Mazhindu, D. (2014). *Statistics for healthcare professionals: An introduction*. Sage.
- Sharma, P., & Hannafin, M. J. (2007). Scaffolding in technology-enhanced learning environments. *Interactive learning environments*, 15(1), 27-46.
- Sury, L., Burns, K., & Brodaty, H. (2013). Moving in: adjustment of people living with dementia going into a nursing home and their families. *International Psychogeriatrics*, 25(6), 867-876.
- Stake, R. E. (1995). *The art of case study research*. sage.
- Ungar, M. (2008). Resilience across cultures. *The British Journal of Social Work*, 38(2), 218-235.
- Wagnild, G. M. & Young, H. M. (1993). Development and psychometric evaluation of the Resilience Scale. *Journal of nursing measurement*, 1, 165-178.
- Wagnild, G. M. (2009). *The Resilience Scale User's Guide: for the US English Version of The Resilience Scale TM and the 14-Item Resilience Scale TM (RS-14 TM)*. Resilience centre.
- World Health Organisation (2020). Available online: <https://www.who.int/news-room/fact-sheets/detail/dementia> [Accessed 2nd March 2020].
- Williamson, T., & Paslawski, T. (2016). Resilience in dementia: Perspectives of those living with dementia. *Canadian Journal of Speech-Language Pathology and Audiology*, 40, 1-15.
- Windle, G. (2011). What is resilience? A review and concept analysis. *Reviews in Clinical Gerontology*, 21(2), 152-169.
- Windle, G., & Bennett, K. M. (2012). Caring relationships: How to promote resilience in challenging times, *The social ecology of resilience* (pp. 219-231): Springer.
- Yin, R. K. (2014). *Case Study Research: Design and Methods (Applied Social Research Methods)*. California: Sage.

## 5.2. Chapter Five. Summary and Segue

Additional material concerning the analysis of the findings that are reported in this paper are available in Appendices 13) to 23). The appendices include an example of the raw quantitative data obtained with dementia care mapping; screenshots with examples of the processes conducted during the analysis; the coding framework exported from NVIVO; examples of the memos written during the analysis; the link between the coding framework categories and the final themes; and information about the results that were obtained using member checking with a relative and professional caregiver participants.

Member checking also involved two participants with dementia. Shortly after their post MARIO interviews, SW asked these participants to provide verbal feedback on her initial interpretation of what they had expressed. During these discussions, both participants agreed that their opinions had been accurately interpreted. Also, peer debriefing was deployed during data analysis. SW and TK (fourth author on paper four), an experienced qualitative researcher who was knowledgeable about resilience theory, worked independently coding the first four transcripts. Then, the authors discussed their sets of coding and they reached a consensus regarding the labelling of codes and the core issues that they had identified in the data.

Chapter five reported an empirical study that applied resilience theory to investigate the effects of MARIO, a social robotic intervention on the wellbeing of people with dementia. The paper focused on the change in resilience outcomes that occurred due to using the robot and the nature of the interactions with the robot that were required to elicit positive changes in resilience. The paper provides insight into the components and nature of resilience for people with dementia living in long-term care that contributes significant knowledge about resilience in this context, to what is currently a relatively small body of research. This paper

also provides substantial evidence that to support resilience, robotic interventions need to empower people with dementia and enable them to co-create meaningful activities to foster positive self-identity. Increased resilience resulted from meaningful activity stimulated by the robot, but this was enacted and realised through the facilitator-person with dementia relationship.

Paper four provides evidence about how one social robot was able to impact resilience with a facilitator present. The findings reported in Paper four concerning MARIO's limited social presence is complemented by additional research that was undertaken by SW and another member of the MARIO team, to examine the response of people with dementia (n=4) to MARIO without the facilitator being present. This research revealed that after MARIO had been introduced and the applications that were relevant to the participant had been opened, one person with mild dementia illustrated that engagement in meaningful activity without a facilitator present was possible for up to five minutes. Engagement without the facilitator being present was not possible for the other three participants. This reaffirmed that MARIO had limited ability to engage people with dementia independently.

What is known about the potential of social robots to support resilience in people with dementia as a result of the body of work presented in this thesis will now be discussed in chapter six.

## Chapter Six. Discussion.

### 6.0 Introduction

This chapter reviews the body of work that has been presented in four papers in this thesis. Firstly, an overview of the thesis scope and its key findings are presented. Then, key issues identified from the findings of the body of work are discussed in relation to the wider literature. Following this, the strengths, and limitations of this body of work are presented and the implications of the thesis for future research and clinical practice are discussed.

### 6.1. Thesis scope and key findings

The body of work presented in this thesis explored the potential of social robots to support the resilience of people with dementia.

**Objective 1:** To identify the factors that impact the acceptability of social robots for people with dementia.

This aim was addressed in paper one. This paper presented a literature review that examined factors that impact the acceptability of social robots for people with dementia. The literature review revealed that:

- Investigating the acceptability of social robots in dementia can be guided by concepts included in the Almere Model (Heerink, 2010) of robot acceptability.
- The acceptability of social robots in dementia is impacted by multiple interacting factors, at the level of the individual, significant others, and wider society.
- People with dementia prefer robots that: use human-like communication, have a capacity for adaptivity that meets a person's needs for trust and control, and that are personalised and respond to unmet needs.
- Most previous studies are of short duration with small sample sizes and many studies are not conducted in real-world contexts.

**Objective 2:** To identify the key components of psychosocial interventions (PSIs) that aim to support resilience and to clarify how the concept of resilience can be defined and operationalised.

This aim was addressed in paper two by conducting a literature review. This literature review revealed that:

- Increased resilience was associated with feelings of empowerment and positive psychology.
- PSIs to support resilience need to: involve meaningful activities, be strength-based, person-centred, reduce stigma, improve communication, increase social support, and enable reciprocal social interactions.
- There is a temporal aspect to resilience in dementia because it can be fostered during and after PSIs
- There is an interplay between individual and community resources that support resilience.
- PSI to support resilience in dementia can be investigated by defining resilience as a process and through using the resilience framework.

## Chapter Six. Discussion

- More PSIs need to be developed to support the resilience of people with dementia who lack the support of family carers and/or have more advanced dementia.

Objective 3: To determine the most appropriate study design to investigate the use and effect of social robots to support resilience in dementia.

This aim was addressed through paper three. This paper presented a critical appraisal of the structured, theoretically derived DESCARTE model. This paper revealed that:

- Case study methodology can be applied to investigate social robots that aim to support resilience in dementia.
- The DESCARTE model provides a useful framework to support the theoretical and rigorous design and use of case study methodology. It facilitates researchers to focus on philosophical cohesiveness, ethical considerations, and reflexivity, during the design, conduct, and reporting of case studies. It also enables the rigorous analysis of multiple data sources.
- The model did not prompt the identification of research questions, specific methods to promote rigor, or reflexive practices throughout the research.
- To improve its utility the model required additional prompt questions which were recommended in paper three.

Objective 4: To investigate how using MARIO affected the resilience of people with dementia by identifying the characteristics of resilience in this context, exploring how resilience changed as a result of using MARIO, and identifying how MARIO was used to impact resilience.

These objectives were addressed by the empirical study that is presented in paper four. Paper four reported a multiple case study that for the first time explored how social robots could impact resilience in people with dementia living in residential care. The study revealed that:

- The resilience of people with dementia in residential care can be envisaged as existing along an adaptivity-wellbeing continuum. When people with dementia are situated at the negative end of the adaptability-wellbeing continuum, they are unable to effectively deploy their personal resilience repertoires without the support of other people.
- The resilience of eight out of ten people was supported while people with dementia were using MARIO.
- There is a small amount of evidence that an increase in wellbeing may be sustained for up to two hours after using MARIO.
- The increase in resilience was realised through the facilitator-person with dementia relationship in which people with dementia were empowered to co-create meaningful activities that fostered a positive sense of self-identity. This meant that while they were using MARIO they were 'doing okay'.
- During the study, Mario was not autonomous and its ability to communicate in a human-like way was insufficient to maintain the engagement of people with moderate and advanced dementia without a facilitator.

## 6.2. Discussion of Key Issues.

The following key issues were identified from the findings of the body of work presented in this thesis. These issues will now be discussed in relation to the wider literature regarding the acceptability of social robots, and the design and use of social robots for resilience in the context of dementia:

1. Can social robots enhance the wellbeing of people with dementia by supporting their resilience?
2. How do social robots need to be designed and deployed to support resilience?
3. Robot-human relationships.
4. Using a holistic approach to investigate social robots and resilience.

### 6.2.1. Can social robots enhance the wellbeing of people with dementia by supporting their resilience?

The findings of this body of work reveal that the development, investigation, and future deployment of social robots can be theoretically underpinned by resilience theory and that social robots do have the potential to increase the wellbeing of people with dementia through supporting resilience. Resilience was supported through interactions with MARIO that increased positive emotions and enhanced a positive sense of self-identity. The capacity of social robots to increase positivity was also identified by Pedersen et al. (2018) in their literature review that involved n=31 studies. However, the findings of this body of research also reveal that social robots are not likely to be able to support the resilience of all people with dementia because, for some people, social robots may not be acceptable or suitable PSIs. This finding concurs with Hebesberger et al. (2017) who found that robots may not be acceptable or able to engage all people with dementia. In addition, because people with strong feelings against social robots are not likely to participate in studies involving social robots (Demange et al., 2018), the percentage of people who find social robots acceptable may be overestimated. This suggests there is an ongoing need to monitor and examine the acceptability rates and the barriers and facilitators to the acceptance of social robots for the use of people with dementia (Thordardottir et al., 2019). It may also be useful to investigate the attitudes amongst people who decline to participate in research that involves robots.

### 6.2.2. How do social robots need to be designed and deployed to support resilience?

The findings reveal that for social robots to support the resilience of people with dementia, their design, development, and deployment needs to acknowledge the agency of people with dementia. And, as discussed further below, the deployment of social robots needs to be underpinned by the principles associated with strength-based care.

#### 6.2.2.1. Acknowledging agency.

The thesis findings reveal that people with dementia are active participants both in the resilience process and the usage of social robots. It was identified in paper one that individuals are active in their interpretation and response to social robots and in deciding whether to engage with robots. Also, as described in paper four, people with dementia are active in co-creating meaningful activities to support their resilience. Indeed, the agency of people with dementia is necessary because

resilience in dementia involves the use of resources to ‘overcome’ dementia (Bailey, 2017). The literature also reveals that resilience requires resources to be used in a way that enables a person to live with dementia with hope and positivity (Sabat, 2018) and a ‘new normal’ as dementia progresses (Matchar & Gwyther, 2014). Therefore, people with dementia must be actively involved in using social robots as a resource if social robots are to successfully promote resilience. Their agency can be supported by other people, as discussed further below, but the involvement of people with dementia cannot be passive if resilience is to be increased. Therefore, this thesis reveals that the full potential of social robots to support resilience will be created by each individual person with dementia throughout their usage of robotic technologies.

The finding that agency is vitally important concurs with the views expressed in a recent theoretical paper which advocates that older adults use technology by creating spaces for it in their lives (Peine & Neven, 2019). And, it has been noted that the active involvement of people with dementia is essential to the success of PSIs (Beard, 2009).

The importance of agency has been indirectly acknowledged during the development of some robots, including MARIO, that deployed user-centred design (Casey, 2016) and participatory design methods (Lee, 2017). These iterative methods involve people with dementia and focuses on their needs throughout the development process and participatory design methods. However, the importance of agency being integral to the successful usage of social robots has not been previously emphasised in the literature.

### 6.2.2.2. The principles associated with strength-based care.

The agency of people with dementia is an important concept within strength-based approaches to care which aim to acknowledge and support a person’s personal assets, their interests, and retained abilities using person-centred care (Moyle, 2014). The thesis findings reveal that the potential of social robots to support positive self-identity and meaningful activity, may be enhanced if social robots are personalised to the needs of individual users; they are used in a person-centred way, and they fulfil the individual user’s unmet psychosocial needs. Indeed, as discussed in paper one, social robots must successfully address these requirements to a high degree if they are to be accepted by people with dementia and caregivers. Furthermore, social robots need to be particularly pertinent and relevant to individuals’ needs if they are to create the quality of personal engagement necessary to enable meaningful activities to positively enhance the user’s self-identity. These findings concur with other research that has recognised that social robots present opportunities for people with dementia to engage in meaningful activities (Bemelmans et al., 2012; Wu et al., 2016; Sarabia et al., 2018; Pu et al., 2019) through their provision of personalised activities (Kerssens et al., 2015) and by addressing unmet needs, particularly when people with dementia living in care homes are agitated or isolated (Abbott et al., 2019).

The nature of dementia as a variable condition was identified and discussed in paper four. Although people with dementia may not consistently have the cognitive ability to rationalise about their needs or communicate them, people with dementia know how they feel (Sabat, 2018). This suggests that people with dementia will know if a social robot meets with their preferences and needs at any specific moment. Therefore, to support resilience social robots will need to be

highly sophisticated in their ability to accurately interpret the variable emotional requirements of people with dementia and to respond to them appropriately.

Another principle of strength-based care is that people with dementia are empowered through supportive relationships to identify and use their resources (Pearson, 2013). The thesis findings, (paper two and four), revealed it is important that social robots are used to empower people with dementia, as an outcome of the resilience process, and as a means of stimulating meaningful activities (Paletta et al., 2018). Empowerment of people with dementia was an essential ingredient of the PSIs that were discussed in paper two and empowerment was important in the empirical study with MARIO when the applications, that were personalised to each individual, enabled people with dementia to demonstrate their expertise. Being empowered through exercising choices has also been identified as important in other robot studies (Joranson et al., 2016; Chu et al., 2017) and those that have involved non-robotic technologies (Huldtgren et al., 2016).

Therefore, the findings suggest that using the principles of strength-based care will enhance the potential of social robots to support resilience in dementia. However, the potential of robots is also impacted by human-robot relationships and the capacity of social robots to create human-like relationships.

### 6.2.3. Robot-human relationships.

The findings of this body of work reveal that the potential of social robots to increase the resilience of people with dementia is dependent on relationships; human-human and human-robot. The research discussed in paper one identified social influence was a significant factor in determining the acceptability of social robots and relational issues were found in paper two and four to be key to the development, outcomes, and the investigation of resilience in dementia. However, the nature of these relationships requires further discussion.

The findings discussed in paper four reveal that social robots can support and improve the human-human relationships between some people with dementia and their relatives, caregivers, and facilitators. This finding is supported by related work that documents that social robots can improve communication between people with dementia with others (Joranson et al., 2016; Rouaix et al., 2017; Joshi et al., 2019; Feng et al., 2019). For example, Liang et al., (2017) found that a social robot improved communication between people with dementia (n=30) and day centre caregivers.

However, as described in paper four, the primary relationship that enabled resilience to be supported by MARIO was human-human, with the facilitator supporting the person with dementia. This finding suggests that robots of a similar capacity to MARIO for human-like communication can enhance the resilience of people with dementia through the robot stimulating human-human interactions and relationships. This means that robots are likely to be more successful and meaningful if they are used alongside other people rather than left for people with dementia to use independently (Neal et al., 2019). This finding also suggests that social robots are effective as embodied multimedia artifacts in a similar way to non-robotic technologies such as CIRCA (Purves et al., 2015) and a commercially available touchscreen-based digital system called It's Never 2 Late (iN2L) (Lazar et al., 2018). CIRCA is a multimedia artifact that has been found to support human-human relationships through mediating reminiscence and communication (Alm et al., 2009). The iN2L is similar having several applications for entertainment and



social involvement and it has been found to increase social interactions, and improve caregiver knowledge of the person with dementia (Lazar et al., 2016). Furthermore, CIRCA has been proposed as a technology that can support resilience through increasing equality between conversational partners and providing positive relationships, environmental mastery, and autonomy for people with dementia (Astell et al., 2018).

The technical capacity of social robots to communicate in a more human-like way is likely to increase in the future because it is the goal of developers to engage and motivate users through creating robots that are capable of participating in empathetic human-robot relationships (Carolis et al., 2017). Currently, developers are working to improve the 'social memory' of robots to enable them to recognise, understand, and respond to users' affective states (De Carolis et al., 2017). For example, the social robot Pepper is being developed through the international CARESSES project (Padadopoulos et al., 2020). Pepper has greater functional ability than MARIO, and it includes a greater range of speech ([www.youtube.com/watch?v=fB0fyhPkis8&feature=youtu.be](http://www.youtube.com/watch?v=fB0fyhPkis8&feature=youtu.be)). Pepper has been developed to recognise the habits of users and aspects of their personality traits (Melo et al., 2018), and it is reported to be able to learn the emotional behaviours from individual users (Tuyen et al., 2018). A proposal to evaluate Pepper has been published (Papadopoulos et al., 2020). This will use an RCT involving older adults living in care homes (n=45) to ascertain to what degree the wellbeing of participants is impacted by social robots that can learn to respond in culturally specific ways and according to the preferences learned from participants.

It is possible that with greater robot technical capacity in the future, the resilience of people with dementia may be supported through different human-robot-human relationships. These may include reciprocal relationships in which human users provide care for robots whilst robots support the care of humans (Dautenhahn, 2007). Reciprocal peer-like human-human relationships, as discussed in paper two and four of this thesis, are key to supporting resilience in dementia. It might be possible for future social robots to create empathetic relationships that enhance the positive self-identity of people with dementia and enable the co-creation of meaningful activity. But, whether the robot-human relationship will ever be sufficiently peer-like and reciprocal to support resilience when the robot is used by people with dementia independently will require further study.

The next section of this discussion builds upon the notion argued here that using social robots to support resilience in dementia concerns relationships. The findings of this body of work reveal the need for a holistic approach to be taken when considering social robots to support resilience in dementia.

#### 6.2.4. The need for a holistic approach.

For social robots to support resilience, the biopsychosocial context into which social robots are deployed needs to be considered. Paper one identified that the usage of social robots by people with dementia is impacted by multiple interacting factors that occur at the level of the individual, their community, and wider culture. It was also discussed in paper two that resilience in dementia is impacted by multiple factors that are external and internal to individual people with dementia. A holistic approach to the examination of social robots is also important because paper two revealed that for resilience to be fostered, PSIs must involve a stigma-free environment. Being holistic must include being mindful as revealed in paper one, that social robots cannot be expected to sustainably support resilience if the

context is not conducive to supporting PSIs that use strength-based principles. Like all technologies, the effectiveness of social robots that aim to support resilience is impacted by the context into which it is introduced (Huter et al., 2020). Caregivers play an important role in the implementation of technologies in the context of dementia and it is very important how the benefits of technologies are perceived by and communicated to caregivers (Thordardottir et al., 2019). For social robots, as novel technologies, this may be a challenge because people in therapeutic professional roles can have a healthy scepticism about new technologies (Zarit et al., 2020). In one study that focused on the social acceptance of an autonomous robot, 47% of professional caregivers (n=66) said they would not like to share their workspace with a robotic aid and some expressed irritation or fear about the robot or a general dislike of technology. Other caregivers (53%) said they would like to work alongside a robot. Some caregivers were interested in the robot and excited by it (Hebesberger et al., 2017). Caregivers can also fear that their role will be undermined or replaced by social robots (Share & Perry, 2018; Casey et al., 2020). Therefore, social robots need to be considered in conjunction with the context in which they are deployed and it must be acknowledged that people with dementia are embedded in rich cultural lives (Pedersen et al., 2018). Zafrani and Nimrod (2019) have also called for a holistic approach to the study of older adults and their interaction with social robots.

As evidenced in paper four, if the context in which care is provided is stigma-free and supportive of strength-based principles and if stakeholders accept social robots, then there are opportunities to support resilience using social robots. However, the findings of this thesis speak to the need for social robots, that aim to support resilience, to be deployed with attention to the culture of care that prevails within the individual contexts. The findings in paper two and four suggest that for long-term sustained impact, social robots as a strength-based psychosocial intervention need to be supported by attitudes and environmental organisation that endorse social rather than medical conceptual models of disability.

### 6.3. Implications for future research

The work in this thesis has highlighted several areas for future research. The current body of research is small, and future research needs to verify the findings of this thesis by conducting large empirical studies as the technical capability of social robots increases. It would be valuable to develop a core outcome set on resilience in dementia. A core outcome set would enable comparison between future social robots. Development of core outcomes for resilience could draw upon the forthcoming work of Harding et al. (2018) who aim to develop an outcome set for the evaluation of nonpharmacological health and social care interventions for people living with dementia in community settings. It could also draw upon previous research that has supported using the concepts of positive psychology and social health as outcome measures for the assessment of psychosocial interventions in dementia (Øksnebjerg et al., 2018).

Future research should also clarify the efficacy of social robots being embodied and having autonomous movement in comparison to non-robotic multimedia artifacts that are used with human facilitators.

Future research needs to establish if the human-robot relationships change with greater robot capability and to what degree future social robots can produce reciprocal peer-like relationships. In addition, because this thesis identified the importance of relational and cultural issues it would be useful to explore how

reciprocal social relationships can be enhanced by using social robots in group-based PSIs for the development of both individual and group resilience. Social robots have been used to deliver PSI in groups (Moyle et al., 2017; Joshi et al., 2019; Feng et al., 2019). However, social robots as group PSIs will still have to enable agency and the co-creation of meaningful activity. Furthermore, the demands placed upon the robots for human-like skills may be even higher in a group situation.

The empirical study of MARIO (paper four) found no evidence that people with dementia were deceived as to the nature of MARIO or the level of the robot's capability and to my knowledge, no evidence of deception has been identified in other empirical studies. However, as robots are developed with more human-like capacity with greater degrees of autonomous movement and adaptability the possibility of deception occurring needs to be monitored (Lazar et al., 2016).

Future investigations should use methodologies that can examine the complexities of clinical environments (Huter et al., 2020), including cultural and relational issues whilst also ensuring that the views of people with dementia are heard and supported. Much research on social robots and resilience involves caregivers and people with dementia as dyads (Matchar & Gwyther, 2014; Liang et al., 2017; Moyle et al., 2019a, 2019b). However, there is evidence that the views of people with dementia and significant others can differ about using social robots (Paletta et al., 2018) and other technologies that are designed for home monitoring (Berridge & Wetle, 2019). It is particularly important to identify the needs and opinions of people with dementia because many robots are being developed for use in gerontology that focus on monitoring the wellbeing of older adults with sensor applications (Huter et al., 2020). If robots are used to fulfil the needs and preferences of caregivers rather than people with dementia the privacy and autonomy of users could be compromised, and social robots may be unlikely to promote the resilience of people with dementia.

### 6.4. Implications for future clinical practice.

To enable social robots to support resilience, guidelines for their design and deployment need to be developed that are underpinned by the principles of strength-based care. A useful starting point may be guidelines recently developed for the usage of digital recreational technologies in memory care settings, which also recommend strength-based principles are adopted (Lazar et al., 2018).

Currently, there is little professional regulation or educational provision to guide how current and future health and social care professionals can work alongside and utilise social robots (Share & Pender, 2018). A response to this gap in provision is being developed by a European wide project ([prospero.via.dk/en](http://prospero.via.dk/en)). This project aims to establish how health and social care professionals can learn to use autonomous technologies, so they can contribute to discourses about the future development and use of social robots (Share & Pender, 2020). Also, multi-disciplinary postgraduate training in digital technology that aims to prepare health and social care providers to use technological resources, is becoming available at some institutions (e.g. MSC Healthcare Technology, the University of West of England Bristol).

### 6.5 Social robots in the context of COVID 19.

The impact of COVID 19 on people with dementia has been considerable. Shocking statistics reveal that 25.6% of all deaths that occurred during May 2020 in England

and Wales from COVID 19 involved people with dementia (Office for National Statistics, 2020). In Ireland, 29.2% of the total 1,245 deaths prior to 20<sup>th</sup> May 2020 have involved people with a chronic neurological disease that includes dementia (Health Protection Surveillance Centre, 2020). It is notable that dementia has not been the focus of government policy discussions about COVID and that people with dementia are at increased risk of COVID because they live in care homes rather than due to dementia per se (Hennelly & Cahill, 2020). Also, people with dementia are at increased and significant risk of social isolation, loneliness, anxiety, and a sense of abandonment, because during the COVID crisis their support services are reduced and there is increased stress on their caregivers (Hennelly & Cahill, 2020).

There have been calls for innovative methods to be used to facilitate people with dementia to engage and stay socially connected. In particular, the COVID crisis has increased the need for people living in residential care to maintain their social connectedness through video calls when visits in person are not possible, and group activities have been cancelled (Hennelly & Cahill, 2020). Telepresence robots and social robots with video call capacity could help people with dementia to maintain contact with their friends and family. But, where they are available, they are being underused and the COVID crisis has exposed a lack of capability amongst caregivers to use ICT alternatives (Calaeb-Solly, 2020).

There are some examples of innovative technology being used during the crisis. For example, one dementia café has been transferred online ([engagingdementia.ie](http://engagingdementia.ie)). Thirty-one percent of people with dementia (n=147) were comfortable using ICT and accessing services online (Alzheimer Society of Ireland, 2020). However, this may over-estimate ICT use and comfort accessing services online as these results were determined using an online survey with a sample of people with dementia that included people under 65 (n=16). Indeed, in Ireland only 38% of people over 80 years have internet access in comparison to 86% of people aged 50-59 (Doody et al., 2020).

COVID 19 is likely to impact people with dementia for the foreseeable future. Social robots may be an innovative way to support people with dementia by supplementing human relationships and care provision. However, the implementation of technologies must attend to the voice of people with dementia (Commissioner for Human Rights, 2020) and they must be deployed with age-friendly strategies to avoid increased reliance on technology that may widen existing health and social inequalities (Marston & Samuels, 2019).

### 6.6. Thesis Strengths

This thesis has identified the factors that impact the usage and effect of social robots to support the resilience of people with dementia and how robots for this purpose can be investigated. The body of work is underpinned by recognised theories of technology acceptance and resilience. In addition, the thesis was informed by a systematic review, stakeholder consultation, and concept analysis of resilience (Windle, 2011) and a systematic review, involving n=38 studies that determined how resilience was understood and had been applied to older adults (Van Kessel, 2013). The research reported in papers one-four records that a logical stepwise approach was used throughout the thesis. The relevant literature was comprehensively reviewed using robust methodologies and the review findings informed the content and analysis of the empirical research. The empirical study which examined the potential of a social robot in a real-world clinical context was

## Chapter Six. Discussion

designed and conducted using rigorous case study methodology guided by a structured theoretically derived model.

### 6.7. Thesis Limitations

Limitations concerning the individual studies have been discussed within papers one-four and there are limitations to the body of work presented in this thesis. Overall the thesis is based on a relatively small body of existing literature, and the empirical study used a small sample size and it investigated only one residential care setting. Another limitation was that MARIO could not be fully autonomous during the study, because the robot was unable to independently navigate around the nursing home because beds and chairs were moved on a daily basis. Nevertheless, this body of work makes a significant contribution to knowledge addressing the gaps in knowledge that are specified in chapter one and those summarised below.

### 6.8. Thesis Conclusion

The thesis presents four papers that report a body of work that significantly contributes to the current limited empirical evidence on how social robots can benefit the psychosocial wellbeing of people with dementia. It provides new evidence as to how social robots can be used to support the resilience of people with dementia through their capacity to enhance human-human relationships and support a sense of positive self-identity. The thesis reveals that to support resilience social robots need to be used according to the principles of strength-based care, particularly respecting and responding to the agency of people with dementia, to create empowerment, meaningful activity, and peer-like reciprocal relationships. Currently, social robots lack the capacity to independently support resilience, but they may be able to do this in the future if they are fully autonomous and able to read and react to the emotional response of users in a more human-like way.

### 6.9. Chapter Six. References

- Alm, N., Astell, A., Gowans, G., Dye, R., Ellis, M., Vaughan, P., & Riley, P. (2009). Engaging multimedia leisure for people with dementia. *Gerontechnology*, 8, 236-246. doi:10.4017/gt.2009.08.04.006.00
- Astell, A.J., Savundranayagam, M.Y., Kelson, E., Purves, B. and Phinney, A. (2018). Fostering Resilience in Dementia Through Narratives: Contributions of Multimedia Technologies. In *Resilience in Aging* (pp. 245-260). Springer, Cham.
- Abbott, R., Orr, N., McGill, P., Whear, R., Bethel, A., Garside, R., Stein, K. and Thompson-Coon, J. (2019). How do “robopets” impact the health and well-being of residents in care homes? A systematic review of qualitative and quantitative evidence. *International journal of older people nursing*, 14(3), p.e12239.
- Alzheimer Society of Ireland. (2020) COVID-19: Impact & Need for People living with dementia and Family Carers. Retrieved from <https://alzheimer.ie/wp-content/uploads/2020/04/Research-report-Covid19-Final..pdf> accessed 6th July 2020
- Bailey, G.H. (2017). ‘This is my life and I’m going to live it’: A grounded theory approach to conceptualising resilience in people with mild to moderate dementia.
- Beard, R. L., Knauss, J., & Moyer, D. (2009). Managing disability and enjoying life: How we reframe dementia through personal narratives. *Journal of Aging Studies*, 23(4), 227-235.
- Bemelmans, R., Gelderblom, G. J., Jonker, P., & de Witte, L. (2012). Socially assistive robots in elderly care: A systematic review into effects and effectiveness. *Journal of American Medical Directors Association*, 13(2), 114-120.
- Berridge, C. & Wetle, T.F. (2019). Why Older Adults and Their Children Disagree About In-Home Surveillance Technology, Sensors, and Tracking. *The Gerontologist*, pp.20-20.
- BOURDIEU, P. 1984. A social critique of the judgement of taste. Traducido del Francés por R. Nice, Routledge: Londres.

## Chapter Six. Discussion

- Calaeb-Solly P. (2020) 'BSG2020 Keynote Interview - Praminda Caleb-Solly interviewed by Professor Jane Powell' 2nd July 2020.  
<https://www.youtube.com/watch?v=JJ82h6oSwvM&feature=youtu.be>
- Casey, D., Barrett, E., Murphy, K., Adamantios K., Daniele S., R., Santorelli, A., Kovaic, T., Gallagher, N., & Whelan, S. (2020). The perceptions of people with dementia and key stakeholders regarding the use and impact of the social robot MARIO. *International Journal of Environmental Research and Public Health*, 17, 8621, 1-19.
- Chu, M., Khosla, R., Khaksar, S. & Nguyen, K. (2017). Service innovation through social robot engagement to improve dementia care quality. *Assistive Technology* 29, 8-18.<https://doi.org/10.1080/1040043520161171807>
- Clarke, C. L. & Bailey, C. (2016). Narrative citizenship, resilience, and inclusion with dementia: On the inside or on the outside of physical and social places. *Dementia*, 15, 434-452.
- Commissioner for Human Rights (2020) Lessons to be drawn from the ravages of the COVID-19 pandemic in long-term care facilities. STRASBOURG statement 20<sup>th</sup> May 2020 Retrieved from <https://www.coe.int/en/web/commissioner/-/lessons-to-be-drawn-from-the-ravages-of-the-COVID-19-pandemic-in-long-term-care-facilities> Accessed 6<sup>th</sup> July 2020.
- De Carolis, B., Ferilli, S. & Palestra, G. (2017). Simulating empathic behaviour in a social assistive robot. *Multimedia Tools and Applications*, 76(4), pp. 5073-5094.
- Demange, M., Lenoir, H., Pino, M., Cantegreil-Kallen, I., Rigaud, A. S. & Cristancho-Lacroix, V. (2018). Improving well-being in patients with major neurodegenerative disorders: differential efficacy of brief social robot-based intervention for 3 neuropsychiatric profiles. *Clinical Interventions in Aging*, 13, 1303-1311.
- Doody, P., Wang, M., Scarlett, S., Hever, A., O'Mahoney, & P., Kenny, R.A. (2020) Internet access and use among adults aged 50 and over in Ireland: Results from Wave 5 of the Irish Longitudinal Study of Ageing. Tilda. Dublin: Ireland.  
[https://tilda.tcd.ie/publications/reports/pdf/Report\\_Covid19InternetReport.pdf](https://tilda.tcd.ie/publications/reports/pdf/Report_Covid19InternetReport.pdf)
- Feng, Y., Yu, S., Van de Mortel, D., Barakova, E., Hu, J., & Rauterberg, M. (2019) LiveNature: Ambient display and social robot-facilitated multi-sensory engagement for people with dementia. DIS 2019 - Proceedings of the 2019 ACM Designing Interactive Systems Conference, 1321-1333.
- Harding, A.J., Morbey, H., Ahmed, F., Opdebeeck, C., Wang, Y.Y., Williamson, P., Swarbrick, C., Leroi, I., Challis, D., Davies, L., Reeves, D., Holland, f., Hann, M., Hellström, I., Hydén, L., Burns, A., Keady, J., & Reilly, S. (2018). Developing a core outcome set for people living with dementia at home in their neighbourhoods and communities: study protocol for use in the evaluation of non-pharmacological community-based health and social care interventions. *Trials*, 19(1), pp.1-13.
- Health Protection Surveillance Centre (2020) Underlying conditions in confirmed cases of COVID-19 in Ireland. <https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/surveillance/underlyingconditionsreports/Underlying%20conditions%20summary%20052020.pdf>
- Hebesberger, D., Koertner, T., Gisinger, C. & Pripfl, J. (2017). A Long-Term Autonomous Robot at a Care Hospital: A Mixed Methods Study on Social Acceptance and Experiences of Staff and Older Adults. *International Journal of Social Robotics*, 9, 417-429.
- Hennelly N and Cahill S. (2020) The impact of COVID-19 on people living with dementia in Ireland. Report. <https://ltccovid.org/2020/06/06/new-report-the-impact-of-covid-19-pandemic-on-people-living-with-dementia-in-ireland/>.
- Huldtgren, A., Mertl, F., Vormann, A. & Geiger, C. Reminiscence of people with dementia mediated by a tangible multimedia book. In: O'Donoghie, J., Ziefle, M., Rocker, C., Maciaszek, L., Maciaszek, L. & Molloy, W., eds. (2016). *SciTePress*, 191-201.
- Heerink M, Kroese B, Evers V, & Wielinga B. (2010) Assessing Acceptance of Assistive Social Agent Technology by Older Adults: the Almere Model. *Int J Soc Robot* 2: 361-375.
- Huter, K., Krick, T., Domhoff, D., Seibert, K., Wolf-ostermann, K. & Rothgang, H. (Under Review, 2020). Effectiveness of digital technologies to support nursing care: results of a

scoping review. PREPRINT article under review BMC Medical Informatics and Decision Making.

Jøranson, N., Pedersen, I., Rokstad, A. M. M., Aamodt, G., Olesen, C. & Ihlebæk, C. (2016). Group activity with PARO in nursing homes: systematic investigation of behaviours in participants. *International psychogeriatrics*, 28, 1345-1354.

Joshi, S., & Šabanović, S. (2019). Robots for inter-generational interactions: implications for nonfamilial community settings. 2019 14th ACM/IEEE International Conference on Human-Robot Interaction (HRI). New York: IEEE.

Kang, H. S., Makimoto, K., Konno, R., & Koh, I. S. (2020). Review of outcome measures in PARO robot intervention studies for dementia care. *Geriatric Nursing*, 41(3), 207-214. <https://doi.org/https://doi.org/10.1016/j.gerinurse.2019.09.003>

Kerssens, C., Kumar, R., Adams, A.E., Knott, C.C., Matalenas, L., Sanford, J.A. & Rogers, W.A. (2015). Personalised technology to support older adults with and without cognitive impairment living at home. *American Journal of Alzheimer's Disease & Other Dementias*®, 30, (1), p. 85-97.

Khosla, R., Nguyen, K. & Chu, M.-T. (2014). Assistive Robot Enabled Service Architecture to Support Home-Based Dementia Care. IEEE 7th International Conference on Service-Oriented Computing and Applications. IEEE.

Lazar, A., Demiris, G. & Thompson, H. J. (2016). Evaluation of a multifunctional technology system in a memory care unit: Opportunities for innovation in dementia care. *Informatics for Health & Social Care*, 41, 373-386.

Lazar, A., Thompson, H.J. & Demiris, G. (2018). Design recommendations for recreational systems involving older adults living with dementia. *Journal of Applied Gerontology*, 37(5), 595-619.

Lee, H.R., Šabanović, S., Chang, W.L., Nagata, S., Piatt, J., Bennett, C. & Hakken, D. (2017) March. Steps toward participatory design of social robots: mutual learning with older adults with depression. In *Proceedings of the 2017 ACM/IEEE international conference on human-robot interaction* (pp. 244-253).

Liang, A., Piroth, I., Robinson, H., Macdonald, B., Fisher, M., Nater, U. M., Skoluda, N. & Broadbent, E. (2017). A Pilot Randomized Trial of a Companion Robot for People With Dementia Living in the Community. *Journal of the American Medical Directors Association*, 18, 871-878.

Marston, H.R. & Samuels, J. (2019) A review of age friendly virtual assistive technologies and their effect on daily living for carers and dependent adults. In *Healthcare* (Vol. 7, No. 1, p. 49). Multidisciplinary Digital Publishing Institute.

Matchar, B. G. & Gwyther, L. P. (2014). Resilience in Early-Stage Dementia. *Topics in Geriatric Rehabilitation*, 30, 170-175.

Melo, N., Lee, J. & Suzuki, R. (2018) Identification of the User's Habits based on Activity Information. In *2018 IEEE/RSJ International Conference on Intelligent Robots and Systems (IROS)* (pp. 2014-2019). IEEE.

Moyle, W. (2014). Principles of strengths-based care and other nursing models. In W. Moyle, D. Parker, & M. Bramble (Authors), *Care of Older Adults: A Strengths-based Approach* (pp. 33-48). Cambridge: Cambridge University Press. doi:10.1017/CBO9781107257122.004

Moyle, W., Jones, C.J., Murfield, J.E., Thalib, L., Beattie, E.R., Shum, D.K., O'Dwyer, S.T., Mervin, M.C. & Draper, B.M. (2017). Use of a robotic seal as a therapeutic tool to improve dementia symptoms: a cluster-randomized controlled trial. *Journal of the American Medical Directors Association*, 18(9), pp.766-773.

Moyle, W., Jones, C., Dwan, T., Ownsworth, T., & Sung, B. (2019a). Using telepresence for social connection: views of older people with dementia, families, and health professionals from a mixed methods pilot study. *Aging & Mental Health*, 23, 1643-1650.

Moyle, W., Jones, C. & Sung, B. (2019b). Telepresence robots: Encouraging interactive communication between family carers and people with dementia. *Australasian Journal on Ageing*, 39(1), pp.e127-e133.

Neal, I., du Toit, S.H. & Lovarini, M. (2019). The use of technology to promote meaningful engagement for adults with dementia in residential aged care: a scoping review. *International Psychogeriatrics*, pp.1-23.

## Chapter Six. Discussion

- NICE (2018) Dementia assessment management and support for people living with dementia and their carers. Technical Report. <https://www.nice.org.uk/guidance/ng97/resources/>
- Øksnebjerg, L., Diaz-Ponce, A., Gove, D., Moniz-Cook, E., Mountain, G., Chattat, R. & Woods, B. (2018). Towards capturing meaningful outcomes for people with dementia in psychosocial intervention research: A pan-European consultation. *Health Expectations*, 21(6), pp.1056-1065.
- Office for National Statistics (2020) Statistical Bulletin. Deaths involving COVID-19, England and Wales: deaths occurring in May 2020. <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsinvolvingcovid19englandandwales/deathsoccurringinmay2020#pre-existing-conditions-of-people-who-died-with-covid-19>
- Paletta, L., Fellner, M., Schüssler, S., Zuschnegg, J., Steiner, J., Lerch, A., Lammer, L., & Prodromou, D. (2018). AMIGO: Towards Social Robot based Motivation for Playful Multimodal Intervention in Dementia. *Proceedings of the 11th Pervasive Technologies Related to Assistive Environments Conference*, (pp. 421-427).
- Papadopoulos, C., Hill, T., Battistuzzi, L., Castro, N., Nigath, A., Randhawa, G., Merton, L., Kanoria, S., Kamide, H., Chong, N.Y. & Hewson, D. (2020). The CARESEES study protocol: testing and evaluating culturally competent socially assistive robots among older adults residing in long term care homes through a controlled experimental trial. *Archives of Public Health*, 78(1), pp.1-10.
- Pedersen, I., Reid, S., & Aspevig, K. (2018). Developing social robots for aging populations: A literature review of recent academic sources. *Sociology Compass*, 12(6), e12585.
- Peine, A. & Neven, L. (2019). From intervention to co-constitution: new directions in theorizing about aging and technology. *The Gerontologist*, 59(1), pp.15-21.
- Peine, A. (2019). The Co-Constitution of Health Systems and Innovation: Comment on "What Health System Challenges Should Responsible Innovation in Health Address? Insights From an International Scoping Review". *International journal of health policy and management*, 8(11), p.665.
- Pu, L. H., Moyle, W., Jones, C. & Todorovic, M. (2019). The Effectiveness of Social Robots for Older Adults: A Systematic Review and Meta-Analysis of Randomized Controlled Studies. *Gerontologist*, 59, E37-E51.
- Purves, B.A., Phinney, A., Hulko, W., Puurveen, G. & Astell, A.J. (2015). Developing CIRCA-BC and exploring the role of the computer as a third participant in conversation. *American Journal of Alzheimer's Disease & Other Dementias*®, 30(1), pp.101-107.
- Rouaix, N., Retru-Chavastel, L., Rigaud, A.-S., Monnet, C., Lenoir, H. & Pino, M. (2017). Affective and Engagement Issues in the Conception and Assessment of a Robot-Assisted Psychomotor Therapy for Persons with Dementia. *Frontiers in psychology*, 8, 950.
- Sarabia, M., Young, N., Canavan, K., Edginton, T., Demiris, Y., & Vizcaychipi, M.P. (2018) Assistive robotic technology to combat social isolation in acute hospital setting. *International Journal of Social Robotics*, 10(1), 607-620.
- Sabat, S.R. (2018). *Alzheimer's Disease and Dementia: What Everyone Needs to Know*®. Oxford University Press.
- Share, P. & Pender, J. (2020) Helping tomorrow's social professionals to learn about social robotics. 6th International Conference on Higher Education Advances (HEAd'20) Universitat Politècnica de València, València. <http://dx.doi.org/10.4995/HEAd20.2020.11205>
- Share, P. & Pender, J. (2018). Preparing for a robot future? Social professions, social robotics and the challenges ahead. *Irish Journal of Applied Social Studies*, 18(1), p.4.
- Thordardottir, B., Malmgren Fänge, A., Lethin, C., Rodriguez Gatta, D. & Chiatti, C. (2019). Acceptance and use of innovative assistive technologies among people with cognitive impairment and their caregivers: a systematic review. *BioMed research international*, 2019.
- Tuyen, N.T.V., Jeong, S. & Chong, N.Y. (2018). Emotional bodily expressions for culturally competent robots through long term human-robot interaction. In *2018 IEEE/RSJ International Conference on Intelligent Robots and Systems (IROS)* (pp. 2008-2013). IEEE.
- Van Kessel, G. (2013). The ability of older people to overcome adversity: a review of the resilience concept. *Geriatric Nursing*, 34, 122-127.



## Chapter Six. Discussion

Windle, G. (2011). What is resilience? A review and concept analysis. *Reviews in clinical gerontology, 21*(2), pp.152-169.

Wu, Y. H., Cristancho-Lacroix, V., & Fassert, C. et al. (2016). The attitudes and perceptions of older adults with mild cognitive impairment toward an assistive robot. *Journal of Applied Gerontology, 35*(1), 3-17.

Zafrani, O. & Nimrod, G. (2019). Towards a holistic approach to studying human–robot interaction in later life. *The Gerontologist, 59*(1), pp.e26-e36.

Zarit, S. H., Chiusano, C., Harrison, A. S., Sewell, L., Krause, C., & Liu, Y. (2020). Rehabilitation of persons with dementia: using technology to improve participation. *Aging & Mental Health, 1*-8.

**Appendix 1) Paper One: Search Strategy.**

The initial search strategy was designed and conducted by a librarian, on behalf of the wider MARIO project, to examine only empirical studies that included people with dementia. In designing this search the population and interventions components of the PICO principle were used to form the search terms and strings in this strategy. A combination of free-text terms and appropriate controlled vocabulary from MeSH and Emtree were used to develop comprehensive search strategies for the databases. Due to inconsistencies in the use and meaning of terms and main concepts, it was decided to keep the search broad to maximise sensitivity although this will have implications for the specificity of the search. The search terms in this initial search are listed in the table below:

Table showing Search Terms used during the Initial Search.	
Population	Phenomenon of Interest
Dementia (indexed terms)	Robotics (Indexed terms)
Dementia* (free-text)	Robot* (free-text)
Alzheimer's Disease (Indexed terms)	
Alzheimer* (free-text)	

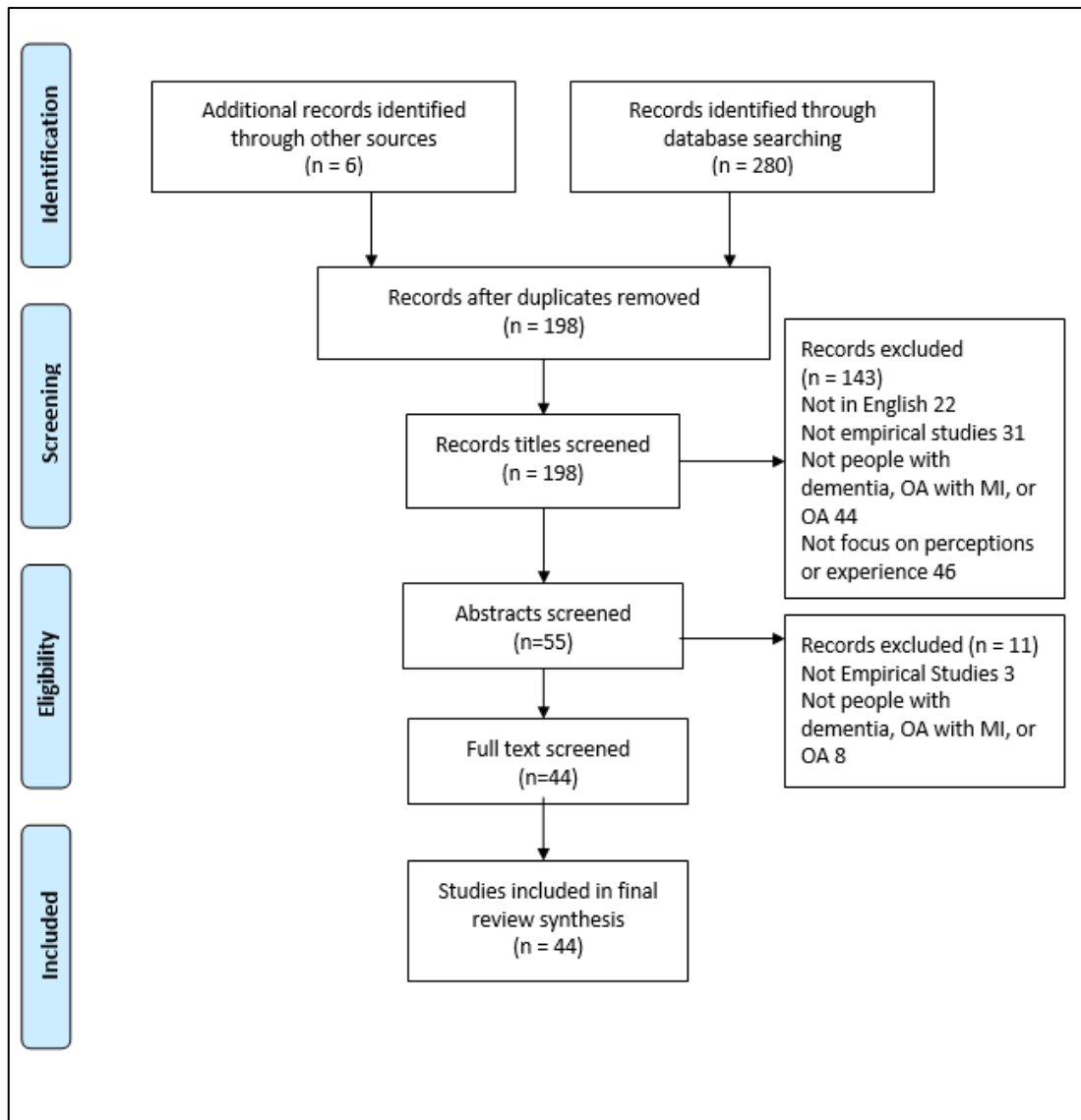
The following databases were agreed upon and searched to identify relevant studies: the Cochrane Library, PubMed, Scopus, CINAHL, EMBASE, Web of Science Core Collection, PsychINFO, and Compendex (Ei Village 2). Search strategies were structured and adapted to suit the functionality of each of the databases. Publication date limits were set from 01/01/2009 to the 17/05/2015. Field limiters were used in different databases when deemed appropriate. Search filters to identify specific study types or language were not applied. The following information was documented for each database: the name of the database and the platform by which it is delivered, the years of coverage of the database, the date the search was conducted, the limits/filters used, the number of results, and the search terms. Details of the identified documents were imported into reference management software and made available via an EndNote library.

In 2016 SW clarified the aims of the review and examined the initial search results. Examination of these results identified only a few papers that described relevant empirical studies involving people with dementia. Therefore, in consultation with the MARIO project team and guided by the keywords, citations and reference list of relevant papers SW amended the search strategy and conducted a second search. This search aimed to identify studies that involved people with dementia, older adults without dementia, and older adults with mild cognitive impairment. In the second search, the publication language was limited to English, its date limits included literature published from 2005-2016, and the indexed and free-text search terms reported in paper 1, were added to increase the search specificity. In addition, the references and citations of relevant papers were hand searched.

**Appendix 2) Paper One: Inclusion and Exclusion Criteria.**

Table showing inclusion and exclusion criteria for literature reviewed in Paper One	
Inclusion	Exclusion
Empirical studies published between 2005 and 2016 in English	Studies published before 2005.
Studies must involve people who are diagnosed with any type and severity of dementia or people with mild cognitive impairment or older adults aged over 65 who do not have dementia.	Studies involving people under 65 who do not have dementia, or mild cognitive impairment.
Studies can involve any outcomes but include a focus on the acceptability or attitude towards robots.	Studies that focus on the technical aspects of robot(s) without including the perceptions or experiences of users.
Studies must involve robots for companionship, designed to support psychosocial wellbeing.	Service robots that are designed to facilitate physical care tasks.
Studies of any design.	

**Appendix 3) Paper One: PRISMA Flow Diagram.**



**Appendix 4) Paper Two: Quality Appraisal of Studies included in the review.**



**CASP**  
Critical Appraisal  
Skills Programme

 [www.casp-uk.net](http://www.casp-uk.net)  
 [info@casp-uk.net](mailto:info@casp-uk.net)  
 Summertown Pavilion, Middle  
Way Oxford OX2 7LG

**CASP Checklist:** 10 questions to help you make sense of a **Qualitative** research

**How to use this appraisal tool:** Three broad issues need to be considered when appraising a qualitative study:

-  Are the results of the study valid? (Section A)
-  What are the results? (Section B)
-  Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.


**About:** These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

**Referencing:** we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

©CASP this work is licensed under the Creative Commons Attribution – Non-Commercial-Share A like. To view a copy of this license, visit <http://creativecommons.org/licenses/by-nc-sa/3.0/> [www.casp-uk.net](http://www.casp-uk.net)

Critical Appraisal Skills Programme (CASP) part of Oxford Centre for Triple Value Healthcare [www.casp-uk.net](http://www.casp-uk.net)



Paper for appraisal and reference: **Matchar et al**

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes

Can't Tell

No

HINT: Consider

- what was the goal of the research
- why it was thought important
- its relevance

Comments: **The study is structured nicely as a general discussion/exploration of resilience through engagement in the memory-makers group. However, there is not a clear statement of the specific aim that the research is trying to achieve. Broadly the aim is: To explore the impact on resilience of an educational support group.**

2. Is a qualitative methodology appropriate?

Yes

Can't Tell

No

HINT: Consider

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments: **Yes good for an exploratory study in which the variables of resilience in dementia are not fully established and measurable. As resilience is operationalised as a dynamic process rather than a trait.**

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes

Can't Tell

No

HINT: Consider

- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments: **It is not possible to ascertain if the research design was appropriate as very little detail of the methods for data collection are provided. And they are not justified in the research report. This includes the general reporting of general observations rather than using specific outcomes measures. Equally data collection and analysis methods are not reported.**

**CASP**  
Critical Appraisal  
Skills Programme

4. Was the recruitment strategy appropriate to the aims of the research?

Yes   
Can't Tell   
No

HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
  - If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments: No explanation of this is provided in the report. The study uses the people who attended the support group. Bias in sampling noted, as PLWD and carers were willing to participate in group and also had their own transport. And had care partners. Eligibility criteria for the group is mentioned but recruitment is not described in detail or justified.


5. Was the data collected in a way that addressed the research issue?

Yes   
Can't Tell   
No

HINT: Consider

- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
  - If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
    - If methods were modified during the study. If so, has the researcher explained how and why
  - If the form of data is clear (e.g. tape recordings, video material, notes etc.)
    - If the researcher has discussed saturation of data

Comments: The data collection strategies and their analysis are inadequately reported in these papers. They are not described and there is not data collection section in the paper.



HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

6. Has the relationship between researcher and participants been adequately considered?

Yes

Can't Tell

No

Comments: **No mention in the report of researcher, participant relationship or reflexivity.**

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes

Can't Tell

No

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments: **Details of ethical considerations and information as to approval from ethics committee are not provided.**

128



**CNSP**  
Critical Appraisal  
Skills Programme

8. Was the data analysis sufficiently rigorous?

Yes   
 Can't Tell   
 No

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
  - To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments: **Methods of data analysis are not provided.**

9. Is there a clear statement of findings?

Yes   
 Can't Tell   
 No

HINT: Consider whether

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments: **They are provided in a descriptive way. Quotations provide illustration of what the findings are derived from. Findings are discussed under headings in Matchar (2018) which could be seen as themes although this is not explicitly stated.**

Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature)
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments: Some of the findings support the developing field of resilience in dementia, but their findings can only be a spring board for further research, because so little methodology was provided. Most of the findings are descriptive and appear almost anecdotal because of this. However, their value is that they are a study of a field of research in which there are few contributions. Yes, their research can probably be generalisable to other populations which are similar to those participants described here. It involves a relatively high number of participants, as it took place over several years, with several cohorts attending the support group. But this research has methodological weaknesses and limitations. It is of value as an initial spring board for further rigorous research.

Paper for appraisal and reference: **Clarke et al (2013, 2018)**

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- what was the goal of the research
  - why it was thought important
  - its relevance

Comments: **To compare the influence of dementia adviser and peer support network services to identify ways they contribute to well-being and resilience of PLWD and care partners.**

2. Is a qualitative methodology appropriate?

Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
  - Is qualitative research the right methodology for addressing the research goal

Comments: **This study examines the experience of living with dementia and it compares the influence of actively managing dementia using two support interventions. Therefore mixed methods approach which privileged the qualitative methodology was appropriate as the goal of the research was to identify ways in which the Dementia adviser and peer support network services contribute to the well being and resilience of PLWD and their care partners. This approach was also compatible with the social constructivist paradigm that guided the study.**


Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments: **Justified the choice of design, to capture a wide range of activities in DA and PSN, to combine the strengths and reduce the limitations of qualitative and quantitative data, and to broaden and deepen the scope of the inquiry and provide supporting evidence, with ratification of emerging ideas.**



HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

4. Was the recruitment strategy appropriate to the aims of the research?

Yes

Can't Tell

No

HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments: **Used a sampling matrix to identify and recruit a range of service users and stakeholders in each site.**

5. Was the data collected in a way that addressed the research issue?

Yes

Can't Tell

No

HINT: Consider

- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
  - If the researcher has discussed saturation of data

Comments: **Clear descriptions supplied with some justification of choices made provided.**

6. Has the relationship between researcher and participants been adequately considered?

Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments: Clarke (2013) discusses the position of the researchers and how this impacts the research and this view is consistent with the research which is guided by the social constructivist research paradigm.

Section B: What are the results?

7. Have ethical issues been taken into consideration?


Yes	<input checked="" type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments: Yes to all these points: there were sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained

- issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study) were discussed
- approval was sought from the ethics committee. In addition, researchers completed training on the Mental Capacity Act



8. Was the data analysis sufficiently rigorous?

Yes

Can't Tell

No

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
  - To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

**Comments:** Yes used NVIVO, for interview data, and coded using descriptive content analysis, initial coding framework then refined until saturation. Survey data into SPSS. Findings integrated, using meta-analysis? p96 this was the termed used to incorporate all the data including qualitative interview data. Precise details as to how this was done are not provided, ? narrative synthesis is used.

9. Is there a clear statement of findings?

Yes

Can't Tell

No

HINT: Consider whether

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

**Comments:** Discussed in relation to original research questions. yes credibility discussed, using PPI to develop research tools, and using interview quotes. Also checked the constructions generated against participants' meanings, used their actual words, and the researchers' personal views were explored. Also discussed auditability.


Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature)
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments: Extensive discussion of results and recommendations of them for policy, practice and future research. The research was valuable due to its national focus and relatively large size, evaluating 40 demonstration sites, and yet it used multiple methods including those that captured the voice and opinions of individuals. This provided depth and breadth in the investigation. Yes identified that the data in this research could be reexamined with public health frame of analysis, and to examine longitudinal impact of the services and to examine them in the future as the demonstration sites continue to evolve.



Paper for appraisal and reference: **Newman et al 2018**

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes

Can't Tell

No

HINT: Consider

- what was the goal of the research
- why it was thought important
- its relevance

Comments: **To evaluate the impact of visual arts enrichment activities on opportunities for resilience. Clearly stated in the abstract of the paper and implied during the paper.**

2. Is a qualitative methodology appropriate?

Yes

Can't Tell

No

HINT: Consider

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments: **Newman et al (2018) states a mixed methods design, which was primarily qualitative, was used as per the protocol Windle et al 2016. However, only qualitative methodologies were collected and analysed to investigate the impact on resilience as described in (2018). This was appropriate to the aim of examining the impact of visual arts enrichments activity on opportunities for resilience within the social-cultural context of the nursing home. And it is noteworthy that this analysis was conducted on the data, after it had been collected for the wider mixed methods project.**

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes

Can't Tell

No

HINT: Consider

- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments: **Yes it was appropriate. As per Windle et al 2016 protocol and the design described in Newman et al 2018. This design, facilitated capture of data and its interpretation during this process and outcome based evaluation.**



**CNSP**  
Critical Appraisal Skills Programme

4. Was the recruitment strategy appropriate to the aims of the research?

Yes

Can't Tell

No

HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
  - If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments: Inclusion and exclusion criteria described in Newman (2018). Full and appropriate recruitment strategy supplied in Windle et al (2016) as per protocol of Dementia and Imagination project. However, it is not clear on what basis the sub-set of participants were selected for interview during the three months follow up after the intervention.

5. Was the data collected in a way that addressed the research issue?

Yes


Can't Tell

No

HINT: Consider

- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
  - If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
  - If methods were modified during the study. If so, has the researcher explained how and why
  - If the form of data is clear (e.g. tape recordings, video material, notes etc.)
    - If the researcher has discussed saturation of data

Comments: Some of the description of data collection methods doesn't contain details in the Newman (2018) paper. i.e. the structured detail of the artist's notes is not provided. However, these details are provided in the companion protocol paper, Windle (2016). The interview schedule is well described, however, details of the structured questions are not provided in Newman but they are included in detail in Windle (2016).



6. Has the relationship between researcher and participants been adequately considered?

Yes

Can't Tell

No

**HINT:** Consider

- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

**Comments:** Reflexivity and the position of the researcher was not discussed in Newman et al (2018) or the Windle et al (2016) paper. In addition, the role of the researcher and the potential for bias not discussed.

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes

Can't Tell

No

**HINT:** Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

**Comments:** Yes ethics committee approval sought; protocols developed; researchers trained and informed consent considered in Newman (2018). The participant's dementia was taken into consideration whilst obtaining consent and details of this procedure are given in Windle (2016).

138

**CNSP**  
Critical Appraisal  
Skills Programme

8. Was the data analysis sufficiently rigorous?

Yes   
Can't Tell   
No

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
  - To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments: Newman et al (2018) described how transcripts were coded in NVIVO and this involved multiple readings. And precise and rigorous methods of analysis are described in Windle (2016).

9. Is there a clear statement of findings?

Yes   
Can't Tell   
No

HINT: Consider whether

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments: It is difficult to ascertain the precise detailed findings of the research from the findings section in Newman (2018) due to its structure. Some points the findings are presented amongst new material and discussion. There are also not very many quotations from participants supplied. The findings section could have benefited from a thematic map or summary table listing key findings. However, the findings that are discussed are very interesting, and useful.

Section C: Will the results help locally?

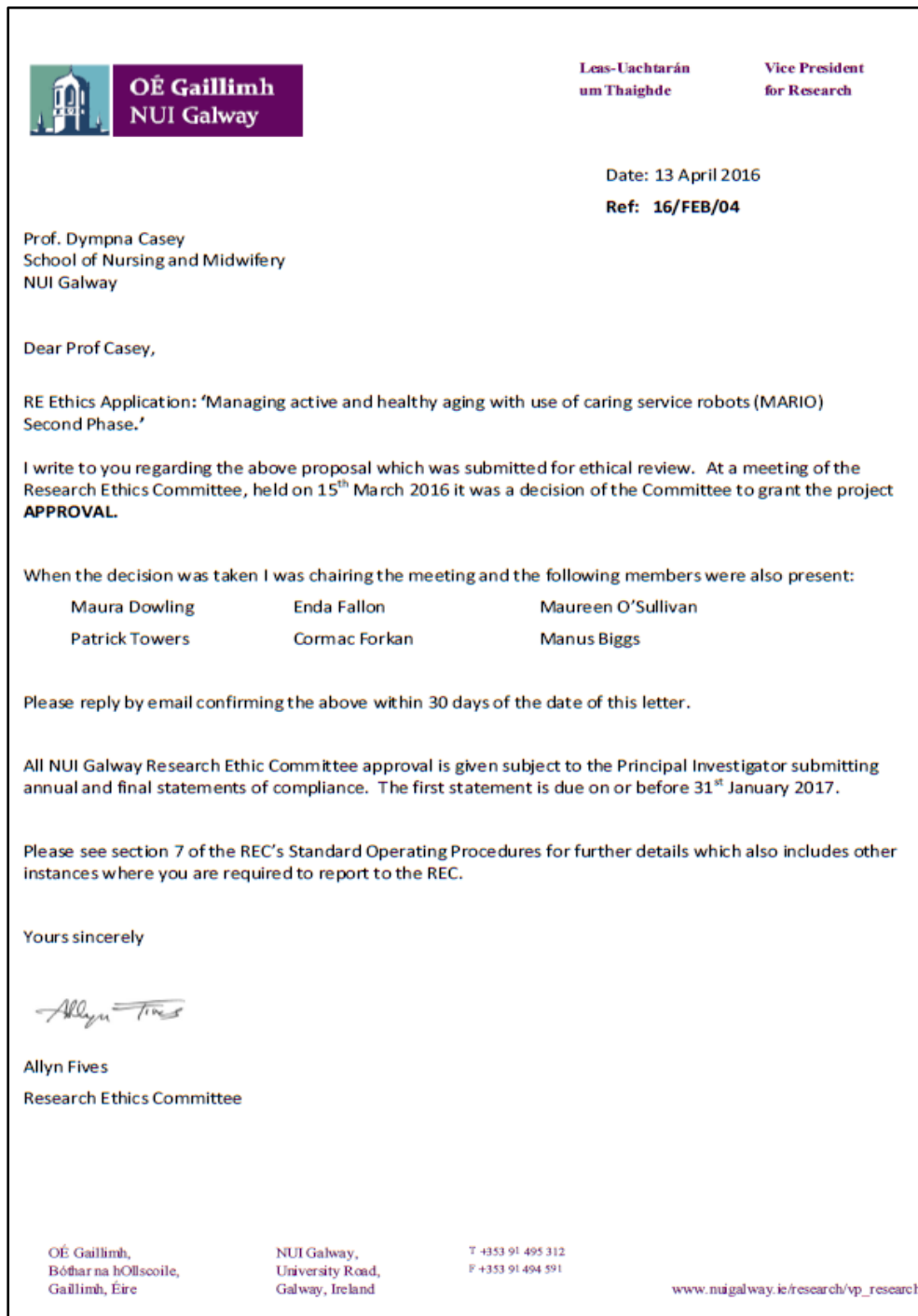
10. How valuable is the research?

HINT: Consider


- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature)
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments: My interpretation is that this study is valuable as a starting point to provide a context for developing resilience in people with dementia in care homes. This is because it is the only study found during this review that investigates resilience to date in a nursing home context, with people who have moderate and severe dementia. It is a relatively large qualitative study involving (n=48) people. It is noteworthy that Newman et al (2018) is a paper that introduces many complex ideas which could benefit further discussion within this context and sample.


**Appendix 5) Paper Four: Copy of the letter granting ethical approval for the empirical study as part of the wider MARIO project.**



Appendix 6) Paper Four: Ethical Distress Protocol.



O'É Gaillimh  
NUI Galway



## MARIO: Ethical Distress Protocol

This procedural protocol is to ensure that the wellbeing and rights of the person with dementia are protected. The steps outlined below are for participants' benefit in the event that they become distressed while MARIO is present or while data collection is being undertaken.

**Dealing with distress.**


In the event that the person with dementia demonstrates signs of distress at any time either when MARIO is present or during data collection, including: restlessness, agitation, repetitive questioning, crying, data collection will be stopped and/or MARIO will be removed from the persons environment. The researcher will try to ascertain the cause of distress and help the person with dementia to alleviate the source of distress if possible. The researcher will check with the person with dementia whether they wish to continue or not and will seek the advice of the health care professional caring for that person and/or inform them of the person with dementia's decision. If the person wishes to continue and the health care professional deems it is safe to do so, the researcher will resume data collection and/or MARIO will be returned. The researcher will continue to be vigilant about distress. If the person continues to show signs of distress, the researcher will terminate data collection and or MARIO will be removed. The researcher will inform the relevant health care professional and will remain on site until the persons becomes calm again.

In the event the person does not wish to continue, data collection will be terminated and MARIO will be permanently removed. The researcher will, with the participant's consent: Ask if it is ok to call later in the day or the next day to return to visit them to make sure they are ok.


The researcher will report the distress to the health care professional and discuss what needs to be put in place to support the person with dementia, s/he will also inform the PI and the Ethics Advisory and Privacy Board.

End

**Appendix 7) Paper Four: Participant Information Sheets, Invitations to Participate and Consent Forms People with Dementia.**



OÉ Gaillimh  
NUI Galway



MARIO

**MARIO: Letter of invitation to participate:  
Information sheet for People with Memory Problems**

**Managing active and healthy aging with use of caring service robots**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. This participant information sheet will tell you about the purpose, risks, and benefits of this study. If you agree to take part, we will ask you to sign a consent form. If there is anything you are not clear about, we will be happy to explain it to you. Please take as much time as you need to read it. You should only consent to participate in this research study when you feel that you understand what is being asked of you, and you have had enough time to think about your decision. Thank you for reading this.

**Who is doing the research?**

This research is being led by a team of researchers from the School of Nursing & Midwifery at the National University of Ireland, Galway. We are all qualified nurses and now work as lecturers in the School of Nursing & Midwifery at the National University of Ireland, Galway. Our jobs involve educating student nurses and qualified nurses. Our research interest is in dementia and older people and we have been involved in several major national studies on dementia over the past few years.

**Purpose of the study**

The overall aim of this study is to develop robot companions to help build resilience, reduce isolation, and loneliness in older people with dementia.

It is a three year study that involves four other countries: Italy, UK, Greece, and Germany.

The first phase of the study involved talking to Carers and persons with dementia to find out how they felt about robot companions, what they would like such a robot to do for them, and how robots could be designed to build their resilience. We took that information and used it to further develop the MARIO robot so that it will provide better companionship to people with memory problems or have dementia.

For the second phase of the study, we brought the robot here to the residential care unit to talk with residents and to provide companionship.

For this, the third phase of the study, the MARIO robot is being evaluated in relation to acceptability, feasibility, and the impact of the robot on resilience and quality of life.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, without giving a reason. Withdrawing or deciding not to take part, will not affect your rights or the care that you receive in any way.

**What will my participation entail?**

If you are willing to participate we will invite you to a brief information/training session on MARIO which will be held in the residential care unit, to explain and show you how he moves and what he can and cannot do. When you have seen MARIO and are familiar with how the robot works, we will confirm with you whether or not you are still happy to be involved in the study.



If you choose to continue to participate we will ask you to provide the researcher with information about your hobbies/interest, important dates, some personal memories, so that MARIO will be able to make conversation with you about these topics. For example, MARIO's 'Calendar' will be able to store dates and remind you about things like birthdays. Also, to best facilitate reminiscence and recall and talk about happy personal events or experiences, we would ask you and your relatives to provide us with relevant personal/family photographs. We will copy these and upload them onto MARIO. Providing this information about yourself and these photographs is voluntary, and the information will be stored securely on MARIO in a way that cannot identify you and will only be accessed and used with you.

We will ask you to interact with MARIO for periods of time over the next 12 weeks, for example, to talk to MARIO, play some music and games. For example, reading the news, reminiscing, and chatting to your friends and family using MARIO. The researchers will observe how MARIO is interacting with you and find out from you what it is like to have MARIO as a companion.

We want to find out how beneficial using MARIO is for you. So, before you start using MARIO and after you have used him several times, if you choose to participate in this research, we would like to interview you and ask you questions about your life.

**Will people know exactly what I said to you?**

The interviews will be recorded so that we can capture exactly what you say during the interview. We will use a code name or pseudonym to protect your anonymity and this code will be used to label any information that you provide to us. Only the lead researcher and the project manager will have access to a list which connects your codename or pseudonym to your name. This list will be kept in a secure and locked file in the project manager's office. Your anonymity and confidentiality will, therefore, be safeguarded, and in no way will you be identifiable in this research.

**Will MARIO be video recording me so that other people will be able to recognise and see me?**

No MARIO will not be video recording you in a way that allows others to see and recognise you. MARIO has two video cameras. The first camera, which will be attached to the front of the robot, is to allow a researcher to navigate the robot from a different room, by viewing what appears on the camera. This camera will allow the researcher to get a view of the general environment around you. Video images or pictures taken with the camera will not be saved or stored on this camera or on the robot.

The second camera will be used to control MARIO's motion behaviour. It will ensure that MARIO can navigate around the nursing home without bumping into people or objects. Only skeletal and point information will be recorded, no images or videos of the environment will be stored. This camera will also record 6-8 seconds of video to form a local database in the MARIO computer for facial recognition to allow MARIO to identify and approach you. These data images will be password protected and stored on the robot. This data will only be accessible by the researcher operating MARIO and will not be shared.

Also, when you are attending to any personal hygiene matters, for example, toileting or bathing, MARIO will not follow you, interact, or approach you at that time.

**Will MARIO record the conversations I have with my grandchildren and relatives who visit me?**

We will place information posters around the nursing home to alert visitors that MARIO is present. We will seek consent from all adult visitors to being audio recorded by MARIO.





If consent is not granted then the speech recognition module on MARIO will be switched off so the robot will act as if the microphone is unplugged and will not record.

**How do I take part?**

If you wish to take part you should sign the consent form.

**What are the benefits of taking part?**

Taking part in this study will provide valuable information and knowledge that will help us to ensure that the robots we develop best meet the needs and priorities of people who have memory problems or dementia.

**What are the possible disadvantages of taking part?**

You might find it tiring at times to have MARIO present. If this happens you can either tell MARIO to leave or tell the researcher or person caring for you that you would like MARIO to leave.

**What happens at the end of the study?**

Your interviews will be transcribed i.e. typed to ensure an accurate representation of what you say is achieved. The interviews will be coded to ensure your anonymity and then analysed and a report of what we find will be created. These findings may also be published at conferences and in health care/technological journals. Your name will not be included within any of these publications and reporting will be in a global fashion, with no individuals identified. Your anonymity and confidentiality will, therefore, be safeguarded.

**What happens if I change my mind during the study?**

If at any time you wish to withdraw your participation from this study you may do so without any consequence to you.

**What if I have a complaint during my participation in the study?**

If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact the chairperson of the NUI Galway Research Ethics Committee, C/O Office of the Vice President for research, NUI Galway, or email them at [ethics@nuigalway.ie](mailto:ethics@nuigalway.ie) Many thanks for taking the time to read this. If you have further concerns please Aileen Connolly at: 091 495938/ Email: AILEEN.A.CONNOLLY@nuigalway.ie

Yours Sincerely

Dympna Casey



## MARIO: Consent Form for People with Memory Problems

**Title of project: Managing active and healthy aging with use of caring service robots (MARIO)**

Participant identification number:

**Please read the following statements and tick the relevant box, then sign your name at the bottom if you agree to take part in this study.**

- Have you read or has your Carer read to you the information sheet for the MARIO study?
- Do you understand what the study is about?
- Do you understand that you do not have to participate if you do not want to?
- Do you understand that you are free to withdraw at any time without any harm to you or your Carer?
- Do you understand that some personal information will be stored on MARIO for the duration of your interaction with MARIO, so that MARIO can communicate with you about your interests, memories, and upcoming important dates?
- Do you understand that MARIO will collect video images of your environment and of your face so that the robot knows who you are and that this data will be safely stored on the robot and will not be shared?
- Do you understand that all data that you or your relative provides for use on MARIO will be stored securely on MARIO?



· I wish to participate in the MARIO study?

**Name of Participant:**

**Date:**

**Signature:**

**Appendix 8) Paper Four: Information Sheet and Consent Form for Formal Caregivers.**

	
<b>MARIO: Information Sheet and Consent form for Formal Caregivers</b>	
<p><b>Managing active and healthy aging with use of caring service robots (MARIO)</b> You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. This participant information sheet will tell you about the purpose, risks, and benefits of this study. If you agree to take part, we will ask you to sign a consent form. If there is anything you are not clear about, we will be happy to explain it to you. Please take as much time as you need to read this information sheet. You should only consent to participate in this research study when you feel that you understand what is being asked of you, and you have had enough time to think about your decision. Thank you for reading this.</p>	
<p><b>Who is doing the research?</b> This research is being led by a team of researchers from the School of Nursing &amp; Midwifery at the National University of Ireland, Galway. We are all qualified nurses and now work as lecturers in the School of Nursing &amp; Midwifery at the National University of Ireland, Galway. Our jobs involve educating student nurses and qualified nurses. Our research interest is in the area of dementia and older people and we have been involved in several major national studies on dementia over the past few years.</p>	
<p><b>Purpose of the study</b> The overall aim of this study is to develop robot companions to help build resilience, reduce isolation, and loneliness in older people with dementia. It is a three year study that involves four other countries; Italy, UK, Greece, and Germany. The first phase of the study involved talking to Carers and persons with dementia to find out how they felt about robot companions, what they would like such a robot to do for them, and how robots could be designed to build their resilience. For the second phase of the study, we brought 2 robots to the residential care setting for several reiterations over a 12 month period to modify and develop the robot based on the feedback from people with dementia, carers, and relatives. In this third phase of the study, the MARIO robot is being evaluated in relation to its acceptability, feasibility, and its impact on the quality of life, and its effect on resilience. You have been asked to participate as you are a Carer looking after someone with dementia or memory loss who lives in residential care and who has agreed to work with the MARIO robot over the next few weeks.</p>	
<p><b>Do I have to take part?</b> It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your rights in any way.</p>	
<p><b>How do I take part?</b> If you wish to take part you should return the consent form enclosed by posting it in the stamped addressed envelope provided or you can give it to one of the research team. We have asked for your contact telephone number on the consent form so that we can phone you to arrange an interview at a time and place convenient for you.</p>	



**How long will my part in the study last?**

You will be asked to attend a maximum of three interviews, each lasting approximately 30 minutes.

**What will my participation entail?**

If you are willing to participate we will invite you to a brief information/training session on MARIO which will be held in the residential care unit, to explain and show you how the robot moves and what it can and cannot do. This is to help you become familiar with MARIO. If you choose to continue to participate we will interview you over the next 4-6 weeks at a location and time suitable for you. In the interviews you will be asked about your experience of working and interacting with MARIO and having the robot present in the residential setting; how you felt about MARIO as a robot companion, what you liked or disliked about him, what helped or hindered your ability to work with MARIO; what would make it easier for you to accept MARIO in your working environment; what improvements would you suggest could be made to MARIO to build the person with dementia's resilience i.e. their ability to cope well with dementia.

**Will people know exactly what I said to you?**

The interviews will be recorded so that we can capture exactly what you say during the interview. We will use a code name or pseudonym to protect your anonymity and this code will be used to label any data that you provide to us. Only the lead researcher and the project manager will have access to a list that connects your codename or pseudonym to your name. This list will be kept in a secure and locked file in the project manager's office. Your anonymity and confidentiality will, therefore, be safeguarded, and in no way will you be identifiable in this research.

**What are the benefits of taking part?**

Taking part in this study will provide valuable information and knowledge that will help us to ensure that the robots we develop best meet the needs and priorities of persons with dementia/memory loss.

**What happens at the end of the study?**

Your interviews will be transcribed i.e. typed to ensure an accurate representation of what you say is achieved. The interviews will be coded to ensure your anonymity and then analyzed and a report of what we find will be created. These findings may also be published at conferences and in health care/technological journals. Your name will not be included within any of these publications and reporting will be in a global fashion, with no individuals identified. Your anonymity and confidentiality will, therefore, be safeguarded.

**What happens if I change my mind during the study?**

If at any time you wish to withdraw your participation from this study you may do so without any consequence to you. If this is following the interview any information you have provided will be destroyed and will not be included.

**What if I have a complaint during my participation in the study?** If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact the chairperson of the NUI Galway Research Ethics Committee, C/O Office of the Vice President for research, NUI Galway, or email them at [ethics@nuigalway.ie](mailto:ethics@nuigalway.ie) Many thanks for taking the time to read this. If you have further concerns please Aileen Connolly at: 091 495938/ Email: [AILEEN.A.CONNOLLY@nuigalway.ie](mailto:AILEEN.A.CONNOLLY@nuigalway.ie)

Yours Sincerely  
Dympna Casey



## MARIO: Consent Form for Formal Caregivers

**Title of project: Managing active and healthy aging with use of caring service robots (MARIO)**

**Participant identification number:**

Please read the following statements and sign at the bottom if you agree to take part in this study.

- I confirm that I have read the information sheet for the above study and have had an opportunity to ask questions.
- I am satisfied that I understand the information provided and have had enough time to consider the information.
- I understand that my participation is voluntary and that I am free to withdraw at any time.

agree to take part in the above study


**Name of Participant:**

**Contact Telephone Number:**


**Date:**

**Signature:**

**Appendix 9) Paper Four: Invitation Letter, Information Sheet and Consent Form for Relatives of People with Dementia.**



OÉ Gaillimh  
NUI Galway



## MARIO: Letter for Relatives of People with Dementia

School of Nursing and Midwifery  
National University of Ireland, Galway

Dear Family Member,

We want to tell you about a research study which aims to improve the quality of life of older people with memory problems. Your relative will be invited to take part in the study so we wish to inform you about the details of the study and their participation. This involves developing robot companions for people with memory problems to reduce isolation and loneliness and improve the ability of people with memory problems to live well. Attached to this letter you will find a 1) Relative information Sheet and 2) Participant consent form (which your loved one would sign). Please read the relative information sheet which will give you more detailed information about the study. It also explains what your relative's participation would involve. A member from the research project at NUI Galway will explain the study in-person to your relative. Once they understand the study, and if they wish to be involved, their consent will then be obtained by signing the consent form, attached. It is important to highlight that it is completely up to your relative to decide if they want to participate. If they do agree to participate, they will be free to withdraw at any time. All information associated with your relative during the study will be protected and encrypted for data protection purposes. This study has been approved by the Research Ethics Committees of NUI Galway. If you have any queries or wish to discuss any part of the information, please contact

Aisling Dolan Tel: +35391495938/email: AISLING.DOLAN@nuigalway.ie.

Yours Sincerely

Dympna Casey



## MARIO: Information Sheet for Resident's Relatives

### **Managing active and healthy aging with use of caring service robots (MARIO)**

Your relative is being invited to take part in the research study. Before we approach them about participation in the study, it is important for you to understand why the research is being done and what it will involve. This relative information sheet will tell you about the purpose, risks, and benefits of this study. If your relative agrees to take part, we will ask them to sign a consent form. If there is anything you are not clear about, we will be happy to explain it to you. Please take as much time as you need to read it. Thank you for reading this.

#### **Who is doing the research?**

This research is being led by a team of researchers from the School of Nursing & Midwifery at the National University of Ireland, Galway. We are all qualified nurses and now work as lecturers in the School of Nursing & Midwifery at the National University of Ireland, Galway. Our jobs involve educating student nurses and qualified nurses. Our research interest is in dementia and older people and we have been involved in several major national studies on dementia over the past few years.

#### **Purpose of the study**

The National University of Ireland, Galway is being funded by the European Commission to undertake an important study to develop robot companions to help build resilience, reduce isolation and loneliness in older people with dementia or memory problems. It is a three-year study with numerous phases, and it involves four other countries: Italy, UK, Greece, and Germany. The first phase of the study involved talking to Carers and persons with dementia to find out how they felt about robot companions, what they would like such a robot to do for them, and how robots could be designed to build their resilience. We took that information and used it to further develop the MARIO robot so that it will provide better companionship to people with memory problems/dementia. For the second phase of the study, we brought the robot here to the residential care setting to talk with residents and provide companionships. During this phase, we continued to modify and develop the robot based on the feedback from people with dementia and carers. For this, the third phase of the study, the MARIO robot is being evaluated in relation to acceptability, feasibility, and the impact of the robot on resilience and quality of life.

#### **Will my relative have to take part?**

It is up to your relative to decide whether or not they wish to take part. If s/he decides to the part they will be given an information sheet to keep, asked to sign a consent form, and return it to a member of the research team. If your relative decides to take part they are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect their service provision rights or any of their care in any way.

#### **What will my relatives' participation entail?**

If your relative is willing to participate we will invite them to a brief information/training session on MARIO which will be held in the residential care unit. This is to explain and show your relative how MARIO moves and what the robot can and cannot do. This will help your relative become familiar with MARIO. We will also introduce MARIO to your relative with their carers giving them a live demonstration of MARIO and go over his capabilities again. Once your relative is happy that they understand MARIO and the research study and comfortable we will then give them the opportunity to interact with MARIO. We will ask your relative to interact with MARIO during this study, for example, to talk to MARIO, play some music, fun games and use other



OÉ Gaillimh  
NUI Galway



applications that are available on MARIO such as reading local and national news, chatting to friends and family, and reminiscing. In this way, the robot can become a companion to your relative. From time to time we will observe how MARIO is interacting with your relative and find out from them what it is like to have MARIO as a companion, how acceptable it is to them, what is going well, what is not and what needs improvement, etc.

**What do you need from me?**

If you are happy for your relative to participate there are two specific things, we would request of you: First, please sign and return the attached consent form. Second, the reminiscence application on MARIO works best if it contains personalized information about your relative such as personal and family photographs. This will facilitate the occurrence of more meaningful conversations between MARIO and your relative. Therefore, if you can provide us with relevant photographs, we will copy them and upload them onto MARIO. These photographs, we will copy and upload them onto MARIO. The photographs will be stored securely on MARIO and will only be accessed and used with your relative.

**Will MARIO be video recording my relative so that others will be able to recognize and see them?**

No, MARIO will not be video recording your relative in a way that allows others to see and recognize them. MARIO has two video cameras. The first camera, which will be attached to the front of the robot is to allow a researcher to navigate the robot from a different room, by viewing what appears on the camera. This camera will allow the researcher to get a view of the general environment around the person only. Video images or pictures taken with this camera will not be saved or stored on this camera or the robot. The second camera will be used to control MARIO's motion behavior. It will ensure that MARIO can navigate around the nursing home without bumping into people or objects. Only skeletal and point information will be recorded, no images or videos of the environment will be stored. This camera will also record 6-8 seconds of video to form a local database in the MARIO computer for facial recognition to allow MARIO to identify and approach your relative. These data images will be password protected and stored locally on the robot. This data will only be accessible by the researcher operating the MARIO robot and will not be shared. Also, when your relative is attending to any personal hygiene matters, for example, toileting or bathing, MARIO will not follow them, interact, or approach them at that time. Will MARIO record the conversations my relative has with their grandchildren and their visitors? We will place information posters around the nursing homes to alert visitors that MARIO is present. We will seek consent from all adult visitors to being audio recorded by MARIO. If young children under 18 visit your relative while MARIO is present, consent will be sought from their respective guardian to record their presence and any interaction with MARIO. If consent is not granted, then the speech recognition module will be switched off so the robot will act as if the microphone is unplugged and will not record.

**How can my relative take part?**

If your relative wishes to take part they should sign and return the consent form to a member of staff.

**What are the benefits of taking part?**

Taking part in this study will provide valuable information and knowledge that will help us to ensure that the robots we develop best meets the needs and priorities of people with memory problems.

**What are the possible disadvantages of taking part?**

Your relative might find it tiring at times to have MARIO present. If this happens, they can either tell MARIO to leave or tell the person caring for them that they would like MARIO to leave.





**What we guarantee you**

All data will be stored securely. In addition, all electronic data stored on computers will be encrypted and password protected. Your relative will not be personally identifiable in this research.

**What happens at the end of the study?**

At the end of the study, all the data will be analysed and written up into a report. These findings may also be published at conferences and in healthcare/technological journals. Your relative's name will not be included within any report or publications and reporting will be in a global fashion, with no individuals identified. Your relative's anonymity and confidentiality will, therefore, be safeguarded.

**What happens if my relative changes their mind during the study?**

If at any time your relative wishes to withdraw participation from this study, they may do so without any consequence to them, whatsoever. If this is following the interview any information they have provided will be destroyed and will not be included.

**What if I have a complaint during my relative's participation in the study?**

If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact the chairperson of the NUI Galway Research Ethics Committee, C/o Office of the Vice President for research, NUI Galway or email them at [ethics@nuigalway.ie](mailto:ethics@nuigalway.ie) Many thanks for taking the time to read this.

IF you have further concerns please contact Aisling Dolan at Tel +35391495938/email: [AISLING.DOLAN@nuigalway.ie](mailto:AISLING.DOLAN@nuigalway.ie)

Yours sincerely,

Dympna Casey.



## MARIO: Resident's Relatives Invitation to Participate

### Managing active and healthy aging with use of caring service robots (MARIO)

You have been asked to participate in the study as you are a Relative of a person with dementia or memory loss who has agreed to work with the MARIO robot over the next few weeks.

#### Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep, asked to sign a consent form, and return it in the stamped addressed envelope provided. If you decide to take part, you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your rights in any way.

#### How do I take part?

If you wish to take part, you should return the consent form enclosed by posting it in the stamped addressed envelope provided. We have asked for your contact telephone number on the consent form so that we can phone you to arrange an interview at a time and place convenient for you.

#### How long will my part in the study last?

You will be asked to participate in one interview that may last up to 30 minutes.

#### What will my participation entail?

If you are willing to participate we will invite you to a brief information/training session on MARIO which will be held in the residential care unit, to explain and show you how he moves and what he can and cannot do. This is to help you become familiar with MARIO. If you choose to continue to participate, we will interview you over the next 4-5 weeks at a location and time suitable for you. In the interviews you will be asked about your experience of MARIO and having him present in the residential setting; how you felt about MARIO as a robot companions, what you liked or disliked about him, what helped or hindered your ability to work with MARIO; what would make it easier for you to accept MARIO; what improvements would you suggest could be made to MARIO to build the person with dementia's resilience i.e. their ability to cope well with dementia. The interviews will be recorded and will be confidential.

#### Will people know exactly what I said to you?

The interviews will be recorded so that we can capture exactly what you say during the interview. We will use a code name or pseudonym to protect your anonymity and this code will be used to label any data that you provide to us. Only the lead researcher and the project manager will have access to a list that connects your codename or pseudonym to your name. This list will be kept in a secure and locked file in the project manager's office. Your anonymity and confidentiality will, therefore, be safeguarded, and in no way will you be identifiable in this research.

#### What are the benefits of taking part?

Taking part in this study will provide valuable information and knowledge that will help us to ensure that the robots we develop best meet the needs and priorities of persons with dementia/memory loss.

#### What happens at the end of the study?

Your interviews will be transcribed i.e. typed to ensure an accurate representation of what you say is achieved. The interviews will be coded to ensure your anonymity and then analyzed and a report of what we find will be created. These findings may also be published at conferences and in health care/technological journals. Your name will not be included within any of these publications and reporting will be in a global fashion, with no individuals identified. Your anonymity and confidentiality will, therefore, be safeguarded.



**What happens if I change my mind during the study?**

If at any time you wish to withdraw your participation from this study, you may do so without any consequence to you. If this is following the interview any information you have provided will be destroyed and will not be included.

**What if I have a complaint during my participation in the study?**

If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact the chairperson of the NUI Galway Research Ethics Committee, C/O Office of the Vice President for research, NUI Galway, or email them at [ethics@nuigalway.ie](mailto:ethics@nuigalway.ie) Many thanks for taking the time to read this. If you have further concerns, please Aileen Connolly at 091 495938/ Email: [AILEEN.A.CONNOLLY@nuigalway.ie](mailto:AILEEN.A.CONNOLLY@nuigalway.ie)

Yours Sincerely

Dympna Casey

---



## MARIO: Consent Form for Relatives of People with Dementia

### MARIO: Consent for Relative Participants

**Title of Research Project: Managing active and healthy aging with use of caring service robots (MARIO)**

Name of Researcher:

Participant identification number:

Please read the following statements and sign at the bottom if you agree to take part in this study.

- I confirm that I have read the information sheet for the above study and have had an opportunity to ask questions.
- I am satisfied that I understand the information provided and have had enough time to consider the information.
- I understand that my relative's participation and my participation in the study is voluntary and that my relative and I am free to withdraw at any time.
- I understand that any personal family photographs that I provide will be stored securely on MARIO and will only be accessed to be used with my relative.

I agree to take part in the above study

Signature:

Name of Participant:

Contact Telephone Number:

Date:

**Appendix 10) Paper Four: Interview Guides for People with Dementia Pre and Post MARIO.**



## **MARIO: Interview Guide for People with Dementia (Pre MARIO)**

- Request an interview with residents at a time of day which according to information from themselves or their carers they are likely to find convenient and not be tired.
- Introduce self and ask permission to talk with resident and permission to sit down.
- Explain that you would like to ask them some questions.
- Work with resident to develop rapport and ensure they are comfortable and have their glasses/hearing aid clean and present in order to aid their communication and participation. Try to minimize any other visual/aural distractions (e.g turn off TV/Radio).
- Remind resident about the MARIO project and re-establish ongoing consent for participation in the research project.
- Explain that you would like to record what they say in answer to the questions and seek permission for this.
- Continue when consent for the interview has been verbally agreed
- Turn on audio-recorder.
- Throughout the interview try to maintain rapport with the resident so they are relaxed and their participation is maximized. This will include using relaxed encouraging nonverbal communication, mirroring the language which they use, verbalizing questions clearly and allowing time for the residents to think and answer. Use communication and motivational interviewing skills including reflective active listening, paraphrasing, summarizing, seeking clarification and requesting elaboration.
- Listen and respond to residents as they relate stories and then gently re-orientate them to the interview topic if needed.

The questions below are a rough guide to the interview content. They can be adapted as necessary, aiming to gently elicit the information using a relaxed conversational style, appropriate to the individual person with dementia.



### Interview Questions

1. I would like to ask you if you have heard of people being resilient and having resilience? Yes/No – (Check understanding)

(If needed explain that) having resilience is about being able to bounce back and be able to keep in good spirits despite having difficulties in life, such as having problems with memory. So, if someone is resilient they are able to keep up their good spirits and adapt so they can manage to live even though they have difficulties in life.

2. So, I would like to ask you if you feel you are resilient? And In what way do you think you are/are not resilient?
3. I would like to know what helps you feel resilient and helps you cope with your life here, for instance:
  - a. Some people tell us that having good relationships with other people can help them cope with memory problems. How do you think that might affect your resilience? Can you tell me a bit more about that?
  - b. Some people say that having good social interactions with other people are important for helping them cope with memory problems. What do you think about that for yourself? Would that be true for you? Can you tell me a more about that?
  - c. Some people say that feeling good about yourself and having a positive attitude are important to help cope with memory problems. How do you think that might be for you? Can you tell me more about that?
4. What about a sense of purpose or being able to be productive? Can you tell me if you think this might help you keep your spirits up and feel good? Can you tell me a bit more about that?
5. Do you think that being independent is important for you to feel resilient? How do you think being independent is important to you in your life here? Can you tell me a bit more about that?
6. What about being able to say and do what you want to when you want to – like having choices? – Would this be important to you in your life here?
7. What do you think about the need to have a fighting spirit? Is that important to help you cope with your memory problem? In what way would it be important to you now?



OÉ Gaillimh  
NUI Galway



8. What about a sense of humour, or an ability to have fun? Is this important in helping you cope with life here? Can you tell me a bit more about that?
9. Is there anything I have not asked you about that you think would be important to help you cope with your life living here in the nursing home?

*Thank the participant very much for talking about their lives and what is important to them. Tell them that their information has been really helpful to the research project.  
(Turn off audio-recorder)*



## **MARIO: People with Memory Problems Interview Guide (Post MARIO)**

### **Aim of the Interview with People with Dementia**

This interview guide aims to capture information concerning the people with dementias' perception of the impact of Mario on quality of life related issues, including loneliness and isolation.

### **Procedure for these qualitative interviews:**

- Request an interview with residents at a time of day which according to information from themselves or their carers they are likely to find convenient and not be tired.
- Introduce self and ask permission to talk with resident and permission to sit down.
- Explain that you would like to ask them some questions.
- Work with resident to develop rapport and ensure they are comfortable and have their glasses/hearing aid clean and present in order to aid their communication and participation. Try to minimise any other visual/aural distractions (e.g. turn off TV/Radio).
- Remind resident about the MARIO project and re-establish ongoing consent for participation in the research project.
- Explain that you would like to record what they say in answer to the questions and seek permission for this.
- Continue when consent for the interview has been verbally agreed
- Turn on audio-recorder.
- Throughout the interview try to maintain rapport with the resident so they are relaxed and their participation is maximised. This will include using relaxed encouraging nonverbal communication, mirroring the language which they use, verbalising questions clearly and allowing time for the residents to think and answer. Use reflective active listening, paraphrasing, summarising, seeking clarification and requesting elaboration.
- Listen and respond to residents as they relate stories and then gently re-orientate them to the interview topic or question if needed.

### **Interview Questions**

The questions below are guide for conducting the interviews the aim is to gently elicit the information using a relaxed conversational style, appropriate to the individual person with dementia.

**When we talked before about 8 weeks ago before you started having sessions regularly with MARIO (music man or whatever the individual person calls MARIO), you told me about how you felt about your life here and about what you thought helps you to be resilience to keep in good spirits, adapt or bounce back if you have a problem or difficulty.**

- 1. I'd like to ask you if you feel that you are resilient now....**

Prompts as relevant:

Can you tell me how you feel you are able to adapt or bounce back if you have a difficulty in your life?

What about taking things in your stride?





Can you talk about if you feel you have meaning in your life here?

Can you say how you manage if you have any difficulties?

Would you say you are friends with yourself?

Can you talk about how much you enjoy your life at the moment?

Individualise the following question prompts as necessary so they are relevant to the individual person with dementia based on the answers from their previous interviews and data obtained from other sources:

You mentioned before when we talked that you .....resilient. Can you tell me how you feel about this now?

When we spoke before about having good relationships you were telling me about.....How would you be feeling about that now? .

We were also talking about needing good social interactions with other people and you were recalling that.....Can you tell me a bit more about if this is still an issue for you now. Or I noticed that....I was wondering about....

In terms of your resilience. You were saying that you feel good about yourself when .....How has this been going for you recently? Or I noticed that..... Could you tell me a bit more about that?

You mentioned before.....how you .....feel about being able to decide what to do you're your day and about being able to do this..... Can you tell me a bit more about how you feel about this at the moment?

You were telling me before how much you liked music/ being reminded about your family/thinking about.....

**2. I would like to ask you about how you felt about using MARIO the robot?**

**Prompts:**

Did you like/not like about using the robot and interacting with him?

What did you like doing/not like doing with the robot?

Can you tell me a bit more about that?

**3. I would also like to ask you if you feel things are different or the same for you now that you have had the chance to use MARIO regularly? ..... Can you tell me a bit more about that?**

**4. How do you think that using MARIO might have helped you, if you think he did help you?.....Can you tell me a bit more about that?**

Prompts as relevant:

How has MARIO helped you to cope better with your memory problems or with living here? How has MARIO helped you feel more settled in the nursing home? How has MARIO made you feel happier or less lonely? In what way, if any, do you feel MARIO the robot has made you feel resilient and helped you adapt or bounce back from any difficulties you have in your life here in the nursing home?


Can you tell me more about why you think MARIO did not help you to .....?

**5. Was there anything that worried you about MARIO or using the robot?**


**6. Is there anything I have not asked you about that you think would be important about MARIO or about you coping with living here in the nursing home?**

Thank the participant very much for talking about their lives and what is important to them. Tell them that their information has been really helpful to the research project. (Turn off audio-recorder).

**Appendix 11) Paper Four: Interview Guide for Relatives of People with Dementia.**



OÉ Gaillimh  
NUI Galway



### MARIO: Relative | Telephone POST Interview Guide

**Managing active and healthy aging with use of caring service robots (MARIO)**

Thank you for agreeing to be interviewed today. We value your opinion and experience and appreciate your help with this research. As you know we are developing a companion robot for people with memory problems called Mario and we want to talk with you today to find out what you think about this robot companion and whether you think it might be able to keep your relative more socially connected, improve their overall quality of life and their resilience i.e. their ability to cope with their dementia. The information that you provide will help us to ascertain whether the robot companions we developed best meet the needs and priorities of persons with memory problems.

(Check consent is signed)

1. Can you tell me if you have seen any contact that \_\_\_\_\_(your relative) has had with MARIO? *How many times have you seen them interact with MARIO? What did you think or feel about it? Where was it? When? Who was involved? What happened?*

[If they have not seen their relative engage with MARIO] Has \_\_\_\_\_ (your relative) mentioned or made any reference to MARIO? *If so, what did they say?*

2. [Skip if answered 'NO' to q1]  
So you have seen \_\_\_\_\_(your relative) interact with MARIO, but have they ever discussed MARIO with you outside of the time that you witnessed them together? *If so, what did they say?*
3. As you know, MARIO's purpose is to aid in reducing loneliness and isolation for users by promoting social interactions, engagements, and conversations. He therefore has a number of apps - Friends and Family apps, Reminiscence app, Calendar/News apps, Music/Games apps  
In what way, if any, have these apps impacted on \_\_\_\_\_(your relatives) life in any way?  
  
*If so, in what way do you feel MARIO has impacted their life?*



- b.** Did they engage in any more conversations? *If so, (ask for examples) with whom and when or what about?*
- c.** Were there any more or different interactions with other family members *If so, (ask for examples) with whom and when or what about?*
- d.** Ability to respond to the challenges of living with their dementia/memory loss. *If so, can you give me an example?*
- e.** If no, he hasn't impacted, then why do they think this is the case?

**Prompts**

- Wellbeing (When we talk about wellbeing, we mean a combination of a person's physical, mental, emotional and social health)
  - Mood
  - Happiness
- 4.** In what way, if any, has the presence of MARIO with \_\_\_\_\_ (your relative) made any difference to their resilience (*which is the ability to bounce back or cope*) of \_\_\_\_\_ (your relative)  
If not, why not? if yes, why so?
- 5.** In what way, if any, has the presence of MARIO with \_\_\_\_\_ (your relative) made any difference to their quality of life (the standard of health, comfort, and happiness experienced by an individual)?  
If not, why not? If yes, why so?

Appendix 12) Paper Four: Interview Guide for Caregivers.



## MARIO: Formal Carer's Interview Guide

1. As you know MARIO has been used on the \*\*\*\*\* (Insert ward name) by \*\*\*\*\* (name the Resident). Can you tell me about any contact you have witnessed between MARIO and \*\*\*\*\* (name Resident)?

Follow up with: What did you think or feel about it? Where was it? When? Who was involved? What happened?

2. What kind of affect do you think MARIO has had on \*\*\*\*\* (name Resident)?

Follow up: what have you noticed in \*\*\*\*\* (name Resident)?

b. Has \*\*\*\*\* (name Resident)? Ever talked to you about MARIO, if so, what did they say?

3. To what extent has MARIO made any difference to the way you care for (\*\*\*\* name of resident\*\*) If yes, in what way? If not, why not?  
b. To what extent has MARIO made any difference to your perception of (\*\*\*\* name of resident\*\*) ability to do things? E.g engage in social activities; complete activities of daily living? If yes, in what way?
4. In what way, if any, has the presence of MARIO with \_\_\_\_\_ (name of Resident) made any difference to their quality of life?

Prompts: (the standard of health, comfort, mood, happiness experienced by an individual; engagement with other residents/staff/family & friends/others)?

If not, why not? If yes, why so?

5. As you know, MARIO's purpose is to aid in reducing loneliness and isolation for users by promoting social interactions, engagements, and conversations. He therefore has a number of apps - Friends and Family apps, Reminiscence app, Calendar/News apps, Music/Games apps  
To what extent do you feel that MARIO has promoted social engagement and interactions for (name of resident)



- b. In what way, if any, have these apps impacted on \_\_\_\_\_ (name of resident) life in any way?

**Prompts**

- Did they engage in any more conversations? If so, (ask for examples) with whom and when or what about?
- Were there any more or different interactions with other family members? If so, (ask for examples) with whom and when or what about?
- Wellbeing (When we talk about wellbeing, we mean a combination of a person's physical, mental, emotional, and social health)
- Mood
- Ability to respond to the challenges of living with their dementia/memory loss. If so, can you give me an example?
- Happiness
- If no he hasn't impacted, then why do they think this is the case?

6. To what extent has having access to MARIO made any difference to their resilience (ability to bounce back or cope)?

Follow up with: if so, what sort of difference and in what way?

(If relevant, explain that you would now like to repeat the questions above and have the care giver think about the answers in relation to another resident under their care. Do this for all the residents that this care giver provides care for).

When this has been done. Explain that you would now like to ask a couple of general questions about they feel about MARIO.

7. What could be done to make MARIO a better companion robot for residents with dementia in the nursing home setting? For other residents in the nursing home?
8. How do you envisage the future for a MARIO type robot in the context of care of older people in residential care? In the community? Or other health care contexts?
9. What sort of tasks related to social engagement and companionship do you think MARIO might be able to do which could potentially free up staff time to devote to other meaningful activities with residents?



OÉ Gaillimh  
NUI Galway



- 10. Are there any ethical issues that you had concerns about prior to the arrival of MARIO? If so what were they? Did they materialize? If yes, how were they managed and resolved?**
- 11. Thinking back on how you felt about MARIO when you first met him. Has your opinion of MARIO changed? In what way did it change? What were these changes?**
- 12. Is there anything we haven't talked about this far, that you think it would be important to mention?**

Thank you for participating in the MARIO project research

**Appendix 13) Paper Four: Example of Raw Quantitative Data obtained using Dementia Care Mapping.**

A picture of a raw data sheet is copied below. This data sheet was used to record the activities and mood and engagement levels of one participant with dementia when he was mapped before he started using MARIO. The raw data sheet shows the behaviour codes and the mood and engagement values that were recorded at five minute intervals between 10.00 am-12.00 pm and 13.00 pm to 16.00 pm, during what caregivers reported was a typical day. The results show that this participant spent the large proportions of his day without overt signs of positive or negative mood. He also spent large amounts of his time being briefly, intermittently engaged, and passively watching his surroundings

**Key to ME –Levels:** -5 Very great signs of negative mood; -3 Considerable negative mood; -1 Small signs of negative mood withdrawn/out of contact; +1 No overt signs of positive or negative mood. Brief, intermittent engagement; +3 Considerable positive mood concentrating but distractible; +5 High Positive mood, deeply engaged. (Bradford, 2016).

**Key to Activity Codes:** A - Interaction with others verbal or non-verbal; B - Being passively engaged (Watching); C - Cool, disengaged; D - Self Care; E - Expressive Creative Activities; F - Eating drinking; K - Standing walking independently; L - Participating in Leisure Activity; N - Sleeping; O - Attachment to Objects; P - Receiving personal care; R - Religious activity; U - Trying to communicate with no response; V - Work-like activity; X - Excretion; Y - Interaction with self. (Bradford, 2016).

Date: 21/11/14		Time periods: 10.00-12.00, 13.00-16.00		Place: [redacted]																								
Total number of service users		Researcher		Observer																								
Participant name	Time	05	10	15	20	25	30	35	40	45	50	55	00	05	10	15	20	25	30	35	40	45	50	55	00	05	Total ME	
JACK	BCC	H	H	H	H	H	H	H	H	H	H	H	H	H	H	H	H	H	H	H	H	H	H	H	H	H	H	
	ME	-	+3	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	
Participant name	Time	05	10	15	20	25	30	35	40	45	50	55	00	05	10	15	20	25	30	35	40	45	50	55	00	05	Total ME	
JACK	BCC	F	E	N	Y	P	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	
	ME	1	2	-	-	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	
Participant name	Time	05	10	15	20	25	30	35	40	45	50	55	00	05	10	15	20	25	30	35	40	45	50	55	00	05	Total ME	
JACK	BCC	U	F	A	A	F	B	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A		
	ME	2	2	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	

Appendices

**Appendix 14) Paper Four: Examples of Initial Coding of Data in NVIVO 12.**

> Phase 1 - General Initial Codes (Open Free Coding) Search Project

Name	Files	References	Created On	Created By	Modified On	Modified By
Agitation		1	09/10/2019 08:54	SAW	01/10/2019 11:54	SW
Alright		3	09/10/2019 08:54	SAW	30/09/2019 16:45	SW
Ameniable likes to get on well with others		2	09/10/2019 08:54	SAW	01/10/2019 10:01	SW
Attention to MARIO		1	09/10/2019 08:54	SAW	30/09/2019 16:48	SW
Attitude to MARIO		3	09/10/2019 08:54	SAW	01/10/2019 13:19	SW
awareness		1	09/10/2019 08:54	SAW	30/09/2019 16:32	SW
Awareness that it is good		2	09/10/2019 08:54	SAW	01/10/2019 13:08	SW
Believes was outside		0	09/10/2019 08:54	SAW	30/09/2019 15:59	SW
Benefit of MARIO		2	09/10/2019 08:54	SAW	01/10/2019 12:17	SW
Bit of Luck needed		1	09/10/2019 08:54	SAW	30/09/2019 16:35	SW
Care has changed		1	09/10/2019 08:54	SAW	01/10/2019 12:23	SW
Carer Controlling of him and his actions		1	09/10/2019 08:54	SAW	30/09/2019 15:19	SW
Carer learnt about M5		1	09/10/2019 08:54	SAW	01/10/2019 12:11	SW
Carer not wanting to interrupt sessions		1	09/10/2019 08:54	SAW	01/10/2019 12:16	SW
Carer passing by talks to M5		3	09/10/2019 08:54	SAW	01/10/2019 09:34	SW
Carer support needed		1	09/10/2019 08:54	SAW	01/10/2019 10:08	SW
Carer surprised at M5's competence talking using MARIO		1	09/10/2019 08:54	SAW	01/10/2019 12:17	SW
Carer will change		1	09/10/2019 08:54	SAW	01/10/2019 12:20	SW
Carers believe care won't change		1	09/10/2019 08:54	SAW	01/10/2019 12:19	SW
Celebrates with facilitator		1	09/10/2019 08:54	SAW	01/10/2019 12:49	SW
Changed opinion of staff		1	09/10/2019 08:54	SAW	01/10/2019 10:49	SW

**Folders**

Codes



**Appendix 15) Paper Four: Example of Codes being Defined and the Hierarchical Structure of codes being developed.**

This screenshot from NVIVO 12 shows the code 'Examines MARIO' being defined and categorised in relation to other codes.

The screenshot displays the NVIVO 12 interface for 'Phase 2 - Categorisation of Codes and Propositional Statements'. On the left, a 'Folders' pane shows a hierarchical tree of codes. A 'Parent Node' label points to 'Using MARIO', and 'Child nodes' label points to its sub-codes, including 'Examines MARIO'. A 'Node Properties' dialog box is open for 'Examines MARIO', showing its name, description, and hierarchical path.

Name	References	Created On	Created By	Modified On	Modified By
Benefit of MARIO	2	09/10/2019 09:55	SAW	01/10/2019 12:17	SW
Impact on Carers	0	09/10/2019 09:55	SAW	01/10/2019 14:22	SW
MARIO filling a gap through individualised care					
no longterm impact					
Painting					
Remembering MARIO					
Skilled facilitation					
Talked to researcher reminiscence					
Using MARIO					
Difficulty using MARIO					
Difficulty using Screen					
Independent usage					
Learning process for M5					
Screen					
Spontaneously using					
Successfully using touchscreen					
Uses and Responds to MARIO like other stimuli					
Doing something with his hands					
Examines MARIO	1	09/10/2019 09:55	SAW	01/10/2019 13:26	SW
Focus on details					
Using MARIO standing up	1	09/10/2019 09:55	SAW	01/10/2019 12:54	SW

**Appendix 16) Paper Four: The Coding Framework with associated files and references after coding data from all the cases.**

Name of Categories/ subcategories, and codes.	Description of categories, subcategories, and codes.	Number of Data Files coded each the code.	Number of Data Referenc es coded to each code.
<b>The Nature of Adversity</b>	This category encompasses the data relating to the stresses and difficulties that are experienced by the people with dementia in this context. It includes factors related to living with dementia including cognitive and communication difficulties, physical ill-health.	0	0
Cognitive difficulty	Reference to cognitive difficulties experienced by participants with dementia including disorientation and belief in a different reality	37	99
Communication Difficulty	References to a participant with dementia having problems communicating including expressive language, hearing problems, unclear speech.	16	33
Physical and mental ill health or difficulties	References to physical or mental ill health, or physical weakness and vulnerability including mobility difficulties, falls, safety.	22	66
Variable Adversity	Reference to difficulties and stressors varying in intensity or coming and going for participants with dementia, including variable awareness of difficulties.	18	31
Bereavement and loss	References to participants with dementia being bereaved and grieving for people and longing for a previous better way of life which has now gone.	10	22
<b>Degree of Adaptability to Adversity and Wellbeing</b>	This category encompasses the data concerning the degree to which individuals have responded to adversity and adapted to it. It concerns the degree of psychological wellbeing experienced by the person with dementia including their emotions experienced and their perceived quality of life. It also includes the degree to	0	0

## Appendices

Name of Categories/ subcategories, and codes.	Description of categories, subcategories, and codes.	Number of Data Files coded each the code.	Number of Data Referenc es coded to each code.
	which they have accepted or resist their current lives.		
<b>Good level of Adaptability and Wellbeing</b>	This subcategory includes evidence of participant with dementia adapting well, to their circumstances in life, in terms of having a positive level of psychological wellbeing. Evidence supporting suggestion that participants with dementia are doing/feeling okay and they are getting on with a limited satisfactory/good enough life.	0	
Acceptance	References to participants with dementia accepting their current life even though it might not be ideal includes doing alright, having enough, doing their best and self- acceptance.	13	41
Doing things	References to participants with dementia liking work, keeping busy, valuing doing things. Showing interest and attentive to something, including acts of self-care. Reaching out to satisfy own desires for food, drink, entertainment.	15	47
Positivity	References to participants with dementia being positive about life, through thoughts and their emotions.	27	136
Proactive Assertion	References to participants with dementia actively initiating, asserting their will. Includes moving, looking for, taking opportunities, seeking help for selves and others. Asserting independence, being strong and forceful. Initiating conversation or changing the subject.	16	55
Stoicism	References to getting on despite problems, putting up with them because no choice.	5	7
<b>Low Adaptability and Poor Wellbeing</b>	This subcategory includes evidence that the participant is not adapting or growing in their current life, they are struggling to accept and resisting their current situation.	0	0

## Appendices

Name of Categories/ subcategories, and codes.	Description of categories, subcategories, and codes.	Number of Data Files coded each the code.	Number of Data Referenc es coded to each code.
	They are showing evidence of poor psychological wellbeing.		
Negativity	References to participants with dementia's negative emotions, thoughts, memories, low self-esteem, low energy, anxiety, agitation.	26	140
Not Accepting	References to the participants with dementia, not accepting their dementia, their life in the nursing home .	6	10
Wanting More	Reference to participants with dementia desiring more of something in their lives including more choice, self-determination, independence, freedom.	10	41
Resistance	Behaviour or words indicating that participants with dementia is fighting back trying to assert power and control over their situation. Active or passive resistance.	6	27
Wanting to be Elsewhere	References to participants with dementia being are physically situated in a place and they would rather be elsewhere, outside in the air, home, wanting to escape, being ready to leave, trying to leave.	26	86
<b>Variability in level of adaptation and wellbeing</b>	This subcategory includes references to variability of the mood or wellbeing of the participants with dementia and variable adaptation, response to environment. Variable mood and engagement.	23	35
<b>Factors Impacting Response to Adversity</b>	This category includes the data related to factors that impact how the individuals with dementia respond to difficulties they experience in their lives. It encompasses their personal resilience repertoires and their current capacity for resilience. It also includes the availability of resources for resilience that are external to the	0	0

## Appendices

Name of Categories/ subcategories, and codes.	Description of categories, subcategories, and codes.	Number of Data Files coded each the code.	Number of Data Referenc es coded to each code.
	individual with dementia. Including the degree relationships are person-centred.		
<b>Availability of Resources that Support Positive Adaptation</b>	This is a subcategory that encompasses data that is related to how available potentially supportive resources are to participants with dementia.	0	0
Availability of Meaningful Interaction with Other People	Reference to the perceptions of participants with dementia that they feel socially supported and connected to other people and evidence that there are opportunities for interaction with other people that are meaningful to the people with dementia and supportive of the participants with dementia positive identity.	3	5
Carers Banter with Participants with Dementia	References to Carers and participants with dementia sharing light-hearted banter	5	10
Chatting with Others	References to participants with dementia usually brief not in-depth personal conversation, unable to discern if this is meaningful or not to the participants with dementia.	7	14
Task Orientated Conversations	Reference to conversations that that focus on physical wellbeing.	6	26
Family Support	Reference to support given by family to participants with dementia .	8	31
Supportive Relationship with Carers	References to carers providing care that is encouraging supportive comforting.	14	48
Meaningful Conversation with carers	References to meaningful person-centred conversations with carers	7	10
Unperson-centred care	References to and examples of unperson-centred care given to participants with dementia includes being ignored by carers,	6	19

## Appendices

Name of Categories/ subcategories, and codes.	Description of categories, subcategories, and codes.	Number of Data Files coded each the code.	Number of Data Referenc es coded to each code.
	not being included in conversations, outpacing, witnessing non person-centred care of other residents.		
Lack of Meaningful Activity	Reference to and indications of there being a lack of meaningful activity.	5	10
Lack of meaningful Interactions	References to participants with dementia being ready or wanting more interaction than they have; feeling lonely; being alone.	32	132
Reaction to Lack of Activity	Reference to the activity and behaviour or what the participants with dementia does when there is little external stimulation available: not doing anything or little; passively watchful or responsive to opportunities for activity.	18	171
Ready for more Person-centred Activity	Reference to participants with dementia eagerly/quickly responding to activity or type of interaction when it is available.	10	24
<b>Resilience Repertoire</b>	This subcategory includes references to participants with dementia range of skills and strategies that help them to adapt and cope.	0	0
Capacity for Resilience	References to participants with dementia about their capacity to cope with difficulties. Self perceptions about their abilities and those of significant others.	23	74
Learned Coping Strategies	Reference to getting better coping strategies, getting stronger having had a problem due to learning how to cope with this and learning from others.	13	48
Resilience Building Strategies	References to strategies participants with dementia react when they have a problem.	9	27
Accepting that life is not perfect	Reference to participants with dementia acknowledging that having problems is to be expected and that these are part of life.	6	12

## Appendices

Name of Categories/ subcategories, and codes.	Description of categories, subcategories, and codes.	Number of Data Files coded each the code.	Number of Data Referenc es coded to each code.
Being Proactive and Persevering	References to participants with dementia's reacting by being self-sufficient; seeking help from others; Trying hard, being determined, and not giving up	10	25
Gratitude and Positivity	References to using gratitude and positivity as being part of personal life philosophy	7	28
Religion and Spirituality	References to participants with dementia using relationship with God and spirituality or cultural religious practices to help them to adapt to adversity.	24	69
<b>Values and Meaning in Life</b>	This subcategory included what participants with dementia said was important to them and what they need to have a meaningful life.	0	0
Meaningful Activities	Reference to the activities that participants with dementia find meaningful and value. Enjoyable and fulfilling activities.	42	160
Preferences for Interaction	Reference to and evidence of the relative value that participants with dementia place on interacting with other people and what they want interactions with others to be like.	41	158
<b>The Culture of Caring</b>	This subcategory encompasses references to and evidence of what the carers and the relatives in the nursing home prioritise with regards to the care that is given by them to the participants with dementia. This encompasses the predominant practices and beliefs of significant others.	0	0
Difficulties addressing Unmet Needs	References to carers finding caring for participants with dementia difficult and that they are aware they are not always able to address needs.	9	33

## Appendices

Name of Categories/ subcategories, and codes.	Description of categories, subcategories, and codes.	Number of Data Files coded each the code.	Number of Data Referenc es coded to each code.
Maintaining Reacting and Problem-solving	References and evidence of carers acting to support and maintain the wellbeing of participants with dementia. Predominantly through reacting and responding to their needs. Reactive rather than proactive	7	29
Maintaining the Routine vs Change	References to the carers attitude towards change and routines in nursing home life.	12	20
Prioritising Physical Care	Evidence of focusing on physical aspect of care or medical aspect of care, rather than social or emotional aspects.	10	34
Staff telling and controlling	Reference to power relationships with staff holding power. Include, direct indirect control of participants with dementia behaviour. Therapeutic lying.	5	16
<b>Factors Impacting Usage of MARIO</b>	This category encompasses factors that impact the readiness of individuals to use MARIO and those that influence how MARIO is used during sessions.	0	0
Ability to use MARIO	Able to use MARIO difficulty using MARIO and impact of time on usage	24	149
Attitudes towards MARIO and beliefs about the robot	Reference to participants with dementia opinions about MARIO including behaviour that suggests feelings about the robot.	39	272
Facilitating use of MARIO	References to help needed by participants with dementia to use MARIO	19	146
Participant Usage of MARIO	Reference to how MARIO was used by participants.	26	145
Unwilling to use MARIO	References to participants with dementia being unwilling to use MARIO, stopped using as tired, Initial reluctance, refusing to use MARIO	13	42
Willingness and Intention to Use MARIO	Reference to participants with dementia being willing, wanting to engage with MARIO	16	83



## Appendices

Name of Categories/ subcategories, and codes.	Description of categories, subcategories, and codes.	Number of Data Files coded each the code.	Number of Data Referenc es coded to each code.
<b>Impact on Resilience between and after Sessions with MARIO</b>	This category concerns the effect of MARIO on resilience in between the sessions with MARIO and after the group of sessions with MARIO has finished.	0	0
Initial but unsustained Impact	Reference to participants with dementia mood and engagement levels in 2 hours after using MARIO.	8	36
Memory of MARIO	Reference to participants with dementia having or not having a memory of MARIO	27	76
Potential for Ongoing Impact	References to impact that could happen due to having used MARIO	18	63
Resilience unchanged or not Increased	Reference to resilience not increasing or changing as a result of using MARIO.	34	187
<b>Impact on Resilience during Sessions with MARIO</b>	This category encompasses data concerning the impact that MARIO has on resilience during the sessions with MARIO.	0	0
MARIO beneficial in the moment	Reference to MARIO having a positive impact whilst it is being used.	14	25
Filling a Gap with Meaningful Activity	References to activities undertaken during sessions with MARIO giving participants with dementia something that they did not usually have.	22	150
Increased Engagement and Stimulation	Reference to the participants with dementia being engaged and stimulated during sessions with MARIO and more than usual.	22	52
Increased positivity	References to participants with dementia enjoying or liking the sessions or material on MARIO and the increasing the positive mood of the participants with dementia.	34	185
Opportunity for Empowered Independence	References to choices, acting, independence, making decisions when	12	88

## Appendices

Name of Categories/ subcategories, and codes.	Description of categories, subcategories, and codes.	Number of Data Files coded each the code.	Number of Data Referenc es coded to each code.
	using MARIO. for independence and empowerment. Making decisions Choosing		
Stimulus as Opportunity to Interact	References to MARIO being an opportunity to communicate with others.	23	151
MARIO harmful	References to MARIO negatively impacting the person with dementia.	4	12
MARIO's Limitations	References to MARIO needing to be improved or being limited in capacity.	7	23

**Appendix 17) Paper Four: Example of how the Data within each Case was Summarised in NVIVO.**

NVIVO enabled the data to be accessed, for each participant, from all data sources for each code. The data for each code was then summarised within each case. This screenshot shows the data for the code Acceptance being accessed, from data sources for participant M20.

The screenshot displays the NVIVO interface. On the left, a 'Folders' pane shows a hierarchical tree under 'Phase 4 Triangulation with Key Informants and Conceptual Mapping'. The 'Acceptance' code is selected, showing 13 files and 41 references. On the right, the 'Coding' pane shows a grid of data sources for participant M20, including 'M20-POST PWD (1)' and 'M20-PRE PWD (2)'. Below this, a text box shows a reference from a file: 'Sure, we do our best, what can we do'. Annotations include a blue arrow pointing from the 'Acceptance' code in the folder list to the reference text, and another blue arrow pointing from the 'M20-POST PWD' source to the same reference text. A text box labeled 'Data regarding Acceptance M20 Post MARIO' is positioned near the reference text. Another text box labeled 'Three data sources M20' has three blue arrows pointing to the 'M20-POST PWD (1)', 'M20-PRE PWD (2)', and 'M5 Miami Transcrip' sources in the grid.

**Appendix 18) Paper Four: An excerpt from the Matrix with summarised within case data.**

A matrix of the codes and cases was created in NVIVO and then exported to Excel where it could be seen in its entirety. Then the summarised data was copied from NVIVO and pasted into the matrix cells in Excel. This screen shot shows a section of the matrix and the data summarised for the participants M1 and M20 under the codes Acceptance, Doing Things and Positivity.

	C : Acceptance	D : Doing things	E : Positivity
<p><b>Cases</b></p> <p>1 : M1 Age = 80+ years MMSE SCORE = 14/30 Number of years you have memory problems = 1-3 years Sex = Male</p>	<p>M1 expresses a degree of acceptance saying that aspects of his life are good, and others are "alright", and sufficient for his needs. 'I have enough' (Interview with M1 Post MARIO)</p> <p>His acceptance also includes that he is doing the best that he can. This seems to acknowledge awareness of limitations.</p> <p>'Well, I play the best I can.' (Interview with M1 Post MARIO)</p>	<p><b>Codes</b></p> <p>M1 is active in his self-care within his physical limitations. At times he is determined.</p> <p>'M1 stares at his cup and takes the lid of it to drink without the lid - successful without spillage and then looks towards putting the lid back on and this takes studied concentration for almost 2 minutes. Again eventually successful with this' (M1 DCM Post MARIO).</p> <p>'Tries to get up - no carer watching. ( DCM M1 Pre MARIO).</p>	<p>M1 says that he feels positive. M1 'I am a year and eight months here now.' Researcher A year and eight months, and are you happy? M1 'I am.' (Interview M1 Post MARIO).</p> <p>His behaviour also reveals that he is happy when stimulated by something he likes, especially his family and music.</p> <p>'Big smile and brightened up engaged chatting and alert when his relatives including his grandchildren arrive for a visit. Holding hands with them' (DCM M1 Pre MARIO).</p> <p>'And you know, he always has tapes and CDs and whatever, he just loved traditional music and in his room all the time he had a CD player and we'd have to play tunes for him' (Interview with Relative R1 Post MARIO).</p>
<p>2 : M20 Age = 80+ years MMSE SCORE = 14/30 Number of years you have memory problems = 4-6 years</p>	<p>M20 expresses a resigned attitude of acceptance that is somewhat stoic. She employs her philosophy on life and this concerns trying hard, making the best of what life has to offer her.</p> <p>'Sure, we do our best, what can we do' (Interview with M20 Pre MARIO)</p> <p>'Try and make the best, try and make the best of life.' (Interview with M20 Pre MARIO)</p> <p>'I am but I make it accepted' (Interview with M20 Post MARIO)</p>	<p>M20 occupies herself intermittently for short periods. She sits in her chair and responds to what she sees and what she can reach.</p> <p>'attempts to pour herself drink from 7 up bottle into glass. Would have missed but stops and re-stops bottle (1 mins) dinks again - the glass was not empty. Then passive and still' (DCM M20 Pre MARIO).</p> <p>'looking at her remote control and examining it. Looks puzzled (she doesn't know what it is)' (DCM M20 Post MARIO).</p> <p>'rearranging objects on the table in front of her.' (DCM M20 Pre MARIO).</p>	<p><b>Summarised Data</b></p> <p>M20 acknowledges that she feels happy but she is aware that there are limits to her positivity.</p> <p>'I feel happy, yes. I feel happy but not awful happy.' (Interview M20 Pre MARIO).</p> <p>M20 also revealed that she thinks about her positive memories.</p> <p>'I see my mother and father were exceptions, they were very good and they were good to me and you were good.' (Interview M20 Post MARIO).</p> <p>M20 reacts positively in response to hearing that her daughter will be visiting.</p> <p>'Carer says she 'always comes in the evening' in reply to M20 question about when she is coming. Saying that then 'I'll get all the news' (DCM M20 Post MARIO)</p>

**Appendix 19) Paper Four: Example of a Memo written in NVIVO summarising all data from all cases, linked to the code Willingness and Intention to use MARIO.**

**Phase 4 Triangulation with Key Informants and Conceptual Mapping**

Name	Files	References
Degree of Adaptability to Adversity and Wellbeing	0	0
Factors Impacting Response to Adversity	0	0
Factors Impacting Usage of MARIO	0	0
Ability to use MARIO	24	149
Attitudes towards MARIO and beliefs about the robot	39	272
Facilitating use of MARIO	19	146
Participant Usage of MARIO	26	145
Unwilling to use MARIO	13	42
<b>Willingness and Intention to Use MARIO</b>	<b>16</b>	<b>83</b>
Impact on Resilience between and after Sessions with MARIO	0	0
Impact on Resilience during Sessions with MARIO	0	0
MARIO beneficial in the moment	14	25
Filling a Gap with Meaningful Activity	22	150
Increased Engagement and Stimulation	22	52
Increased positivity	34	185
Opportunity for Empowered Independence	12	88
Stimulus as Opportunity to Interact	23	151
MARIO harmful	4	12
MARIO's Limitations	7	23
The Nature of Adversity	0	0
Cognitive difficulty	37	99

**Summary of Willingness and Intention to Use MARIO**

**Willingness and Intention to Use MARIO** OME observations and written notes of what was said during interactions

Willing to use M16 (OME) M20 (evidence from S18 and OME )M5 (evidence from S16) M14 (OME) M17 willing to use invited researchers with MARIO back again (OME) M18 M20 M12 (Ome and Interview) M5 (OME)M13 (R13). M1 (Interview and OME); M12 wanted to buy a MARIO (Ome)s

R13 'I think she [M13] really welcomes having the robot'

Was willing and happy to try various applications M12 (OME)M17 OMEs M12 OME M18 wanted to see photo (Ome) M20 wanted to try (OME)

Did not want to stop some interactions and usage of MARIO M12,

Some participants particularly welcomed interactions with the researchers on occasion rather than with MARIO per say – M12 asking the whereabouts of the researcher she particularly likes; M18 and M20 M13 greeting researchers warmly

**Slight hesitation but not refusing MARIO** M17 Ome S19 about M20's first try with MARIO

**Reluctance to Use MARIO** M18 (Interview Post MARIO)

Intermittent reluctance or when MARIO was not perceived as needed M14, M5 in that mood, if the person was offered the robot when they perceived that the had everything they needed or when they were in a bad mood M14 M16 (OME/Carers) As M14 said:

M14 'You can only do things when you feel it'

**Initial hesitation** M5 M20 M18 M17 some participants needed encouragement and support to use MARIO M14 (OME) Session 4:

At first very hesitant to interact with MARIO thought it would be too hard to use and she wouldn't be

### Appendix 20) Paper Four: Example of an Analytical Memo.

During phase 7 of data analysis, analytical memos were written to derive explanatory meaning from the data. An example of an analytical memo is presented below.

**MEMO Title:** Initiating and Maintaining Readiness to Use MARIO

#### Definition

This issue arises from the data that reveals that people with dementia varied within cases and between cases regarding how ready they were to use MARIO at the start of sessions and throughout their duration.

#### Nodes and categories that it relates to:

Variable willingness and intention to Use MARIO; Unwilling to use MARIO; Attitudes towards MARIO and beliefs about the robot; Personification of MARIO; Ability to use MARIO; Robot factors; facilitating use of MARIO; participant usage of MARIO.

#### Summary of the argument and references to the literature

The Merriam-Webster online dictionary defines readiness as a quality or state of being ready. Pearson (2011) states that the concept of readiness concerns being prepared due to possessing the ability and willingness to participate in something. The concept includes three dimensions: resources, conditions and attitudes (Pearson 2011). A definition retrieved from (<http://www.businessdictionary.com/definition/readiness.html>) states that readiness is a 'State of preparedness of persons, systems, or organizations to meet a situation and carry out a planned sequence of actions. Readiness is based on thoroughness of the planning, adequacy and training of the personnel, and supply and reserve of support services or systems.'

The concept of readiness concerns a person having conducive attitudes, willingness to use the robot and the ability to participate in sessions with MARIO. The concept of readiness has been used both in education (Beller 1970) and healthcare context regarding nurses the support of people with chronic health conditions (Dalton and Gottlieb 2003). Used in the current context of this theme, readiness encompasses data concerning the acceptability of the robot to participants and the actions of facilitators, who acted to support people with dementia to both initiate and maintain their readiness to use MARIO.

People with dementia of the severity of the participants need compensatory support of other people to initiate and maintain their use of MARIO. Indeed, compensatory support is needed for people with dementia to facilitate communication with other people and for many daily living activities.

In this context, the support needed to initiate and maintain readiness to use MARIO was related to the variability of the participants' adversity and their level of wellbeing as well as their attitudes towards and willingness to use MARIO. It concerned their mood and degree of lucidity. Whereas, maintenance of their readiness concerned the variable ability of the person to maintain their concentration on the task during the session. Compensatory support of the facilitator during initiation

was required to increase the readiness of the participant with dementia through preparing the environment and through rapport with the participants with dementia. During the interactions with MARIO, facilitators helped maintain readiness through providing skilled scaffolded assistance to the participants with dementia.

### Summary of the data with quotations

During the sessions engagements, the attitudes of participants was mostly positive. The range of attitudes exhibited by participants, their most frequent attitudinal level and the highest attitudinal levels during the sessions are summarised in Table \*\*. The data revealed that attitudinal levels varied from a small minority that were somewhat negative for short periods of time, to most participants who had a positive attitude for most of the time during most sessions. In addition, it was most common for a very positive attitude to be achieved by participants at some point during sessions.

Facilitators helped all participants to gain access to MARIO by creating a conducive environment for the interactions with MARIO. This work was conducive before and during sessions with MARIO. It involved manipulating the external environment to ensure that it was as free from distractions as possible and MARIO was prepared so that each participant could access their pre-personalised files without delay. The latter reduced the chance of the participants becoming distracted away from the robot once their attention had been piqued initially. In addition, what could be regarded as the internal environment of the participant with dementia, regarding their level of wellbeing had to be ready to use the robot. This is explained further below.

Making the external environment ready varied with each participant's needs and location. For example, as M5 was often walking in the corridor and preferred, during his early sessions with MARIO, to remain standing, he needed to be encouraged to walk to a quieter part of the corridor and MARIO's touchscreen had to be tilted upwards so M5 could see the screen's contents. For other seated participants, they might need doors shut to reduce noise or blinds pulled so reduce glare on MARIO's screen. Preparation might include helping the participant move to a more conducive place. The need to help a participant move to a more conducive place varied. Four participants who spent most of their time in their own bedrooms did not need to be moved at all. M5 was encouraged to move 6 times, and the remaining 5 participants were moved on 1-3 occasions.

Willingness to interact with MARIO was impacted by perceptions as to whether MARIO would be useful to participants, and how participants perceived and personified the robot at the time it was offered to them. The data revealed that these factors varied and how the robot was personified by participants was influenced by their mood, which as discussed above was variable. For example, on occasions some participants said that MARIO was silly or a waste of time, because they didn't have money to pay for it, or they had everything they needed, or they didn't like computers. However, expressing negative attitudes in the moment, could also coincide with evidence of the participant with dementia enjoying the robot. The rate of refusing the robot was recorded in the quantitative OME data. This reveals that on one occasion M5 refused the robot and M16 refused MARIO on the first two occasions that it was offered to him. These refusals were related to M5 being preoccupied with thoughts of going home when he said he was too busy. For M16, his refusal of MARIO occurred on days that he was refusing everything that carers offered to him.

There is considerable data, from multiple sources, that records participants willingness to use the robot. For example, R13 who observed several sessions, noted:

*'I think she [M13] really welcomes having the robot'(Interview with R13).*

However, the data reveals that although participants always welcomed the facilitators sometimes participants were not initially in a state of readiness to use MARIO and that they needed the support of a facilitator, a rapport developed with them to achieve readiness to access the robot. The degree this was needed varied between individual participants. For M13, what R13 called the 'preamble' between the facilitator and the participants, prior to her using MARIO was important. M13 needed to be comfortable with the facilitator before she could engage with MARIO. For other participants, they needed the facilitator communicate with them about what they were preoccupied with when they were offered MARIO. For example, at the beginning of one session the facilitator found that M20 was in her alone in her room alone hallucinating and disorientated. The facilitator needed to spend time with M20 until she was ready to use MARIO. This started with the facilitator joining M20 in with her reality in which M20 considered that she was dealing with her young sick child. The following was observed:

School run today and young. [M20] asking has the Dr come. Fellow [her child] off sick today. Not fully engaged with MARIO until reassured. [Facilitator] Talked to [M20] and reassured her Dr coming and that boy will be alright. Talked and later [M20] willing to engage with MARIO smiling to music (Observation OME M20 Session 4).

Sometimes participants were initially slightly hesitant to use MARIO. Initial reluctance was impacted by participants' confidence, their energy levels and their mood and level of wellbeing when they were offered the robot. When wellbeing was low participants occasionally expressed that they were feeling tired, or too old, or that they did not think they could use the robot. The following extract concerned M14 and was typical of the initial hesitation that was observed and the actions the facilitator took to lift the mood of M14 to enable her to start using MARIO:

*At first [M14] hesitant to interact with MARIO, she thought it would be too hard to use and she wouldn't be good at it. Research started to play some music and then M14 picked up and was happy to have MARIO and wanted to look at photos. [M14] was happy about interaction at the end of the session and thanked facilitator for coming out with MARIO and said would be happy for MARIO to come back. (Observation OME M14 Session 4).*

During the interactions with MARIO, due to the cognitive and physical debility and robot factors, facilitators needed to help participants maintain their readiness to use MARIO. This support was given in a scaffolded style that reflected participants needs which varied along with their dementia and physical frailty the degree of which varied within and between participants with dementia throughout and between the sessions.

All participants needed a degree of facilitation to support them in their usage of MARIO's touchscreen, but with this support they were able to use the touchscreen particularly using a stylus which increased participants' accuracy touching the appropriate place on the screen. Successful usage was observed and reported by relatives and carers:



S16 'Once the task was there in front of him and he [M5] knew what he had to do, he was like on the job.'

All participants had some degree of difficulty using MARIO and managing the touchscreen (Table \*\*.) The degree of difficulty due to cognitive and dexterity issues varied between cases from not having any difficulty to having very great difficulty. But between cases the most frequent level of difficulty was slight. Within cases the degree of difficulty varied across sessions. The degree of dextrous difficulty was not related to the level of cognitive difficulty (-0.36365 Pearson's Co-Efficient). The degree of cognitive difficulty apparent using MARIO was barely related to level of cognitive disability (-0.46365). Difficulties included manipulating the stylus, reaching the screen with hands or arms getting tired. Some participants pressed too hard, used a multiple tap, or tapped in the wrong part of the screen.

Participants also had difficulty maintaining their concentration as they were easily distracted. This was more problematic due to external factors for M1, whom facilitators could not easily move to a quieter place as he was only mobile with the assistance of two carers and help to move M1 was frequently unavailable to facilitators. Even when there were few external sources of distraction, some participants were frequently intermittently unable to maintain their concentration during sessions. The data reveals that all participants varied between no distraction to this occurring for most of the time, throughout the sessions as to the amount they were distracted and that the frequency and amount they were distracted was slightly negatively associated related to their degree of dementia (-0.61961 Pearson's Correlation). However, this is distraction that occurred with the facilitator present and acting as explained below.

Robot factors also impacted the readiness of participants to use MARIO. Software issues caused difficulty occasionally and there were three technical failures that required the engineer to reset MARIO. Difficulties were also noted for individual participants. For example: MARIO's voice was difficult to understand for M18, the robot's screen was difficult to read by participants sat in low chairs, the robot read the news too fast for M1 and one game had too many choice options for M1.

The facilitator acted to support participants through giving explanatory and reminding prompts, when focus was reduced, encouragement, advice, reassuring, trouble-shooting or occasionally stepping in to manipulate the touchscreen. The facilitator acted pragmatically as individuals needed aiming for the participant with dementia to doing as much as they were able whilst keeping them interested and enjoying maintaining the interaction. For example:

Facilitator says: 'Tap a little bit harder' verbal direction and then [as no response from M20] physical demonstration facilitator, 'Like this' (Observation OME M20 Session 6).

For M1, who had difficulty initiating and maintaining conversation, the facilitator prompted and supported conversation. The following reminiscence conversation was stimulated by photographs on MARIO:

Facilitator 'Was it a nice day'

M1 'Yes'

Facilitator 'It looks sunny'

M1 'It was'

Facilitator 'What's all this machinery for?'

M1 'Farming' (Observation OME M1 Session 11).

The facilitator was observed to build up the mood of the participants and help them to maintain positivity and focus during sessions. The facilitator's role was emphasised by R13 who noted that training for skilled facilitation needed to be part of a 'proper strategy for delivering' MARIO. The importance of having a skilled facilitator was observed when M13's daughter pointed out to M13 that she could not correctly identify herself in a picture and this M13's buoyant mood to deflate.

The data from carers and observations reveal that given the current capability of MARIO, it is unlikely that people with this level of dementia would be able to initiate and maintain their readiness to use MARIO without a facilitator. S15 and S14 considered that participants would always need someone to set up MARIO and remind them how to use the robot. Some spontaneous unprompted touchscreen use was observed as participants moved successfully through the applications. Observations were also conducted when some participants used MARIO for between 2-5 minutes without the facilitator present, after the session had been set up for participants. The degree of successful independent usage was related to the individual's degree of cognitive difficulty and physical frailty.

#### Deviant cases

M15 was a deviant case who found MARIO less acceptable than the other cases. M15 was most unready in to use MARIO and illustrated this through her lack of willingness to engage with the robot and her withdrawal from the research project. M15 said clearly that she had used MARIO twice and did not want to use it again and that when she saw MARIO '*He upsets me*'. This lady did not really explain what aspect of MARIO she found upsetting but made an interesting comment, saying that MARIO would probably be good for her sister in law because she lived on her own. It can be surmised that part of her reason for not using MARIO is because she did not need it because she had sufficient company. In addition, it could have been that the presence of the robot she found upsetting because she linked its presence with the prospect of having reduced contact with people. This is supposition however, without supporting data.

M17 also said that she did not want to use MARIO again after using it 4 times, she was unable to express in depth the reason why but said she did not like the robot. Her withdrawal was also linked to its possible negative impact upon her, which is discussed below.

#### Points and questions for further consideration

When does encouragement and facilitation to increase readiness become manipulation? Skill of the facilitator is important again here. Refusal is refusal so there is a clear difference.

Readiness involves what the robot means to the participant with dementia: what it can do for them in terms of usefulness.

END

**Appendix 21) Paper Four: Table showing the Coding Framework categories and the Final Themes.**

The Coding Framework Categories and the Final Themes			
Name of Framework Categories	Description of Framework Categories	Name of Final Themes	Description of Themes
The Nature of Adversity	This category encompasses the data relating to the stresses and difficulties that are experienced by the people with dementia in this context. It includes factors related to living with dementia including cognitive and communication difficulties, physical ill-health.	Resilience changes minute to minute	This theme describes how PWD experienced and responded to adversity with fluctuating degrees of adaptation and wellbeing, which impacted how they used MARIO
Degree of Adaptability to Adversity and Wellbeing	This category encompasses the data concerning the degree to which individuals have responded to adversity and adapted to it. It concerns the degree of psychological wellbeing experienced by the person with dementia including their emotions experienced and their perceived quality of life. It also includes the degree to which they have accepted or resist their current lives.	Initiating and maintaining readiness	This theme describes what needed to be addressed before and throughout each interaction with MARIO, to enable PWD to use MARIO. It concerns PWD's attitudes towards MARIO, their willingness and ability to use MARIO, and the support PWD required from facilitators to enable them to access and engage with MARIO.
Factors Impacting Response to Adversity	This category includes the data related to factors that impact how the individuals with dementia respond to difficulties they experience in their lives. It encompasses their personal resilience repertoires and their current capacity for resilience. It also includes the availability of resources for resilience that are external to the individual with dementia. Including the degree relationships are person-centred.	Active co-creation of meaningful activity	This theme describes how sessions with MARIO provided PWD with increased opportunities for meaningful activity. It also describes how PWD were active in responding to MARIO and worked in partnership with facilitators to actively create how MARIO was used for meaningful activity.
Factors Impacting Usage of MARIO	This category encompasses factors that impact the readiness of individuals to use MARIO and those that influence how MARIO is used during sessions.		
Impact on Resilience during Sessions with MARIO	This category encompasses data concerning the impact that MARIO has on resilience during the sessions with MARIO.	Impact on resilience	This theme describes the positive impact on resilience that occurred during sessions with MARIO. It also includes questions as to whether the impact was sustained after the sessions were over.
Impact on Resilience between and after Sessions with MARIO	This category concerns the effect of MARIO on resilience in between the sessions with MARIO and after the group of sessions with MARIO has finished.		

**Appendix 22) Paper Four: Member checking of draft findings report – Caregiver participant.**

During phase 8 of the data analysis the themes were finalised in a written report. One caregiver was invited by email to read the draft findings report and to consider if the findings seemed plausible. The caregiver was then invited to meet SW to provide the researcher with feedback and to discuss the caregivers impressions about the findings. On the 9<sup>th</sup> December 2019 SW and the Caregiver participant met and the notes copied below on key issues discussed were recorded. Following the discussion, the caregiver strongly agreed that the findings concurred with their experience and they were happy to sign a statement to record their agreement. Following the meeting, SW recorded her reflections on the meeting in an excerpt of the reflective diary that is copied below.

**Notes on Key Issues discussed during Feedback meeting:**

1 S16 agreed overall that the findings were plausible

2 The lack of meaningful activities and their importance 'rang true' for S16 and she reflected that this needs to be highlighted for caregivers.

3 Discussed the constraints of the physical environment and architecture and how this impacts care.

4 S16 found the findings in relation to the facilitator accurate and that their skills impacted the MARIO sessions and the impact of MARIO.

5 S16 mentioned that the ability of people with dementia to learn something new was clear in the findings and she suggested that caregivers need to appreciate this.

6 She reflected that unfortunately the residents' feelings of being trapped and the language used by caregivers were familiar to her.

7 S16 was surprised at the relative lack of engagement with MARIO's news application, as in her experience older people like the news. But she speculated that it might have been easier for residents to engage with the painting and music application.

8 S16 noted that the tendency of residents to forget MARIO was similar to them forgetting any other activity. So it was not a reflection on MARIO.

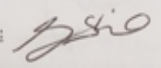
9 S16 endorsed the themes and said that they were plausible fitted with her experience. In particular she said commented saying variability was true for most people with dementia and that very few residents were happy all the time. Also, she considered that MARIO worked because it was person-centred and because the residents had a good therapeutic relationship with the facilitator that was based on trust.

10 S16 also considered that some caregivers are more resistant to all types of change than are other caregivers. So, the finding that caregivers attitude towards MARIO was mixed was not a surprise to her and she considered this typical.

**Researcher Question:** How much do the findings of the study resonate with your experience?

**Caregiver Response:**

Disagree very much	Disagree Slightly	Neutral	Agree Slightly	Agree Strongly
--------------------	-------------------	---------	----------------	----------------

Signature of Participant: 

Date: 09.12.2019.

**Exert from Reflective Diary Entry 9<sup>th</sup> December 2020**

*'This was an interesting experience and I am reflecting after the interview with the caregiver that I chose the right caregiver to approach! She gave thoughtful in depth feedback which indicated that she had read the whole report and engaged deeply with it. I am mindful that there is the potential with member checking that participants may be offended by the findings. This was not the case with this caregiver as she had enough objectivity to realise that the findings supported her efforts to improve care.*

*She affirmed that a lack of memory of MARIO was similar to other activities that could be meaningful at the time. These too may not be remembered. She also reminded me that caregivers can be sceptical about any new initiatives, they will be variously received by caregivers. i.e. there is a lot about MARIO that is not particularly different to other psychosocial interventions. Attitudinal differences may be a reflection of resistance to any change. Her feedback also emphasised the role of the facilitator and their skills in making MARIO person-centred and therapeutic. In particular she articulated that trust and the quality of this relationship was central MARIO being successful. This point is pertinent and revealed in the data.*

*It was also insightful for me to have the opportunity to discuss the meaning of the findings with this experienced dementia nurse. S16 also pointed out that the residents who are relatively busy, may be involved in activities that are not meaningful to them and they forget when they have been employed meaningfully. And, being busy in a group may not be meaningful for residents and people with dementia might not be able to engage fully within a group without one to one support. This caregiver emphasised that MARIO's impact was derived from its activities being personalised and its facilitation being person-centred. These two factors may not be possible in group settings.*

*We also discussed that the MMSE is not in this caregivers opinion helpful for people with poor education or those who might not have a good experience of school, particularly in the historical Irish context. Eg being asked to spell the word WORLD backwards. I am reminded of a recent conversation with a person who said that they were never once encouraged when they were in school or told that they had done something well. She mentioned that some residents might say they don't know something for fear of getting an answer wrong and in an attempt to stop the researcher asking them another question. This raises interesting issues about the context (both internal and external to the person) which impacts the usage and results obtained in the MMSE and other cognitive tests.'*

**Appendix 23) Paper Four: Member checking of draft findings report - Relative participant.**

During phase 8 of the data analysis the themes were finalised in a written report. A relative of a person with dementia who used MARIO who was a relative participant in the study was invited by email to read a report of the study draft findings report and to provide feedback. The relative was unable to meet with the researcher in person to discuss the findings but an email, which is copied below, was received from them on February 6<sup>th</sup> 2020

**Email from Relative Participant:** *'So sorry for the delay in sending this back to you. I'm retiring this summer and I'm up to my eyes trying to ensure all is done. This is a very good report and you present the findings well. I added a few comments but you have made a difficult topic easy to follow. I think the use of quotes helps to ground it in the reality of living with dementia.'*

The following reflective diary excerpt refers to the relative's feedback and it records how SW judged appropriate to incorporate the relatives' views into the findings report.

**Exert from Reflective Diary 7<sup>th</sup> February 2020:** *'...she [the relative] endorsed and supported the findings. Judging by the spelling and editorial amendments on the report she [the relative] has clearly engaged with the report and thoughtfully reviewed its contents. She [the relative] has clearly endorsed the findings. Her main comment was to stress that no participant with dementia was distressed by MARIO. This point will be added to reports about the findings.'*

**Appendix 24) Permission to Reproduce Published Material in this Thesis.**

**SPRINGER NATURE LICENSE TERMS AND CONDITIONS**

**This Agreement between National University of Ireland Galway -- Sally Whelan ("You") and Springer Nature ("Springer Nature") consists of your license details and the terms and conditions provided by Springer Nature and Copyright Clearance Centre.**

**License Number 4904280051639**

**License date Sep 08, 2020**

**Licensed Content Publisher Springer Nature**

**Licensed Content Publication International Journal of Social Robotics**

**Licensed Content Title: Factors Affecting the Acceptability of Social Robots by Older Adults Including People with Dementia or Cognitive Impairment: A Literature Review**

**Licensed Content Author Sally Whelan et al**

**Licensed Content Date Mar 1, 2018**

**Type of Use Thesis/Dissertation|**

**Requestor type non-commercial (non-profit)**

**Format print and electronic**

**Portion full article/chapter**

**Will you be translating? no**