The Factors Influencing Adjustment to Nursing Home Admissions as Perceived by Caregivers of Persons Living with Dementia

A dissertation presented to the Faculty of Health Sciences in part-fulfilment of the requirements for the Degree of Master of Science in Nursing at the University of Malta

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Abstract

Overview of the Dissertation

This dissertation investigates the factors that influence adjustment for persons with dementia when admitted to nursing homes as perceived by their informal caregivers.

Background of the Study

When persons with dementia are admitted to nursing homes it can be very difficult for them to adjust, especially with a new environment and routine. By understanding the factors that influence adjustment, their transition can be made easier throughout all the phases - pre, mid, and post transition. This can improve their quality of life at the nursing home, especially during the transition process.

Key Research Question

What are the factors influencing adjustment to nursing home admissions as perceived by the caregivers of persons with dementia?

Methodology

This dissertation is a narrative qualitative approach. Six semi-structured interviews were conducted during the months of October and November 2022. The TRANSCIT model was used to critically discuss the findings.

Key Results

The findings were analysed using a software called MAXQDA which is a tool for qualitative data analysis and data management. The themes generated were: *nursing home environment, regular visits, maintaining a routine, nursing home staff and engaging activities.*

Conclusion and Recommendations

Optimum adjustment requires an organised transition from hospital/home to nursing home which should include a pre-transition phase. A person-centred approach that supports individualised activities can facilitate the transition process. Staff education and training on person centred dementia care especially to acute hospital staff is needed. Moreover, a dementia friendly environment in residential homes is recommended.

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Table of Contents

Authenticity and Research Ethics Form ii
Abstract iii
Acknowledgements iv
Table of Contents v
List of Figures x
List of Tables xi
Abbreviations and Acronyms xii
Chapter 1 1
1. Introduction 1
1.1 Introduction 1
1.2 The Problem Being Investigated 1
1.3 The Purpose of the Study 2
1.3.1 The Reasons for Selecting the Area of Study 2
1.3.2 The Research Question and Research Aims 2
1.3.3 The Research Methodology 3
1.4 The Study's Relevance and Significance and How it Adds to the Theoretical Body of Knowledge in the Field 3
1.5 Epidemiology of Older Persons with Dementia and Admissions to Nursing Homes 3
1.6 Narrative Inquiry 4
1.7 The Outline of the Research Project 5
1.8 Conclusion 6
Chapter 2 7
2. Literature Review 7
2.1 Introduction 7
2.2 The Theoretical Framework and its Application to the Research Topic 7
2.3 The Search Strategy 10
2.3.1 Boolean Operators and MeSH Terms 11
2.3.2 Study Selection 14
2.4 Characteristics of the Included Studies 15
2.5 PRISMA 2009 Flow Diagram 16
2.6 Quality Appraisal of the Qualitative Studies 24
2.6.1 Sampling and Participant Recruitment of the Qualitative Studies 24

2.6.2 Data Analysis of the Qualitative Studies 25
2.6.3 Data Rigour 25
2.6.4 Quality Appraisal of the Systematic Reviews by Sury et, al., (2013), Brownie et, al., (2014) and Yong et, al., (2020) 26
2.7 Quality Appraisal of the Quantitative Studies by Reinardy et, al., (1992) and Wareing et, al., (2021) 29
2.7.1 Strengths and Limitations in the Quantitative Studies 30
2.8 Discussion of the Findings of the Factors Influencing Adjustment to a Nursing Home 30
2.8.1 Factors Influencing Nursing Home Adjustment 33
2.8.1.1 Depression in Older Persons/persons with Dementia 33
2.8.1.2 Older Person/person with Dementia's involvement in Decision-making. 33
2.8.1.3 Activities and Hobbies in the Nursing Home 34
2.8.1.4 Limited Function, Health and ADLs 35
2.8.2 Recommendations 36
2.9 Conclusion 38
Chapter 3 39
3. Research Methodology 39
3.1 Introduction 39
3.2 Problem Being Investigated 39
3.3 Aims and Objectives 39
3.4 The Epistemology, Research Design and Research Paradigm Implemented in the Research Project 40
3.5 The Methodology: Narrative Inquiry 40
3.5.1 Constructivism 42
3.6 Sampling Technique 42
3.6.1 Sample Size and Sampling Method 42
3.6.2 Inclusion Criteria 43
3.6.3 Sample Recruitment 44
3.6.4 Research Setting 44
3.7 Data Collection 45
3.7.1 The Interview Research Method 45
3.7.2 Applying Reflexive Interviewing 45
3.8 Data Analysis 48

3.8.1 The Coding Exercise 49
3.9 Quality and Rigour 53
3.9.1 Verification Strategies 53
3.9.2 Quality Control 53
3.9.3 Achieving Trustworthiness as Expressed by Lincoln and Guba (1985) 54
3.9.4 Achieving Validity Amongst Interviews 55
3.10 Ethical Considerations 56
3.10.1 Informed Consent 57
3.10.2 Research Confidentiality and Anonymity 57
3.10.3 Risk of Harm 57
3.10.4 Role of the Researcher 57
3.11 Conclusion 58
Chapter 4 59
4. Key Findings 59
4.1 Introduction 59
4.2 Data Analysis Tool and the Demographic Characteristics of the Participants 59
4.3 The Coding Schema 63
4.4 Theme 1: Nursing Home Environment 64
4.4.1 Sub-category: An Engaging Environment 64
4.4.2 Sub-category: A Small and Quiet Ward 65
4.4.3 Sub-category: Adjusting to a New Environment 66
4.4.4 Sub-category: A Closed Environment 68
4.5 Theme 2: Regular Visits 70
4.5.1 Sub-category: Regular Visits by Family Members 70
4.5.2 Sub-category: Regular Phone Calls by Family Members 72
4.5.3 Sub-category: Animal Visits 72
4.6 Theme 3: Maintaining a Routine 73
4.6.1 Sub-category: Adjusting to the New Ward Routine 74
4.6.2 Sub-category: Engaging Routine 75
4.7 Theme 4: Nursing Home Staff 76
4.7.1 Sub-category: Personal Qualities of the Staff 76
4.7.2 Sub-category: Staff Well Trained in Dementia Care 78
4.7.3 Sub-category: Welcoming Staff 80

4.8 Theme 5: Engaging Activities 81
4.8.1 Sub-category: General Activities 81
4.8.2 Sub-category: Specifically Tailored Activities 82
4.8.3 Sub-categories: Having a Yard Outside, Going Outside, and Outings 83
4.9 Conclusion 85
Chapter 5 86
5. Discussion of Findings 86
5.1 Introduction 86
5.2 The TRANSCIT Model in Relation to the Research Findings 86
5.2.1 The Use of MAXMaps 88
5.3 Theme 1: *Nursing Home Environment* 89
5.3.1 Sub-category: *An Engaging Environment* 89
5.3.2 Sub-category: *Adjusting to a New Environment* 90
5.3.2.1 Advantages of Special Care Dementia Units 91
5.3.3 Difference Between Admission from Home and Admission from Hospital 91
5.4 Theme 2: *Regular Visits* 93
5.4.1 Sub-category: *Regular Visits by Family Members* 93
5.4.2 Sub-category: *Animal Visits* 95
5.5 Theme 3: *Maintaining a Routine* 96
5.5.1 Sub-category: *Adjusting to the New Ward Routine* 96
5.5.1.1 Setting Routines such as 'Regular Outings' 97
5.6 Theme 4: *Nursing Home Staff* 98
5.6.1 Sub-category: *Personal Qualities of the Staff*: *Compassionate Care (PCA)* 98
5.6.2 Sub-category: *Welcoming Staff* 100
5.6.3 Sub-category: *Staff Well-trained in Dementia Care* 100
5.6.3.1 Dementia care in acute hospitals and the need to provide person-centred dementia care in these settings 101
5.7 Theme 5: *Engaging Activities* 103
5.7.1 Sub-category: *Specifically Tailored Activities* 103
5.7.1 Sub-category: *General Activities* 105
5.8 Conclusion 105
Chapter 6 106
6. Conclusions and Recommendations 106
6.1 Introduction 106

6.1.1 Summary of the Dissertation Process 106
6.2 Summary of the Study and Relevant Findings 106
6.3 Implications and Recommendations for Practice 108
6.3.1 Implementing the "This is Me" booklet (Alzheimer's Society) into Practice in Dementia Units and Residential Homes 108
6.4 Implications and Recommendations for Education 109
6.4.1 Staff Training on Dementia and a Person-Centred Care 109
6.5 Implications and Recommendations for Management 109
6.6 Implications and Recommendations for Further Research 110
6.7 Summary of the Implications and Recommendations 111
6.8 Strengths and Limitations 111
6.9 Conclusion 112
References: 113
Appendices 119
Appendix 1: CASP Tool for Systematic Review 119
Appendix 2: CASP Tool for Qualitative Studies 123
Appendix 3: CASP Tool for Quantitative Studies 129
Appendix 4: Intermediary Letter 136
Appendix 5: Information and Consent Letter (English) 137
Appendix 6: Information and Consent Letter (Maltese) 141
Appendix 7: Request for Permission to Conduct Research at St. Vincent de Paul Long-term Care Facility 145
.... 145
Appendix 8: General Data Protection Clearance Declaration Form 146
Appendix 9: Request for Psychological Support to Study 147
Appendix 10: Approval by FREC via email to Conduct Research Study 148
Appendix 11: Interview Schedule: English Version 149
Appendix 12: Skeda tal-Intervisti: Verżjoni bil-Malti 150
Appendix 13: Reflexive Diaries 151
Appendix 14: "This is Me" Booklet by the Alzheimer's Society 154
Appendix 15: The Coding Schema 160
Appendix 16: The Code Matrix Browser for the Resultant 161
Categories and Sub-categories 161

List of Figures

Figure 1: The TRANSCIT Model by Groenvynck et, al., (2021) ... 7
Figure 2: Screenshot of the Coding Paradigm using MAXQDA with its Four Interactive Screens ... 49
Figure 3: An Extract of the Code System for the Resultant Categories and Sub-categories ... 51
Figure 4: A Screenshot of the Code Matrix Browser for the Resultant Categories and Sub-categories with their Respective Weight Scores ... 52
Figure 5: The Resultant Framework's Themes (Categories) and Sub-categories ... 63
Figure 6: Code Matrix Browser Illustrating the Resultant Coding Intensity for Theme 1: Nursing Home Environment ... 64
Figure 7: Code Matrix Browser Illustrating the Resultant Coding Intensity for Theme 2: Regular Visits ... 70
Figure 8: Code Matrix Browser Illustrating the Resultant Coding Intensity for Theme 3: Regular Routine ... 73
Figure 9: Code Matrix Browser Illustrating the Resultant Coding Intensity for Theme 4: Nursing Home Staff ... 76
Figure 10: Code Matrix Browser Illustrating the Resultant Coding Intensity for Theme 5: Engaging Activities ... 81
Figure 11: The TRANSCIT Model (Groenvynck. L, et. al., 2021) ... 86
Figure 12: MAXMap Demonstrating the Theme - Nursing Home Environment ... 89
Figure 13: MAXMap Demonstrating the Theme - Regular Visits ... 93
Figure 14: The Care Triads Displaying Interactions and Matching Identity Positionings (Koster, 2021) ... 94
Figure 15: MAXMap Demonstrating the Theme - Maintaining a Routine ... 96
Figure 16: MAXMap Demonstrating the Theme - Nursing Home Staff ... 98
Figure 17: MAXMap Demonstrating the Theme - Engaging Activities ... 103

List of Tables

Table 1: Objectives of the Research Project ... 2
Table 2: An Outline of the Chapters in the Dissertation ... 5
Table 3: The Four Components of the TRANSCIT Model ... 9
Table 4: Explanation of the Search Engines/Databases Used for this Research Topic ... 11
Table 5: The PEO Elements and their Relevant MeSH Terms ... 12
Table 6: Audit-Trail of the Search ... 14
Table 7: Inclusion and Exclusion Criteria ... 15
Table 8: Descriptions and Characteristics of the Research Articles to be Appraised ... 17
Table 9: Qualitative Data Rigour Validated by the Criteria of Guba and Lincoln (1985) ... 26
Table 10: Types of Biases ... 28
Table 11: Summary of the Findings in Qualitative Studies ... 32
Table 12: Summary of the Findings in Quantitative Studies ... 33
Table 13: A Summary of the Recommendations Generated from the Literature Review ... 37
Table 14: Objectives of the Research Project ... 40
Table 15: Main Elements of a Qualitative Narrative Inquiry ... 41
Table 16: Inclusion and Exclusion Criteria ... 43
Table 17: Reflexive Diary: Extract from Reflexive Interview nº5 ... 46
Table 18: Mistakes and Recommendations for a Reflexive Interview by Passoa et, al., (2019) ... 47
Table 19: Fontana and Frey's (1994) Six Key Considerations ... 56
Table 20: Demographic Characteristics of the persons with Dementia that Participated in the Research Project ... 62
Table 21: Explanation of how the Four Components are Needed in Each Transition Phase ... 88
Table 22: The Meaning of the Colour-Coded Connecting Links of the MAXMap ... 89
Table 23: Brief Meaning of the Four Triads Established by Koster et, al., (2021) ... 94
Table 24: Flexibility and Persistence According to Groenvynck et, al., (2021) ... 95
Table 25: The 5 Elements Needed for Loving Care According to Kitwood (1997) ... 100
Table 26: A Segment from This is Me Booklet by Alzheimer's Society ... 104
Table 27: The Five Themes from the Research Study Representing the Five Most Important Factors Influencing Nursing Home Adjustment ... 108

Abbreviations and Acronyms

ADL: Activities of Daily Living

CASP: Critical Appraisal Skills Programme

CEO: Chief Executive Officer

CINAHL: Cumulative Index of Nursing and Allied Health Literature

Covid-19: Coronavirus Disease 2019

FREC: Faculty Research Ethics Committee

HCP: Health Care Professional

MAXMaps: MAXQDA Software Package Mapping Function

MAXQDA: MAX Qualitative Data Analysis Software

MDH: Mater Dei Hospital

MDS: Minimum Data Set

MEDLINE: Medical Literature Analysis and Retrieval System Online

MeSH: Medical Subject Headings

NHA: Nursing Home Adjustment

NHAS: Nursing Home Adjustment Scale

PCA: Person-Centred Approach

PHQ-9: Patient Health Questionnaire 9

PsychINFO: Psychological Information database

PubMed: Public/Publisher MEDLINE

RACF: Residential Aged Care Facility

STROBE: Strengthening the Reporting of Observational Studies in Epidemiology

SVPR: St. Vincent de Paul Residence

TAP: Tailored Activity Program

TRANSCIT: Transition - Support, Communication, Information and Time

UOM: University of Malta

Chapter 1

1. Introduction

1.1 Introduction

This Chapter will familiarise the reader with the topic being investigated in this research project. The researcher will be focusing on the factors influencing the adjustment of a person with dementia when being admitted to a nursing home from the perspective of informal caregivers. This research project will seek to identify the main factors and recommend suggestions on how to improve nursing practices during this time of adjustment. Finally, this will improve the overall experience of the person with dementia being admitted to the nursing home as their adjustment can be improved if these recommendations are introduced in practice.

The outline of Chapter 1 is as follows; the problem being investigated, the purpose of the study, the study's relevance and how it adds knowledge to the theoretical body of the field, epidemiology of dementia and admissions to nursing homes, the research methodology and finally the outline of the research project.

1.2 The Problem Being Investigated

The scope of this dissertation is to understand from the informal caregiver's perspective of the factors influencing the adjustment of a nursing home admission of persons living with dementia. This study aims to improve nursing practice and to identify what is required to facilitate a better quality of life for the person with dementia in a nursing home. Current knowledge, albeit limited, already indicates that the adjustment is difficult for the person with dementia and for their informal caregivers as the person with dementia may experience increased agitation, confusion, and falls. During this transition, the informal caregiver of the person with dementia may experience increased burden and a feeling of failure (Sury, 2013). Importance needs to be given to the transitional process and particularly to how it affects the relatives of a person with dementia. Their experience will determine what are the issues and what is missing in the transitional process. This research study will identify what could be done to achieve better outcomes during the transition to a nursing home, thus improving the quality of life of a person with dementia and his or her informal caregivers.

1.3 The Purpose of the Study

1.3.1 The Reasons for Selecting the Area of Study

A good number of persons with dementia may require admission to a nursing home once they are deemed not fit to live alone and their caregivers can longer take care of them. Unfortunately, what happens is that once admitted, some do not adjust because the transition process may not be adequate. Therefore, the researcher wanted to find out more about this phenomenon and how to improve the overall transition and adjustment.

1.3.2 The Research Question and Research Aims

The research question is:

What are the factors influencing adjustment to nursing home admissions as perceived by the informal caregivers of persons with dementia?

Table 1 outlines the objectives of the dissertation.

Objectives
1. Examine the informal caregiver's experience on how their relative with dementia adjusted during the first week of admission and then during the first month.
2. Identify the factors influencing the adjustment of persons with dementia to nursing homes.
3. Identify the barriers that affected the adjustment of the persons with dementia.
4. Identify the areas that need improvement in nursing homes to meet the needs of these persons so that they can adjust better during this transition.

Table 1: Objectives of the Research Project

1.3.3 The Research Methodology

The research methodology that the researcher will be implementing in this dissertation is Narrative Inquiry. This type of qualitative approach will help the researcher view the whole story of the caregiver of the person with dementia as they narrate it. Content analysis will be used to code and identify the factor influencing the adjustment to nursing home admissions. This will aid in categorising codes on the certain phrases participants say.

Data collection is going to occur from primary sources through semi-structured interviews. The participants will be chosen from the dementia wards at St Vincent de Paul Residence - a long-term care institution in Malta. The interviews will be held with informal caregivers of these chosen residents. MAX Qualitative Data Analysis (MAXQDA) software will be used as a qualitative data management tool for data management, storage, and analysis. This will help the researcher in identifying codes for identifying the themes and the factors influencing transition to nursing home.

1.4 The Study's Relevance and Significance and How it Adds to the Theoretical Body of Knowledge in the Field

Findings from this research study will assist nurses to better understand the factors at play and how they can use a person-centred care approach to the new admissions and help them adjust. The study will emphasise on the importance of the transition phases- pre, mid, and post and how importance should be given to all these phases in order to achieve optimum adjustment. The phases have been developed by Groenvynck et, al., 2021 in the TRANSCIT model that described the four important elements leading to successful transition, namely support, communication, information, and time. This model will be mentioned and discussed further to better understand the findings in the following Chapters. The findings from the study along with the implications and recommendations will ultimately provide more knowledge on how to improve adjustment.

1.5 Epidemiology of Older Persons with Dementia and Admissions to Nursing Homes

Dementia affects many people above the age of 65 worldwide (about 55 million people) (WHO, 2023) and only 4.4% being under the age of 65 (Alzheimer's Society, 2018). With the numbers always growing it is important to know how to make these persons with dementia's life easier and improve their quality of life. Sury et, al., (2013), identified strategies such as "orientation

of the residents and their families to the new environment, a buddy system on arrival, collaboration with families in the care planning process and telephone calls to families". There are no local studies that investigate this phenomenon, hence the importance of this study. There are also very few international studies focusing on adjustment of persons living with dementia with most studies focusing on residents with no cognitive impairment. Moreover, the perspective of informal caregivers of persons with dementia during the transition phase have also been poorly studied.

Nevertheless, the number of admissions to nursing homes because of dementia still continues to grow. In the United States alone in 2023, about 1.4 million people are living in nursing homes, and almost 50% (McCain, 2023) of them have dementia. It is estimated that 23% of these nursing homes (McCain, 2023) have dementia units and according to Jett (2018) the quality of life and quality of care is much better in these units when compared to general geriatric units.

Dementia is an umbrella term that describes a set of symptoms related to memory, language visual perception and other higher executive brain functions. There are different types of dementia the most common being, Alzheimers' Disease, Vascular dementia, frontotemporal dementia and Lewy body dementia. Since there is no cure of this disease, the only way to control it is with medication once diagnosed to delay the progression (Duong, 2017). Nursing homes and the residential staff in them should make the lives of the persons with dementia as comfortable as possible given the fact that they will remain there till death and that there is no cure for them to get better.

1.6 Narrative Inquiry

According to Eastoe et, al., (n.d), narrative inquiry is a good method to link individual human stories and events that they narrate into "interrelated aspects" of an understandable phenomenon. The researcher will be able to come up with codes from the similarities of the responses and gain a richer understanding of the subject from the deep discussions in the interviews.

1.7 The Outline of the Research Project

Table 2 below shows the outline of this dissertation.

Chapter	Outline
Chapter 2	This Chapter will offer a literature review with evidence-based peer reviewed research. The search strategies, discussion and analysis of the literature will be provided. Any gaps in knowledge will be explored.
Chapter 3	This Chapter will discuss the research methodology used in the research project. Research objectives will be discussed along with the tools used for data analyses. Ethical considerations will be explored along with the quality and rigour of the research.
Chapter 4	This Chapter will discuss the results from the data analysis with a representation of themes, categories, and sub-categories. They will be further supported with the portrayed quotes.
Chapter 5	This Chapter will discuss the research findings and each theme will be analysed with relation to the theoretical framework, The TRANSCIT Model. The findings will also be discussed in relation to the literature review as obtained from Chapter 2. This is to identify any gaps in knowledge. Strengths and limitations of the research project will end this Chapter.
Chapter 6	This is the last Chapter, and it will summarise the findings and emphasise the conclusions from this research project. A discussion will take place whether or not the research objectives from Chapter 1 were answered. Implications for better nursing practice and recommendations will also be discussed.

Table 2: An Outline of the Chapters in the Dissertation

1.8 Conclusion

A brief overview of the backgrounds and methodology that will be used was given and served as an introduction to this dissertation along with the objectives and purpose of this study. Chapter 2 will discuss the findings from the literature review followed by an analysis to elaborate on any gaps in knowledge.

Chapter 2

2. Literature Review

2.1 Introduction

The purpose of this literature review is to assist the researcher in further developing the research topic and identifying any gaps in the literature. Given that this research topic is particular and gaps are inevitable, the search strategy was not limited to persons living with dementia. Studies related to the transition to a nursing home of older persons with no cognitive impairment were also included. This can provide useful insight into the adjustment of a person being admitted to a nursing home. The TRANSCIT model by (Groenvynck et, al., 2021) will serve as a guide and a foundation for categorising the data gathered from the systematic review.

2.2 The Theoretical Framework and its Application to the Research Topic

In this section a discussion on the model chosen will be given. The TRANSCIT model (Groenvynck et, al., 2021), was chosen for this study which adapts very well as it focuses on the adjustment of older persons admitted to a nursing home, which can be influenced by the four components of the model. The word "TRAN" from TRASNSCIT stands for transition, and the SCIT from TRANSCIT stands for support, communication, information, and time. Figure 1 below portrays the model.

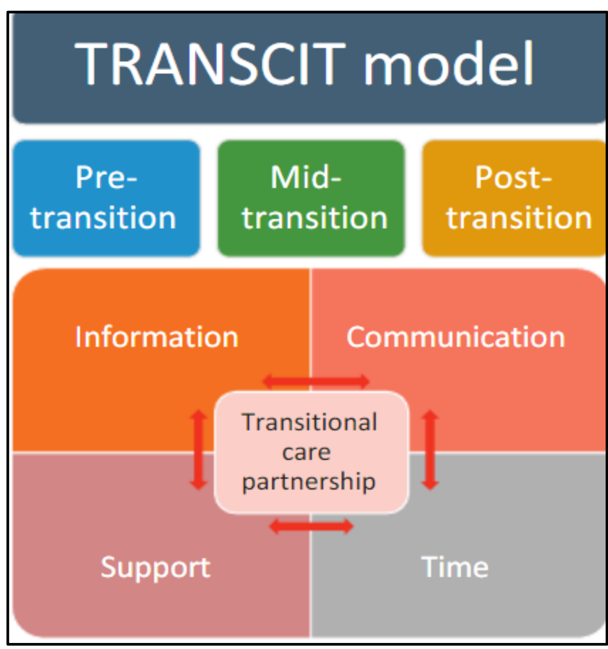


Figure 1: The TRANSCIT Model by Groenvynck et, al., (2021)

This model has been proposed by Groenvynck et, al., (2021), in a literature review study based on the experiences of older persons and their caregivers. Transitional care interventions often do not have a comprehensive approach which leads to a fragmented care approach. This model ensures to meet the needs of both the residents and their caregivers. The TRANSCIT model portrays the need for all four components: support, communication, information, and time, in every phase of the transition process: pre, mid, and post. Partnership is needed to ascertain that the components are met in each phase to subsequently meet a need.

According to Groenvynck et, al., (2021), this model can help nurses identify problems arising from this transition and improve outcomes and adjustment. It can advise policy makers and researchers to develop better transitional care interventions by using the TRANSCIT model as a guideline. This will aid in meeting the needs of older persons and their caregivers. An emphasis is put on the need for partnership for this to work accordingly. This model was chosen as it was deemed optimal for this dissertation. In Table 3 below, information and knowledge gathered from the literature review of Groenvynck et, al., (2021), is given on the four components of the model.

Support	**Communication**	**Information**	**Time**
Informal caregivers felt support throughout the phases emotionally, physically and mentally from the nursing home staff. It was recommended that in the **pre-transition**	The importance of an open dialogue was established throughout all phases. This means communication on feelings, expectations and exchanging knowledge. Interactions should take place pre and mid-transition phases to ease the transition and they should be positive and respectful.	The study by Groenvynck et, al., (2021), established that there needs to be a "person centred information" in educating the residents and their caregivers on the transition process. Information should be given on the general process **pre-transition** by the residential staff, and the caregivers should give information on any	For continuity of care to take place, time was required to prepare and make an ideal individualised care plan for the resident. It was expressed that for this to happen, a multidisciplinary team is required in the **pre-transition phase**.

phase, support is given by the residential staff when making the decision and offer practical support. In the **mid transition** phase, caregivers expressed how support was needed from the residential staff to pack belongings etc. In the **post-transition phase**, compassion, support and a feeling of home was needed.	It was found that adjustment is improved when the resident is exposed to the future home to familiarise oneself with the residential staff and other residents. In the **post-transition phase**, a "meeting" was held which really helped adjustment as caregivers had the chance to express opinions, feelings and questions to the residential staff and this allowed the development of a partnership.	specific things about the resident. In the **mid-transition phase**, the information gained needs to be transferred to the resident needs. At the **post transition phase**, any new information noted by both residential staff and caregivers about the care plan should be communicated and brought forward in order to subsequently benefit the resident and improve their adjustment.	Timely meetings were done at **mid-transition phase** to give updates and anticipate the move to allow time for the belongings to be gathered and settled. This allowed for a flexible and simple admission to take place. Time at the **post-transition phase** was imperative since it allowed the residents to establish the routine and potential new activities or hobbies.

Table 3: The Four Components of the TRANSCIT Model

Furthermore, for this all to work accordingly, a transitional care partnership is needed. The residential staff and the informal caregivers need to form a relationship, otherwise known as a *partnership*, to ultimately benefit the resident. This allows any new knowledge, opinions, ideas,

experiences, queries and even complaints to be addressed. The four components of the model act as the *ingredients* for a successful partnership, to help the adjustment of the elderly.

According to Groenvynck et, al., (2021), the TRANSCIT "defragments" the transition from home to a nursing home. By defragmenting care, the quality of the care improves and consequently, any negative outcomes are avoided. This in turn also allows the continuity of care from the health care professionals on the transition from home to a nursing home. This continuity of care promoted by the TRANSCIT model can also decrease the workload on healthcare professionals.

There is a lack of transitional care in the transition from home to a nursing home which makes the pathway difficult and limited standard care is kept. This is why the TRANSCIT model should be used, to monitor the pathway and use the components. If healthcare organisations use this model, they can benefit from it by comparing the care that is already in use with the recommendations from the model. This model thus acts as a guideline for interventions to be put in place.

2.3 The Search Strategy

This section will describe how the search strategy was carried out to identify the studies that would be eventually used to critically appraise the relevant literature. Table 4 describes the search engines used for the search strategy and the reason for doing so.

Search Engine or Database	**Reason**
PubMed	This database uses literature linked to life sciences hence why it was good to use in this search as it comes across health sciences as well.
MEDLINE Complete	MEDLINE is a sub-category of PubMed which was used in order to make sure every possible article was identified.
Google Scholar	This database allows for a search of scholarly literature such as academic journals, book

	Chapters and dissertations.
CINAHL Complete	This database is ideal for nursing-related literature as it has journals and publications related to nursing since they come from the National League for Nursing and the American Nurses Association.
AgeLine	This database focuses on the subject of ageing and since this study is related to dementia, it was ideal to use.
PsycInfo	This database covers all literature on psychology, behaviour and social sciences and goes all the way back to 1800 till the present.
HyDi	The University of Malta provides this platform to search literature which is ideal as one can retrieve local studies.

Table 4: Explanation of the Search Engines/Databases Used for this Research Topic

2.3.1 Boolean Operators and MeSH Terms

MeSH terms were used for the search strategy to get the most appropriate studies. Along with MeSH terms, Boolean operators were used such as "AND", "OR" or "NOT" to further expand the search and make sure adequate results were obtained. Furthermore, truncation symbols such as "*" within a word were also used in for example "caregiver*". This allows for a vast variety of endings of a term. For example, when looking for terms related to caregivers, the truncation symbol ("caregiver*") would ensure that other words such as "caregivers" or "caregiving" would be included. For different spellings of a word, wildcards were used such as "?". For example, "institutional?ed" was used as it could be spelt with a "z" or an "s". Table 5 describes the PEO elements and their relevant MeSH terms.

Population	Caregivers of persons with dementia	“Caregiver*” “Person with Dementia” “Relative*” “Next of Kin” “Person with Alzheimer*”
Exposure	Nursing home admissions	“Nursing home admission” “Institutional?ed” “Nursing home”
Outcome	Status of adjustment	“Adjustment” “Transition” “outcome”

Table 5: The PEO Elements and their Relevant MeSH Terms

No date restrictions were applied on the search itself. A manual search was also done to retrieve relevant studies that might have been missed from the traditional way of searching studies using databases or search engines. After the search, the researcher went through the studies to make sure that the conducted search retrieved studies within the inclusion criteria.

Table 6 below gives a detailed summary of the search strategy conducted that retrieved the chosen studies.

Date	**Database**	**Filters used**	**Key terms & Boolean terms**	**Total studies accumulated**	**Relevant studies**
05/08/2022	Google Scholar	/	“Person with Dementia” OR “caregiver*” AND “Nursing home	17,000	20

			admission” AND “Nursing home admission”		
08/08/2022	HyDi	Peer-reviewed Journals; Articles.	“Person with Dementia” OR “caregiver*” AND “Nursing home admission” AND “Nursing home admission” OR “Institutionali?ed”	5,219	9
08/08/2022	CINAHL Complete	English Language, Academic journals.		328	2
12/08/2022	PubMed	/		40	3
12/08/2022	Medline Complete	English Language, Academic journals.		38	11
17/08/2022	AgeLine	/		16	2

17/08/2022	PsychInfo	/		2	1

Table 6: Audit-Trail of the Search

2.3.2 Study Selection

The articles were screened for eligibility using the inclusion and exclusion criteria as shown in Table 7.

	Inclusion	**Exclusion**
Population	- Elderly people above the age of 65 being admitted to nursing homes with cognitive impairment. - Primary caregiver such as a spouse, sibling, daughter/son.	Elderly people without cognitive impairment*. * *An exception was made and this is discussed in section 2.6.*
Exposure	Nursing home.	Being admitted to a long hospital stay.
Outcome	Caregiver's view on how their relative being admitted to the nursing home has adjusted or not.	How the caregivers themselves have adjusted rather than their relatives.
Setting	At the nursing home following admission.	Participants own a house. Hospital.
Study Design	Systematic reviews and meta-analysis, phenomenological studies, quantitative studies.	Reviews, opinions, articles, and program interventions.

Language	English.	Non-English.

Table 7: Inclusion and Exclusion Criteria

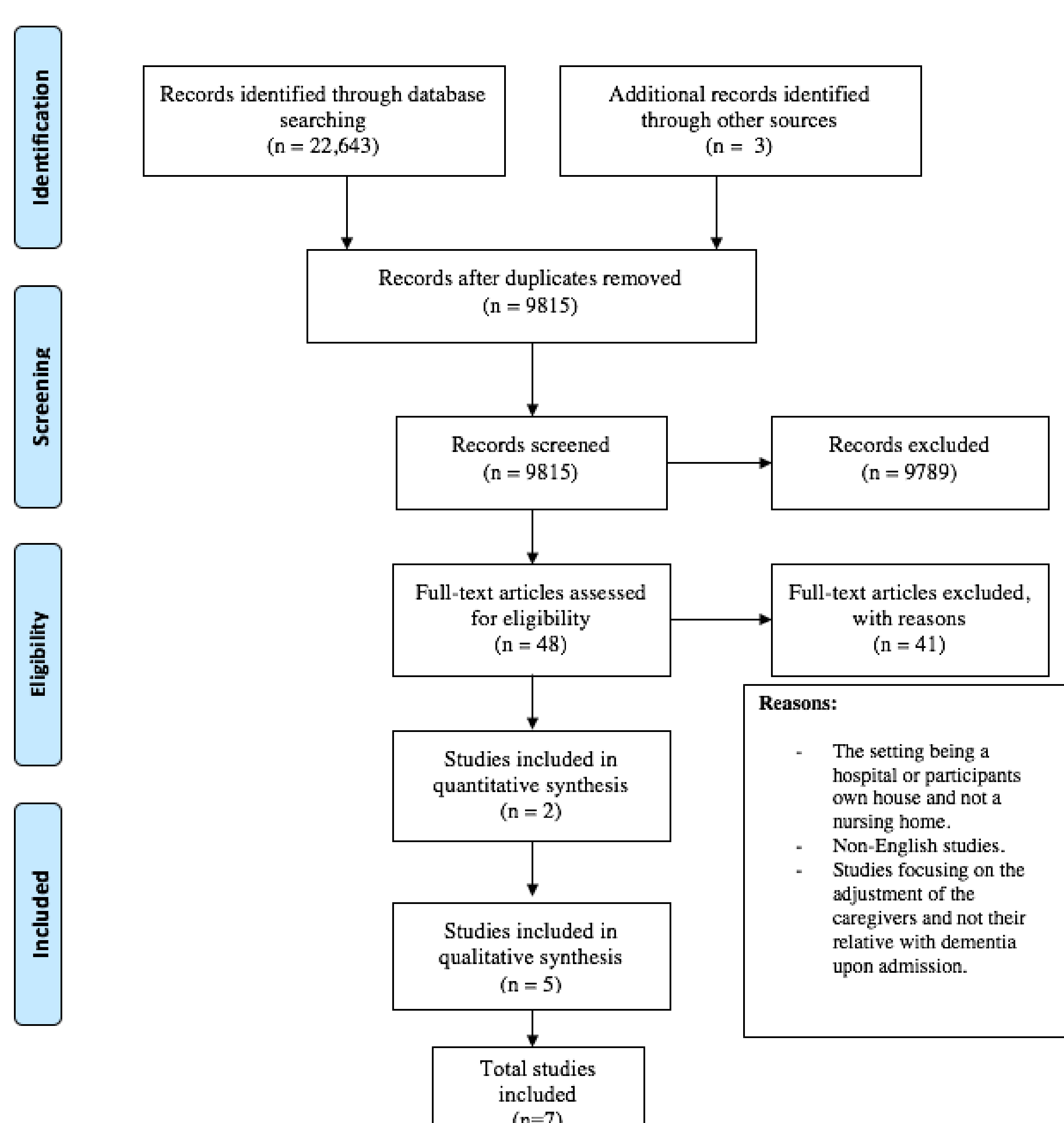
2.4 Characteristics of the Included Studies

The Critical Appraisal Skills Program (CASP, 2018) tool checklists were used and applied for the studies. The CASP tool assesses its validity, results, and clinical relevance. It consists of a checklist where the guided questions can be answered with “yes”, “no” or “can’t tell”. The researcher can identify any bias through the CASP tool and the clinical significance of the study results.

Furthermore, as shown in Table 8, the seven included studies consisted of two quantitative and five qualitative studies with dates ranging from 1992 to 2021. Three of the papers included persons with dementia where the interviewees were staff or relatives. The other five studies included persons without cognitive impairment, and they were the ones being interviewed. The studies ranged from China, Japan, and Australia to the United States.

Below one can find the PRISMA diagram which “depicts the flow of information through the different phases of a systematic review” (PRISMA, 2021). It shows how many records were identified, and the reasons for excluding or including them.

2.5 PRISMA 2009 Flow Diagram



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *Preferred Reporting Items for Systematic Reviews and Meta-Analyses*: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.

Table 8: Descriptions and Characteristics of the Research Articles to be Appraised

Authors /date	**Title**	**Research design**	**Population**	**Method**	**Results**
James R. Reinardy **1992**	Decision Control in Moving to a Nursing Home: Post Admission Adjustment and Well-Being.	Quantitative study.	502 newly admitted residents to 10 different nursing homes.	Residents were interviewed within 3 to 4 weeks from admission, then at 3 months and 12 months from baseline. The main predictor variables used in this study are two items: a "dichotomous question asking whether the respondent made the decision themselves" to move, and another question on whether the participant had the desire to move to the home.	Decisional control and the input from the resident being admitted had a significant impact on adjustment to the nursing home. Residents who decided and also wanted (desire) to move to the nursing home were significantly related to short-term change ($p<0.01$) in the activities of the daily living domain. "Their relationship to improvement in ADLs was interactive ($p<0.005$)". It seems that those who participated in the decision and who had the desire to move had high positive changes (adjusted ADL mean change score = 3.1). However,

					those who did participate in the decision to move but found it undesirable and those who found it desirable but without having made the decision "experienced significantly less positive changes (1.1 and 1.4, respectively)". So in conclusion, the best outcome is when one makes the decision but also has the desire to move.
Misa Komatsu, Akiko Hamahata and Joan K. Magilvy **2007**	Coping with the changes in the living environment faced by older persons who relocate to a health-care facility in Japan.	Descriptive qualitative study.	8 residents (>65) who were able to walk independently, with mild to moderate dementia and could express feelings, and were being admitted to a nursing home.	3 semi-structured interviews with 8 elders in the first week, 1 month, and 2 months after admission to the nursing home.	In 1st week: residents complained of having nothing to do, having difficulty forming interpersonal relationships and experiencing a boring life. In the 1st month: some residents started realising it is not as easy anymore to just go out, in fact, they cannot. They miss the feeling of going outside for a walk freely. In the 2nd month: some residents finally found a buddy and someone who

					understands them. However, some did not adapt and complained of - loneliness, decreased mental function, discomfort and distrust of the care of the staff, small environment and no freedom.
Marguerite Bramble, Wendy Moyle and Margaret McAllister **2009**	Seeking Connection: family care experiences following long-term dementia care placement.	Descriptive qualitative study.	10 participants, who were relatives of a person with dementia living in a long-term facility.	Semi-structured interview of 1 hour over 2 months. Questions were on their story of how they felt in the process of placement of their loved one, their perception of the care given to their relative and how it has changed.	- Burden and isolation due to a feeling of crisis since the diagnosis of dementia. - Grieving - they were not prepared for this transition. - Not involved in the care of their relatives from the staff. - No complaints on the adjustment of the person with dementia as hygiene, food intake and general appearance was good as perceived by the caregivers. The only problem was when they saw their relatives with other people's clothes which was hard to control in a large facility. - Other complaints were low-staff ratios

					and not enough attention given to patients and no specific meaningful relationships being built.
Laura Sury, Kim Burns and Henry Brodaty **2013**	Moving in: adjustment of people living with dementia going into a nursing home and their families.	Systematic review.	Papers discussed persons with dementia and examined nursing homes.	49 articles were included derived from Embase, Scopus, and Medline databases. Articles only published in English between 1990 and 2011 using specified search terms were included.	Behavioural symptoms included more agitation and depression. Cognition was decreased and frailty along with falls were increased for the people with dementia. For the caregivers there were feelings of guilt, failure, and depression. Burden was also a common finding. Improvement in quality of life was reported several times. It was concluded “that successful transitions may be assisted “by ensuring that the person with dementia has input into decision-making” (Sury, 2013), and having some type of orientation procedures prior to admission. A “buddy”

					system for new arrivals would be ideal.
Sonya Brownie, Louise Horstmanshof, Rob Garbutt. 2014	Factors that impact residents' transition and psychological adjustment to long-term aged care: A systematic literature review.	Systematic review.	Residents in nursing homes and without cognitive impairment.	Academic Search Premier, Cinahl, Medline, PyscINFO, Psychology and Behavioural Sciences Collection and Scopus databases for observational, and descriptive studies published between January 1995 and July 2013. 19 studies were chosen.	Some studies had common emerging themes from the interviews which were: The feeling of helplessness, feelings of loss, grief, powerlessness and depression. Adjustment to new "rules" was difficult for many residents. Troubles establishing relationships with staff and other residents and a lack of privacy was an issue.
Binbin Yong, Rongjin Lin, Huimin Xiao 2020	Factors associated with nursing home adjustment in older adults: a systematic review.	Systematic review.	Selected studies consisted of participants who were residents in a nursing home without cognitive impairment.	A systematic search of the literature in Pubmed, Embase, CINAHL, PsycINFO, Cochrane Library, China National Knowledge Infrastructure, China Wanfang Database, Chinese Biomedical Literature Database, and Chinese Periodical Full-text Database for studies published from inception to	NHA (nursing home adjustment) was enhanced when there was religious involvement in the residents as psychologically well-being improved. Depression was also a common factor in the studies, which affected the adjustment process. Common factors that helped in

				March 2020. 20 studies were chosen for this systematic review. Studies included all used self-reported questionnaires to interview the participants.	adjustment to the nursing home were social support, regular visits from relatives, participation in leisure activities provided by the nursing home, voluntary admission, number of "roommates" in each room. Age was a common factor for NHA, the younger the resident was, the more active they are hence why they adapt better and have a better quality of life.
Susan Wareing, Kristen A. Sethares, Elizabeth Chin, Brian Ayotte **2021**	Entry and Passage Variables Associated with Nursing Home Adjustment in Older Adults with Dementia.	Non-experimental, descriptive, correlational quantitative study.	67 nursing home residents with dementia. Staff participants included 43 staff members working in a 103-bed facility in the north-eastern United States. Residents were chosen based on their	Information about the chosen participants was collected from "proxy responses to the Nursing Home Adjustment Scale". Data was then analysed "at three periods of time: less than 1.5 years, 1.5-3 years and > 3 years" (Wareing, 2021).	An inverse relationship between nursing home adjustment and depression was indicated from the results. This was measured by the Patient Health Questionnaire 9 (PHQ-9).

			diagnosis of dementia from their Minimum Data Set (MDS).		

2.6 Quality Appraisal of the Qualitative Studies

Five qualitative studies exploring the adjustment of the person admitted to the nursing home were included. Due to the limited studies related specifically to the adjustment of a person with dementia upon admission to a nursing home, some of the studies chosen discussed the adjustment of persons without cognitive impairment to a nursing home. The exclusion criteria mention persons without cognitive impairment, however, there were very few studies that explored persons living with dementia hence these studies were included as an exception. Moreover, the findings of studies related to older persons without cognitive impairment are still very relevant and may apply to those with cognitive impairment such as dementia. In this section, a critical review of these five qualitative studies will be provided in this section to further analyse each study and examine their strengths and limitations, data rigour, sampling and participation recruitment.

Two of the five qualitative studies used thematic analysis while the other three were systematic reviews. The qualitative studies by Bramble et, al., (2009) and Komatsu et, al., (2007) will be discussed first. The three systematic reviews by Sury et, al., (2013), Brownie et, al., (2014) and Yong et, al., (2020), will be discussed separately because the results and findings were pooled together.

2.6.1 Sampling and Participant Recruitment of the Qualitative Studies

Purposive sampling was used by Bramble et, al., (2009) and Komatsu et, al., (2007). This was the most suitable sampling method to be used since the participants recruited were based on the characteristics needed for the sample which in turn yields favourable results. A presenting weakness to this is that potential participants in the target population could have easily been missed, potentially having delivered a contribution to the results. Purposive sampling offers more significance to the research study since the phenomena will be greatly manifested by the participants chosen. Finally, semi-structured interviews in both studies were used to obtain results and data offering a convenient method for data collection, since the data collected will be focused on the related topic whilst giving space to the participants to express their stories, perceptions, and experiences.

Komatsu et, al., (2007) conducted three semi-structured interviews during the first week of admission, the first month and the first two months. Besides the interviews, participants were observed for about four to five hours per day, three days per week for the two months. This

triangulation method used by Komatsu et, al., (2007), using both interviews and observations enabled a more comprehensive collection of data. Bramble et, al., (2009) also conducted semi-structured interviews over a period of two months. In this study, however, the participants were the caregivers of the person with dementia being admitted to the nursing home. Bramble et, al., (2009) study has a higher risk of recall bias since the interview was done over 2 months and not after the first week of admission as in Komatsu et, al., (2007) study.

2.6.2 Data Analysis of the Qualitative Studies

Both studies (Komatsu et, al., 2007; Bramble et, al., 2009) used thematic analyses. Moreover, in Komatsu et, al., 2007 study, analyses were done simultaneously with data collection. The data collected from the interviews were coded, and the content was then put into seven different categories according to the conceptual framework. Each participant had three datasets obtained from the three time points and was compared to see how their experience changed over time. The use of the framework to guide the data analysis assisted the research in providing a more thorough view of the findings. In Bramble et, al., (2009), codes and themes were identified and broken down into main themes. These will be discussed later on in subsequent sections.

2.6.3 Data Rigour

Both studies used different processes in order to assure rigour. Komatsu et, al., (2007) used the recommendations by Lincoln and Guba (1985). Table 9 compares the approaches that were used in both studies. Overall Komatsu et, al., (2007) used a more rigorous approach.

Criteria	**Komatsu et, al., (2007)**	**Bramble et, al., (2009)**
Credibility	Expert qualitative researchers examined the data.	A clear “audit trail, audiotaping of interviews, and checking of transcripts and analysis through reflection and discussion with members of the research team” (Bramble, 2009) was done.

Transferability	Other investigators were provided a full description to assess whether the findings were transferable.	/
Dependability	Multiple researchers examined the process of the research study and data triangulation was undertaken.	/
Confirmability	Multiple researchers examined the data/content from the research study and grounding of the findings was ascertained.	/

Table 9: Qualitative Data Rigour Validated by the Criteria of Guba and Lincoln (1985)

2.6.4 Quality Appraisal of the Systematic Reviews by Sury et, al., (2013), Brownie et, al., (2014) and Yong et, al., (2020)

Sury et, al., (2013) examined the factors influencing adjustment to moving into a nursing home for both residents and their relatives. A literature search of Embase, Scopus, and Medline databases was conducted. The 174 titles encountered in this literature were screened and reference lists were hand-searched, however, there was no mention of a review protocol to assess the risk of bias in each chosen study.

In the study by Brownie et, al., (2014), the factors influencing adjustment and transition to long-term facilities were examined. A literature search was done from Academic Search Premier, Cinahl, Medline, PsycINFO, Psychology and Behavioural Sciences Collection and Scopus databases. This systematic review used STROBE (the Strengthening the Reporting of Observational Studies in Epidemiology), to appraise the quality of reporting of study designs. The aim of this was to provide guidance on how to report observational research since these types of studies were also included in this systematic review. However, the STROBE quality

assessment was not used to evaluate the quality of observational research. For additional relevant articles, reference lists of the articles were searched.

Yong et, al., (2020), evaluated the factors associated with adjustment into a nursing home. The literature search used Pubmed, Embase, CINAHL, PsycINFO, Cochrane Library, China National Knowledge Infrastructure, China Wanfang Database, Chinese Biomedical Literature Database, and Chinese Periodical Full-text Database. Just like Sury et, al., (2013), the references listed in the included studies were manually checked and the 11-item Agency for Healthcare Research and Quality checklist was used to assess the quality of the eligible studies. Each item was scored '0, 0, or 1', corresponding to the answers 'NO', 'UNCLEAR', and 'YES', respectively. Overall quality was determined to be high (8-11), moderate (4-7), or low (0-3). Unlike the other systematic reviews, this one used a review protocol, and it was registered on PROSPERO. Table 10 provides an overview of the type of biases found in the three selected systematic reviews.

Types of biases	**Sury et, al., (2013)**	**Brownie et, al., (2014)**	**Yong et, al., (2020)**
Language bias	English language restriction was applied.	English language restriction was applied.	The search strategy mentioned restricting the language to only Chinese and English.
Reporting bias	Two of the three authors checked any papers that were in doubt whether to use or not.	42 studies were read independently by the three authors to check for eligibility for inclusion.	The data was synthesized adequately since a preliminary synthesis was developed to collate results and present them in tubular form. This data was then explored and was discussed and put

			into categories where any uncertainties were discussed. Regular research team meetings were conducted to reach a final decision.
Detection bias	Not all studies cited were specific to dementia and to new admissions hence there were methodological differences.	There were little differences in outcome measurements in each study used.	There were high levels of heterogeneity since there were different nursing home admission measures and various outcomes to explain adjustment.
Intervention or Exposure bias	The adjustment process was analysed from the caregiver's perspective which mean that they are likely to be biased since the caregivers "are more physically and emotionally involved in the care of the person with dementia.	There was little variation in exposure / intervention in this systematic review since studies included were strict with the inclusion criteria.	Geographic information of the nursing homes was not included. People's previous experiences and living arrangements could influence NHA. Persons with cognitive impairment were excluded. This could restrict the representativeness of the findings.

Table 10: Types of Biases

2.7 Quality Appraisal of the Quantitative Studies by Reinardy et, al., (1992) and Wareing et, al., (2021)

Two studies used a quantitative approach. Wareing et, al., (2021) study used a non-experimental, descriptive, correlational quantitative design of 67 nursing home residents with dementia. The nursing home adjustment scale was used. The data collected came from different time periods of admission of the persons with dementia - 1.5 years, 1.5-3 years and >3 years. The participants who were asked to complete the NHAS scale (the Nursing Home Adjustment Scale) were staff members who knew the patients well and were most familiar. Registered nurses and licensed practical nurses were also included in the completion of the NHAS scale in order to validate its reliability.

In Reinardy et, al., (1992), the residents were interviewed by nurses that were trained in using the Nursing Home Resident Questionnaire, a multidimensional assessment tool. The patient record was collected along with data on the diagnosis, source of admission and discharge. The assessment tool consists of scales measuring the physical, social, and psychological domains of the resident. The time periods analysed changes in scale scores between admission (baseline scores) and 3 months and 12 months. This was used to measure post-admission adjustment and well-being.

Any variable which is considered to have a statistical relationship with the dependent variable qualifies as a covariate. The confounding variables found by Reinardy et, al., (1992), where the possible bias there might have been when the data was collected on perceived control within four weeks of admission. This is because respondents may have forgotten their first initial experience at the nursing home. Moreover, the time that has passed between data collection and admission might affect the analyses. In Wareing et, al., (2021), there was not a profound mention of confounding variables. The sample of residents in this study had been at the facility for a considerable length of time which may have contributed to a lack of variability in adjustment scores.

For Wareing et, al., (2021), cross-sectional data was obtained from the residents that stayed for less than 1.5 years (group 1) and more than 3 years (group 2) in order to explore if the adjustment scores were different "at various intervals after admission". This was done with One-way ANOVA. The finding was that between these groups (1 & 2), there were no significant differences in levels of adjustment.

2.7.1 Strengths and Limitations in the Quantitative Studies

In Wareing et, al., (2021) study, the data was collected from only one nursing home which limits the external validity of the findings. The residents were also compared to each other rather than comparing the adjustment of individual participants over time.

In Reinardy et, al., (1992), a limitation was discussed regarding the data collection time frame. This is because there was no assessment done on the variables prior to a baseline such as ADL status. Since the participants could have already been suffering from a health condition, their ADL was going to decline nevertheless, and they would be less able to have control of this due to their worsening condition. This is an issue as adjustment will most probably be affected because of this and it will not be analysed properly with other variables. ADL status is an important covariate as it can influence adjustment.

In Reinardy et, al., (1992) study, a regression analysis was used which is a strength of this study. It was used to measure changes in scale scores at three months which in turn identifies the predictors of adjustment. According to Alchemer, (2021), regression analysis "is a reliable method of identifying which variables have an impact on a topic of interest". This will allow the determination of the factors that are significant, the ones that can be ignored and how they influence each other.

2.8 Discussion of the Findings of the Factors Influencing Adjustment to a Nursing Home

Table 11 and Table 12 provide a summary of the findings from the qualitative studies and the quantitative studies, respectively.

Research study	**Main findings**
Komatsu et, al., (2007)	Themes identified: ● Decisional control in residents prior to entering the facility impacted how one will quickly adjust. Only one person "toured" the facility prior to admission. ● There was a decrease in physical function which came from a lack of activities in the facility. Moreover, a change in environment promotes the inability to do the things one likes or used to do which leads to decreased self-esteem and stress.

<table>
<tr><td></td><td>Some had adopted an attitude of resignation as a means of coping.</td></tr>
<tr><td>Bramble et, al., (2009)</td><td><u>Themes identified:</u>
“Seeking connection and meaning with staff” - there was not enough information provided prior to admission and there was little contact with the staff. The caregivers wanted to remain in the care of their relatives in terms of dislikes and likes of food, vision problems etc.</td></tr>
<tr><td>Sury et, al., (2013)</td><td><u>Yielded results from the systematic review:</u>
There was an increase in behavioural symptoms - <u>depression and agitation.</u>
There was a decrease in cognition, and an increase in frailty and falls.
For the caregivers, feelings of guilt, and depression were also evident with the added burden.
The concept of the input of <u>decision-making</u> by the person with dementia was discussed in order to have more successful transitions.
There should be “orientation procedures” for them prior to admission, a “buddy” system should be applied as well.</td></tr>
<tr><td>Brownie et, al., (2014)</td><td><u>Yielded results from the systematic review:</u>
Those in better health adjusted more positively than those with already declining health.
Some residents expressed that “they had no choice”, were helpless and experienced a loss of autonomy, meaning that they probably were <u>not involved in decision-making</u>.
<u>Continuity of activities</u> and hobbies in the nursing home positively influenced adjustment.
The concluding factor was that the extent to which residents were involved in the decision-making process for admission to the residential aged care facility (RACF) was an imperative</td></tr>
</table>

	determinant of their adjustment.
Yong et, al., (2020)	Yielded results from the systematic review: ● Physiological factors - ADLs were examined as a risk factor for adjustment in nursing home admissions. Five studies demonstrated that ADLs were related to adaptation to living in a nursing home. ● Psychological factors - there was a significantly positive relationship between self-efficacy and nursing home admissions. Coping styles that were adopted significantly impacted residents' way of adjusting to the new lifestyle. ● Social factors - adaptive behaviour was demonstrated when participating in leisure activities. ● Relocation factors - Seven studies demonstrated that input in decision-making by the residents prior to admission had a positive impact on adjustment. ● Facility factors - In 165 residents, institution type was "significantly associated" with adjustment to the nursing home.

Table 11: Summary of the Findings in Qualitative Studies

Research study	**Reinardy et, al., (1992)**	**Wareing et, al., (2021)**
Main findings	Decisional control - "those who made the decision were inclined to feel positively towards the move". The source of admission was "significantly associated with the decision ($p < .05$)". Almost 60% of the residents admitted to the homes had not made the decision and this impacted their adjustment, health, and ADLs over the short-term period	Depression made a statistically significant and "unique contribution to the equation ($p < 0.05$)". An evaluation of partial correlation coefficients was done, and it indicated that depression contributed of 9% of the variance in nursing home adjustment. A regression model was done to predict adjustment for passage-level variables such as the Patient Health

	following admission.	Questionnaire 9 (PHQ-9). “The correlation between PHQ-9 and nursing home adjustment was negative ($r = .31$; $p < 0.05$)”.

Table 12: Summary of the Findings in Quantitative Studies

2.8.1 Factors Influencing Nursing Home Adjustment

The factors influencing nursing home adjustment were extracted from these findings as follows:

1. Depression in older persons/persons with dementia.
2. Older person/person with dementia’s involvement in decision-making.
3. Activities and hobbies in the nursing home.
4. Older person/persons with dementia’s limited function, health, and ADLs.

2.8.1.1 Depression in Older Persons/persons with Dementia

Depression was mentioned in a few of the studies appraised to be a recurring theme among caregivers and the resident being admitted. According to Wareing et, al., (2021), from their own research looking into a study by Kvael et, al., (2017), it was found that of a “sample of 170 nursing home residents with mild-moderate dementia, 23.5% of them were depressed”. Another systematic review conducted by Ray et, al., (2015), found that “depressive behaviours increased significantly for individuals with dementia relocated from the hospital to a nursing home”. Wareing et, al., (2021), concluded that future research to evaluate depression specifically in persons with dementia in the adjustment process is indicated.

2.8.1.2 Older Person/person with Dementia’s involvement in Decision-making.

In the study by Reinardy et, al., (1992), the regression model measured changes in scale scores at three months which were then used to measure postadmission adjustments in the following domains: Activities of daily living, Self-reported health, Cognitive status, Satisfaction, Social interaction, the effect of feelings, indoor and outdoor activities. Overall respondents who had

a say in the decision and who were then able to show the desire of wanting to be admitted, had a significant and positive outcome on effect and satisfaction ($p= <0.0001$).

In the systematic review by Brownie et, al., (2014), it was found that residents who had a sense of control over their life, i.e., made the decision or were involved in the decision, to go to the nursing home, showed lesser levels of anxiety and depression. In the systematic review by Sury et, al., (2013), a summary was done at the end to portray the negative factors found to be influencing resident adjustment to moving into a nursing home. Similar to other studies, lack of decisional control resulted in a lower level of residents' adjustment since they felt "abandoned by family". This could lead to depressive symptoms in the nursing home. Since they were not involved in the decision-making, they did not visit the nursing home prior to admission, hence there was a loss of familiarisation and little to no preparation prior to admission. This heavily increased anxiety levels.

The study by Komatsu et, al., (2007) discussed that there were environmental factors such as changed bathing routines, relationships with staff and other residents and meals that made the residents in this study bewildered. Environmental factors can be the cause of why residents experience depression, low self-esteem, and stress. However, with that being said, the way in which people adjust may be subjective. This is because Komatsu et, al., (2007), later found that after 2 months some became accustomed to life at the nursing home, and some did not. So, in conclusion it is important to note that certain factors affect certain people depending on their environment and background as some adjust quicker than others.

2.8.1.3 Activities and Hobbies in the Nursing Home

According to the studies reviewed, the activities and hobbies available in the nursing homes, not only improve adjustment but the quality of life of the resident. In the study by Sury et, al., (2013), stimulating activities such as music therapy improved the resident's quality of life and made them feel fulfilled. It was also found that adjustment improved with an increased home-like environment such as having adequate outdoor areas, animals, and gardens in the nursing home. It is also imperative to mention that "the adjustment of people with dementia to nursing homes may also be influenced by cultural background" (Sury, 2013). Not all residents will be of the same religion or cultural background, hence some celebrations which are not usually celebrated in that country will leave those residents left out, missing their ethnic foods and the

significance of these celebrations. This may hinder the process of adaptation to residential care for both the residents and their families.

The study by Brownie et, al., (2014) also showed that the relocation experience was positively influenced by having hobbies at the nursing home. The authors explained that reminiscence therapy encouraged people to recall and share their past experiences. This can be done in various ways such as having relatives bring old photographs, perfumes, books and past meaningful objects to stimulate memories of life experiences.

In the systematic review by Yong et, al., (2020), some studies reported that adaptive behaviour was shown when leisure activities were being introduced and residents were part taking in them. Furthermore, the amount of engagement in activities is dependent on the cognitive level or score of the resident. This means that if a person has very little to no cognitive level, it may be difficult for them to interact in activities. Reinardy et, al. (1992), found that those with very low cognitive scores did not participate in activities hence decreasing their chances of a better adjustment. Those with higher cognitive scores participated more in nursing home activities ($p=<0.01$), had more social interaction ($p=<0.0001$) and improved their ADL functions ($p=<0.001$). However, it is important to note that persons with dementia **should** be included in activities. In fact, activities should be tailored to them as discussed in an article by Newsome, (2019).

2.8.1.4 Limited Function, Health and ADLs

The primary cause of admission is usually due to poor health, inability to perform ADLs and limited physical function. This will have an impact on adjustment to the nursing home as not everyone might be getting the attention and help they need since they are dependent on others. Brownie et, al., (2014) study found that the residents who had mobility problems (consisting of 70% of the total residents) found relocation very difficult. This could be due to a lack of staff training or awareness that persons with dementia, especially those with poor physical function and limited ADLs, need to have certain aspects tailored to them which will help them adjust and feel welcome in the nursing home. The systematic review by Yong et, al., (2020), found that ADLs were the most significant physical factor in older adults' adaptation to living in a nursing home. Evidence shows that older persons who are independent enough in their ADLs have "stronger self-control", and a "better mental state", and with that comes more opportunities to interact with others.

In Reneirdy et, al., (1992) quantitative study, a conclusion was established regarding ADL and adaptation. It was found that those with low ADL scores at baseline predicted more positive ADL change over the time period than those who had high ADL scores at baseline. In other words, this means those who had low mobility, for example, improved which in turn may improve adjustment because they will be able to move around more and increase their self-esteem. This point mentioned is important since those with already high scores have little room for improvement which in turn can make their adjustment actually worse rather than better. This is because they would feel they entered a facility they don't belong to, especially if surrounded by people with low ADL scores and mobility. Hence why it is important to note that even for these individuals who enter the nursing home with good health and high ADL scores, they need attention and tailored activities etc.

2.8.2 Recommendations

Below in Table 13 is a summary of the identified recommendations from this literature review and possible potential interventions that could be done with an explanation.

Intervention	**Explanation**
Involvement in decision-making.	Listen to their perspectives and expectations. Prepare them for what to expect and plan out with them their options if they have little to no cognitive impairment. Involve them with decisions on meals, room allocation and routines. Involving them in decision-making, it will allow them to talk about their feelings and build a relationship with the staff.
Orientation of nursing homes prior to admission.	This will help the resident and even the caregiver to get an idea of how life will be for the resident. The families can collaborate with the staff prior to admission on what their relatives' likes and dislikes and plan a care plan out. A buddy system (Sury, 2013) can also help upon arrival.

Provide a home-like environment.	Introduce familiar objects, frames with photos, teddy bears, homemade food, etc. Promote the use of activities already provided by the facility such as music therapy, outdoor activities, and going outside to the garden. Frequent telephone calls with updates or any news to the family will help adjust for both.
Assess and monitor residents upon admission.	For feelings of grief and symptoms of depression. Provide access to information, counsellors and social workers to help build coping skills. Promote effective communication by building trust with residents so that they portray their feelings. Implement a personalised care plan and try to understand socio-cultural experiences and promote opportunities to preserve cultural heritage.
Provide staff training to improve the detection and management of relocation anxiety.	Although not mentioned above, (since the studies critically appraised did not examine staff training on the level of adjustment), it is a crucial note to point out that any unnoticed behaviour and feelings can become noticed and managed with staff training. Staff can also provide loving care to persons with dementia which will make them feel more comfortable and at home.

Table 13: A Summary of the Recommendations Generated from the Literature Review

2.9 Conclusion

This Chapter has provided insight into studies related to the adjustment in a nursing home to older persons and persons living with dementia. The TRANSCIT Model was used to get further understanding on what is required to optimise the transition and adjustment for a person with dementia going into a nursing home. The studies chosen for this systematic review generally focused on the adjustment of the person going into the nursing home from their perspective and not from an informal caregiver's perspective. This is because a gap was found in the literature where the experience of persons with dementia was not being studied from an informal caregiver's perspective which is what this dissertation will investigate. Since studies have not yet explored this topic, this study will contribute to reducing this gap and therefore more knowledge will be gained on the nursing home adjustment of a person with dementia rather than older persons without cognitive impairment. The next Chapter elaborates on the research methodology and methods used to gather and collect data to provide a tentative answer to the research topic.

Chapter 3

3. Research Methodology

3.1 Introduction

The research methodology used to answer the research question of this study will be described in this Chapter. This Chapter presents a discussion on the research design, the necessary philosophical underpinnings to understand the methodology, data collection methods, and data analyses. The ethical considerations and how data rigour was maintained will also be presented.

3.2 Problem Being Investigated

Experiencing adjustments when transitioning to a nursing home may be initially very challenging for older persons and their relatives. It is therefore crucial for healthcare staff at the nursing home to understand the factors that influence adjustment for these persons to make their transition easier and subsequently result in a good adjustment to the home. There are no local studies that have sought to identify these factors. This emphasises the relevance and importance of this research project as it aims to improve the health and social care services when persons with dementia are admitted to nursing homes and need to go through a phase of adjustment in their daily life.

3.3 Aims and Objectives

In Chapter 2, it was established that there is a knowledge gap with regards to the factors influencing adjustment in persons with dementia that were admitted to nursing homes. This research project aims at filling this gap with a view of identifying practical strategies on what needs to be done to further improve nursing practice in nursing homes especially during the admission process. The research question is as follows:

What factors influence adjustment to nursing home admissions as perceived by informal caregivers of persons living with dementia?

The four objectives of this research project that fills the purpose of this study are described in Table 14 below.

1. Examine the informal caregiver's experience on how their relative with dementia adjusted during the first week of admission and then during the first month.
2. Identify the factors influencing the adjustment of persons with dementia to nursing homes.
3. Identify the barriers that affected the adjustment of the persons with dementia.
4. Identify the areas that need improvement in nursing homes to meet the needs of these persons so that they can adjust better during this transition.

Table 14: Objectives of the Research Project

3.4 The Epistemology, Research Design and Research Paradigm Implemented in the Research Project

For this research study the researcher felt that a constructivist approach was ideal to use. Such an approach has enabled the researcher to be closer to where the information was, by becoming also more alert and sensitive to any conditions that arose using the researcher's experience (Charmaz, 2006). The researcher's experience in working in a government nursing home was instrumental in developing the interview questions as this helped the participants to reflect on their stance more thoroughly, enabling the researcher to obtain rich data and identify gaps surrounding the area under study. Piaget's (Adom, 2016) theory of constructivism argues that people produce knowledge and form meaning based on their experiences.

3.5 The Methodology: Narrative Inquiry

For this dissertation, qualitative narrative inquiry was the design used. According to O'Toole (2018), the main purpose of narrative is to bring forth attention to the life experiences of the interviewees/participants through "rich thick stories" and storytelling. Table 15 portrays the three main elements of a qualitative narrative inquiry.

Temporality	The time the experiences took place and how they may possibly influence the future.
Sociality	Any personal and cultural influences of the experiences.
Spatiality	The experiences' environmental surroundings and how this may possibly influence them.

Table 15: Main Elements of a Qualitative Narrative Inquiry

According to O'Toole (2018), narrative inquiry consists of the biographical aspects of "C. Wrights Mills" trilogy of biography, history, and society. People generate their experiences in the way they craft or construct them and then tell them. Researchers then are drawn to these stories and are analysed which consequently show a "multi-layered" approach which is the form, content and context of the story based on its temporality, sociality, and spatiality.

Ntinda, (2020), refers to the events that are still ongoing as a "temporal transition". This means the researcher can be led towards the past, present, and future. Sociality refers to the researcher taking note of the personal and social conditions of the experience. Examples of personal conditions are the feelings, reactions, and desires of the person. Social conditions refer to the person's conditions under which the event is being taken place. Lastly, spatiality is the place where the event took place, and it is important to note the specific "topological boundaries" of the place. As Ntinda, (2020), puts it;

"Narrative research allows for comprehending, describing, and acting within the frame of the storyteller's experiences; the story is how we make sense of the world".

Finally, narrative research encourages the researcher to seek the meaning of the participant's experience. It seeks to understand and value the experience, because the participant is the main source of knowledge. Narrative research portrays reality as a changing spectrum and reveals reality as being constructivist.

3.5.1 Constructivism

For this dissertation, the approach the researcher believes is best suitable is the constructivist approach. According to Bodner (1986), constructivism describes how learners construct understanding and knowledge. As Bodner (1986), states; "*learners do not simply mirror and reflect what they are told or what they read. Learners look for meaning and will try to find regularity and order in the events of the world even in the absence of full or complete information".* Similarly, Charmaz (2006), emphasises the importance of the researcher's experience and the relationship with the interviewees as this helps the researcher to better understand the phenomena under scrutiny since '*a constructivist approach places priority on the phenomena of study and sees both data and analysis as created from shared experiences and relationships with participants'* (Charmaz 2006, p. 130).

Knowledge in constructivism is constructed in our minds to "fit" reality rather than to "match" reality, just like how a key fits a lock. The difference between the concept of "fit" and "match" reality is that when knowledge matches our reality, many other individuals will have the same realities in their minds. However, when we take a constructivist approach and make knowledge "fit" our reality rather than "matching' it, we will all have different views of reality since each of us builds our own view of reality to make it fit and to "find order" in the abundance of signals life gives (Bodner, 1986).

Moreover, according to Adom, et., al, (2016), the constructivist philosophical paradigm describes people as reflecting on their personal experience and then constructing knowledge from these experiences. These people, in other words, are *learners* who do not learn from being taught by teachers, but the learning occurs from doing and experimenting.

3.6 Sampling Technique

3.6.1 Sample Size and Sampling Method

Six participants were deemed to be ideal to interview for this research project. This is because according to Subedi (2021), a small sample size for narrative research is ideal since a more in depth, thick description and exploration is made of the data retrieved. Purposive sampling was

applied to achieve a homogenous sample pool and to obtain suitable participants for this research project to meet its objectives.

3.6.2 Inclusion Criteria

The following criteria shown in Table 16 were chosen to ensure adequate participant selection.

Criteria	***Inclusion***
Population	Older persons above the age of 65 that are admitted to a nursing home. They must be recently admitted no longer than 6 months from the time of interview. Older persons with a diagnosis of dementia (any type and severity). Primary caregiver such as a spouse, sibling, daughter/son. and any gender above 18 years.
Exposure	Nursing home.
Outcome	Caregiver's story of the admission process and how their relative being admitted to the nursing home has adjusted or not.
Setting	At the nursing home following admission.
Study	Systematic reviews and meta-analyses, phenomenological studies, and quantitative studies.
Research and Publication	English language.

Table 16: Inclusion and Exclusion Criteria

3.6.3 Sample Recruitment

The potential participants for this study were those who had relatives in four dementia units at St. Vincent De Paul Residence. Dementia units were chosen because it was easier to ensure that the residents had a diagnosis of dementia, unlike in the geriatric wards where residents (even with cognitive impairment) may not have had a dementia diagnosis. The researcher chose an intermediary to send out the consent forms to these wards. The charge nurses of these four wards then acted as the gatekeepers and approached the participants that fitted the inclusion criteria after having discussed them with the researcher. Those that signed the consent form and hence were willing to be interviewed gave the consent form signed back to the intermediary where the researcher collected them. The researcher then approached the participants to arrange a date for an interview.

3.6.4 Research Setting

The setting is in St. Vincent de Paul Residence (SVPR) which is a nursing home for geriatric residents. SVPR has general wards where there are 30+ geriatric residents with all kinds of underlying conditions or none at all. SVPR also has dementia wards where they are *closed* meaning all doors, cupboards and drawers are locked making it a safe environment for the persons with dementia being admitted there and avoiding any escapes since most wander around. These wards are smaller and fit about 24 residents. In SVPR, the persons with dementia being admitted specifically go to these dementia wards hence why the participants chosen are selected from these units and not the normal geriatric units.

Moreover, the participants were given a choice to have the interview online on Zoom or face-to-face. Those who chose online were sent a zoom link on a time and date when they were available. Those who chose face-to-face were interviewed, on their availability in the charge nurse's office in the ward of their relative (with granted permission from the charge nurse). This room was ideal as in each ward, it was not near the nursing station but rather in a quiet place at the ward and the researcher was able to close the door for privacy.

3.7 Data Collection

3.7.1 The Interview Research Method

The interviews took place between 10 October 2022 and 17 November 2022. The interview sessions took around 35 to 45 minutes long and for the researcher to reach the objectives of the research study a pre-planned set of open-ended questions was prepared beforehand. The interview guide helped to shape the interview, consequently allowing the researcher to adapt to certain answers and follow up on further questions.

Moreover, the researcher also conducted a pilot interview so that any adjustments that needed to be made were amended. This provided the researcher with a better understanding of how to go about with the actual interviews and be more prepared. The researcher recognised the importance of letting the interviewee freely talk and say her story, especially since this research study is using narrative inquiry. Interrupting and asking questions might make the interviewee feel that they cannot say everything and that what they are saying is wrong or not appropriate. The interviewee will be able to express themselves more when the researcher does not interrupt. Furthermore, the fact that questions were asked in chronological order gave structure to the interview and helped them express their thoughts on how their relative was during the first week of admission, and then after the first month (Delve, 2020).

The researcher asked two overarching questions to get the interviewee answer in a story-telling manner which is essentially what narrative approach is about. The questions and remaining subsequent open-ended questions were very general and gave the interviewee an opportunity to talk openly and freely and narrate what happened.

3.7.2 Applying Reflexive Interviewing

Reflexive writing helps the researcher to ground the knowledge they have gained through the gathering of empirical data directly from the field. Since the researcher is a staff nurse working in that area of speciality, previous knowledge can interfere with the findings. Reflexivity also prevents the researcher from diverting the conversation with the participants.

Table 17 below is an extract of one of the reflexive interviews. The reflexive diary with the other interviews can be found in Appendix 13. The reflexive diaries were made right after the interview was conducted which helped the researcher understand and construct the knowledge collected from the participants.

Interview 5: 14 November 2022 *"This participant was quite jittery at first and made an impression that she was nervous. Her answers at times were sometimes all over the place as I noticed she wanted to tell me everything but was too excited. However, as 20 minutes passed, she calmed down and answered accordingly as I gently redirected the discussion. I still let her say all she wanted and needed to say as there was no rush at all and did not want to make her feel uncomfortable. She stressed a lot the need for loving care and for regular visits as she visits her relative with dementia every day with other family members. As a nurse mostly working in the dementia wards (being a reliever), this made me want to express the importance of regular visits to family members of persons with dementia and show them that their relative with dementia must not be forgotten and in most cases, will help them adjust, especially being newly admitted! She made me realise the importance of loving care as well, as by this stage of the interviews (she was nº5 of 6), everyone had mentioned it and they all said that we as nurses should always provide loving care as persons with dementia would otherwise notice, and one can tell the difference when someone has been spoken to with love rather than being shouted at. She expressed how they are more willing to cooperate or settle when spoken to with love, hence adjusting better and not feeling scared all the time."*

Table 17: Reflexive Diary: Extract from Reflexive Interview nº5

According to Passoa et, al., (2019), to conduct a good interview one must avoid the following mistakes presented in Table 18 with the recommendations used to overcome these mistakes.

Mistakes	**Recommendations**
Atmosphere being uncomfortable	To have a comfortable physical atmosphere, one must make sure they are in a quiet room and with

	the door closed if the interviewee does not mind. For a comfortable conversation, the researcher told the interviewee beforehand that there is no right or wrong answer.
Interrogating interviewee	Since this dissertation is a narrative inquiry, it is vital to not interrogate the interviewee and let them narrate their story. If they are interrogated, they will feel uneasy and uncomfortable and might produce "distant responses" (Passoa et, al., 2019). The way in which the researcher avoided this was by simply letting the participant talk and not rudely stop them to ask another question.
Diverting to irrelevant topics	It is normal that with interviews, the discussion gets redirected to unrelated topics and it is the researcher's responsibility to divert it back in a calm professional manner. The researcher should not make it seem as though the topic was irrelevant but should gently divert it with respect and sensitivity. Hence why prompts were used.
Anxiety and nervousness	If the researcher is anxious and nervous, this energy might be passed onto the interviewee and will generate a discomfiting atmosphere. The researcher was prepared beforehand on what to always ask and stayed calm. In case the interviewee was becoming increasingly stressed, the interview would be stopped, and the participant would be given the option to ask for psychological support.

Table 18: Mistakes and Recommendations for a Reflexive Interview by Passoa et, al., (2019)

3.8 Data Analysis

MAX qualitative data analysis (MAXQDA Analytics Pro) software was used for data management, storage, and analysis. MAXQDA is a management tool for data analysis designed for coding activities using four interactive screens to concurrently view the transcribed interviews; the coding hierarchy which the researcher developed; the text of the interview under analysis; and the text of a chosen category for a chosen interviewee. The recorded interviews were transcribed by the researcher on a word document and were uploaded into the MAXQDA (after being translated in both English and Maltese). A coding system was developed by the researcher which provided the means for conceptualising the theme underlying the text extracted from the interview being analysed. This process proved to be much more efficient than a traditional pen and paper method where one would assign codes and take a longer period to complete the analyses.

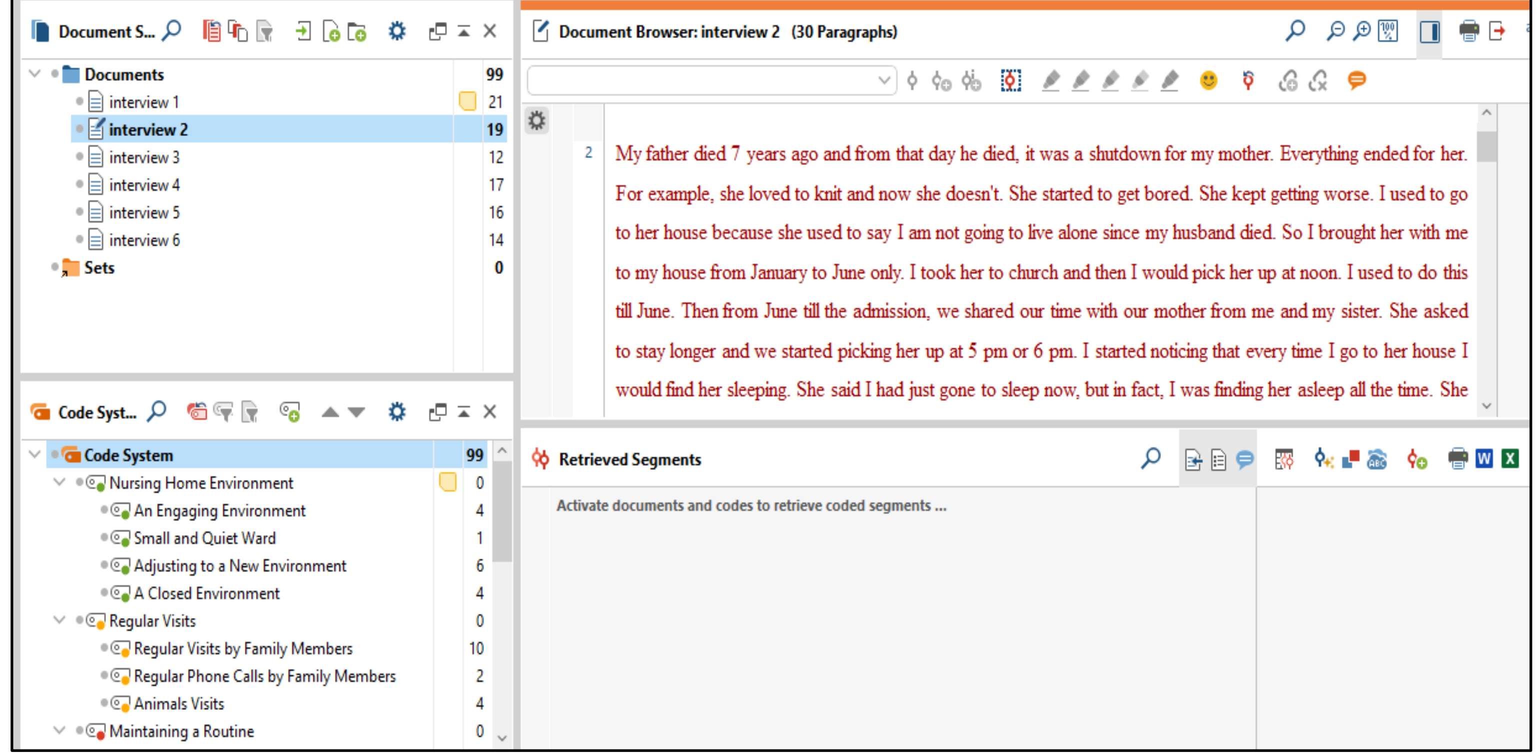


Figure 2: Screenshot of the Coding Paradigm using MAXQDA with its Four Interactive Screens

As shown in Figure 2, on the top left-hand side, the document system can be viewed. This is where all the documents/transcribed interview word documents are stored with the number of references (i.e., concepts and themes) each interview generated are shown on the right side next to the title. The Document Browser on the top right is showing Interview 2 where the researcher can read it and allocate it to a code within the Code System in the bottom left corner. This is done by highlighting the sentence and then dragging it under the code system's corresponding theme and then put under a category or a sub-category which in turn becomes a placeholder for emerging themes and concepts. The bottom right corner portrays the Retrieved Segments section where the researcher can see the highlighted sentence more clearly when activated.

3.8.1 The Coding Exercise

The process started with transcribing the interviews in Maltese (since the interviews were all held in Maltese), translating the transcripts in English, and uploading the translated interview documents into MAXQDA. With the aid of a pilot interview, the researcher developed a coding schema with a view to having an idea of what the code system will consist of. The coding

schema continued to be developed when more interviews were analysed as more categories and sub-categories emerged under the themes that have been identified. The name or the phrase that was chosen for each code had a particular meaning with respect to a relevant theme, or incident produced.

The pilot interview was eventually used as it contained relevant data. The data analysis of each interview commenced by first reading each interview after it was uploaded to MAXQDA and then by relating the context of the text to the coding schema. This was done by dragging the corresponding text from the transcribed interview in the Document Browser into the categories or sub-categories of the Coding System. These main themes and categories were building up as more data was being analysed and eventually after more refinement each main theme/category had its own sub-categories as more details emerged from data collection through the interviews.

The resulting five main themes that emerged were: *environment, regular visits, routines, staff, and activities.* Each individual theme has a minimum of three categories up to six. Figure 3 portrays the themes, categories and sub-categories. For example, the theme *staff* has a category of *loving care* which in turn has a sub-category of *sweet voice* and *being a part of their family.*

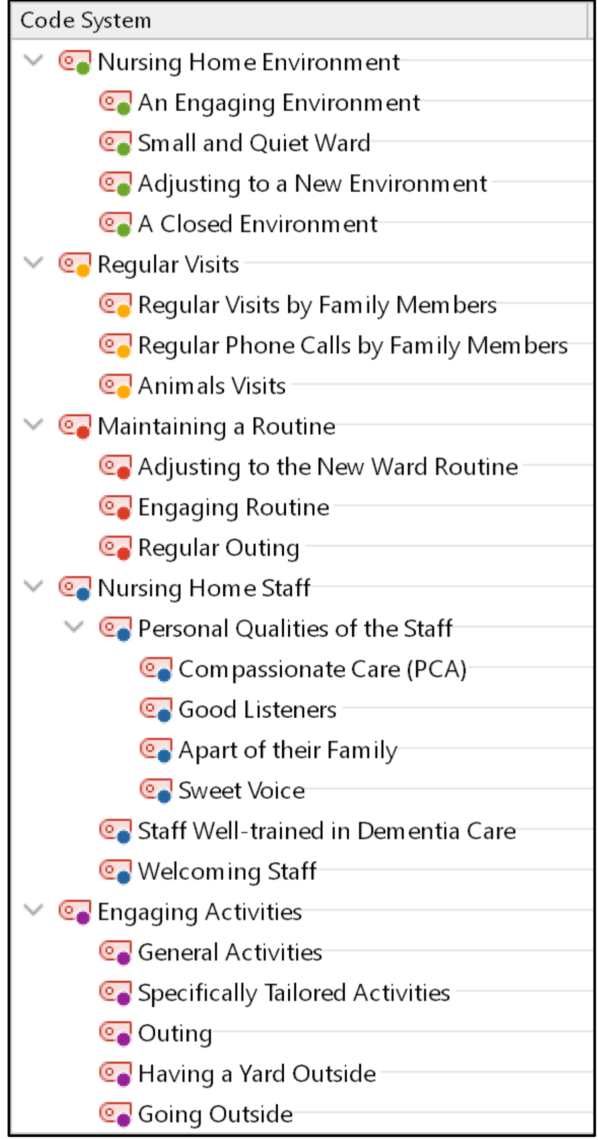
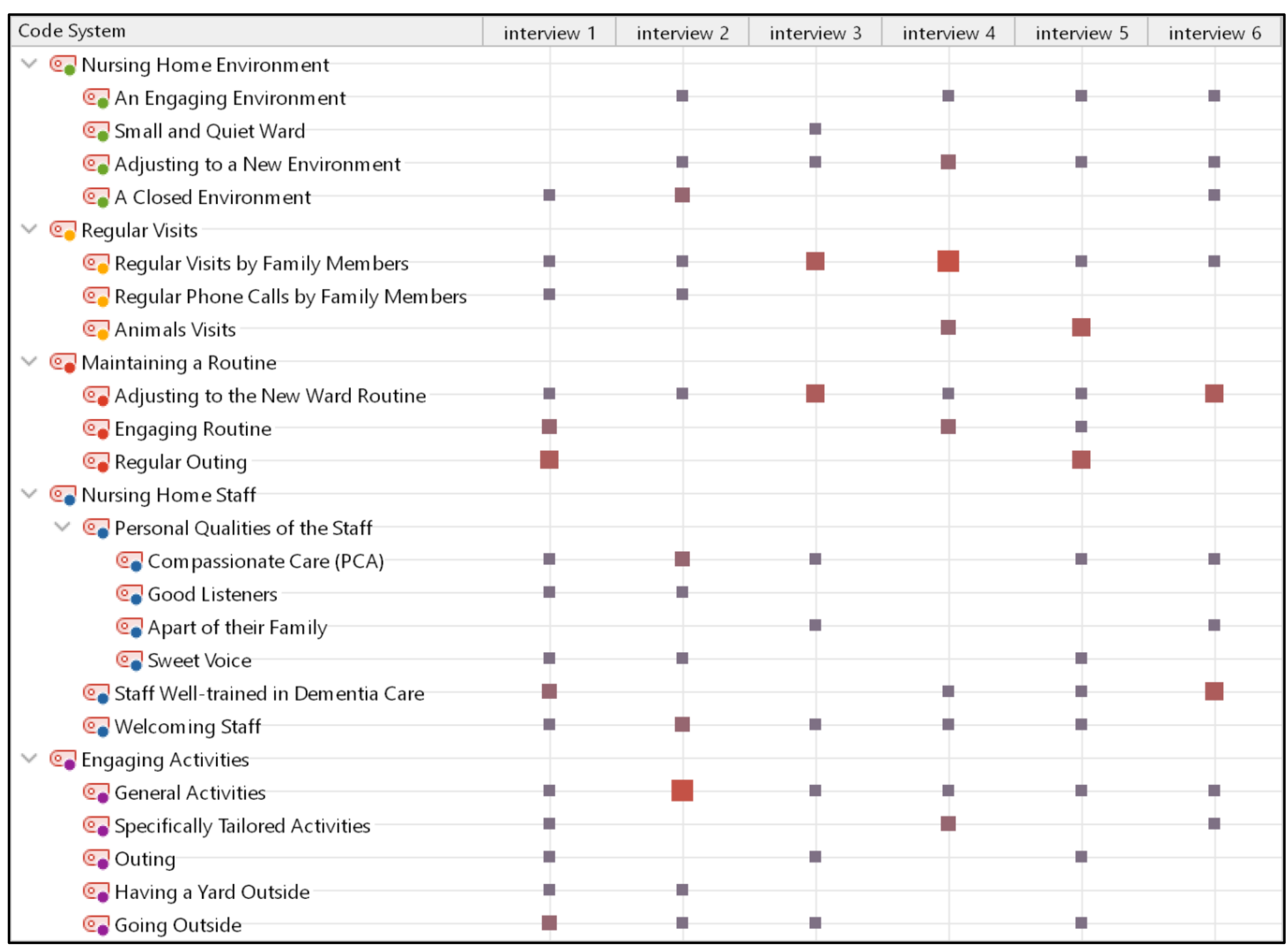


Figure 3: An Extract of the Code System for the Resultant Categories and Sub-categories

One of the important features of MAXQDA is the Code Matrix Browser. In line with content analysis, this feature provides the possibility to assess the coding intensity of each interview in comparison to other interviews by showing how much intensity is being placed on particular categories and their sub-categories once the coding is completed. This is demonstrated through areas of concentration by showing high or lesser coding intensity which becomes more evident once the interviews are coded.

The following Figure 4 shows the resultant Code Matrix Browser of the coding system. The level of the coding intensity per interview of the categories is shown by the size of the coloured boxes. This type of weight scoring to the segments allows the researcher to meet the research objectives which aim at determining the importance of the emerging data under each theme and category.

Figure 4: A Screenshot of the Code Matrix Browser for the Resultant Categories and Sub-categories with their Respective Weight Scores



To visualise the network of the data gathered under each theme, the researcher also made use of the MAXMaps. This feature of MAXQDA provided the means for the researcher to demonstrate through a graphic representation another perspective of how the emergent empirical data from the coded interviews and intensity of the coding relates to each theme as a category, and corresponding sub-category. This will be shown in Chapter 5.

3.9 Quality and Rigour

3.9.1 Verification Strategies

As the interview was being conducted, the interview guide that was developed beforehand by the researcher, was used to keep track of the responses so that the interview does not divert. Sampling adequacy was achieved since purposive sampling was used at the beginning of data collection. Data saturation was evident because the amount of data that emerged under each theme during the data analysis was adequate and enough for the researcher to develop further the categories and the sub-categories,

Furthermore, there were negative and positive impacts on the interviewees as was evident from their personal stories. The objectives of the research were met because there was consistency between the research methodology, narrative analysis, and the data collected.

3.9.2 Quality Control

In this section, a discussion of Yardley's (2000) four considerations on how to secure quality control will be reviewed. These four main dilemmas portrayed below as highlighted by Yardley (2000), are imperative to ensure quality control throughout the research process.

- ➢ *Sensitivity to context.*
- ➢ *Commitment and rigour.*
- ➢ *Transparency and coherence.*
- ➢ *Impact and importance.*

Sensitivity to context was achieved in this research study using purposive sampling, thereby including participants who were the best candidates for the research question. The researcher refrained from diverting the responses to interpret a different meaning and let the participants express their experiences and tell a story.

Commitment and rigour were achieved because the researcher prepared herself by researching and acquiring the data analytics skills. A thorough review of the literature was done beforehand

to have a clear view of the topic in question and the theoretical framework. In terms of rigour, the researcher was very attentive in capturing any incident or concept mentioned by the participant and made sure that the coding exercise reflected what had emerged from the data collected.

Transparency and coherency in analysing data were ensured throughout the process of data collection, management, and analysis. The information collected from each interviewee was correctly transcribed and reported and when the analysis of the data was being carried out, the researcher ensured coherency in the way that data was coded and analysed. The researcher also ensured coherency by using a reflective diary hence enabling a deeper reflection of the findings. According to Chenail et, al., (2011), coherency was achieved since the research question, literature review and data analysis were aligned allowing a logical connection to happen.

Impact and importance were ensured by the researcher by selecting the right participants who were going through the experience of having relatives with dementia being admitted to nursing homes and adjusting to the new environment. It is hoped that the outcome of this study will provide the elements for the policymakers to address the gaps that have been found so that the well-being of persons living with dementia admitted to nursing homes will be improved.

3.9.3 Achieving Trustworthiness as Expressed by Lincoln and Guba (1985)

In this section the researcher will shed light on the Guba and Lincoln, 1981, criteria of achieving trustworthiness and how it was applied. The criteria consist of - credibility, dependability and confirmability, and transferability.

The purpose of *credibility* is to make sure that the data is true and credible (Forero et, al., 2018). To achieve this, Forero et, al. (2018), recommended strategies to be applied in the researcher's study. The strategy applied by the researcher was centred around having the duration of the interview to be 35 to 45 minutes long; enough time to endure a deep discussion to enrich data collection.

The purpose of *dependability and confirmability* is to ensure that the results of the study can be repeated or in other words, other researchers can confirm the findings from their studies.

This was achieved by implementing reflexive writing and by providing the steps of data collection in the previous Chapter.

The purpose of *transferability*, according to Forero et, al., (2018), is the extent that the results can be "transferred to other contexts/settings". This was achieved by the researcher since the right characteristics of the participants, the site and methodology were given due importance so that it can be replicated in similar settings i.e., nursing homes.

3.9.4 Achieving Validity Amongst Interviews

Representation of the six key considerations by Fontana and Frey (1994) to use while carrying out interviews are presented in Table 19 below. The Table discusses how the researcher achieved each consideration and how the researcher made use of it.

Fontana and Frey's (1994) considerations	*How it was achieved*
Accessing the setting	The researcher is a staff nurse at the nursing home St. Vincent de Paul, and it was very feasible to gain access to the closed dementia wards where patients were admitted living with dementia and not capable of living alone.
Understanding the Language and Culture of the Respondents	All interviewees were Maltese, and the interviews were conducted in the Maltese language as they preferred it that way.
Deciding on How to Present Oneself	The researcher presented herself as a staff nurse but as a novice researcher as well. At no moment, did the researcher show arrogance as this would have refrained from any connection that was built between them and would have omitted a fruitful discussion.

Locating an Informant	For locating potential interviewees, an intermediary was used, and a gatekeeper handed out the consent forms. Once signed, the forms were handed to the researcher.
Gaining Trust	The interviewee's identity was kept anonymous throughout the study and the researcher ensured the interviewees were aware of this. This helped in gaining and retaining their trust. The researcher only approached a potential interviewee or formed any type of contact after the interviewees signed the consent letter and agreed to this study.
Establishing Rapport	Throughout the interview, the researcher always remained empathetic during the discussion. The researcher established a good rapport with the interviewees and made sure to explain the purpose and the format of the interview to make them feel comfortable. Interviewees were assured that if they had any questions before the interview they were free to elaborate.

Table 19: Fontana and Frey's (1994) Six Key Considerations

3.10 Ethical Considerations

This research study could not commence without the approval from the Faculty Research Ethics Committee (FREC) in collaboration with the University of Malta (UoM), by the Faculty of Health Sciences. SVPR granted institutional permission by getting data protection approval from the Chief Executive Officer (CEO) which can found in the Appendix 8. Further discussion on how ethical responsibilities were met will be discussed below along with how participants' ethical rights were not breached at any time in the study.

3.10.1 Informed Consent

Potential participants were all given a consent form and an information letter about the study. Those who wanted to participate, signed the consent form that was given to them by the intermediary at the respective ward. The signed consent form was then handed to the researcher (Appendix 5 & 6) The information letter made it clear that the participant can withdraw at any time with no consequences. Participants were given the possibility to finish the interview at any time if they felt uncomfortable. The purpose of the study and the length of the interview was also explained.

3.10.2 Research Confidentiality and Anonymity

Pseudonyms were given to the participants to maintain their anonymity. No personal information was included in this research study. The data was only accessed by the researcher and was not shared with anyone. The coded data was accessed by the supervisor and the examiner. The laptop used for this research study was password-protected and the data was stored in an encrypted format. The data will remain in an anonymous format and personal details will be destroyed once the study is completed.

3.10.3 Risk of Harm

One can never be certain that there will be no possibility for the participants to endure psychological harm during the interviews. The researcher understood that risk of harm is possible, hence remained attentive if the interviewee showed signs of distress, in which case the participants were referred for psychological support if they wanted to. In the information letter it was clearly stated that if they experience psychological distress, a free-of-charge service will be offered. This service is given by a health care professional from the Psychology Department at MDH and was granted approval prior to the study (Appendix 9).

3.10.4 Role of the Researcher

The role of the researcher in this research study is to interpret the interviewee's story as they narrate and come up with a category of codes to further understand the phenomenon. The role of the researcher was to also provide comfort and not make it a strict uncomfortable experience.

The researcher acted as an active listener and provided holistic care one can say to the interviewee as they listened to the issues of the phenomenon. As seen above in section 3.7.2, the researcher used reflexive writing to reduce bias. Moreover, the researcher was an insider to this research study since they work in the same setting giving them greater access to the participants and information (Research Guides, 2023). An advantage of this is that since the researcher is a nurse in this setting, the researcher has experienced similar experiences where the relatives of the person with dementia express their experience and concerns. This gives the researcher more of a base for understanding the phenomenon since the researcher has been exposed to it.

3.11 Conclusion

To summarise, this Chapter explored the methodology used in this research study and provided an overview of how the researcher collected the data and the methods and tools used in analysing it. Chapter 4 will discuss the findings from the empirical data retrieved from this research study.

Chapter 4

4. Key Findings

4.1 Introduction

This Chapter will present the findings of this research study. Quotes from the interviewees themselves will be presented as well. This research study aimed:

To find the factors influencing adjustment to nursing home admissions as perceived by informal caregivers of persons living with dementia.

Both positive and negative factors that influence adjustment, along with the barriers were mentioned. The researcher used The TRANSCIT Model (Groenvynck et, al., 2020) to better describe the findings and help in coming up with recommendations on how to improve adjustment when nursing home admissions take place, ease the transition process and improve nursing practice. This will be discussed in Chapter 5.

4.2 Data Analysis Tool and the Demographic Characteristics of the Participants

As explained in Chapter 3, MAXQDA software was used to assist the researcher in organising the data and in conducting data analysis. The pilot study served as a base for deriving the coding schema from the transcribed interview and further served for building the categories through the coding exercise which the researcher performed. The coding schema kept growing with categories and sub-categories as each interview was analysed and became robust.

In Table 20, the researcher portrayed the characteristics of the participants and kept their anonymity by providing a “fake” name.

	Interview 1	**Interview 2**	**Interview 3**	**Interview 4**	**Interview 5**	**Interview 6**
Pseudonym of the relative of the person with dementia.	Anna	Lucia	Monica	Ruth	Janet	Robert
Relation to the person with dementia.	Daughter	Daughter	Sister	Wife	Wife	Son
Nationality of relative.	Maltese	Maltese	Maltese	Maltese	Maltese	Maltese
Person with dementia's age.	81	86	84	80	77	77
Person with dementia's gender.	Female	Female	Female	Male	Male	Female
Reason for admission.	Resident went for a coffee by herself and fell and broke her arm. She was taken to MDH for 1 month and a half	The Resident's husband died, and her daughters had to take care of her. She would forget to cook, take her	The resident started to forget to pay the shop owner when buying groceries. She lived alone due to her husband	Resident went missing for 27 hours when he wandered off for unknown reasons. When found he did not even realise, he was missing.	Resident fainted in a supermarket and was taken to MDH. They discovered a tumour, and he was operated on. After the operation,	Resident lived alone and was not eating properly or showering. She then fell and broke her hip bone which became even harder for

	and was diagnosed with dementia and was not capable of living alone. This resulted in her being transferred to SVPR.	medicine, and shower and spend her time sleeping as she would forget that she had just slept and woken up. She no longer remembered her husband and would occasionally forget she had children. She broke her hip and was sent to MDH where she was diagnosed with dementia and transferred to SVPR after convincing her daughters that it is not ideal for her to remain at home.	dying and had no children. Her siblings could not take care of her as they are the same age and had their own problems, hence why they applied for her to go to SVPR.	He started to deteriorate, and his wife could not take care of him any longer as he was too heavy since his feet also started to deteriorate. His wife applied for him to be sent to SVPR.	he started to mess up his words and was recommended to go to a nursing home. However, his wife took him home, but then he started to wake up in the middle of the night to go shopping for groceries and confused things such as putting water in the toaster. Hence, he was then eventually put into SVPR as his wife could no longer take care of him.	her children to take care of her as they work. They decided it was time to send her to a nursing home. She was transferred to SVPR from MDH.

Month of admission.	End of July 2022	End of March 2022	July 2022	20 June 2022	June 2022	June 2022
Duration of the stay at the nursing home from time of interview.	3 months	6 months and a half	3 months	4 months	4 months	4 months

Table 20: Demographic Characteristics of the persons with Dementia that Participated in the Research Project

4.3 The Coding Schema

Figure 5 portrays the resultant framework of the coding schema. As can be seen, the coding system is made up of categories (themes) and sub-categories showing the focus of the findings from the interviews. As already explained in Chapter 3, MAXQDA was used in deriving the coding system which provided the means for conceptualising the theme underlying the text extracted from the transcribed interviews. Each individual theme will be discussed below along with the citations from the interview, to further deepen the understanding of the theme in the context of the findings.

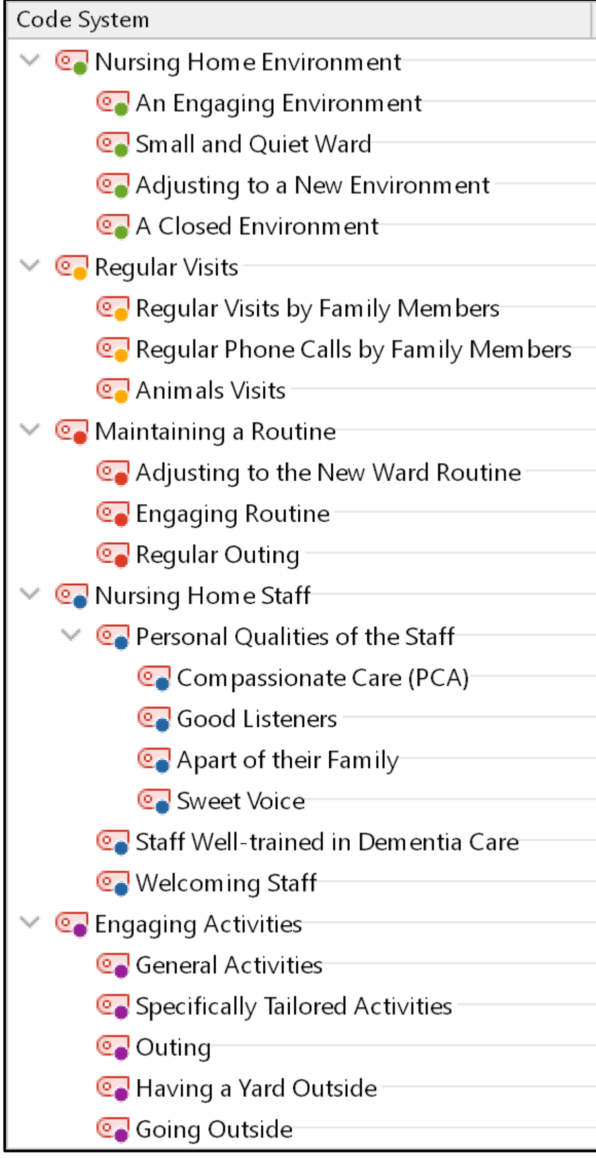


Figure 5: The Resultant Framework's Themes (Categories) and Sub-categories

4.4 Theme 1: Nursing Home Environment

This theme is shown below in Figure 6. The sub-category *"adjusting to a new environment"* had the most references and was emphasised in interview 4 from Ruth. The sub-category "*an engaging environment*" was the second most talked about with three interviewees mentioning it again emphasised most by interview 4 as shown by the difference in the colour of the box. Box colours and sizes show the intensity of the number of citations.

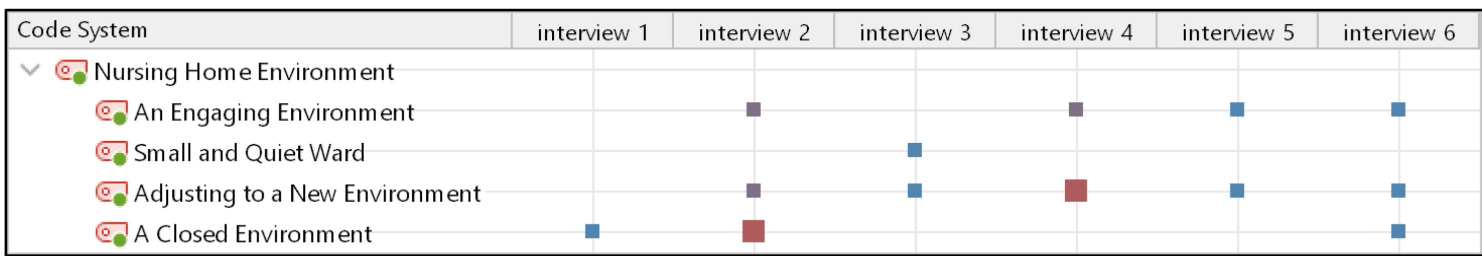


Figure 6: Code Matrix Browser Illustrating the Resultant Coding Intensity for Theme 1: Nursing Home Environment

4.4.1 Sub-category: An Engaging Environment

It was evident that some wards were more engaging. This helped the residents to adjust, as something is always happening to keep them distracted and busy. Lucia, Ruth, and Robert expressed the importance of this.

Ruth expressed that by her husband having engagement, action and conversations happening with the staff, he settled since there is always something going on to cheer him up.

Ruth:

"I feel he is better here than he was at home. His dementia is still horrible but here he is settled and even the fact that he sees activities going on and staff and residents speaking to him… it's helping him so much more. At home, he only had the TV on which did not help him as he doesn't understand it with his dementia. I've seen the difference that he is doing better."

"Inħoss li huwa aħjar hawn milli kien id-dar. Id-dimensja tiegħu għadha orribbli imma hawn hu stabbilit u anke l-fatt li jara attivitajiet għaddejjin u staff u residenti jitkellmu miegħu...

Qed tgħinu ħafna aktar. Id-dar, kellu biss it-tv u ma għenux għax ma jifmux bid-dimensja li għandu. Rajt id-differenza li sejjer aħjar."

Robert also agreed that by having an engaging environment, the residents do better than if they were at home alone where nothing goes on, especially since his mother lived alone.

Robert:

"But at the end of the day, there is action and movement so she is better off there than at home doing nothing."

"U at the end of the day hemm naqra moviment u azzjoni, aħjar milli qegħdha tkun ma' tagħmel xejn."

Lucia expressed that since residents walked around, her mother walked with them and in turn improved her mobility which in turn makes her happy. This is because her mother would seem sad all day just sitting on the couch.

Lucia:

"In terms of mobility we saw that she improved as in her house she would sit on the couch for hours and be sad but in the ward, since there are many residents, she walks with them and her mobility improved and she looks happy."

Dwar il-mobility tagħha, aħna rajna li mpruvjat għax id-dar kienet toqgħod bilqegħda għal sieghat twal imdejqa u hawn fil-ward, peress li hemm ħafna residenti, toqgħod timxi magħhom u l-mobilita' tagħha impruvjat u tidher ferħana."

4.4.2 Sub-category: A Small and Quiet Ward

This sub-category was not common in the other interviews, however Monica mentioned that her sister was put into a very chaotic ward at first. In fact, the ward she was put into at first was not a dementia ward but a general ward with many residents. The ward she is in now is a dementia ward which has fewer residents. She expressed her concerns with the home management and asked them to transfer her sister into a dementia ward. This shows that with

adequate communication and planning, this situation could have been avoided and her adjustment would have been faster.

Monica:

*“In the beginning, she was sad and said – ‘where did you bring me here? This is a place for crazy people!’. Because the ward she was put in at first was quite chaotic. There were residents yelling. They then quickly put her in another ward. A very quiet one, this one. This ward is much better in terms of environment. She is happy here, it's a small ward unlike ***** with 30+ patients. We all decided as siblings to put her here.”*

*"Fil-bidu, kienet imdejqa u qalet - fejn ġibtni hawn dan huwa post għal nies imġienen! Minħabba li s-sala li tpoġġiet fiha għall-ewwel kienet pjuttost kaotika. Kien hemm residenti jgħajtu eċċ. Imbagħad malajr poġġewha f'sala oħra. Waħda kwieta ħafna din. Din is-sala hija ħafna aħjar f'termini ta 'ambjent li hija kuntenta hawn, hija sala żgħira b'differenza mis- ***** bi 30+ pazjenti. Ilkoll iddeċidejna bħala aħwa li npoġġuha hawn."*

This quote indicates the importance for persons with dementia to be put in a ward where their needs are met.

4.4.3 Sub-category: Adjusting to a New Environment

This sub-category had some similarities with the sub-category - *routine*. This is because essentially a change of environment leads to a change of routine. This was evident in Roberts's response as he saw his mom unsettled in the first week as the environment drastically changed, along with the routine. However, once settled it became like her new home.

Robert:

“Yes! Because her problem is when you change her routine, but now she settled. She made it her home. In the first week, she would say - “let's go!”

"Iva! Minħabba li l-problema tagħha hija meta tibdel ir-rutina tagħha, iżda issa ssetiljat. Hija għamlitha d-dar tagħha. Fl-ewwel ġimgħa, kienet tgħid - "ejja mmorru!"

Ruth:

"... Even the fact that he did not want to shower didn't help, as he would not shower before even at home, so the changing of environment didn't help… He was confused; he didn't even want to shower. He was aggressive but he would not hit… It could be because of the changing environment…"

"... Anke l-fatt li ma riedx jinħasel ma għenx, peress li ma kienx jieħu jinħasel qabel lanqas id-dar u għalhekk il-bidla fl-ambjent ma għenitx ... Huwa kien konfuż li lanqas biss ried jinħasel. Huwa kien aggressiv iżda ma kienx se jagħti ... Jista' jkun ta' tibdil fl-ambjent..."

Ruth explained how difficult it was for her husband to shower as he was not used to it, which in turn does not help in adjusting, as showering was not a regular habit of his.

Monica:

"She was quiet and only confused a bit due to the change of environment in the beginning… but now she says, "this is my home" and looks very content here…"

"Fil-fatt kienet kwieta u konfuża biss ftit minħabba l-bidla fl-ambjent fil-bidu ... imma issa tgħid "din hija dari" u tidher kuntenta ħafna hawn..."

When asked about what could have affected Monica's sister's adjustment, she had expressed that from changing her sister's environment from her home to the residential home, she got confused but later she settled down. This point indicates that time needs to be given for adjustment, especially for a person with dementia to adapt to the new life, environment, and situation.

Lucia:

"We did a period where we would share the time our mother spent with me and my sister. She would do 8 weeks with me and then vice versa. We used to notice that every time we changed, as she changed her environment, she would get a bit worse every time and we didn't realise we were doing her harm in adjusting… or giving her time to adjust. So basically no… changing her environment was not that good for her."

"Għamilna perijodu ta' żmien fejn konna naqsmu l-ħin li ommna qattgħet miegħi u ma' oħti. Kienet tagħmel 8 ġimgħat miegħi u mbagħad viċi versa. Konna ninnutaw li kull darba li

biddilna, bħal fil-bidla fl-ambjent tagħha, kienet tmur daqsxejn agħar kull darba u ma rrealizzajniex li konna qed nagħmlu l-ħsara tagħha fl-aġġustament... jew fil-fatt tagħti l-ħin tagħha biex taġġusta. Allura bażikament le ... Li tbiddel l-ambjent tagħha verament ma kienx daqshekk tajjeb għaliha."

Lucia was very concerned that the change in the environment was not helping. She had expressed that her mother would get confused every time she switched home between her and her sister. They had finally decided to put her into a long-term care setting to avoid changing her environment every time.

4.4.4 Sub-category: A Closed Environment

One factor that was noted was that the dementia wards are 'closed wards', meaning all doors are locked leaving the residents to wander around in a very small area. This is common in dementia units since it avoids the possibility of the resident escaping. However, the wards could have been designed a bit bigger and more opportunities should be created for residents to go outside with supervision. Robert was particularly not happy with that as he expressed to the researcher how it is not fair that other wards in the home have a garden and with light coming through everywhere as there are many windows.

Robert:

*"The *** ward is much better… much, much better with light coming in from everywhere, sofas, a big garden outside, and better ambience and I think that affects how residents adjust."*

*"Is-sala *** hija ħafna aħjar ... ħafna, ħafna aħjar bid-dawl dieħel minn kullimkien, sufani, ġnien kbir barra, u atmosfera aħjar u naħseb li taffettwa kif jaġġustaw ir-residenti."*

This is a significant point to note that for a person with dementia to adjust, an aesthetically pleasing environment could really be useful for them. Even just the light coming through is enough to increase their dopamine levels affecting their mood.

During the Covid-19 pandemic, all the wards in SVPR were closed and as a result no visiting and activities were taking place. In some wards, even the rooms were closed meaning residents

could not interact with other residents from another room or go into the dining hall. Lucia stated that her mother had lost weight due to not eating enough, which could be linked to the fact that she was sad and did not know how to cope. This shows that a closed environment may affect the mood of residents with dementia and the way they adjust to the new environment. In this case, Lucia's mother had more difficulty adjusting on admission, since the transition happened around the time when that particular ward was closed due to the Covid-19 pandemic.

Lucia:

"The difference was that when they closed the ward for Covid, after opening, we saw that she lost weight and was sad, so she could have not been eating..."

"Id-differenza kienet li meta għalqu s-sala għall-Covid, wara li fetħu, rajna li tilfet il-piż u kienet imdejqa, jista' jkun ma' kinitx qed tiekol..."

Anna also firmly believed that her mother was worsened by the closed environment they have in that ward. This ward is the same as Robert and Lucia's mother. Monica, Ruth, and Janet are in different wards and their family caregivers did not touch on this topic. This could mean that the fact the ward environment was a closed ward has a significant effect on these residents.

Anna:

"... I think she worsened due to the "closed environment" as she is always locked in!..."

"... Naħseb li marret għall-agħar minħabba l-"ambjent magħluq" peress li hija dejjem imsakkra!..."

4.5 Theme 2: Regular Visits

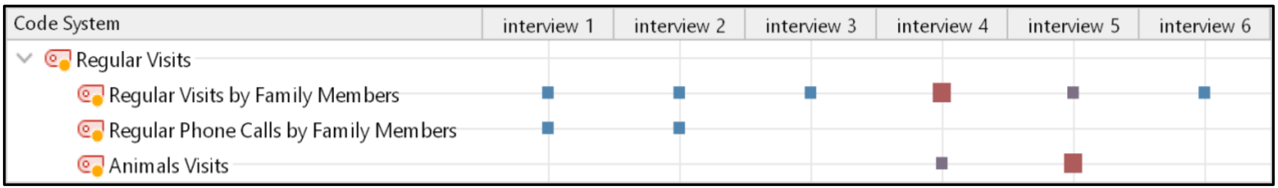


Figure 7: Code Matrix Browser Illustrating the Resultant Coding Intensity for Theme 2: Regular Visits

4.5.1 Sub-category: Regular Visits by Family Members

This sub-category was very evident with more than 80% of interviewees discussing it in this research study. Almost all except one interviewee mentioned how important regular visits are for a person with dementia to adjust quicker and more efficiently once admitted into a nursing home.

Lucia explained that the ward her mother was in was closed due to Covid-19, she seemed very sad and was not eating. This could also be from the change of environment as well as discussed in section 4.4.4. However, Lucia had said that she goes to see her mother almost every day and her loss of appetite could also be because of the lack of visits.

Lucia:

"... She was sad and maybe noticed that no one was visiting her..."

"... Kienet imdejqa u forsi ndunat li ħadd ma kien qed iżurha..."

On the other hand, Monica sees her sister only once a week, but she had explained that her sister was not very dependent on her and that just once a week was enough. However, she made it clear to the researcher that this regular routine visit, just like with Anna's mother, helped her sister to adjust as she would see a recognizable face and get happy. In this case, being happy equalled a better adjustment at the nursing home because the person with dementia was not completely "abandoned" and by visiting, a sense of home was established.

Monica:

"She gets so happy when she sees us so I think it helps that we come once a week. Often she says "look, that's my sister" and that makes me happy."

"Hija tieħu pjaċir ħafna meta tarana u għalhekk naħseb li tgħin li niġu darba fil-ġimgħa. Ħafna drabi tgħid "ara dik oħti" u dan jagħmilni kuntent."

Ruth was a strong believer in regular visits and visited her husband every single day. She explained how the transition was easier for him to adjust to the nursing home as she would be there every day supporting him. This also ensured her husband would remember her.

Ruth:

"He was a "bniedem tar- rutina" so the fact that they have a routine in the ward helps, also our timely visits every day. We would see him less confused because of the fact that we were visiting. Some people only come once in two months and they forget them obviously! … I feel like subconsciously… they know…"

(Ruth is referring to the fact that persons with dementia subconsciously might know when their loved one stops visiting)

"Since June we have been here every day… from 5 pm to 7 pm! Maybe that helped him with his adjustment… I believe so!"

"Kien "bniedem ta rutina" u għalhekk il-fatt li għandhom rutina fis-sala jgħin, ukoll iż-żjarat f'waqthom tagħna kuljum. Konna narawh inqas konfuż u ħabba l-fatt li konna qed inżuruh. Xi nies jiġu darba biss f'xahrejn u jinsewhom ovvjament! ... Inħoss li subkonxjament ... jafu ..."

"Minn Ġunju ilna hawn kuljum... mill-5 pm sas-7 pm! Forsi dan għenu fl-aġġustament tiegħu ... Nemmen hekk!"

Similar to Ruth, Janet felt that her husband did not forget her because he feels as if he is still with her, in turn making him adjust better and accept the fact that he is in the nursing home.

Janet:

"He adjusted more since he's been here, it's like he has accepted it, but the fact that we come here every day helped a lot… That helps for sure! He feels he is still with me."

"Huwa aġġusta aktar minn meta kien hawn, qisu aċċettah imma l-fatt li niġu hawn kuljum għen ħafna ... Dan jgħin żgur! Iħoss li għadu miegħi."

4.5.2 Sub-category: Regular Phone Calls by Family Members

Anna expressed to the researcher that her mother was very agitated and would start yelling at times and the only way to calm her down was when the nurse would call her and let her speak to her mother as she would recognise her voice. This sub-category was included in the code matrix. Her mother would recognise her physically as well which is why regular visits helped her to adjust as a regular routine visit was implemented in her mother's life.

Anna:

"The fact that she sees us makes her happy and helped her adjust… and even if the nurse calls us just for her to listen to our voice, she instantly calms down and helps her agitation."

"Il-fatt li tarana jagħmilha kuntenta u għenha taġġusta ... u anke jekk l-infermiera ssejħilna biss għaliha biex tisma' leħinna, hi mill-ewwel tikkalma u tgħin l-aġitazzjoni tagħha."

4.5.3 Sub-category: Animal Visits

Both husbands of Janet and Ruth are in the same pet friendly ward. The staff bring in ponies and goats to calm down residents and is a regular activity. In Ruth's case, she brings the dog with her when visiting her husband and he recognises him and feels immediately happy and calms down. This indicates how bringing animals or their own pets can help adjust better when transferred to the nursing home, because it feels like persons with dementia would have never left home.

Janet:

"The activities definitely help and they even bring animals like a pony sometimes… I did not see a huge difference, but I could see he gets content and not sad."

L-attivitajiet żgur jgħinu u saħansitra jġibu annimali bħal poni kultant... Ma rajtx differenza kbira imma stajt nara li jkun kuntent u mhux imdejjaq."

Ruth:

"We bring his dog every day and you can tell he enjoys it!... We would see him less confused with the dog"

"Aħna nġibu l-kelb tiegħu kuljum u tista 'tgħid li jgawdi!... Konna narawh inqas konfuż mal-kelb"

4.6 Theme 3: Maintaining a Routine

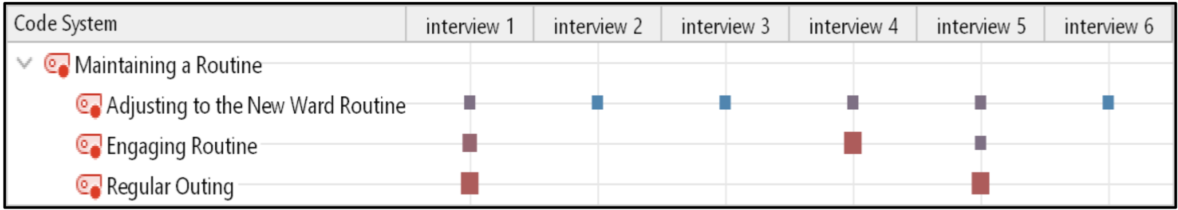


Figure 8: Code Matrix Browser Illustrating the Resultant Coding Intensity for Theme 3: Regular Routine

It was evident to see under this theme that by keeping the previous daily routine, the interviewees felt their relatives had adjusted more and the nursing home became like their home. In Janet and Ruth's case, both of their husbands had a routine before the admission and this routine was kept at the nursing home. This meant that their husband adjusted better.

Monica:

"In the beginning, she used to say I want to go home and did look rather sad but now she says "this is my home" and looks very content here, she adapted to the routine you know ... "

"Fil-bidu, kienet tgħid li trid tmmur id-dar u dehret pjuttost imdejjaqa imma issa tgħid "din hija dari" u tidher kuntenta ħafna hawn, adattat ir-rutina li taf ... "

Ruth:

"He was a "bniedem ta rutina" so the fact that they have a routine at the ward helps…"

"Kien "bniedem ta' rutina" allura l-fatt li għandhom rutina fis-sala jgħin ..."

Janet:

"... But we get him out every day since day 1, as before his admission he used to do that, so we kept the routine."

"... Imma noħorġuh kuljum mill-bidu, għax qabel ma' daħal kien jagħmel hekk, żammejna r-rutina."

4.6.1 Sub-category: Adjusting to the New Ward Routine

Robert believed strongly that adjusting to the new ward routine helped in adjusting to the home on admission. He discussed how his mother did not adjust well at first on admission because of the change in the environment and routine. He expressed how eventually, she settled better with the adapted ward routine and that she became less confused. It is evident that adjusting to the ward routine is an important part of adjustment to the home in persons with dementia.

Robert:

"... Yes! Because her problem is when you change her routine, but now she settled. She made it her home. In the first week, she would say "let's go!"

"... Iva! Minħabba li l-problema tagħha hija meta tibdel ir-rutina tagħha, iżda issa ssetiljat. Hija għamlitha d-dar tagħha. Fl-ewwel ġimgħa, kienet tgħid "ejja mmorru!"

Robert:

"Even though she has dementia, she has adapted because the nurses are now part of her family, routine is such an important aspect, because then you confuse them, that's why she adjusted. When we used to bring her home, she would open all the drawers and would be confused, because we broke the routine, but now there she has a (new) routine and she is much more settled. It's crucial…crucial…"

"Minkejja li għandha d-dimensja, hija adattat għax l-infermiera issa huma parti mill-familja tagħha, ir-rutina hija aspett tant importanti, għax imbagħad tħawwadhom, huwa għalhekk li aġġustat. Meta konna nġibuha d-dar kienet tiftaħ il-kxaxen kollha u tkun konfuża għax kissirna r-rutina, imma issa hemm għandha rutina (ġdida) u hi ħafna aktar settled. Huwa kruċjali ... kruċjali ..."

4.6.2 Sub-category: Engaging Routine

An ‘engaging’ routine was mentioned in Anna’s interview as she tried to make a point that in the ward, her mother is admitted, they have a routine, but it is a boring one. She suggested incorporating activities into their routine such as regular outings.

Anna:

“The fact that they would dress them up and do their hair up nice would cheer them up. She is always locked in, and her routine is a boring routine, not an exciting one, one can get used to…”

"Il-fatt li kienu jilbsuhom u jagħmlu xagħarhom sabiħ kien iferraħhom. Hija dejjem imsakkra u r-rutina tagħha hija rutina boring, mhux waħda eċċitanti, wieħed jista 'jidra ..."

Anna:

“She does not have a routine to look forward to, for example knowing that tomorrow she has an outing.”

"M'għandhiex rutina biex tħares 'il quddiem, per eżempju, billi tkun taf li għada għandha ħarġa."

Anna expresses that, unlike the other participants, her mother did not benefit or adjust better from the regular adopted routine because it is a boring one. She told the researchers that her mother used to go out all the time with her aunts and would dress up which no longer happens at the nursing home. This could be avoided if the components of communication and support took place between the residential staff and the caregivers to try and incorporate more activities. This is further discussed in Chapter 5 within the context of the TRANSCIT model.

4.7 Theme 4: Nursing Home Staff

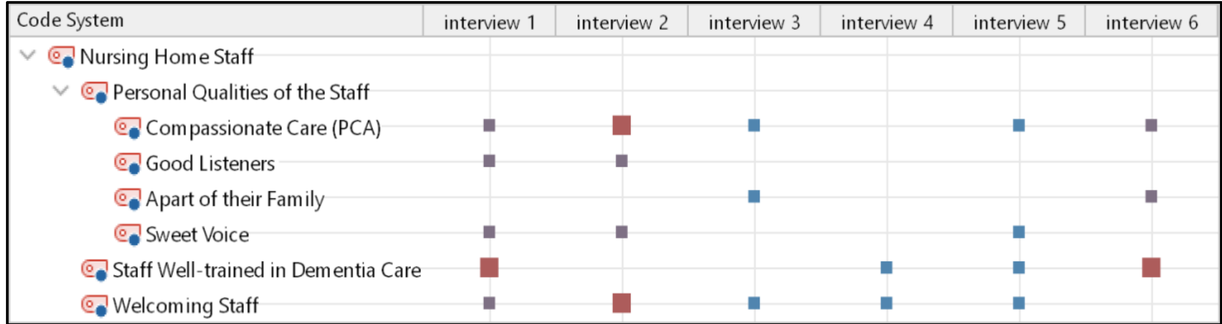


Figure 9: Code Matrix Browser Illustrating the Resultant Coding Intensity for Theme 4: Nursing Home Staff

This theme was the most active and discussed by the interviewees. The term *nursing home staff* includes nurses, doctors, nursing aids and carers. These are the people (mostly nurses and carers/nursing aids) that provide the first point of contact with the relatives and the person with dementia on admission. It was evident that persons living with dementia adjusted better when being cared for by loving, caring, and welcoming staff. This was mentioned by more than 65% in the interviews. That is, by having the staff well trained in dementia, the adjustment process of the person with dementia is quicker and better. It must be noted that the staff working at these wards (apart from the relievers) happened to be trained in dementia care since the participants were admitted to dementia wards and not general geriatric wards.

4.7.1 Sub-category: Personal Qualities of the Staff

Anna and Lucia focused on the fact that thanks to the care provided by the staff, their mothers ate more and consequently were happier. In order to provide person-centred dementia care, one needs to be well-trained in dementia care. This point is also evident in Lucia's citation in category 4.7.2 where she compares the staff with other institutions. This is discussed further below.

Anna:

"There needs to be a type of loving care and patience and it must be coming from the heart especially working with elderly patients. For example, in feeding them, a certain sweet tone in the voice would encourage them to eat more, which is what they do, so yes, I think it

helped her adjust, as she is not being shouted at to eat, which will consequently make her irritated. She probably subconsciously knows she is being taken care of in mealtimes… for example, because if she is being shouted at, I think they (the residents) would realise and be conditioned to be scared at mealtimes, no?"

"Jeħtieġ li jkun hemm tip ta' kura u paċenzja ta' mħabba u jrid ikun ġej mill-qalb, speċjalment min jaħdem ma' pazjenti anzjani. Per eżempju fit-tmigħ tagħhom, ċertu ton ħelu fil-vuċi jħeġġiġhom jieklu aktar. Dak li jagħmlu, allura iva naħseb li għenha taġġusta, peress li mhix qed jagħjtu magħha biex tiekol, li konsegwentement tagħmilha irritata. Probabbilment subkonxjament taf li qed jieħdu ħsiebha fil-ħinijiet tal-ikel... per eżempju, għax kieku kellhom jagħjtu magħha, naħseb li (ir-reżidenti) jindunaw u jiġu kkundizzjonati għax jibżgħu fil-ħinijiet tal-ikel le?"

Lucia:

"The staff pushed her to eat in a gentle way and she is eating very well there and much more than she did when she was in her house as she would only eat boiled vegetables."

"L-istaff ħeġġiġa biex tiekol b'mod ġentili u qed tiekol tajjeb ħafna hemm u ħafna aktar milli kienet tagħmel meta kienet f'darha peress li kienet tiekol biss ħaxix mgħolli."

Robert:

"Even though she has dementia, she has adapted because the nurses are now part of her family, … that's why she adjusted."

"Minkejja li għandha d-dimensja, hija adattat għax l-infermiera issa huma parti mill-familja tagħha, ... Huwa għalhekk li aġġustat."

Anna:

"I think all the nurses are good, they listen to us well."

Anna:

"Naħseb li l-infermiera kollha huma tajbin jisimgħuna wkoll."

4.7.2 Sub-category: Staff Well Trained in Dementia Care

A well-trained-dementia nurse influences adjustment since sometimes, the person with dementia can be quite aggressive like Anna's mother and needs extra patience and one-to-one care and attention.

Anna:

" ... But yes, I think training is important especially with someone like my mom as she is quite aggressive and to calm her down to make her happy, a well-trained nurse is needed."

" ... Imma iva, naħseb li t-taħriġ huwa importanti speċjalment ma' xi ħadd bħal ommi peress li hija pjuttost aggressiva u biex tikkalmaha, biex tagħmilha kuntenta, għandha bżonn infermiera mħarrġa."

Ruth:

"The staff really helped so I have no recommendations. I believe there should be staff training as there is always a need for people to work within the dementia specialisation. Even doing activities specifically for dementia. "Hemm bżonn żgur!"

"L-istaff verament għen u għalhekk m'għandi l-ebda rakkomandazzjoni. Nemmen li għandu jkun hemm taħriġ fl-istaff għax dejjem hemm bżonn li n-nies jaħdmu fi ħdan l-ispeċjalizzazzjoni tad-dimensja. Anke jekk tagħmel attivitajiet speċifikament għad-dimensja. "Hemm bżonn żgur!"

Janet mentioned how her husband needs special loving care as well, and that the staff at that ward is very calm and well-trained to handle dementia patients.

Janet:

"As training for the staff, some of them have tactics, there is one, you know what he tells him come on get up, in a calm way, and not shouting or he pulls him, that kind of loving care. And praise them and give them my congratulations, as this helps a lot, a lot, in their adjustment..."

"Rigward it-taħriġ lil-ħaddiema, wħud minnhom. għandhom certi tattiċi. Hemm wieħed, taf x'jgħidlu.. "ejja qum", b'mod kalm, u ma jgħajjatx jew jiġbdu, dik it-tip ta' kura ta' mħabba. U jien infaħħarhom u nagħtihom l-prosit, peress li dan jgħin ħafna, ħafna, fl-aġġustament tagħhom"

Robert:
"Yes, they play with a ball, because the staff knows how to get along with persons with dementia and how to look out for them…"

"Iva, jilagħbu b'ballun għax l-istaff jafu jimxu ma' persuni bid-dimensja u kif joqgħodu attenti għalihom..."

" … But to conclude the staff is nice and there is a strong staff in that ward focusing on dementia because I noticed…"

" ... Imma biex nikkonkludi l-istaff huwa gentili u hemm staff tajjeb f'dik is-sala li jiffoka fuq id-dimensja, għax innutajt..."

Lucia was very emotional when asked about the staff. Her mother was in the acute wards before she was admitted to the dementia ward, and she really felt the difference. She told the researcher that staff makes a significant difference in the adjustment of persons with dementia because her mother was very sad in the acute ward, due to there being a lack of one-to-one care and well-trained nurses in dementia.

Lucia:
"... I say that because the staff here are so much better than in (the acute hospital) for example, they are so caring here and show loving care. She was in the acute ward after breaking her hip before her admission here and the staff was not caring at all for her as they did not know how to go well with dementia patients. You could tell she was sad there every time I went to visit! They would not even feed her. One of the times I went to visit, I had left when they were handing out food and about to feed so you would assume they would feed her since she cannot feed herself. Then I came to visit again on the same day but later in the evening and you won't believe it… the food was still there! The plate hadn't been touched, no one went to feed her! Of course, she would be sad!"

"... Jien ngħid li minħabba li l-istaff hawnhekk huwa ħafna aħjar mis-swali akuti, per eżempju, tant qed jieħdu ħsieb hawn u juru mħabba fil-kura tagħhom. Hija kienet fis-sala akuta wara li kisret ġenbejha qabel daħlet hawnhekk u l-istaff ma kien qed jieħu ħsiebha xejn peress li ma kinux jafu jmorru tajjeb mal-pazjenti bid-dimensja. Tista tgħid li kienet tkun imdejjqa hemm kull darba li mort inżurha! Lanqas biss kienu jitimgħuha. Waħda mid-drabi li mort inżurha, kont tlaqt meta kienu qed jagħtuha l-ikel u assumejt li se jitimgħuha peress li ma tistax titma' lilha nnifisha. Imbagħad ġejt nerġa' nżurha fl-istess ġurnata imma aktar tard filgħaxija u ma temminhiex... l-ikel kien għadu hemm! Il-platt ma kienx intmess, ħadd ma mar jitmagħha! Naturalment, kienet tkun imdejqa!"

4.7.3 Sub-category: Welcoming Staff

The last sub-category from this theme portrayed how a welcoming staff introduced comfort to both the relative and the person with dementia. This, in turn, improved adjustment for them.

Anna:

"We will always expect more from carers as since it is not their mother you know … they might not really care that much, but… there are very good ones. The staff helped in her adjustment and they were welcoming for sure."

"Aħna dejjem nistennew aktar mill-carers peress li peress li mhix ommhom taf ... jistgħu ma tantx jimpurtahom daqshekk, imma ... Hemm oħrajn tajbin ħafna. L-istaff għen fl-aġġustament tagħha u żgur li kienu akkoljenti."

Lucia:

"The staff were of sugar! When you go inside the ward you don't smell bad smells of poo and pee. We are relieved she is in a safe place. And there is always someone with her. The staff were very welcoming and took good care of her."

"L-istaff kien taz zokkor! Meta tidħol ġewwa s-sala ma xxomx irwejjaħ ħżiena ta' "poo u pee". Aħna moħna mistrieħ li tinsab f'post sigur. U dejjem hemm xi ħadd magħha. L-istaff kienu akkoljenti ħafna u jieħdu ħsiebha sew."

Janet:

"The staff is incredible here, "allahares jiccaqalaq min hawn". Hafna welcoming. God forbid he moves out of here!"

"L-istaff huwa inkredibbli hawn, "allahares jiccaqalaq min hawn". Hafna akkoljenti. Alla jipprojbixxi li joħroġ minn hawn!"

4.8 Theme 5: Engaging Activities

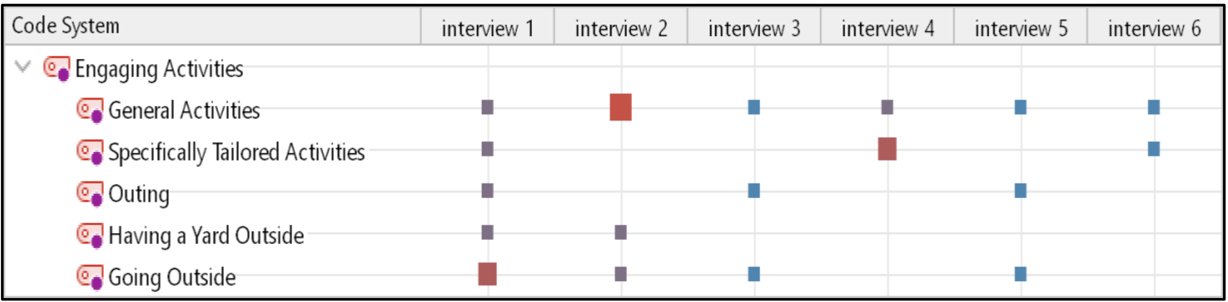


Figure 10: Code Matrix Browser Illustrating the Resultant Coding Intensity for Theme 5: Engaging Activities

This theme was the second most evident theme after Theme 4; Nursing Home Staff. Anna had firm opinions on how activities helped the adjustment. It was clear that by having general activities along with specifically tailored activities, a person with dementia will adjust better. This is because the relatives expressed that if there is always something going on, it will keep them busy and happy. More so, if the activity is tailored to their likes and dislikes. Having likes and dislikes communicated with the residential staff and taken into consideration for every person admitted is crucial and will be discussed further in Chapter 5 as a recommendation.

4.8.1 Sub-category: General Activities

Lucia goes to see her mother every day and stays for a long period of time there, hence why she sees the activities going on. She noticed that the residents became happy after the activity. Janet also goes every day to see her husband and takes him outside which is something he used to love. She expressed to the researcher that he adjusted well because of this everyday routine. This could indicate that having an activity every day may improve the level of adjustment for these residents.

Lucia:

"I believe they have everything there. Sometimes they have a singer that comes in and fun activities. Even in summer, they do BBQs adapted for them which is great for dementia residents to enjoy. Since there were covid cases they had stopped but after covid, they started again."

"Nemmen li għandhom kollox hemm. Kultant ikollhom kantant u attivitajiet divertenti. Anke fis-sajf, jagħmlu BBQs adattati għalihom li huwa xi ħaġa sabiħa għar-residenti tad-dimensja biex igawdu. Peress li kien hemm xi każijiet tal-covid kienu waqfu iżda wara l-covid, reġgħu bdew."

Lucia:

"Yes because there's always something going on that subconsciously makes them happy to be there and they are all smiling!"

"Iva għax dejjem hemm xi ħaġa għaddejja li subkonxjament tagħmilhom kuntenti li jkunu hemm u kollha jkunu qed jitbissmu!"

Janet:

"They do a lot of activities like church and hot dog days etc. But we get him out every day since day 1 as before his admission he used to do that, so we kept the routine. The activities definitely help"

"Jagħmlu ħafna attivitajiet relatati mall-knisja u ġranet tal-hot dog eċċ. Imma noħorġuh kuljum sa mill-ewwel jum, bħal qabel l-ammissjoni tiegħu kien jagħmel hekk żammejna r-rutina. L-attivitajiet żgur jgħinu"

4.8.2 Sub-category: Specifically Tailored Activities

Anna was saddened by the fact that they do not play bingo in the ward her mother is in as it is one of her favourite activities to do. The relatives were not asked what activities their loved one with dementia likes and it was evident that with tailored activities, one adjusts better.

Anna:

“Singers come in, but she does not participate as she does not like them. My mother loves bingo and I tell them many times that when she is agitated the only thing that calms her down is bingo and they should implement it as an activity in the ward. It hindered her adjustment. She is sad because of that.”

"Il-kantanti jidħlu imma hi ma tipparteċipax għax ma jogħġbuhiex. Ommi tħobb it-tombla u ngħidilhom kemm-il darba li meta tkun aġitata l-unika ħaġa li tikkalmaha hija t-tombla u għandhom jimplimentawha bħala attività fis-sala. Żgur li xekkel l-aġġustament tagħha. Hija mdejqa minħabba f'hekk."

Ruth:

“I've seen the difference that he is doing better. He loves music and one time they played some music and he would beat to the rhythm and it calmed him down as sometimes he seems nervous. Even doing activities specifically for dementia. There is a need for sure!”

"Rajt id-differenza li sejjer aħjar. Huwa jħobb il-mużika u darba minnhom kienu jdoqqu xi mużika u kien jisfen għar-ritmu u jikkalma ghax kultant jidher nervuż. Anke jekk tagħmel attivitajiet speċifikament għad-dimensja. Hemm bżonn żgur!"

Robert:

“Yes, I believe that they calm her down, she was a teacher so when they do crosswords, I believe they help.”

"Iva, nemmen li jikkalmawha, kienet għalliema u għalhekk meta jagħmlu “crosswords”nemmen li jgħinu."

4.8.3 Sub-categories: Having a Yard Outside, Going Outside, and Outings

Anna really expressed her thoughts on how an outing would benefit her mother as she used to go out a lot before her diagnosis and admission to the nursing home.

Anna:

“The adjustment would have been better if there were activities and taking them out for an outing with the van.”
"L-aġġustament kien ikun aħjar kieku kien hemm attivitajiet u joħorġuhom għal ħarġa bil-vann."

Anna:
“There is a big yard outside the ward and they should let us, for example, every Sunday for us to come as a family and be with our mother and be outside. She loves being outside.”

"Hemm bitħa kbira barra s-sala u għandhom iħalluna, pereżempju, kull nhar ta' Ħadd biex aħna niġu bħala familja u nkunu ma' ommna u nkunu barra. Hi tħobb tkun barra."

Anna:
“She was confused, and aggressive the first week, saying she went to the farm and church, wanting to get out. We found it a big deal that she cannot go outside anymore and not do these things. She used to go to the farm every day and would never get lost. We found it a big deal that the doctors deemed her not fit to live alone after she would do all these things alone. She was also depressed because her voice became heavy.”

"Kienet konfuża, u aggressiva l- ewwel ġimgħa, u qalet li marret fir-razzett u l-knisja, riedet toħroġ. Sibniha ħaġa kbira li ma tistax toħroġ aktar barra u ma tagħmilx dawn l-affarijiet. Kienet tmur ir-razzett kuljum u qatt ma kienet tintilef. Sibnieha ħaġa kbira li t-tobba qiesuha mhux tajba biex tgħix waħedha wara li kienet se tagħmel dawn l-affarijiet kollha waħedha. Kienet ukoll tinħass dipressa għax leħinha ma jkunx sew."

4.9 Conclusion

The main key findings from the empirical data collected from the six interviews have been presented in Chapter 4 with a comprehensive description of it. Narrative inquiry was used as the methodological approach using a constructivist paradigm. Chapter 5 will offer a more in-depth discussion of the key findings from the empirical data and any possible recommendations and implications that could be done to improve nursing practice, and ultimately improve the adjustment of a person with dementia into a nursing home. The findings in this study will be compared with relevant studies that have been critically appraised in Chapter 2. Finally, Chapter 5 will conclude with a discussion on the strengths and limitations of the research.

Chapter 5

5. Discussion of Findings

5.1 Introduction

This Chapter will offer a discussion based on the research findings yielded from the data analysis presented in Chapter 4. Each theme as a category with corresponding sub-categories will be discussed in relation to the TRANSCIT model by Groenvynck et, al., (2021). Differences and similarities that they may share with the conducted literature will be discussed to identify any gaps. The TRANSCIT model and how it was adapted to the research findings will be discussed in order to offer a pillar to how the findings can be better understood in the context of the persons with dementia transitioning and adjusting in the nursing home as perceived by their informal caregivers. MAXMaps, which are part of the MAXQDA software package, demonstrated a vital role in carrying out the content analysis of the stories and identifying the factors influencing successful adjustment as perceived by the caregivers. In this Chapter, MAXMaps will be introduced to each theme to provide a visualisation and graphic interpretation of data and the interrelationships between them.

5.2 The TRANSCIT Model in Relation to the Research Findings

Figure 11 portrays the TRANSCIT model adapted by Groenvynck et, al., (2021). Table 21 goes more into detail on how each component is needed in each phase - pre, mid, and post.

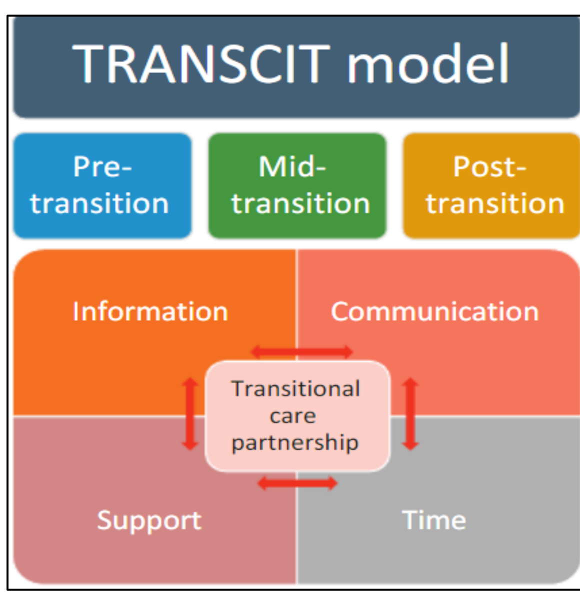


Figure 11: The TRANSCIT Model (Groenvynck. L, et. al., 2021)

For a successful transition from home into a nursing home, four key components must be included which are: information, communication, support, and time. They must be included in each phase of the transition process - pre, mid, and post. This model can develop interventions for an optimal transition, hence promoting adjustment. The data collected had some gaps with regards to the components from the model which in turn affected adjustment, and they will be discussed further below. The box in the middle of the four components of the model states "transitional care partnership". This is indicating that the person with dementia and the informal caregivers, need to form a relationship with the healthcare workers. This allows any knowledge, requests, recommendations, and information to be given to the staff so that the transition process can be facilitated even more to allow optimum adjustment.

	Pre-transition phase	**Mid-transition**	**Post-transition**
Information	Information on: registration process, nursing home, alternative options to nursing home, environment of nursing home, perspectives of healthcare staff on decision making process.	Information on: needs of a person with dementia being admitted, family situation, process of admission, regulations of the nursing home, medical information, the profile of the person with dementia.	Information on: the role of the informal caregiver, health care professionals, the daily routine of the nursing home, expectations, "preferences of the older person and informal caregivers", habits and regulations.
Communication	With regards to the decision-making process, communication with persons with dementia, family, and health care professionals. Communication on feelings and possible stigma regarding admission. Acknowledging emotions	Communication with the healthcare professionals on the day of the move and the first-day post-move. Sharing experiences.	The person with dementia's experience living in the nursing home needs to be expressed and discussed with the staff in order to make any necessary improvements. Informal caregivers are to be recognized as they voice their opinions and expectations.

	of grief.		Experience on the transition to be discussed.
Support	Emotional support. Caregivers receive support when taking new roles such as advocating for their relatives with dementia or seeking information and navigating.	Support caregivers while adapting to new roles. Support for the grieving process from caregivers. Support from family on the day of the move. Warm welcome.	Informal caregivers to be supported by their family, lawyers etc., to be supported when making decisions about any arrangements or changes at the nursing home for their relatives.
Time	Feeling prepared to transition. Having a care plan. Knowing if it is the right time for admission.	Checklist planning actual transition. To prepare and plan the admission procedures.	There needs to be contact with the family for continuity of care for the person with dementia. Staff needs to find time for the family to express any feelings regarding the admission.

Table 21: Explanation of how the Four Components are Needed in Each Transition Phase

5.2.1 The Use of MAXMaps

As mentioned in section 5.1, MAXMaps will be used to show the sub-categories under each theme as a category which were identified as a result of the analysis of the data. Figures 12, 13, 15, 16, and 17 display the themes with their corresponding sub-categories. In each MAXMap, the chosen theme is the main element as a category at the top centre, and it has the connecting links to the corresponding sub-categories which are coloured and size coded. The thickness of each connecting link demonstrates the strength of each sub-category of said theme in terms of coding intensity. This means that the thicker the connecting line is, the more references it has, thus the finding becomes more significant. The colour of the connecting links demonstrates the

intensity of the coding and therefore the importance of the sub-category and is depicted in different colours as explained in Table 22 below. The sub-categories that will be discussed in the context of the theoretical model and relevant studies are the red ones and the orange ones that were more significant and have 6 or more references. The yellow and orange ones with 5 references and below will not be discussed.

Red	*Strongly referenced*: 8 and above references.
Orange	*Moderately referenced*: 5-7 references.
Yellow	*Mildly referenced*: 4 and less references.

Table 22: The Meaning of the Colour-Coded Connecting Links of the MAXMap

5.3 Theme 1: *Nursing Home Environment*

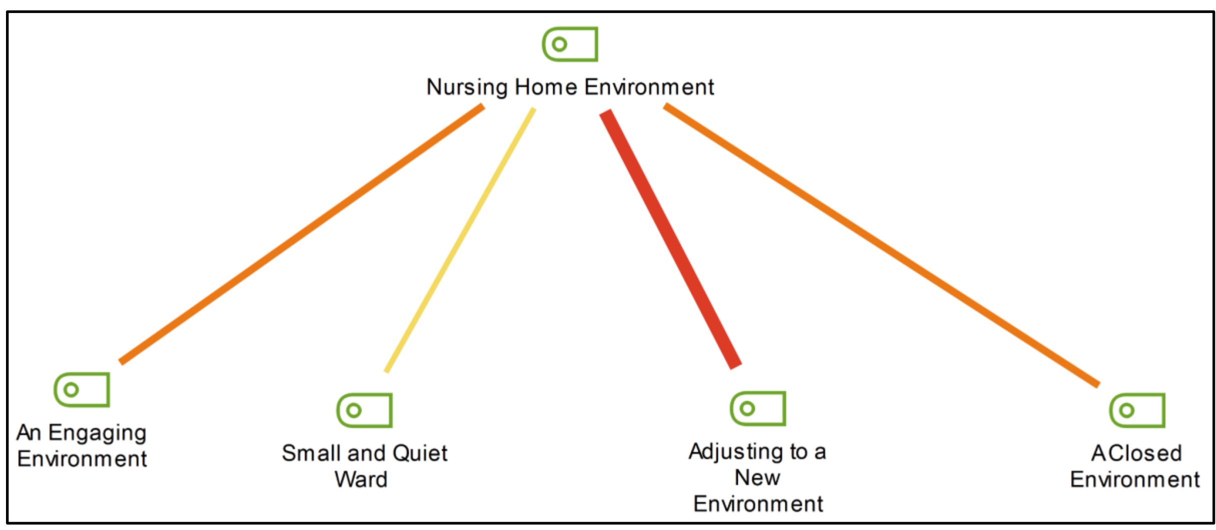


Figure 12: MAXMap Demonstrating the Theme - Nursing Home Environment

5.3.1 Sub-category: *An Engaging Environment*

The sub-category of *an engaging environment* (under the theme nursing home environment) as discussed in Chapter 4 was prominent among the interviewees as a necessary need for adjustment. This falls under the component of communication and information in the post-transition phase of the model. This is because this information was communicated with the informal caregivers that there will be engaging activities or just an engaging environment in general at the nursing home. The feedback from the caregivers was given to the staff that their

relative with dementia is adjusting much better due to this environment. The health care staff must provide time as well for the residents to have the freedom to move in the activities provided and encourage such movement.

5.3.2 Sub-category: *Adjusting to a New Environment*

The importance of the sub-category *adjusting to a new environment* was the most prominent among the interviewees as in this case, there was a lack of communication between the healthcare staff and the caregivers regarding this. The residents found it difficult to adjust at first (as perceived by the caregivers) and this falls under the mid-transition phase of the TRANSCIT model. There was a lack of information and communication given because the caregivers felt as if they were not "prepared" for what is to come in the transition. Lucia had expressed;

"No… they did not show us around before the admission, so we did not know what to expect and it was a big change of environment for her…".

This could have been avoided by communicating and making any necessary adjustments to make it feel more like home for the person with dementia, in this case, her mother. According to Groenvynck et, al., (2021), there is a need for the family to familiarise themselves with the "future home" by exchanging experiences with other residents and by exchanging knowledge and demands with healthcare professionals '.

Moreover, when the person with dementia does not adjust, this may lead to depression as discussed in Chapter 2. According to Komatsu (2007), depression in older adults could be caused by environmental factors such as changes in the environment. The residents were not adjusting well to the new nursing home because it was a quick change of environment along with other changes such as changes in their routines (especially for those admitted from their own home) and they were not prepared for this change. This could be because there was not a smooth transition from home/hospital to a nursing home. With respect to the TRANSCIT model, the findings indicate that in the *pre-transition phase,* the components were not followed through appropriately, so as to reach the *transitional care partnership, as suggested by the model* (Groenvynck, 2021).

The sub-category *closed environment* was expressed by the interviewees in a way that it doesn't improve adjustment. This falls under the phase post-transition and the component support

within the TRANSCIT model. The informal caregivers expressed to the researchers that the closed environment was not ideal for their relatives, and this was not supported as much by the healthcare staff since they did not try to improve the situation by encouraging them to go outside with their caregivers. The caregivers expressed to the researcher that their loved one was not prepared for the closed environment upon admission and because of this, the chances of adjustment were lower.

5.3.2.1 Advantages of Special Care Dementia Units

A special dementia care unit (SCU) signifies a unit that meets the following criteria; contains residents with cognitive impairment, has a modified environment with wandering paths with dementia-friendly features, a controlled entry, "specialized ongoing staff training and support" (Maslow, 2001). In SVPR the dementia units are considered 'closed' meaning they have a controlled environment where all doors and cabinets/cupboards are locked at all times and only those with dementia can reside in these units. However, as seen from the responses, this 'closed' environment is not adequate enough for the residents living there, as there aren't any controlled *safe* pathways or gardens where the dementia residents can walk into and still be safe. According to Maslow et, al., (2001), SCU placements have their advantages over other general geriatric wards, such as better behaviour and social interactions, improving agitation and confusion. However, for this to happen, Maslow et, al., (2001) suggests that family involvement needs to take place where the family expectations are discussed. According to the observational study (Kutner et, al., 2011), decreased agitation was associated with the quality of the environment such as a small unit with "home-like qualities". Day time rest for the prevention of over stimulation was also beneficial.

Moreover, this means that if SVPR, 'upgrades' its dementia units like the SCU discussed above, it would improve the quality of life for these residents. Fortunately, SVPR (at the time of writing this dissertation) has been constructing a *dementia friendly garden* where it will span 3000 metres squared (Malta Daily, 2022) and will be ideal for persons with dementia to enjoy activities. This will certainly improve adjustment for future admissions once constructed.

5.3.3 Difference Between Admission from Home and Admission from Hospital

There was a noticeable difference in the discussion between the researcher and the interviewees (caregivers) because three of them had their loved one coming from their own home, and the other three were coming from the hospital. Based on the participants interviewed, it seems that

the transition was harder for the person with dementia coming from the hospital into the nursing home when compared to participants who were transferred from their own home. Similarly, Ray et, al., (2015), concluded that there was a significant increase in depression for persons with dementia being transitioned from a hospital to a nursing home.

Furthermore, Lee et, al., (2021), conducted a systematic review and meta-analysis looking specifically at transitional care from a hospital to a nursing home. It was concluded that there needs to be at least an adequate solid base of components and interventions that aid the transition such as: involving residential staff and caregivers in the care plan, managing any underlying health conditions before the transition, making sure needs are met for the older person being transitioned, continuity of care being provided by the caregivers and supported by the residential staff and educating or promoting self-management to the older person. The study also concluded that for older frail adults, there needs to be extensive geriatric assessment and adequate discharge planning with a suitable care plan to improve or maintain their functional abilities.

The TRANSCIT model relates to the components mentioned in Lee et, al., (2021) study such as communication and support. From the empirical data collected, there was a lack of communication between the residential staff at the hospital and the caregivers. It seems that an adequate care plan was not being followed through from the discharge plan and it all seemed "*rushed*" as both Anna and Lucia said.

A person-centred approach to care will benefit the person with dementia being admitted to the nursing home (Mitchell, 2015). By making sure that the nursing home staff gets to know the person with dementia and their relatives, before transferring the resident, the transition could be smoother for the patient as the informal caregivers, since the latter would have already shared any important information about the resident. This also goes for the health care professionals at the hospital, since for continuity of care to be appropriate, there should have been communication with the ward at the nursing home to ensure that the adjustment process happens smoothly.

However, the caregivers of persons with dementia coming from the hospital, were the ones who provided negative feedback on the transition process and how it ultimately affected their adjustment. This says a lot about the lack of care/organisation that is being given to

transitioning patients from hospital to nursing home. With the use of better communication channels, this could have been avoided or been more transparent.

5.4 Theme 2: *Regular Visits*

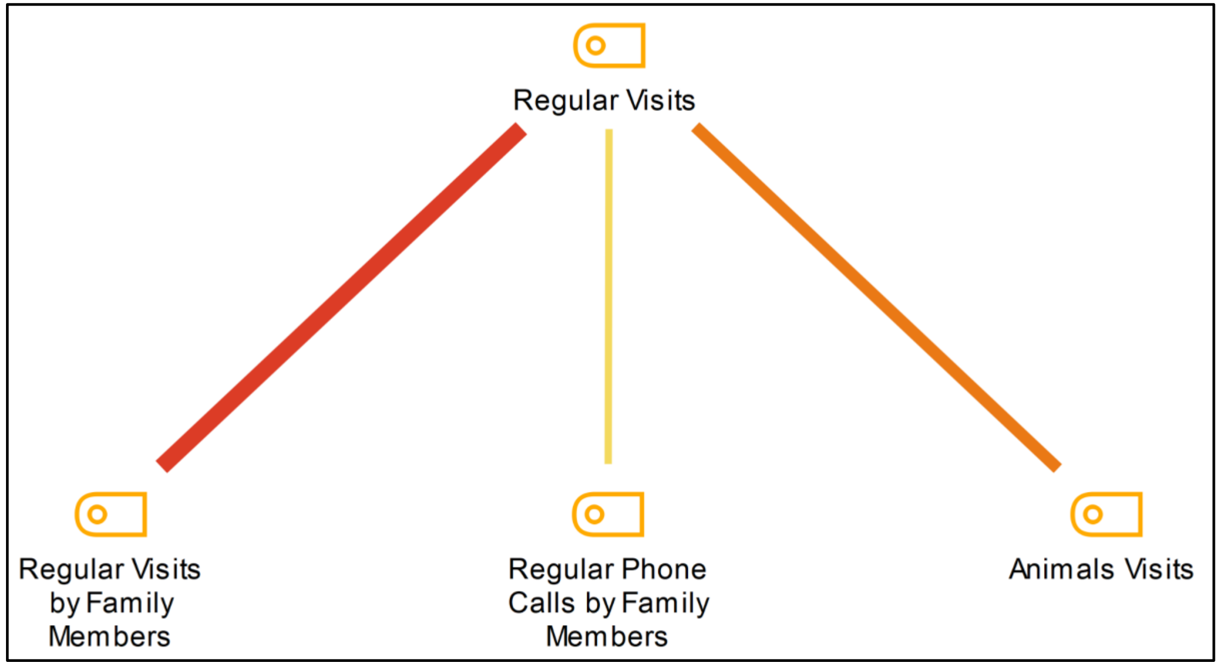


Figure 13: MAXMap Demonstrating the Theme - Regular Visits

5.4.1 Sub-category: *Regular Visits by Family Members*

Over 80% of the interviewed caregivers felt that *regular visits by family members* are very important to promote nursing home adjustment. This is related to the post-transition phase of the model and the component's support and time. For the transition to be easier, the caregivers were aware that with regular visits, the adjustment process in a new nursing home would be better if they regularly visited to promote continuity of care. This is because the person with dementia will regularly see and even recognise the person every time they visit and sustain a *home-like* feeling. This strengthens the importance of informal caregivers and the healthcare professionals working in residential homes need to support the new role of informal caregivers as part of the care triad.

According to a study conducted by Koster et, al., (2021), the interrelations between "the concepts and differences of user and family involvement" were unravelled. This is because the findings displayed how the person with dementia, caregivers and nurses (while entangled in a care triad relationship) can use their "position to accomplish a variety of involvement

activities" (Koster, 2021). The findings contributed in making of the following four care triads explained in Table 23 and shown in Figure 14 below.

Triad 1	The right of residents to receive professional, tailored care: this focuses motivated nurses to learn and execute the residents' care preferences and needs.
Triad 2	The right of family members to be supported in dealing with the disabling condition of their loved ones: this imperative was underlined by both the nurses and the residents.
Triad 3	The right of residents and their family members to feel socially valuable and included in the home: this, nurses expressed, was also their responsibility.
Triad 4	The right of nurses to be recognized for and supported in their workload.

Table 23: Brief Meaning of the Four Triads Established by Koster et, al., (2021)

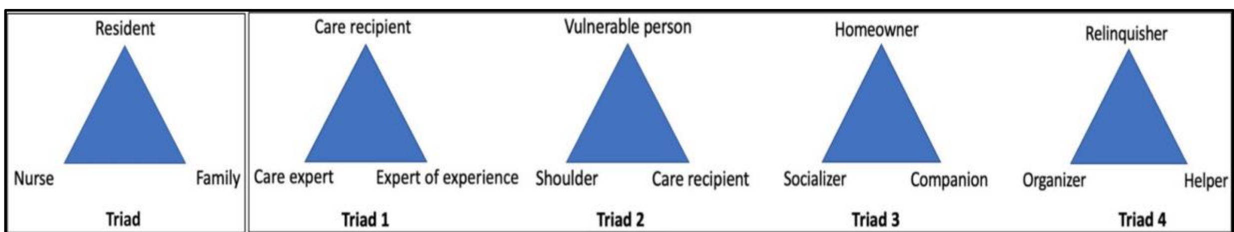


Figure 14: The Care Triads Displaying Interactions and Matching Identity Positionings (Koster, 2021)

Communication also plays a role since the residential staff will be in contact with informal caregivers regularly. This allows for any noted behaviour change to be voiced and investigated. Regarding the component time, the caregivers need to make time for their loved ones in the nursing home and for the residential staff to create time to listen to the caregivers. According to Groenvynck et, al., (2021), in the post-transition phase, time is related to "persistence and flexibility". Table 24 explains what is meant by these terms.

Flexibility	Allows persons with dementia to be admitted to establish old routines and habits and create new activities.
Persistence	This is created when persons with dementia stay connected to their family and continuity of care takes place along with communication with residential staff.

Table 24: Flexibility and Persistence According to Groenvynck et, al., (2021)

Moreover, according to Davidhizar et, al., (1994), there are several benefits of including the use of communication in the care triad such as; increasing support and understanding to the caregiver and resident, increasing compliance, improving the nurse's knowledge on the resident and introducing a more person centred approach by "facilitating positive patient-family relationships"

5.4.2 Sub-category: *Animal Visits*

Animal visits were also common among the responses. Ruth explained how bringing in a familiar animal, in this case, her husband's dog, helped a lot in his adjustment as this was a familiar activity in his previous routine. Similarly, Brownie et, al., (2014), emphasised *reminiscence therapy* and having familiar objects, pets etc, at the nursing home to promote adjustment and continuity of care.

Furthermore, a systematic review by Posadas et, al., (2019), found that persons with dementia in nursing homes improved their behaviour after being introduced to pet therapy, specifically DAT (dog-assisted therapy). Benefits included more interaction, less agitation and anxiety, laughing and smiling, positive energy and a feeling of relaxation. All these benefits improve adjustment since the residents will get used to having their pets visiting them every week. This relates to the mid-transition part of the model where the residential staff and caregivers should communicate on previous likes such as animal visits and make sure that it is introduced once transitioned.

5.5 Theme 3: *Maintaining a Routine*

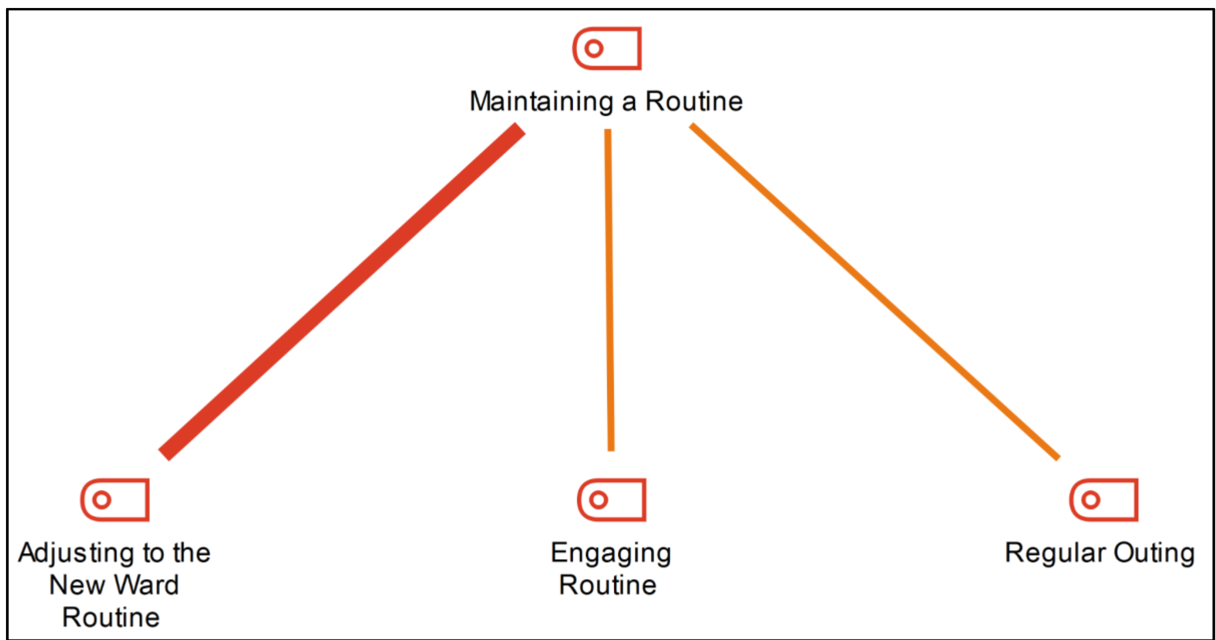


Figure 15: MAXMap Demonstrating the Theme - Maintaining a Routine

5.5.1 Sub-category: *Adjusting to the New Ward Routine*

The most discussed sub-category was *adjusting to the new ward routine.* The residents adjusted better when they had a regular daily routine. According to Groenvynck et, al., (2021), routine is a very important aspect of adjustment for persons with dementia and it is a vital aspect of the TRANSCIT model. For a routine to be implemented, adequate *information* and *time* need to be given to the caregivers by residential staff during the *post-transition* phase. For a successful transition and implementation of a routine, *information* should be provided to the informal caregivers about the nursing home's routine, expectations, and preferences. Moreover, caregivers should inform residential staff of the previous routines that the persons with dementia had. In terms of *time*, there needs to be enough time and flexibility given to allow previous rituals and routines to take place (Groenvynck, 2021). In this study, the information that was given to the caregivers on the routine practices of nursing helped in adjustment. Time was also given for them to adjust to a new nursing home's routine and for any changes that needed to be made to be taken care of.

Persons with dementia will experience a "stressful and emotionally challenging" transition and will find it difficult to adjust at first (Groenvynck, 2021). According to Heerema, (2022), a regular routine can simply be getting up every morning and eating the same breakfast, regular

napping and sleeping schedule, having a regular outing, regular bathroom schedule and having a regular activity schedule. The benefits of this are that the person with dementia will decrease their anxiety levels, help maintain their ADLs by performing activities, improve their independence or maintain it, as well as reducing the stress levels of informal caregivers (Heerema, 2022). The caregivers interviewed felt they were reassured when they knew that their loved one had a routine and that they were able to get used to this daily routine.

5.5.1.1 Setting Routines such as 'Regular Outings'

The findings indicate that setting *"regular outings" as part of the regular daily routines increased the* caregivers' satisfaction with the transition process. In the interview, Anna really believed that regular outings outside the nursing home every Sunday would benefit her mother as she would be looking forward to it. According to Heerema, (2022), outings for persons with dementia need to be adequately planned so that they will have adequate time to rest as well. The outing must be planned at a time when the person with dementia is functioning at their best and is not tired.

5.6 Theme 4: *Nursing Home Staff*

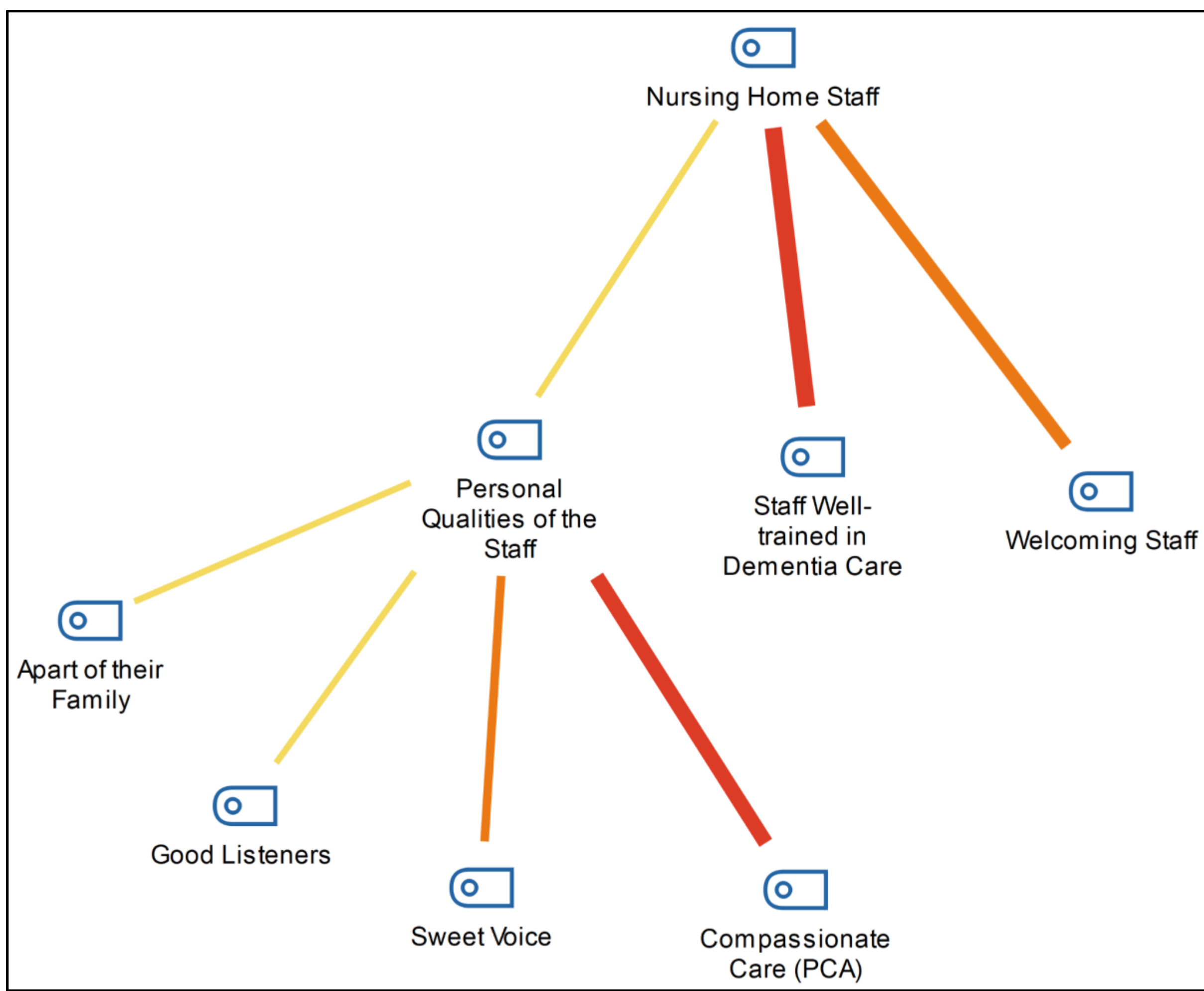


Figure 16: MAXMap Demonstrating the Theme - Nursing Home Staff

5.6.1 Sub-category: *Personal Qualities of the Staff*: *Compassionate Care (PCA)*

The second most common sub-category for this theme was *Personal Qualities of the Staff with* its property *compassionate care (PCA)* as the most prominent. The importance of compassionate care was mentioned in almost all the interviews as having a significant impact on adjustment. The caregivers felt like they received 'loving' care and support from the residential staff which is an imperative component of the TRANSCIT model. The support was given mainly throughout the mid and post-transition phases. The caregivers felt that the residential staff were looking after their loved ones very well and knew how to get along with them. They felt safe and if they required anything, they knew the residential staff were willing to help so that their loved ones would adjust well.

Moreover, the term loving or compassion care is vague and what it truly means and encompasses (as believed by the researcher) is the true desire to want to help, provide support and give attention to those who really need it or just a simple act of kindness to anyone. A more proper term is *person-centred care/approach (PCA).* Kitwood (1997), explains that to provide love for a human being, especially those who are losing their mental capability, their psychological needs need to be met and encompass these five elements; attachment, comfort, identity, inclusion and occupation. Table 25 explains these five elements needed to show *love* in more detail.

Attachment	Persons with dementia may feel a loss of security due to their cognitive impairment and the need for attachment is enhanced. This creates a bond and the sense of uncertainty that the person with dementia will be reassured with attachment and any anxiety and fears will diminish.
Comfort	To give comfort is to help a person to become strong. the staff must enable the person with dementia to "remain in one piece" (Kitwood, 1997) when they are at their lowest. If there is a sense of loss, for example, because of not being able to do certain activities of daily living, comfort is needed.
Identity	For a person with dementia to know who they are, there needs to be continuity of care. In other words, the elements of inclusion and occupation really play a role in this element because if the person is experiencing and being occupied with things they did before, they will have an identity and not be lost.

Inclusion	Since they have cognitive impairment, it is common that their social life will diminish. The need for inclusion is so vital since it gives the person with dementia a purpose and the possibility of them becoming numb and declining overall will be diminished. with inclusion, they will have action in their life and have a role.
Occupation	Occupation will avoid boredom by being occupied with the company of others, or with activities. For this to happen, there needs to be a good understanding of what the person with dementia likes and dislikes in order for them to feel important and be able to enjoy the activity.

Table 25: The 5 Elements Needed for Loving Care According to Kitwood (1997)

Furthermore, with these five elements, one will affect the other, hence why they all need to be present and in unison in order to ensure loving and compassionate care for a person-centred approach. With one missing, the psychosocial needs of persons with dementia will not be met.

5.6.2 Sub-category: *Welcoming Staff*

This sub-category portrayed the welcoming atmosphere of the residential staff towards the caregivers and the persons with dementia. Regarding the TRANSCIT model, this falls under the mid and post-transition phases during which residential staff support was used appropriately. It was clear to the researcher that all caregivers felt the support of the care staff during the transition of their loved ones.

5.6.3 Sub-category: *Staff Well-trained in Dementia Care*

The caregivers expressed how the care staff were very careful in the way they handle persons with dementia and were diligent in their approach. They spoke in a sweet soft tone and the person with dementia was not afraid of them and became part of their family. Komatsu et, al., (2007), found that persons with dementia were not able to adjust well following admission to

a residential home because they did not trust the caring staff who did not approach them with a caring attitude. Bramble et, al., (2009), argued that in view of low-staff ratios, not enough attention was given to persons with dementia which decreased the possibility of building trusting relationships with the care staff. This was also found in Brownie et, al., (2014) study.

When compared to dementia units, (as noted by the researcher given they work in SVPR) general geriatric units are generally low-staffed, and the staff may not be adequately trained in dementia as they would be in dementia units. As a result, care staff may be unable to provide the right attention. This was the case with Monica's sister when she was placed in the nursing home. There was no adequate planning or communication before the transfer, which led to Monica's sister being placed in an "open" general ward which was not dementia-friendly and was felt to be *"chaotic"*.

5.6.3.1 Dementia care in acute hospitals and the need to provide person-centred dementia care in these settings

Moreover, as mentioned above, three persons with dementia came from MDH and the other three were from their own homes. There was again a difference in the responses of the caregivers when asked about the care staff. The patients admitted directly from their own homes, highly applauded the staff working in the dementia unit. However, the other three caregivers compared the staff working in the dementia units with the staff working in the acute hospital. They argued that the care staff in the acute hospital was not welcoming and was untrained about dementia care. They had complained that the hospital staff was indifferent and too busy for dependent patients with dementia. This strengthens the argument that for a person with dementia to adjust better, it is ideal if the staff is well-trained in dementia to prevent any confusion, agitation, and anxiety in them. It is also ideal for them to be put into a dementia ward and dealt with in a dementia-friendly environment. It could be that acute care staff took for granted the time and attention a person with dementia requires.

Scerri et. al., (2018), indicated that the quality of care of persons with dementia in acute hospital settings is not optimal. Findings have reported that there is a general "lack of staff awareness" on how to care for persons with dementia which indicates that there needs to be staff training and support on this. In fact, Boaden, (2016), reported that from the responses of the informal caregivers, 60% of them stated that they did not see their relative with dementia being treated right with dignity while in the hospital. The hospital environment was also deemed frightening

with more than 90% of the responses saying it made their relatives with dementia more confused and delayed discharges. With that being said this affects the pre-transition phase of the TRANSCIT model to optimise transition and adjustment. With the pre-transition phase being non existing, the transition will not be easy if the person with dementia has already experienced a 'bad' experience before the admission at the hospital. This is why a person-centred care approach in all settings is needed, so that those who have cognitive impairment are not left out.

Moreover, Perruchoud et, al., (2022) conducted a systematic review where the staff conditions that the nurses were working in were explored regarding the impact, they have on the quality of care they give. This has to do with the point made above on *staff ratio* and how important it is for a person with dementia to be admitted to a proper dementia care unit and not a general ward so they will be more likely to have one-to-one care. Perruchoud et, al., (2022), discussed that the "nursing staff's qualification levels, i.e., having specific skills and more knowledge on dementia, impacted heavily and had positive influences on the quality of care given to elderly living in long-term facilities. Clinical outcomes were also improved for residents when nurses worked together with the multidisciplinary team and caregivers because the ward got more organised and an adequate care plan was made, thus benefiting the residents. This point strengthens the importance of using the TRANSCIT model since it advocates to work with the multidisciplinary team and caregivers using all its four components to truly benefit the person being transitioned.

5.7 Theme 5: *Engaging Activities*

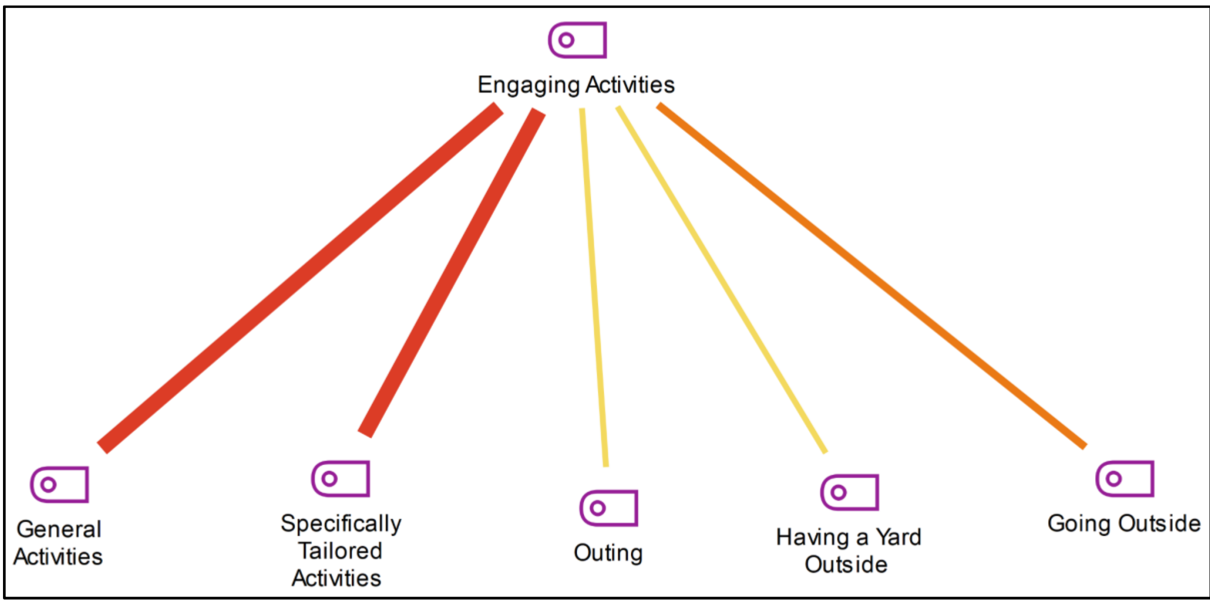


Figure 17: MAXMap Demonstrating the Theme - Engaging Activities

5.7.1 Sub-category: *Specifically Tailored Activities*

For adjustment of a person with dementia to take place, the researcher found out that tailoring activities to the person's needs are essential in nursing homes. This is because persons with dementia would feel as if they are at home and are doing things that they used to do before. For this to happen there needs to be communication with the caregivers about the likes and dislikes of their loved one at the pre-transition phase of the TRANSCIT model so that when they are transferred, there is already a tailored person-centred care plan and possible activities ready to be implemented. This unfortunately did not happen with the caregivers interviewed. Robert, Anna, and Ruth emphasised a lot on this issue and touched upon how their relatives would have adjusted better if they were asked what they liked as activities and eventually be implemented post-transition.

Moreover, Alzheimer's Society has a booklet ('This is me' found in Appendix 13) that contains information to be filled in for a person with dementia or Alzheimer's before their transition to the nursing home by their caregiver. It has sections including *about me, my background, my habits and routines, my communication and mobility, and my personal habits.* This is an excellent way of building a relationship with the caregiver and the resident, and for the person with dementia to have an adequate care plan with a document in their file that describes them as a person. This will help their adjustment because the care staff can organise activities that

they know the person with dementia will like such as Bingo (in Anna's mother's case). It also aids in avoiding any activities that might negatively affect their mood or behaviour since the care staff would be aware that their fears and dislikes will be listed down. This information is significantly important to be added to the care plan of residents because there are many relieving staff that work in residential care and dementia wards. As a result, they may not know the residents as well as the regular staff working in these wards. This hinders the practice of *continuity of care* and may, for example, trigger anxiety in a person with dementia if they are presented with a food item that the resident does not like. Other information such as mobility, speech and language pathologist recommendations for food and other basic information such as mental status and diagnosis is mentioned. Information as shown in Table 26 should be incorporated not only in dementia wards but in all geriatric wards to ensure that per-centred dementia care is provided. These documents need to be regularly updated to ensure that any other information that is acquired over time about the resident, or provided by the informal caregiver whilst visiting, is updated on the document.

According to Baillie et, al., (2018), findings showed how residential staff should use personal information documents such as 'This is Me' by The Alzheimer's Society in daily practice for person-centred care. It was indicated that there is a need to complete these documents from the pre-transition phase following the diagnosis of dementia, and then eventually embed it and use it throughout the resident's stay for optimum care.

The following routines are important to me	…
Things I like to do for myself/likes	…
Things I might want help with	…
Things that may worry or upset me/dislikes	…
What makes me feel better if I am anxious	…

Table 26: A Segment from This is Me Booklet by Alzheimer's Society

According to Groenvynck et, al., (2021), *personalised care* is promoting a “person-centred care approach” that ultimately benefits the resident. This systematic review examined several interventions such as tailored interventions for the needs and preferences of the residents. Communication was used with the caregivers to discuss any unmet needs and an “individualised session” was conducted to discuss ways to meet these needs. Some studies also assessed the residents during the pre-transition phase and did a *needs assessment* to create “meaningful activities and even increase the autonomy” (Groenvynck, 2021) for the residents. This indicates that there is a need for more communication between caregivers and residential staff.

5.7.1 Sub-category: *General Activities*

This study found that *general activities* are an imperative part of adjustment as discussed by the caregivers to the researcher. Some of the activities conducted in the long-term care institution where the study was conducted are ball games, a singer coming in to sing for them, indoor balloon games, bingo, arts and crafts, hot dog days, public holiday parties, a woodwind band coming in to play for them, van rides and church activities. These are all fun activities that keep the residents excited, busy and looking forward to attending. In the literature review, the study by Brownie et, al., (2014), and Yong et, al., (2020) showed that activities such as music therapy, reminiscence therapy and hobbies heavily influenced the level of adjustment because the quality of life of the residents improved, and the day became meaningful and engaging. This indicates that other activities such as the ones mentioned should be included along with the varied activities according to the needs of the residents.

5.8 Conclusion

This Chapter discussed the findings by comparing it with the TRANSCIT model and other relevant studies. The model acted as a guide to the researcher to be able to attain a greater understanding of the results. This discussion compared the findings with relevant literature as that was reviewed in Chapter 2 as well as new literature. In the next Chapter, a summary of the key findings is presented and recommendations and implications for better nursing practice to improve outcomes will be discussed.

Chapter 6

6. Conclusions and Recommendations

6.1 Introduction

This Chapter will conclude this dissertation and draw conclusions from the research findings obtained. Implications and recommendations for practice, training, management, and future research will be provided. To what extent the research objectives were met, will be discussed.

6.1.1 Summary of the Dissertation Process

The aim of this study was to understand from the perspective of informal caregivers, what are the factors influencing the adjustment of a nursing home admission of a person living with dementia. These factors were sought to improve the resident's adjustment and their quality of care.

Research Question

What are the factors influencing adjustment to nursing home admissions as perceived by informal caregivers of persons living with dementia?

Research Design, Methodology and Sources

The research methodology used a narrative approach to seek to collect the relatives' stories of the transfer from home or hospital to residential home and how they perceived their family members adjusted to this move. The TRANSCIT model (Groenvynck et, al., 2021) was used to discuss the findings. Data collection occurred from primary sources through structured interviews either via ZOOM or through face-to-face interviews. Content analysis was used to identify the five main themes supported by the MAXQDA software tool for qualitative data analysis and data management.

6.2 Summary of the Study and Relevant Findings

There were five themes established consisting of the most important factors supporting adjustment, as perceived by the family members as identified from the research study. These themes and their sub-categories along with a brief explanation for further understanding are portrayed below in Table 27.

Themes	*Sub-Categories*	*Brief Explanation*
1. Nursing home environment	● *An engaging environment.* ● *A small and quiet ward.* ● *Adjusting to a new environment.* ● *A closed environment.*	*An engaging and quiet environment with movement, activities and with a small number of residents was ideal for adjustment. A closed environment with no access to a garden hindered adjustment.*
2. Regular visits	● *Regular visits by family members.* ● *Regular phone calls by family members.* ● *Animal visits.*	*Having regular visits, either by family members or animals, helped adjustment, along with regular phone calls to promote communication.*
3. Maintaining a routine	● *Adjusting to the new ward routine.* ● *Engaging routine.* ● *Regular outing.*	*Having an engaging routine with activities and outings helped adjustment. Adjusting to the new routine was difficult, but when it was engaging, residents adjusted quickly.*
4. Nursing home staff	● *Personal qualities of the staff - good listeners, sweet voice, compassionate care (PCA), a part of their family.* ● *Staff well trained in dementia care.* ● *Welcoming staff.*	*A PCA and being welcoming along with the other personal qualities of the home staff helped adjustment. Staff need to be well-trained in dementia for better understanding of how to deal with a person with*

		dementia.
5. Engaging activities	● *General activities.* ● *Specifically tailored activities.* ● *Outing.* ● *Having a yard outside.* ● *Going outside.*	*Regular activities, specifically tailored to their likings, improved adjustment since it engaged the residents. Other activities like having a regular outing outside or a yard would improve adjustment.*

Table 27: The Five Themes from the Research Study Representing the Five Most Important Factors Influencing Nursing Home Adjustment

The findings were evaluated with respect to the TRANSCIT model which helped the researcher understand how the four elements in the model (information, communication, time, and support) are related to the main themes as developed by the study and understand how the transitional care partnership can support persons with dementia and their family members throughout the different transition phases (pre, mid, and post-transition).

Following the analysis and discussion of the main findings, several implications and recommendations for practice, education, management, and further research were proposed as highlighted in the subsequent section.

6.3 Implications and Recommendations for Practice

6.3.1 Implementing the "This is Me" booklet (Alzheimer's Society) into Practice in Dementia Units and Residential Homes

As discussed in Chapter 5, the implementation of this booklet will be very helpful to guide the residential staff working in dementia units and residential homes to know what the resident likes and dislikes thereby avoiding upsetting them. It will promote *continuity of care* since many relieving staff work in these dementia units who do not know the resident like the permanent staff do. According to the caregivers interviewed in this study, their relatives with dementia would have benefited from the implementation of tailored activities to their liking and this would have improved their adjustment. This would enable the residents to feel more at home since their favourite hobbies and activities are included in their care plan.

Unfortunately, such a booklet is not used in public residential homes, hence why it is imperative to implement it and ensure that it is being used by staff working in these settings to provide more person-centred activities.

6.4 Implications and Recommendations for Education

6.4.1 Staff Training on Dementia and a Person-Centred Care

It was evident that the three persons with dementia coming from the acute hospital had different experiences from the other three coming from home to the nursing home. The caregivers of the persons with dementia who were transferred from the acute hospital wards, explained how the staff working in hospitals were not compassionate and that person-centred dementia care was limited and even non-existent. This indicates that hospital staff need further training on person-centred dementia care. Similarly, Scerri et, al., (2018) argued that family caregivers complained that the hospital staff was not well trained enough to care for cognitively impaired patients, and they do not use a person-centred approach to care.

Persons living with dementia require admissions to acute hospitals because they may experience falls or acute illnesses requiring emergency and medical care. Hence it is crucial that hospital staff have adequate training on how to deal with a person living with dementia and also know how to meet their needs. Courses should be offered in acute hospitals regarding person-centred dementia care for nurses and other staff. In residential homes such as SVPR, a *dementia course* already exists and it is very informative and promotes the PCA, is free of charge, and any nurse can apply for it Moreover, a streamlined care pathway is needed for optimum adjustment to happen. Hence it is imperative that all staff from acute hospitals and residential homes have adequate training in PCC that is adjusted according to their needs, so that there are no bumps and mistakes along the transition. This may diminish delirium and confusion in the residents especially during the first few days following the transition to the home.

6.5 Implications and Recommendations for Management

The management of residential homes need to invest further towards ensuring that persons with dementia are provided with person-centred activities and ensure that the residential home is ‘homely’ to improve residential adjustment. The residential home where the study was conducted is developing a dementia sensory garden so that the residents can enjoy themselves

safely. Moreover, more frequent contact between the caregivers and the persons with dementia may facilitate an easier transition, for example through regular and more extensive family visiting times. A recommendation would be to implement a timely schedule every week where the residential staff make a phone call to the caregivers with any updates or simply just to tell them that their loved one with dementia is ok and if they wish to speak with them. The findings of this study showed how phone calls between the informal caregiver and their loved one with dementia improved adjustment (since the resident would calm down). The findings also showed that phone calls between the informal caregivers and the residential staff improved communication since any concerns or updates were discussed and a relationship was built.

Moreover, management can improve the pre-transition phase when transferring patients from acute hospitals to nursing homes. It was evident from the findings, that this phase was non-existent, and the caregivers felt that the transfer was very rushed thereby hindering appropriate adjustment. This could be because communication between the acute hospital and the residential home was minimal, and the handover was not adequate. Acute hospitals need to make sure that they give a proper handover and set up a clear discharge plan to pre-empt any obstacles in the transition process and support adjustment to the home. Unfortunately, most of the discharges are rushed and the patient ends up becoming more confused as the nursing home as the staff will not be prepared. They will not know detailed information about the transferred persons with dementia and will not have a chance to speak to the family to develop a care plan. There needs to be more emphasis on the pre-transition phase, even for those who came from home such as in Monica’s sister's case. She was placed in the general geriatric ward and not a dementia ward where her adjustment was hindered, and she was very sad and unsafe there. This is due to improper pre-transition planning.

6.6 Implications and Recommendations for Further Research

This dissertation focused on the perspective of the caregivers of the person with dementia and how they believed they adjusted. It would be of more benefit if the persons with dementia were interviewed themselves. This would allow more of a first-hand experience to be analysed instead of getting the information from their caregivers. However, in this case, the person with dementia would have to be at an early stage of dementia where they are still able to communicate well and have a fruitful discussion. It would also be interesting to find out the factors influencing adjustment from the perspective of residential staff. The nurses and care staff can give more insight into what is going on in the nursing home, as some caregivers do

not visit every day, hence they would not have seen how the persons with dementia adjust over the first few days.

The lack of relevant literature on the factors influencing adjustment specifically focusing on persons living with dementia, as indicated from the literature review, shows that further studies are needed on this topic. The extant literature is mostly focused on older persons with no cognitive impairment based on reported interviews of older persons themselves or by their caregivers. Considering that more persons living with dementia are being admitted to residential care, there is a need for further studies focusing on this cohort, so that staff will be better equipped to care for persons with dementia especially during the transition phase to residential care.

6.7 Summary of the Implications and Recommendations

In summary, for a person with dementia to adjust well into their new life at a nursing home, there needs to be:

- *An organised transition from hospital/home to nursing home giving importance to the pre-transition phase.*
- *A person-centred approach to enable continuity of care, example: using the "This is Me" booklet and development of person-centred activities.*
- *Staff education and training on dementia especially in acute hospitals.*
- *Regular communication with the family caregivers.*
- *A dementia friendly environment in residential homes.*

6.8 Strengths and Limitations

The following section discusses the strengths and limitations of the study.

A narrative inquiry was ideal for this research study since it allowed interviewees to express their stories and experiences. This approach ensures that an in depth account as informal caregivers narrate the transition period. The researcher had a good understanding of the phenomena being investigated (since she works in the residential home where the study was conducted) and this helped in asking appropriate questions to guide the conversation.

However, since the interviewees knew they were being recorded, they might have exaggerated their experiences or "sugar-coated" them. The researcher did not find a great amount of

difficulty in the interpretation of the data, however, there could have been slight alterations to the sentences said by the interviewees upon translation and analysis of the findings, which may have altered or lost their true meaning. However, the development of the emerging themes were discussed with the supervisor to ensure that the themes truly represent what the interviewees were saying.

Furthermore, the study findings could not be generalised to other residential settings, both locally and abroad. For a better understanding of this phenomenon, future similar studies should be conducted with larger sample sizes. However, the findings of this study resonate with the general conclusions drawn from similar studies and transitional theories.

Using a theoretical model to discuss the findings of the study, improved the rigour of this study. However, the model used (TRANSCIT model) is still relatively new. Therefore, there is not much empirical evidence in using this model and not many researchers have used it in their studies. However, this model is focused on the needs of an older person and informal caregivers that make the transition from home to nursing home easier. Certain models focus on only one phase, that being post-transition, however, this model focuses on the whole transition process including key components to emphasise the need for consistency. The transition is seen as a process, and it starts at the pre-transition phase which could be either in the person's own home or the hospital setting.

6.9 Conclusion

This dissertation has highlighted the factors that influence the adjustment of persons living with dementia when admitted to a nursing home as perceived by their caregivers. The implications and recommendations have been discussed to improve practice and future research. There seems to be a gap in the literature specifically regarding the adjustment of persons with dementia that shows the need for further studies like this one. Ultimately, the findings of this dissertation will hopefully be used by policy makers and managers to improve the quality of life for residents with dementia during the transition to residential homes.

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Appendices

Appendix 1: CASP Tool for Systematic Review

CASP Checklist: 10 questions to help you make sense of a **Systematic Review**

How to use this appraisal tool: Three broad issues need to be considered when appraising a systematic review 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.

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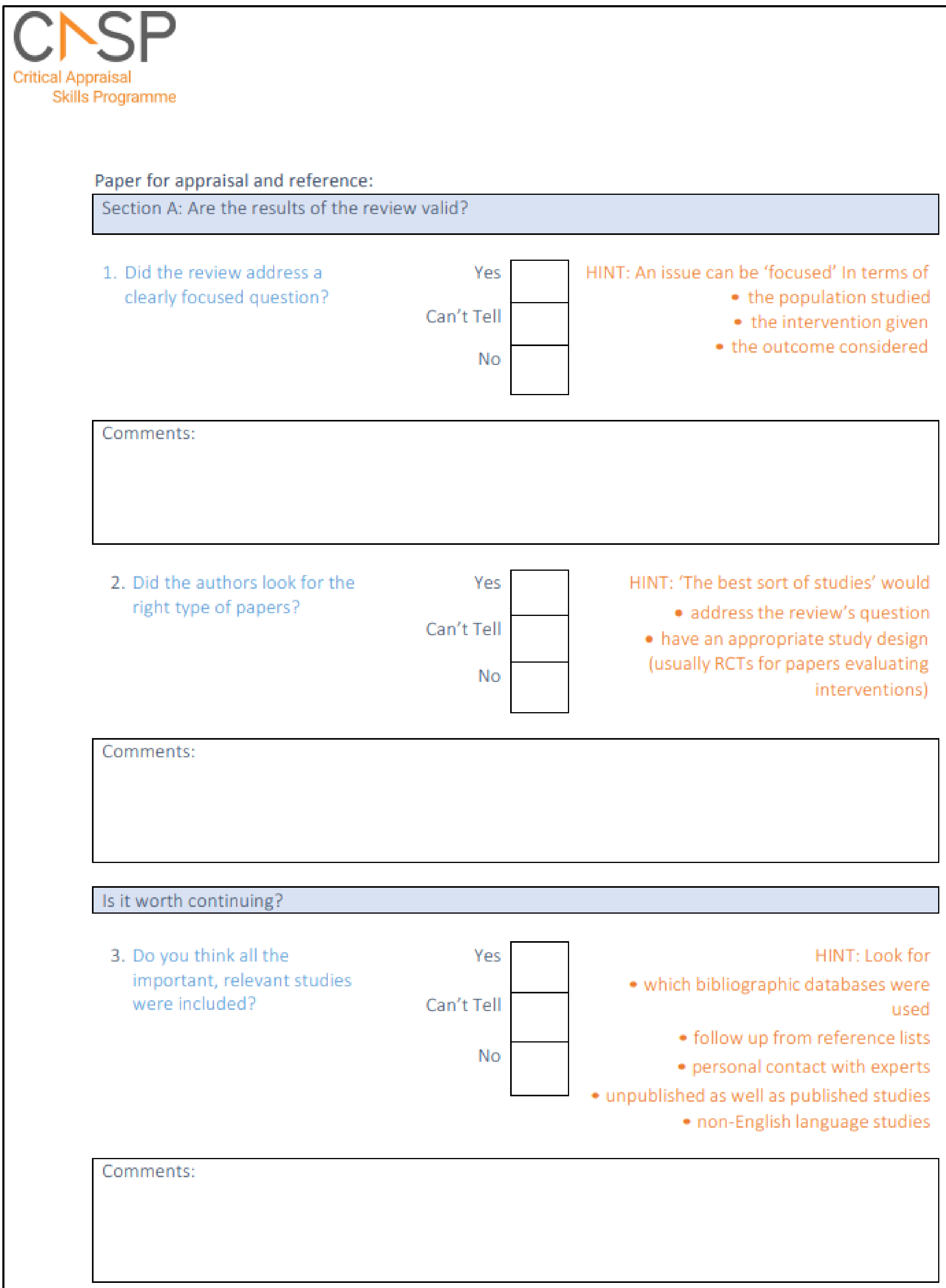

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Paper for appraisal and reference:

Section A: Are the results of the review valid?

1. Did the review address a clearly focused question?

Yes / Can't Tell / No

HINT: An issue can be 'focused' In terms of
- the population studied
- the intervention given
- the outcome considered

Comments:

2. Did the authors look for the right type of papers?

Yes / Can't Tell / No

HINT: 'The best sort of studies' would
- address the review's question
- have an appropriate study design (usually RCTs for papers evaluating interventions)

Comments:

Is it worth continuing?

3. Do you think all the important, relevant studies were included?

Yes / Can't Tell / No

HINT: Look for
- which bibliographic databases were used
- follow up from reference lists
- personal contact with experts
- unpublished as well as published studies
- non-English language studies

Comments:

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4. Did the review's authors do enough to assess quality of the included studies?

Yes ☐
Can't Tell ☐
No ☐

HINT: The authors need to consider the rigour of the studies they have identified. Lack of rigour may affect the studies' results ("All that glisters is not gold" Merchant of Venice – Act II Scene 7)

Comments:

5. If the results of the review have been combined, was it reasonable to do so?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- results were similar from study to study
- results of all the included studies are clearly displayed
- results of different studies are similar
- reasons for any variations in results are discussed

Comments:

Section B: What are the results?

6. What are the overall results of the review?

HINT: Consider
- If you are clear about the review's 'bottom line' results
- what these are (numerically if appropriate)
- how were the results expressed (NNT, odds ratio etc.)

Comments:

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7. How precise are the results?

HINT: Look at the confidence intervals, if given

Comments:

Section C: Will the results help locally?

8. Can the results be applied to the local population?

Yes
Can't Tell
No

HINT: Consider whether
- the patients covered by the review could be sufficiently different to your population to cause concern
- your local setting is likely to differ much from that of the review

Comments:

9. Were all important outcomes considered?

Yes
Can't Tell
No

HINT: Consider whether
- there is other information you would like to have seen

Comments:

10. Are the benefits worth the harms and costs?

Yes
Can't Tell
No

HINT: Consider
- even if this is not addressed by the review, what do **you** think?

Comments:

Appendix 2: CASP Tool for Qualitative Studies

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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.

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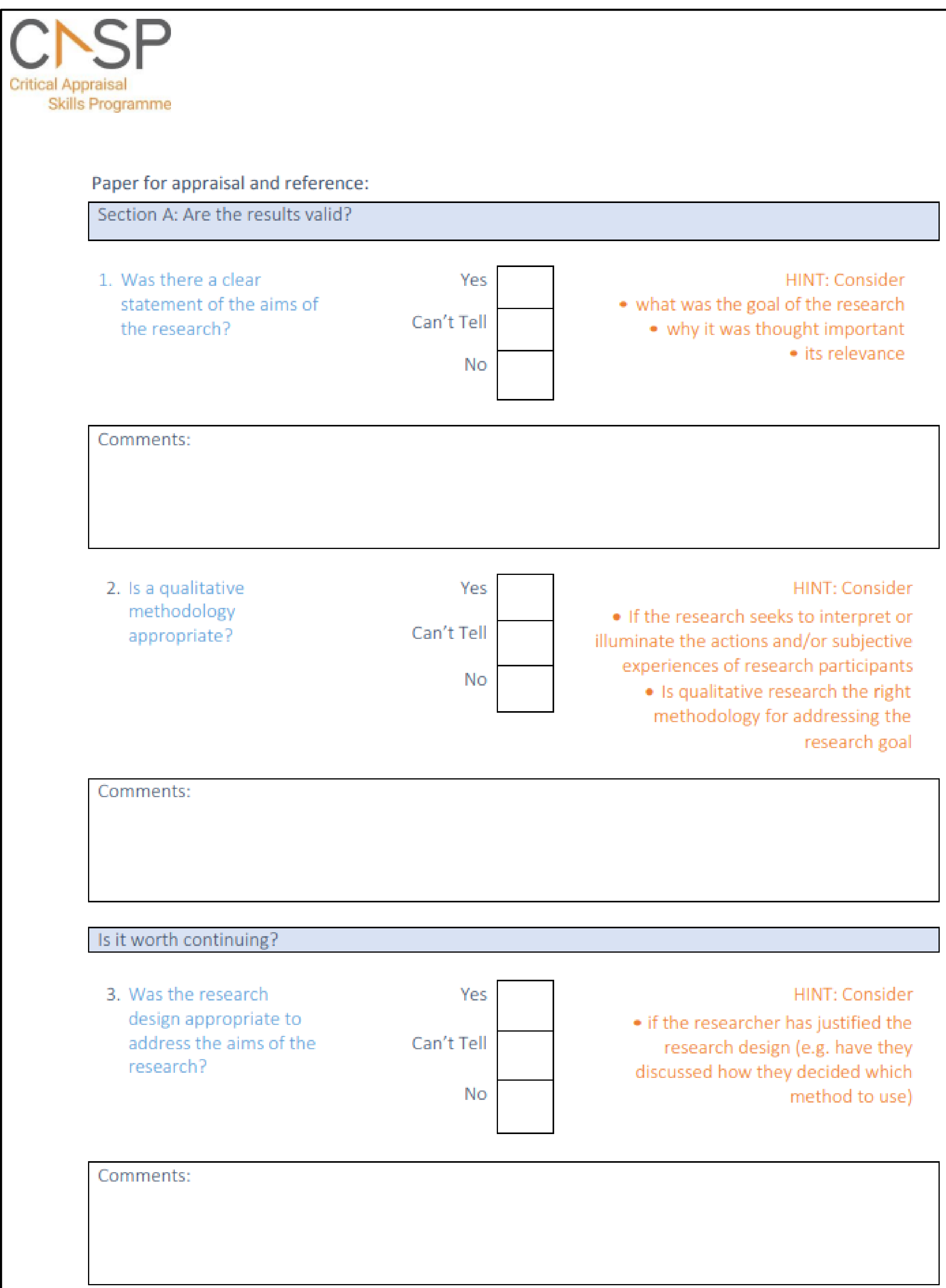

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Paper for appraisal and reference:

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:

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:

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:

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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:

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:

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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:

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:

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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:

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:

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:

Appendix 3: CASP Tool for Quantitative Studies

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CASP Checklist: 12 questions to help you make sense of a **Cohort Study**

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

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

The 12 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.

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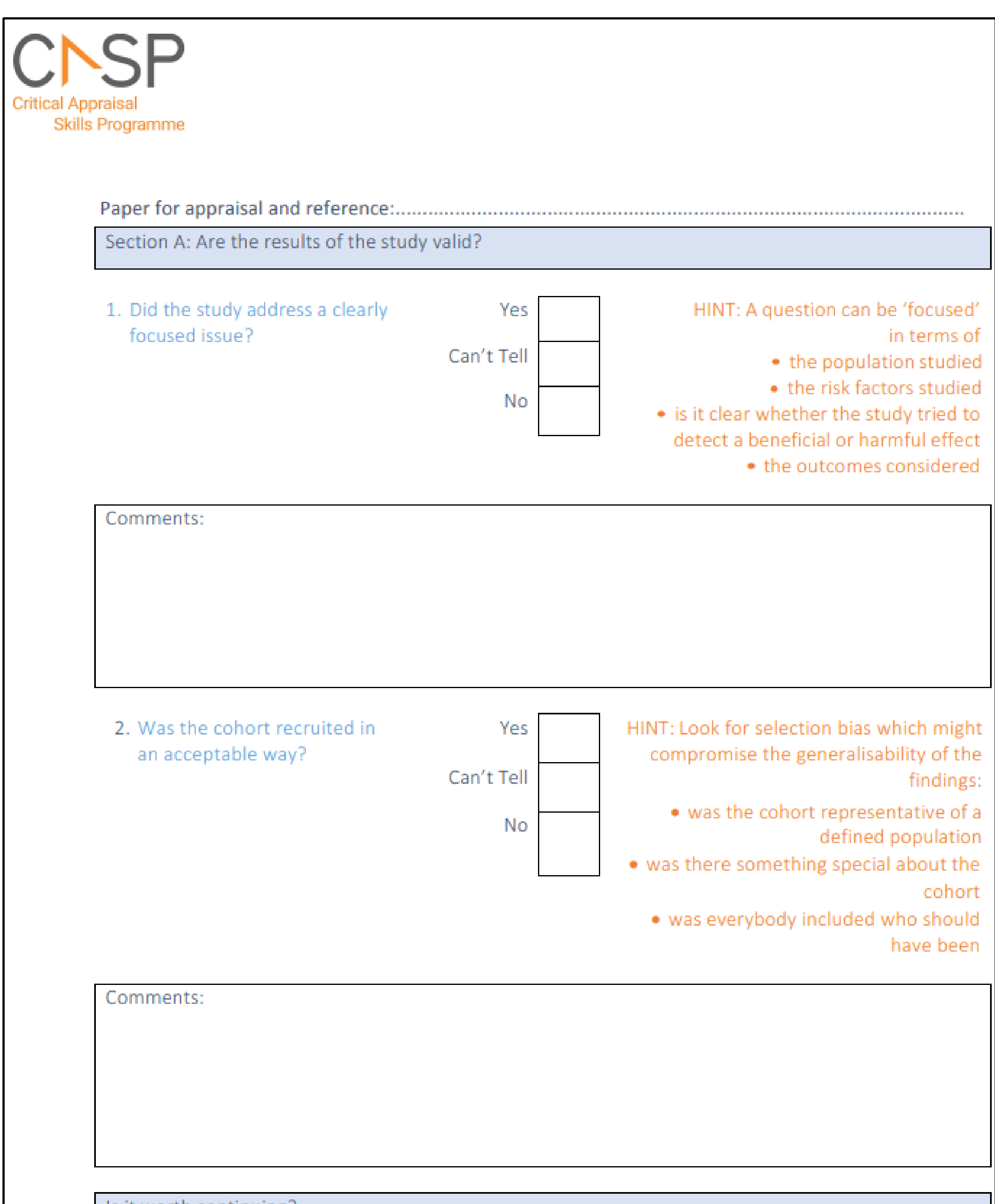

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Paper for appraisal and reference:...

Section A: Are the results of the study valid?

1. Did the study address a clearly focused issue?

Yes ☐ Can't Tell ☐ No ☐

HINT: A question can be 'focused' in terms of
- the population studied
- the risk factors studied
- is it clear whether the study tried to detect a beneficial or harmful effect
- the outcomes considered

Comments:

2. Was the cohort recruited in an acceptable way?

Yes ☐ Can't Tell ☐ No ☐

HINT: Look for selection bias which might compromise the generalisability of the findings:
- was the cohort representative of a defined population
- was there something special about the cohort
- was everybody included who should have been

Comments:

Is it worth continuing?

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3. Was the exposure accurately measured to minimise bias?	Yes Can't Tell No	HINT: Look for measurement or classification bias: • did they use subjective or objective measurements • do the measurements truly reflect what you want them to (have they been validated) • were all the subjects classified into exposure groups using the same procedure

Comments:

4. Was the outcome accurately measured to minimise bias?	Yes Can't Tell No	HINT: Look for measurement or classification bias: • did they use subjective or objective measurements • do the measurements truly reflect what you want them to (have they been validated) • has a reliable system been established for detecting all the cases (for measuring disease occurrence) • were the measurement methods similar in the different groups • were the subjects and/or the outcome assessor blinded to exposure (does this matter)

Comments:

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5. (a) Have the authors identified all important confounding factors?

Yes
Can't Tell
No

HINT:
- list the ones you think might be important, and ones the author missed

Comments:

5. (b) Have they taken account of the confounding factors in the design and/or analysis?

Yes
Can't Tell
No

HINT:
- look for restriction in design, and techniques e.g. modelling, stratified-, regression-, or sensitivity analysis to correct, control or adjust for confounding factors

Comments:

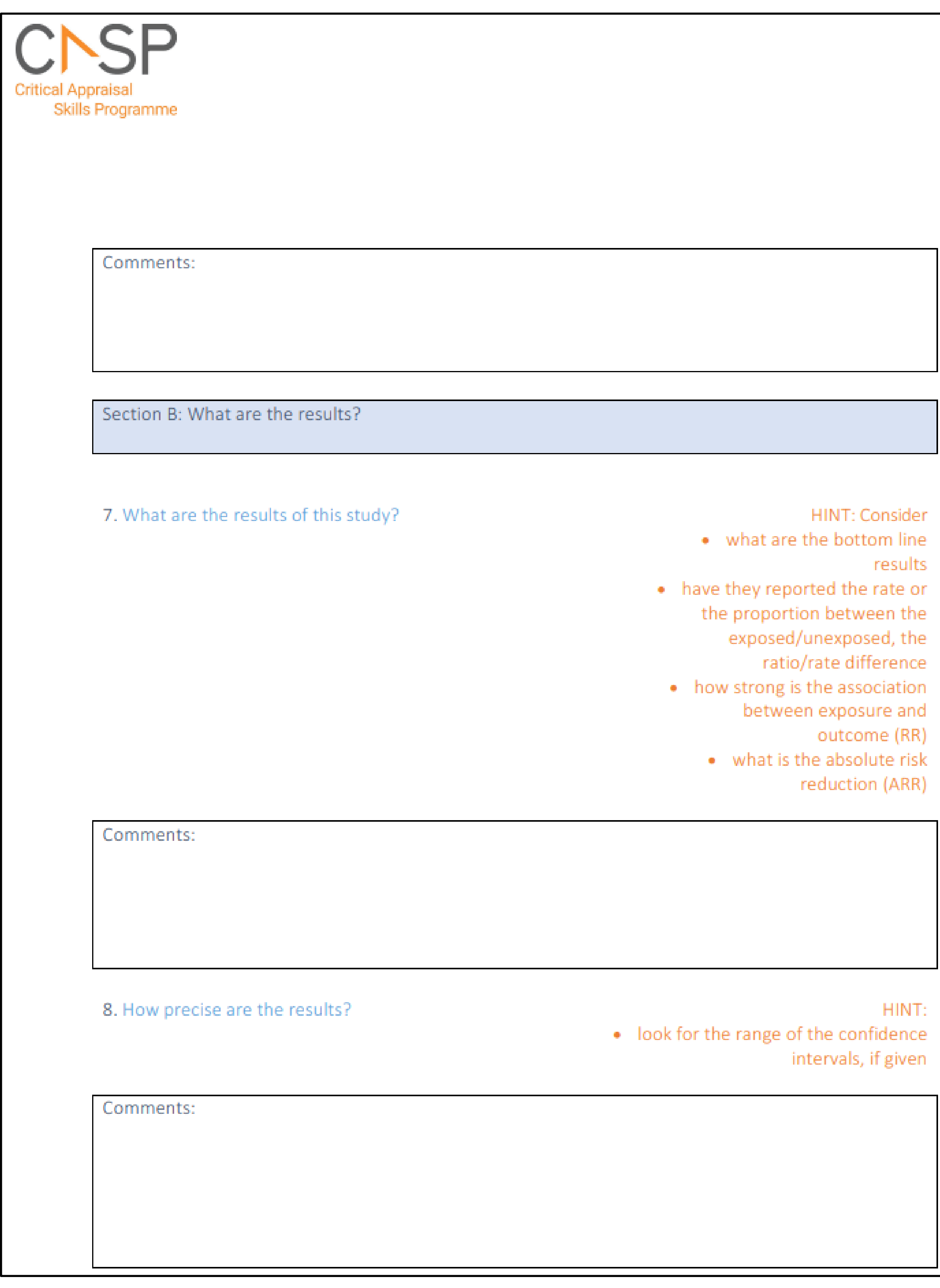
6. (a) Was the follow up of subjects complete enough?

Yes
Can't Tell
No

HINT: Consider
- the good or bad effects should have had long enough to reveal themselves
- the persons that are lost to follow-up may have different outcomes than those available for assessment
- in an open or dynamic cohort, was there anything special about the outcome of the people leaving, or the exposure of the people entering the cohort

6. (b) Was the follow up of subjects long enough?

Yes
Can't Tell
No



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Comments:

Section B: What are the results?

7. What are the results of this study?

HINT: Consider
- what are the bottom line results
- have they reported the rate or the proportion between the exposed/unexposed, the ratio/rate difference
- how strong is the association between exposure and outcome (RR)
- what is the absolute risk reduction (ARR)

Comments:

8. How precise are the results?

HINT:
- look for the range of the confidence intervals, if given

Comments:

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9. Do you believe the results?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- big effect is hard to ignore
- can it be due to bias, chance or confounding
- are the design and methods of this study sufficiently flawed to make the results unreliable
- Bradford Hills criteria (e.g. time sequence, dose-response gradient, biological plausibility, consistency)

Comments:

Section C: Will the results help locally?

10. Can the results be applied to the local population?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- a cohort study was the appropriate method to answer this question
- the subjects covered in this study could be sufficiently different from your population to cause concern
- your local setting is likely to differ much from that of the study
- you can quantify the local benefits and harms

Comments:

11. Do the results of this study fit with other available evidence?

Yes ☐
Can't Tell ☐
No ☐

Comments:

CASP
Critical Appraisal
Skills Programme

12. What are the implications of this study for practice?	Yes	☐	HINT: Consider
	Can't Tell	☐	• one observational study rarely provides sufficiently robust evidence to recommend changes to clinical practice or within health policy decision making
	No	☐	• for certain questions, observational studies provide the only evidence
			• recommendations from observational studies are always stronger when supported by other evidence

Comments:

Appendix 4: Intermediary Letter

The Training Centre

St Vincent de Paul LTC Facility

Florence Nightingale Street

Luqa

24th June, 2022

The Training Centre, SVP accepts to take part as an Intermediary for Ms Maria Sciberras undergoing an MSc in Nursing Studies to distribute information letters and consent forms among Charge Nurses of selected wards and caregivers among persons with dementia.

The title for this study is 'Factors influencing adjustment to nursing home admission as perceived by caregivers of persons living with dementia' conducted in St Vincent de Paul Long-Term Care Facility.

Will look forward for end results and findings and hoping you could share your findings with us.

Yours Sincerely,

Ms Rebecca Cutajar

Appendix 5: Information and Consent Letter (English)

Participants` Information Sheet

Dear Participant,

My name is Maria Sciberras and I am currently reading for Masters' of Science in Nursing at the University of Malta. As part of my course requirements, I am conducting a research study entitled, Factors influencing adjustment to nursing home admission as perceived by caregivers of persons living with dementia. The aim of this study is to identify factors influencing care transition to a nursing home admission for persons with dementia in order to improve adjustment and improve the quality of care for these residents. Your participation in this study would help us gain a better understanding about the main factors influencing the transition and adjustment and what are the outcomes whether good or bad for both the relative and the dementia patient. Furthermore, all data collected from this research shall be used solely for the purpose of this study.

You are being invited to participate in an interview exploring your experiences of how your relative who has dementia has adjusted since being admitted to St. Vincent de Paul Residence and how the transition took place. The interview will take approximately 1 hour and will be held at a time and place most suitable for you. You are not obliged to answer all the questions and may withdraw from the study at any time without giving a reason. Furthermore, withdrawal from the study will not have any negative repercussions on you or your relative who is currently resident at SVPR and any data collected will be erased. Data will be stored anonymously if it is impossible to delete (e.g. if it has already been anonymised). Unless you have any objections, this interview will be audio-recorded. I can assure you that confidentiality will be maintained throughout the study and that your identity and personal information will not be revealed in any publications, reports or presentations arising from this research. All data collected will be pseudonymized meaning that the transcripts will be assigned codes and that this data will be stored securely and separately from any codes and personal data. This data may only be accessed by the researcher. The academic supervisor/s and the examiners will typically have access to coded data only. There may be exceptional circumstances which allow the supervisor and examiners to have access to personal data too, for verification purposes. The coded audio-recordings, and transcripts will be stored on the researcher`s personal computer that is password protected and in an encrypted format. Any material in hard-copy form will be placed in a locked cupboard.
In the event that you feel distressed due to participation in the interview, the service of a healthcare professional Mr. Paul Sciberras (a warranted health Psychologist – 25256900/1) will be available at no financial cost on your part.

Participation in this study is completely voluntary and you are free to accept or refuse to take part without giving a reason. A copy of the information sheet and consent form will be provided for future reference. As a participant, you have the right, under the General Data Protection Regulation (GDPR) and national legislation that implements and further specifies the relevant provisions of said regulation, to access, rectify and where applicable ask for the data concerning you to be erased. Once the study is completed and the results are published, the data will be retained in anonymous form. Any personal details will be destroyed.

This study has been approved by the Research Ethics Committee of the Faculty of Health Sciences at the University of Malta.

Thank you for your time and consideration. Should you have any questions or concerns do not hesitate to contact me on 99363996 or by e-mail maria.sciberras.18@um.edu.mt or my supervisor Dr. Anthony Scerri on anthony.t.scerri@um.edu.mt or +356 2340 1178.

Yours Sincerely,

Maria Sciberras

Researcher

Anthony Scerri

Research Supervisor

Participants` Consent Form

The factors influencing adjustment to nursing home admission as perceived by caregivers of persons living with dementia

I, the undersigned, give my consent to take part in the study conducted by Maria Sciberras. The purpose of this document is to specify the terms of my participation in this research study.

1. I have been given written and verbal information about the purpose of the study and all questions have been answered.
2. I understand that I have been invited to participate in an interview, in which the researcher will ask questions to explore on the adjustment of a person with dementia in a nursing home and any factors influencing this and how one can facilitate a better quality of life for the person with dementia in a nursing home.
3. I am aware that the interview will take approximately 1 hour. I understand that the interview is to be conducted in a place and at a time that is convenient for me.
4. I am aware that this interview will be audio recorded and transcribed (written down as it has been spoken).
5. I am aware that the transcripts will be coded and that this data will be stored securely and separately from any codes and personal data.
6. I am aware that the researcher is the only person who has access to this data. The academic supervisor/s and examiners will typically have access to coded data only. There may be exceptional circumstances which allow the supervisor and examiners to have access to personal data too, for verification purposes.
7. I am also aware that the coded audio-recordings and transcripts will be stored on the researcher`s personal computer that is password protected and in an encrypted format. Any material in hard-copy form will be placed in a locked cupboard and kept until results are published.
8. I am aware that my identity and personal information will not be revealed in any publications, reports or presentations arising from this research.
9. I also understand that I am free to accept, refuse or stop participation at any time without giving any reason. This will have no negative repercussions on myself or my relative currently resident at SVPR and that any data collected from me will be erased. Data will be stored anonymously if it is impossible to delete (e.g. if it has already been anonymised).

10. I also understand that my contribution will serve to improve future practice, the quality of life of these patients and improve the issues on what is missing in the transitional process.
11. If I feel that the interview has distressed me in any way, a warranted health

psychologist – Paul Sciberras (25256900/1) will be available to provide a service at no financial costs on my part. There are no other risks that could happen from this interview.

12. I understand that under the General Data Protection Regulation (GDPR) and national legislation that implements and further specifies the relevant provisions of said regulation, I have the right to access, rectify, and where applicable ask for the data concerning me to be erased.
13. I also understand that once the study is completed and results are published the data will be retained in anonymous form. Any personal details will be destroyed.
14. I will be provided with a copy of the information letter and consent form for future reference.
15. I have read and understood the points and statements of this form. I have had all the questions answered to my satisfaction, and I agree to participate in this study.

Participant: ____

Signature: ____

Date: ____

Anthony Scerri

Research Supervisor

356 23401178

Maria Sciberras

Researcher

99363996

Appendix 6: Information and Consent Letter (Maltese)

Formula ta' Informazzjoni għall-Parteċipanti

Għażiż/a Parteċipant/a,

Jiena Maria Sciberras, fil-preżent qed insegwi Masters of Science in Nursing fl-Università ta' Malta. Bħala parti mir-rekwiżiti tal-kors, qed nagħmel riċerka bit-titlu, "Fatturi li jinfluwenzaw l-aġġustament għad-dħul fid-djar tal-anzjani kif perċepit minn dawk li jieħdu ħsieb persuni li jgħixu bid-dimenzja". L-għan ta' dan l-istudju hu li ninvestiga u nidentifika fatturi li jinfluwenzaw it-tranżizzjoni tal-kura għal dħul f'dar tal-anzjani għal persuni bid-dimenzja sabiex jitjieb l-aġġustament u tittejjeb il-kwalità tal-kura għal dawn ir-residenti. Is-sehem tiegħek f'dan l-istudju jista' jgħin biex ikollna aktar għarfien aħjar dwar il-fatturi ewlenin li jinfluwenzaw it-tranżizzjoni u l-aġġustament u x'inhuma r-riżultati kemm jekk tajbin jew ħżiena kemm għall-qarib kif ukoll għall-pazjent tad-dimenzja. Kull informazzjoni miġbura tintuża biss għall-għan jew l-għanijiet ta' dan l-istudju.
Bħala parteċipant/a inti se tintalab tieħu sehem f'dan l-istudju sabiex ninvestigaw l-esperjenzi tiegħek ta' kif il-qarib tiegħek li għandu d-dimenzja aġġusta ruħu minn meta ddaħħal fil-Residenza San Vinċenz de Paule u kif seħħet it-tranżizzjoni. Jekk taċċetta li tieħu sehem inti tintalab sabiex tiltaqa' mar-riċerkatriċi Maria Sciberras f'post u f'ħin li jkun konvenjenti għalik. Din il-laqgħa se tieħu madwar siegħa.
M'intix obbligat/a li twieġeb il-mistoqsijiet kollha u tista' twaqqaf l-istudju fi xħin trid mingħajr ma tagħti l-ebda raġuni. Dan mhux ħa jkollu riperkussjonijiet negattivi fuqek u l-informazzjoni li tingħabar mingħandek titħassar. Id-data se tinħażen b'mod anonimu kemm-il darba jkun impossibbli li titħassar (eż. jekk diġà kienet anonimizzata).

Sakemm m'għandek l-ebda oġġezzjoni, ir-risposti tiegħek se jiġu rrekordjati bl-awdjo. Nassigurak li se tinżamm il-kunfidenzjalità matul l-istudju kollu u l-identità tiegħek u kull informazzjoni personali miġbura mhuma se jiġu żvelati mkien fit-teżi, ir-rapporti, il-preżentazzjonijiet u/jew il-pubblikazzjonijiet li jistgħu jirriżultaw minnha. Kull tagħrif miġbur se jiġi psewdonomizzat, jiġifieri id-data kollha se tkun protetta permezz ta' sistema ta' kodiċi u miżmuma separatament mill-informazzjoni personali.

Ir-Riċerkatriċi biss ser ikollha aċċess għall-informazzjoni miġbura, filwaqt li s Superviżur/a akkademiku/a (jew is-Superviżuri akkademiċi) u l-eżaminaturi se jkollhom biss aċċess għal data kkodifikata. Is-Superviżuri akkademiċi u l-eżaminaturi jista jkollhom bżonn aċċess għall-informazzjoni miġbura għal skop ta' verifika.
L-awdjo rrekordjat u d-data kollha se jinħażnu fuq il-kompjuter personali tar-Riċerkatriċi permezz ta' kodifikazzjoni tad-data (data encryption) u li hi protetta b'password. Barra minn hekk, il-materjal stampat se jinqafel f'post sigur. F'każ li tħoss li l-istudju ħoloqlok diffikultà u tixtieq li tiddiskuti x'qed tħoss ma' professjonist/a mill-qasam tal-kura tas-saħħa, is-Sinjur Paul Sciberras (Psikologu tas-saħħa bil-warrant - 25256900/1) se jkun qed jipprovdi servizz ta' għajnuna mingħajr ħlas min-naħa tiegħek. Il-parteċipazzjoni tiegħek f'dan l-istudju hija għażla

għal kollox volontarja u inti ħieles/ħielsa li taċċetta jew tirrifjuta li tieħu sehem mingħajr ma jkun hemm konsegwenzi fil-konfront tiegħek jew fuq il-qarib tiegħek li bħalissa huwa residenti fl-SVPR. Se tingħata kopja tal-ittra ta' informazzjoni u tal-formula ta' kunsens sabiex tkun tista' taċċessahom fil-futur. Barra minn hekk, skont ir-Regolamenti Ġenerali dwar il-Protezzjoni tad-Data (GDPR) u l-leġiżlazzjoni nazzjonali li timplimenta u tispeċifika aktar il-provvedimenti relevanti tar-regolamenti msemmija, inti għandek id-dritt li taċċessa, tirretifika, u fejn japplika titlob sabiex titħassar id-data li tikkonċerna lilek. L-informazzjoni personali kollha se titħassar hekk kif jintemm dan l-istudju ta' riċerka u jkunu ppubblikati r-riżultati miksuba.

Dan l-istudju ġie approvat mill-Kumitat għall-Etika fir-Riċerka fi ħdan il-Fakultà tax-Xjenzi tas-Saħħa fl-Università ta' Malta.

Grazzi ħafna tal-ħin u s-sehem tiegħek f'dan l-istudju. F'każ li jkollok xi mistoqsijiet jew tixtieq tiċċara xi ħaġa, tista' ċċempilli fuq jew tibgħatli email fuq +356 99363996. Tista' wkoll tikkuntattja lis-Superviżur Dr. Anthony Scerri fuq +356 2340 1178 jew billi tibgħat email fuq anthony.t.scerri@um.edu.mt.

Dejjem tiegħek,

Maria Sciberras
Riċerkatriċi

Dr Anthony Scerri
Is-Superviżur tar-riċerka

Formula ta' Kunsens tal-Parteċipanti

Fatturi li jinfluwenzaw l-aġġustament għad-dħul fid-djar tal-anzjani kif perċepit minn dawk li jieħdu ħsieb persuni li jgħixu bid-dimenzja

Jien, hawn taħt iffirmat/a, nagħti l-kunsens tiegħi biex nieħu sehem fl-istudju mmexxi minn Maria Sciberras. L-għan ta' dan id-dokument hu li jiġu speċifikati t-termini tal-parteċipazjoni tiegħi f'dan l-istudju ta' riċerka.

1. Jien ingħatajt informazzjoni miktuba u verbali dwar l-għan tal-istudju u l-mistoqsijiet kollha twieġbu.
2. Nifhem li se nkun qed nipparteċipa fi studju, fejn ir-Riċerkatriċi se tistaqsi mistoqsijiet biex tesplora dwar l-aġġustament ta' persuna bid-dimenzja f'dar tal-anzjani u kwalunkwe fattur li jinfluwenza dan u kif wieħed jista' jiffaċilita kwalità ta' ħajja aħjar għall-persuna bid-dimenzja f'dar tal-anzjani.
3. Naf li l-istudju se jieħu madwar siegħa. Nifhem, li l-laqgħa se ssir f'post u ħin konvenjenti għalija.
4. Jien konxju/a li r-risposti tiegħi se jkunu qed jiġu rrekordjati permezz ta' tagħmir awdjo u se jinkitbu r-risposti fuq formuli apposta.
5. Naf ukoll li se ssir kodifikazzjoni tad-data u din se tinżamm separatament mill-informazzjoni personali.
6. Naf ukoll li r-Riċerkatriċi hi l-unika persuna li se jkollha aċċess għal din l-informazzjoni, filwaqt li s-Superviżur akkademiku (jew is-Superviżuri akkademiċi) u l-eżaminaturi se jkollhom aċċess għal data kkodifikata biss. Is-Superviżuri akkademiċi u l-eżaminaturi jista jkollhom bżonn aċċess għall-informazzjoni miġbura għal skop ta' verifika.
7. Barra min hekk, naf li l-awdjo rrekordjat u d-data se jinħażnu fuq il-kompjuter personali tar-Riċerkatriċi permezz ta' kodifikazzjoni tad-data (data encryption) u li hi protetta b'password. Barra minn hekk, naf li l-materjal stampat se jitqiegħed f'post sikur u se jinżamm sakemm joħorġu r-riżultati.
8. Naf li l-identità tiegħi u l-informazzjoni personali mhuma se jinkixfu mkien fit-teżi, fir-rapporti, fil-preżentazzjonijiet u/jew fil-pubblikazzjonijiet li jistgħu jirriżultaw minnha.
9. Nifhem ukoll li jien liberu/a li naċċetta, nirrifjuta jew inwaqqaf il-parteċipazzjoni f'kull ħin bla ma nagħti raġuni. Dan mhux ħa jkollu riperkussjonijiet negattivi fuqi jew fuq il-qarib tiegħi li bħalissa huwa residenti fl-SVPR. Nifhem ukoll li la darba nirtira minn dan l-istudju, l-informazzjoni miġbura se titħassar. Id-data se tinħażen b'mod anonimu kemm-il darba jkun impossibbli li titħassar (eż. jekk diġà kienet anonimizzata).
10. Nifhem ukoll li l-kontribuzzjoni tiegħi ser isservi biex tittejjeb il-prattika futura, il-

kwalità tal-ħajja ta 'dawn il-pazjenti u ttejjeb il-kwistjonijiet dwar dak li huwa nieqes fil-proċess transitorju.

11. Madanakollu, jekk inħoss li l-istudju ħoloqli diffikultà u nixtieq li niddiskuti x'qed inħoss, naf li s-Sinjur Paul Sciberras (Psikologu tas-saħħa bil-warrant – 25256900/1) se jkun qed jipprovdi servizz ta' għajnuna mingħajr ħlas min-naħa tiegħi. M'hemm l-ebda riskju ieħor li jista' jiġri minn din l-intervista.
12. Nifhem ukoll, li skont ir-Regolamenti Ġenerali dwar il-Protezzjoni tad-Data (GDPR) u l-leġiżlazzjoni nazzjonali li timplimenta u tispeċifika aktar il-provvedimenti relevanti tar-regolamenti msemmija, jiena għandi d-dritt li naċċessa, nirretifika, u fejn japplika nitlob sabiex titħassar id-data li tikkonċernani.
13. Naf ukoll li meta jintemm l-istudju u r-riżultati jkunu ppubblikati, l-informazzjoni personali miġbura titħassar.
14. Fl-aħħar nett, naf ukoll li se ningħata kopja tal-ittra ta' informazzjoni u tal-formula ta' kunsens sabiex inkun nista' naċċessahom fil-futur.
15. Jien qrajt u fhimt il-punti u d-dikjarazzjonijiet f'din il-formula. Inħossni sodisfatt/a bit-tweġibiet li ngħatajt għall-mistoqsijiet li kelli, u qed naċċetta minn jeddi li nipparteċipa f'dan l-istudju.

Parteċipant:___________________________________

Firma:_______________________________________

Data:____

Maria Sciberras

Riċerkatriċi

maria.sciberras.18@um.edu.mt

356 99363996

Firma:

Dr Anthony Scerri

Is-Superviżur tar-riċerka

anthony.t.scerri@um.edu.mt

356 2340 1178

Firma:

Appendix 7: Request for Permission to Conduct Research at St. Vincent de Paul Long-term Care Facility

De: **Cutajar Josianne at SVP** josianne.cutajar@gov.mt
Assunto: RE: Request for permission to conduct research at St Vincent de Paul Long-term CareFacility
Data: 24 de Junho de 2022 às 16:36
Para: Maria Sciberras maria.sciberras.18@um.edu.mt
Cc: Anthony Scerri anthony.t.scerri@um.edu.mt, Briffa Valerie at SVP valerie.briffa@gov.mt, Fiorentino Ronald at SVP ronald.fiorentino@gov.mt

CJ

Dear Maria
You have my go ahead on Dr Fiorentino's approval.

Jos

Josianne Cutajar
Chief Executive Officer
Ceo Office
St Vincent de Paul Long Term Care Facility

t: +356 22912400 e: josianne.cutajar@gov.mt
www.gov.mt | www.publicservice.gov.mt | fb.com/servizzpubbliku

MINISTRY FOR ACTIVE AGEING
St Vincent de Paul Long Term Care Facility, Florence Nightingale Road,
Luqa, Malta

Kindly consider your environmental responsibility before printing this e-mail

This email communication, including any file or document attached thereto, is confidential, may be legally privileged and solely intended for the use of the intended recipient(s). If you are not the intended recipient and received this message by mistake, you should not disseminate, distribute, print or otherwise copy its contents, but should take immediate action to notify me by return email and permanently destroy the email from your system.

From: Maria Sciberras <maria.sciberras.18@um.edu.mt>
Sent: Friday, 24 June 2022 16:33
To: Cutajar Josianne at SVP <josianne.cutajar@gov.mt>
Cc: Anthony Scerri <anthony.t.scerri@um.edu.mt>; Briffa Valerie at SVP <valerie.briffa@gov.mt>; Fiorentino Ronald at SVP <ronald.fiorentino@gov.mt>
Subject: Request for permission to conduct research at St Vincent de Paul Long-term CareFacility

CAUTION: This email originated from OUTSIDE the Government Email Infrastructure. DO NOT CLICK LINKS or OPEN attachments unless you recognise the sender and know the content is safe.

Dear Dr Cutajar,

I hope to find you well. I would like to conduct a research study at St Vincent de Paul Long-term Care Facility (SVP) entitled - **Factors influencing adjustment to nursing home admission as perceived by caregivers of persons living with dementia.** This study aims to identify factors influencing care transition to a nursing home admission for persons with dementia in order to improve adjustment and improve the quality of care for these residents. The supervisor of this study is Dr Anthony Scerri.

I am hereby seeking your permission to carry out interviews with around six participants (caregivers) who have relatives with dementia at SVP. Charge nurses of the wards once selected will be contacted by an intermediary, who will send the informational letter together with informed consent to all participants chosen. Those who accept to participate will be asked to sign an informed consent and send it by email to the researcher. The researcher will then arrange the consented participants a prospective date for an interview session. The interview will be recorded, but the participant will be given the opportunity not to record the session or to stop the recording at any time. The session is estimated to take no more than an hour. Participants will be given a referral to psychological support if this is needed during the session. Although data saturation will determine the number of participants, it is expected that around six participants will be recruited.

Participation will be entirely voluntary and participants will be free to withdraw at any point, without any repercussions. Data collected will be anonymized and there will be no other personal data collected. All data collected will be pseudonymised meaning that the transcripts will be assigned codes and that this data will be stored securely and separately from any codes and personal data. This data may only be accessed by myself and viewed by my supervisor. Participants will be asked whether they wish to have a certificate of participation in which case it will be sent after the interview.

Should you require further information, please do not hesitate to contact me on the contact details below.

Thank you for your kind consideration of this request.

Sincerely,
- Maria Sciberras

Appendix 8: General Data Protection Clearance Declaration Form

25th June 2022

Dear Ms Maria Sciberras

I am pleased to inform you that your request to conduct your research proposal with the title "Factors influencing adjustment to nursing home admission as perceived by caregivers of persons living with dementia" within St. Vincent de Paul Long-Term Care Facility has been fully approved.

May I inform you that as we have to abide to the General Data Protection Regulation and the Data Protection Act (Cap.586) we cannot provide you with a list of data subjects' (residents/staff) personal contact details. Where statistics are involved, only encrypted data in terms of age, gender etc can be forwarded to you. Furthermore, an information gate keeper will be assigned to you.

May I bring to your attention that you are obliged to apply necessary safeguards as a condition for carrying out this research, namely:

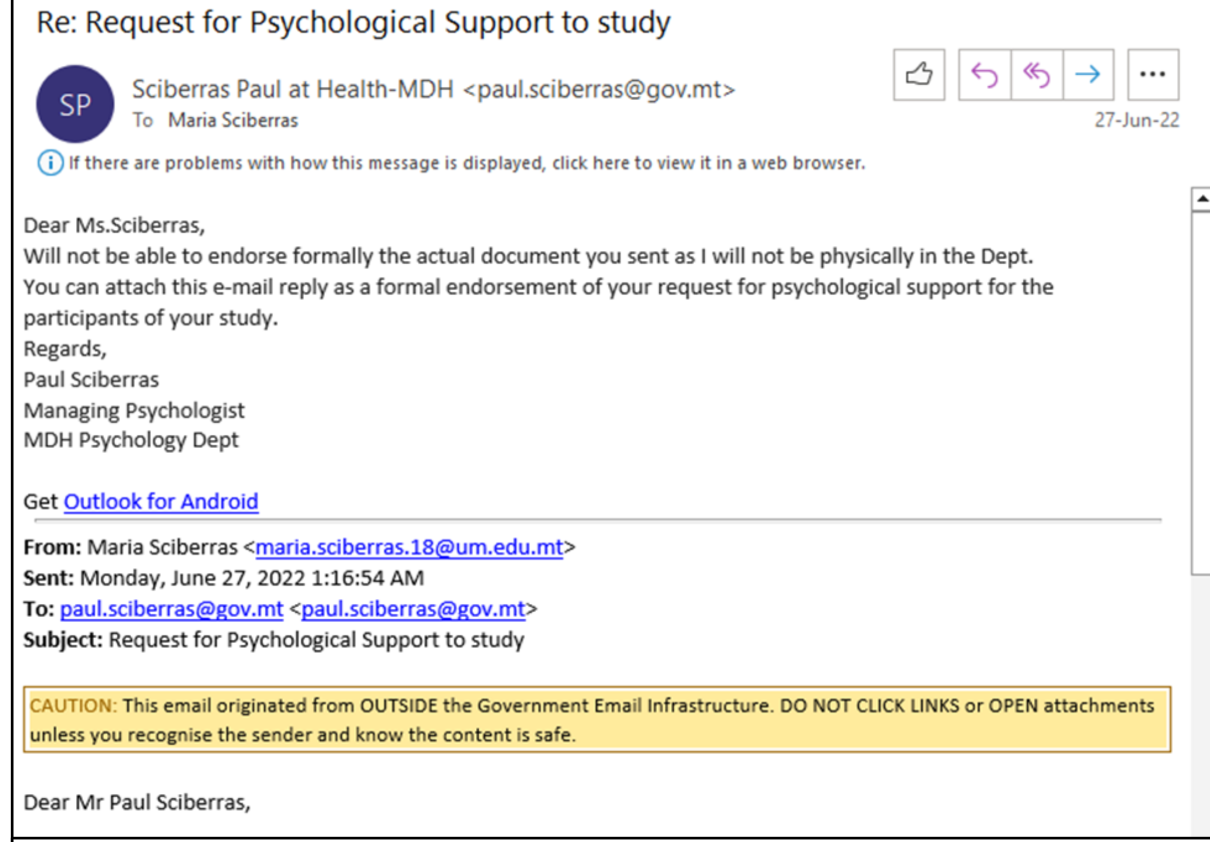
- The personal data of data subjects accessed, given or collected are only to be explicitly used for that specific purpose to conduct the research and for no other purpose;
- Documentation of personal data collected should be adequately destroyed once the research is finalised;
- All references to personal data should be omitted unless an informal consent is specifically obtained from the person being identified in the research report;
- Participation in the research being conducted should be at the discretion of the individual and participation can be refused or withdrawn at any time if they so wish;
- If data subjects (residents/staff) are going to be interviewed, video or audio recorded, photographed or given a non-anonymous questionnaire to compile, an informed consent form should be signed by the participating data subject and a privacy policy statement read to them. Faces should be hidden or digitally modified as to conceal identity. Any modifications of this approach would have to be first discussed with the Data Protection Officer;
- All other relevant measures deemed fit by the SVP Administration and interpretation prior to finalisation.

You are also obliged to submit a copy of your research to the Office of the CEO at the end of your study.

I sincerely wish you every success in your studies.

Dr Ronald Fiorentino
f/CEO

Appendix 9: Request for Psychological Support to Study



Re: Request for Psychological Support to study

SP Sciberras Paul at Health-MDH <paul.sciberras@gov.mt>
To Maria Sciberras
27-Jun-22

If there are problems with how this message is displayed, click here to view it in a web browser.

Dear Ms.Sciberras,
Will not be able to endorse formally the actual document you sent as I will not be physically in the Dept.
You can attach this e-mail reply as a formal endorsement of your request for psychological support for the participants of your study.
Regards,
Paul Sciberras
Managing Psychologist
MDH Psychology Dept

Get Outlook for Android

From: Maria Sciberras <maria.sciberras.18@um.edu.mt>
Sent: Monday, June 27, 2022 1:16:54 AM
To: paul.sciberras@gov.mt <paul.sciberras@gov.mt>
Subject: Request for Psychological Support to study

CAUTION: This email originated from OUTSIDE the Government Email Infrastructure. DO NOT CLICK LINKS or OPEN attachments unless you recognise the sender and know the content is safe.

Dear Mr Paul Sciberras,

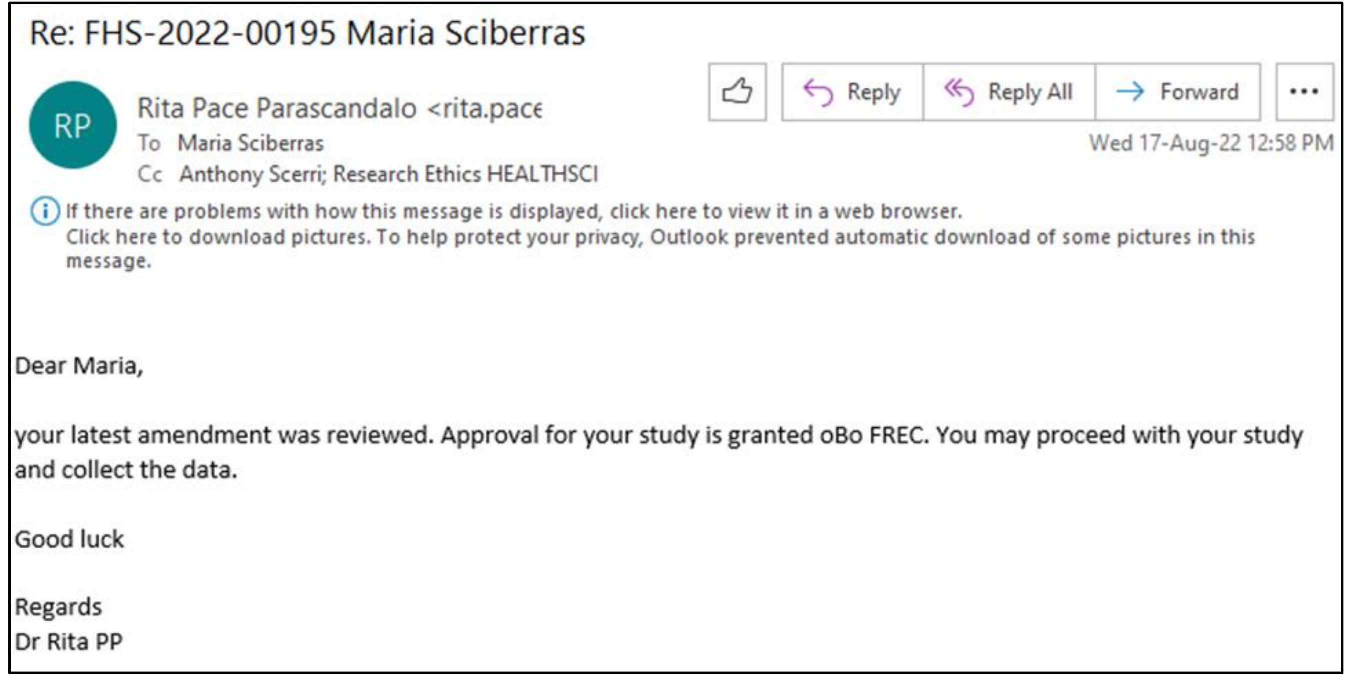
I, Maria Sciberras, am working on a proposal to conduct a research study entitled Factors influencing adjustment to nursing home admission as perceived by caregivers of persons living with dementia – a narrative analyses study. The supervisor of this study is Dr Anthony Scerri.

This study aims to identify factors influencing care transition to a nursing home admission for persons with dementia in order to improve adjustment and improve the quality of care for these residents. In the eventuality that participants feel distressed due to the emotions elicited during the interview, they would be offered free debriefing sessions and psychological support. As a warranted Health Psychologist, would you be willing to provide these debriefing sessions to support participants' psychological wellbeing if they request for them? If you cannot provide this support, can you indicate to us anyone who would be willing to do so?

Apologies for sending an email late. My FREC / ethics application is due today 27th June in the evening. My thesis approval was sent late to me (only last Thursday) from the faculty and I sent out all necessary emails on Friday so that hopefully I get approved permissions by today. I sent an email to Ms Savona Ventura on Friday and she got back to me yesterday and recommended that I ask you for this request as she is in maternity leave.

Thank you for understanding.

Appendix 10: Approval by FREC via email to Conduct Research Study



Re: FHS-2022-00195 Maria Sciberras

RP Rita Pace Parascandalo <rita.pace

To Maria Sciberras

Cc Anthony Scerri; Research Ethics HEALTHSCI

Reply | Reply All | Forward

Wed 17-Aug-22 12:58 PM

If there are problems with how this message is displayed, click here to view it in a web browser.
Click here to download pictures. To help protect your privacy, Outlook prevented automatic download of some pictures in this message.

Dear Maria,

your latest amendment was reviewed. Approval for your study is granted oBo FREC. You may proceed with your study and collect the data.

Good luck

Regards
Dr Rita PP

Appendix 11: Interview Schedule: English Version

Factors Influencing Adjustment to Nursing Home Admission as Perceived by Caregivers of Persons Living with Dementia

Pseudonym:__________

Relationship to person with dementia: __________

Overarching question 1: Can you tell me about your initial experience when your family member/relative with dementia was admitted to the nursing home?

Possible probes related to the first few days of admission:

- How were the first few days of admission for you?
- How were the first few days of admission to your relative/family member?
- Did anything happen that helped you to adjust during the initial days of admission?
- Did anything happen that hindered you to adjust during the initial days of admission?
- Did anything happen that helped your relative/family member to adjust during the initial days of admission?
- Did anything happen that hindered your relative/family member to adjust during the initial days of admission?

Overarching question 2: Now that your relative has been admitted to the nursing home for around a month what is your current situation?

Possible probes related to the current situation:

- Can you tell me whether your relative/family member has adjusted now?
    - If not, why do you think he/she is not able to adjust?
    - If yes, what do you think helped his/her adjustment?
- How are you feeling now?
- Were there any strategies you have used to cope during the transition?
- Do you feel any personal growth that may have occurred after this transition?

Appendix 12: Skeda tal-Intervisti: Verżjoni bil-Malti

Fatturi li Jinfluwenzaw l-Aġġustament għad-Dħul fid-Dar tal-Anzjani kif Perċepit minn Min jieħu ħsieb Persuni li Jgħixu bid-Dimensja

Psewdonimu:_________

Relazzjoni ma'persuna bid-dimenzja:__________

Mistoqsija ġenerali 1: Tista' tgħidli dwar l-esperjenza inizjali tiegħek meta l-membru tal-familja/qarib tiegħek bid-dimenzja ddaħħal fid-dar tal-anzjani?

Sondi possibbli relatati mal-ewwel ftit jiem tad-dħul

- Kif kienu għalik l-ewwel ftit jiem tad-dħul?
- Kif kienu l-ewwel ftit jiem tad-dħul ghal qarib/membru tal-familja tiegħek?
- Ġrat xi ħaġa li għenitek taġġusta matul il- jiem inizjali tad- dħul?
- Ġrat xi ħaġa li xekklitek biex taġġusta matul il- jiem inizjali tad- dħul?
- Ġrat xi ħaġa li għenet lill-qarib/membru tal-familja tiegħek jaġġusta matul il-jiem inizjali tad-dħul?
- Ġrat xi ħaġa li xekklet lill-qarib/membru tal-familja tiegħek biex jaġġusta matul il-jiem inizjali tad-dħul?

Mistoqsija ġenerali 2: Issa li l-qarib tiegħek ilu ddaħħal fid-dar tal-anzjani għal madwar xahar x'inhi s-sitwazzjoni attwali tiegħek?

Sondi possibbli relatati mas-sitwazzjoni attwali

- Tista' tgħidli jekk il-qarib/membru tal-familja tiegħek aġġustax issa?
  - Jekk le, għaliex taħseb li hu/hi mhux kapaċi jaġġusta/taġġusta?
  - Jekk iva, x'taħseb li għen l-aġġustament tiegħu/tagħha?
- Kif qed tħossok issa?
- Kien hemm xi strateġiji li użajt biex tlaħħaq matul it-tranżizzjoni?
- Tħoss xi tkabbir personali li seta' seħħ wara din it-tranżizzjoni?

Appendix 13: Reflexive Diaries

Interview 1: 26 October 2022

"This was my first interview and I was a bit nervous as it was on zoom and was not sure if everything will turn out ok or if there will be technical difficulties or hearing problems. She is the daughter of the person with dementia in SVPR and she was very calm and collected as she spoke. I could feel the sense of frustration as she stated that she is the only daughter of 3 siblings and her brothers do not really help her. Overall, she was happy with the decision to put her mother in SVPR, however she really emphasised on the fact that they do not do tailored activities for the residents there who have specific activities they enjoy. She was rather sad in the way she spoke as she stated that her mother gets quite aggressive at times and activities or outings would really help her because she feels as if her mother is "trapped". This made me reflect because residents and their caregivers should not feel this way in dementia units, but rather at ease. She was also upset that the transition was rather "rushed" and there was not enough planning pre-transition from MDH to SVPR. This made me realise how important the pre-transition phase is for a smooth care-pathway to adjustment."

Interview 2: 26 October 2022

"This interview is the one that spoke out to me the most. The daughter of the person with dementia had tears in her eyes at times when she was narrating her story and experiences of her mother at SVPR. She and her sister really did not want to admit her mother to SVPR but they could not take care of her anymore and they were very saddened about this as their mother was everything to them. The mother came from MDH and the daughter emphasised greatly on the need for a loving and caring staff well educated on dementia care. When she went to visit her, she was shocked to find her mother in the ward at MDH with an untouched plate of food in front of her as no one would go and feed her. She experienced neglect from the staff at MDH and really applauded the staff at SVPR when her mother got admitted to SVPR from MDH. The transition was also rushed and not greatly planned out well with minimal communication from MDH to SVPR on the needs of her mother. During this discussion I empathised with the daughter as one could tell she was hurt inside. I made her

feel as comfortable as possible so that she would be able to fully converse with me and not feel guilty for showing feelings of sadness."

Interview 3: 28 October 2022

"*I remember this interview being quite different from others as she was the only one who was a sibling of the person with dementia in SVPR from the interviews. She was having trouble remembering things as she narrated which was understandable due to her age being above 70. She also was very nervous in the beginning because she told me that she hopes that what she is telling me is correct and I quickly reassured her that this is a safe space for her to answer however she wants and feels and that nothing is correct or incorrect. She felt comfortable after reassuring her and the interview went by calmly and smoothly. I noticed that for her it was important that a person with dementia is put into an appropriate environment. In her case her sister was mistakenly put into a general geriatric ward which hindered her adjustment. This made me reflect on the importance of the pre-transition phase and how important communication is for proper planning."*

Interview 4: 14 November 2022

"This participant was very calm and eager to tell me everything about her husband being in SVPR. She was upset with the fact that it had to be this way and she showed some signs of guilt as well. She expressed how visits by family members are important to do regularly since she goes and sees her husband every day and sees the difference it can make. This showed me the importance of how involvement of family caregivers with the care of their loved ones with dementia is. She mentioned how vital it is for tailored activities which happen at the ward her husband is in. It was nice to hear that they play music, given that he was a music fan before, and that he seems to enjoy it and calms down. This made me reflect on the importance of integrating past hobbies in dementia units of those living there."

Interview 5: 14 November 2022

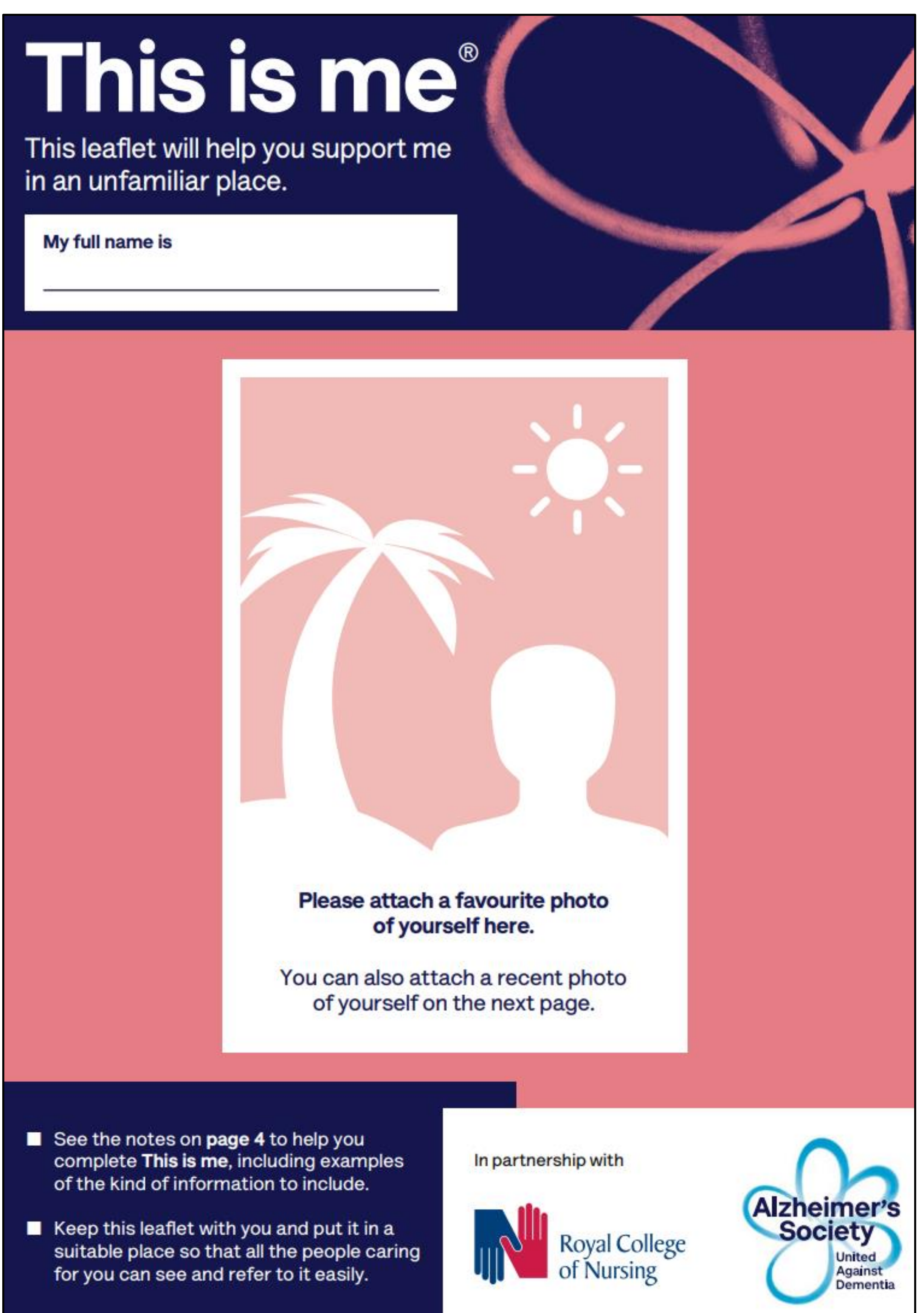
"This participant was quite jittery at first and made an impression that she was nervous. Her answers at times were sometimes all over the place as I noticed she wanted to tell me everything but was too excited. However, as 20 minutes passed, she calmed down and

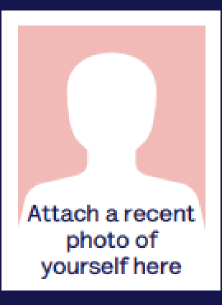
answered accordingly as I gently redirected the discussion. I still let her say all she wanted and needed to say as there was no rush at all and did not want to make her feel uncomfortable. She stressed a lot the need for loving care and for regular visits as she visits her relative with dementia every day with other family members. As a nurse mostly working in the dementia wards (being a reliever), this made me want to express the importance of regular visits to family members of persons with dementia and show them that their relative with dementia must not be forgotten and in most cases, will help them adjust, especially being newly admitted! She made me realise the importance of loving care as well, as by this stage of the interviews (she was nº5 of 6), everyone had mentioned it and they all said that we as nurses should always provide loving care as persons with dementia would otherwise notice, and one can tell the difference when someone has been spoken to with love rather than being shouted at. She expressed how they are more willing to cooperate or settle when spoken to with love, hence adjusting better and not feeling scared all the time."

Interview 6: 16 November 2022

"This interview was over a zoom call, and I remember him being not nervous at all. He was answering differently from the other interviews as he was very precise with his answers and did not spend much time answering. He would get straight to the point however, making sure he said everything he needed to say precisely, short and simple. I remember having to give him some prompts but making sure not to make him feel as if what he is saying is wrong. This was to get a bit more information out of him about his mother with dementia so he could narrate a bit more as some key information was not being discussed because he thought it was not important. I reassured him that everything he is saying is vital and that whatever he is thinking he should tell me if comfortable. He was a quiet man but would sometimes keep to himself. He mentioned how crucial it is for staff training to take place along with tailored activities."

Appendix 14: "This is Me" Booklet by the Alzheimer's Society





A person who has dementia, delirium or other communication difficulties can find changes, like moving to an unfamiliar place or meeting new people who contribute to their care, unsettling or distressing. **This is me** can help to reduce this distress. It helps health and social care professionals build a better understanding of who the person really is, which can help them deliver care that is tailored to the person's needs.

This is me should be completed as early as possible, so the person can take it to a new place or give it to new people who contribute to their care. It should be updated as necessary.

This is me should be filled in by the individual(s) who know the person best and, wherever possible, with the person involved. It is not a medical document.

About me

(See the notes on **page 4** for ideas about the kind of information to include)

Name I like to be called

Where I live (area not the full address)

The carers/people who know me best

I would like you to know

My personal history, family and friends, pets and any treasured possessions

My background

(See the notes on **page 4** for ideas about the kind of information to include)

My cultural, religious and spiritual background

My interests, jobs and achievements

Favourite places I have lived and visited

My habits and routines

(See the notes on **page 4** for ideas about the kind of information to include)

The following routines are important to me

Things I like to do for myself

Things I might want help with

Things that may worry or upset me

What makes me feel better if I am anxious or upset

My communication and mobility

(See the notes on **page 4** for ideas about the kind of information to include)

My hearing and eyesight

How we can communicate

My mobility

My personal habits

(See the notes on **page 4** for ideas about the kind of information to include)

Things that help me sleep

My personal care

How I take my medication

My eating and drinking

Other

(See the notes on **page 4** for ideas about the kind of information to include)

Other notes about me

Date completed

Completed by

Relationship to the person

☐ I am happy for the information I have provided to be used by health and social care professionals to provide care and support. If they wish to use it for a different purpose, they must ask first.

Guidance notes to help you complete **This is me**®

Name I like to be called: Enter your full name on the front page and the name you like to be called on **page 1**.

Where I live: The area (not the full address) where you live and how long you have lived there.

The carers/people who know me best: This may be a partner, relative, friend or carer.

I would like you to know: Include anything you feel is important about who you are and that will help staff to get to know and care for you. For example: I have dementia; I have never been in hospital before; I prefer female carers; my partner and I are not married; I am allergic to... ; I am left-handed; other languages I can speak.

My personal history, family and friends, pets and any treasured possessions: Include your place of birth, education, marital status, children, grandchildren, friends and pets. List any possessions you like to have near you – photographs, books, jewellery.

My cultural, religious and spiritual background: Include information about your cultural or religious community if this is important to you. Do you like to attend religious services? Do you celebrate certain festivals, holidays and events? Do you observe certain practices on particular days or at specific times? Do you follow certain hygiene practices? Are aspects of your clothing and appearance important to you? Are there certain foods you don't eat?

My interests, jobs and achievements: List any accomplishments that you are proud of. Include clubs and memberships, hobbies or sports. Add any past jobs and volunteering activities that are important to you.

Favourite places I have lived and visited: Include any former or childhood homes that are important to you, and also any favourite or significant places that you have visited.

The following routines are important to me: What time do you usually get up/go to bed? What time do you prefer to have your breakfast, lunch, evening meal? Do you enjoy a snack, walk or nap at a particular time of the day? Do you have a hot drink before bed, carry out personal care activities in a particular order or like to watch the evening news?

Things I like to do for myself: Include ways in which you like to be independent such as dressing, eating, personal hygiene.

Things I might want help with: Describe ways people can help with activities such as dressing, getting up, eating.

Things that may worry or upset me: Include anything you may find troubling, such as family concerns, being apart from a loved one or being alone; or physical needs such as being in pain, constipated, thirsty or hungry. List environmental factors that may make you feel anxious, such as open doors, loud voices or the dark.

What makes me feel better if I am anxious or upset: Include things that may help if you become unhappy or distressed, such as comforting words, music or TV. Does it help to have company, or do you prefer quiet time alone?

My hearing and eyesight: Can you hear well? Do you need a hearing aid? How is it best to approach you? Is the use of touch appropriate? Do you wear glasses or need any other vision aids?

How we can communicate: How do you usually communicate – verbally, using gestures, pointing or a mixture of both? Do you read and write, and does writing things down help? How do you indicate pain, discomfort, thirst or hunger? Include anything that may help staff know what you need.

My mobility: Are you mobile? Do you need help to get around? Do you need a walking aid? Can you use stairs? Can you stand unaided from a sitting position? Do you need handrails? Do you need a special chair or cushion, or do your feet need to be raised to make you comfortable?

Things that help me sleep: Include your usual sleep patterns and bedtime routine. Do you like a light to be left on or do you find it difficult to find the toilet at night? Do you have a favoured position in bed, special mattress or pillow?

My personal care: List your usual practices, preferences and how much assistance you need in the bath, shower or other. Do you prefer to wash at a particular time of day – for example, in the morning or before you go to bed? Do you prefer a male or female carer? Do you have preferences for brands of soaps, cosmetics, toiletries, continence aids, shaving or teeth cleaning products and dentures? Do you care for or style your hair in a particular way? How often do you wash your hair?

How I take my medication: Do you need help to take medication? Do you prefer to take liquid medication?

My eating and drinking: Do you prefer tea or coffee? Do you have favourite meals or food that you dislike? Do you need help to eat or drink? Can you use cutlery or do you prefer finger foods? Do you need adapted aids such as cutlery or crockery to eat and drink? Does your food need to be cut into pieces? Do you wear dentures to eat? Do you have swallowing difficulties? What texture of food do you need to help – soft or liquidised? Do you need thickened fluids? List any special dietary requirements or preferences including being vegetarian, and religious or cultural needs. Include information about your appetite and whether you need help to choose food from a menu.

Other notes about me: Include any details about you that are not listed above and help to show who you are – for example, your favourite TV or radio programmes; significant events in your past; expectations and aspirations you have. Indicate any advance plans that you have made, including the person you have appointed as your attorney, and where health and social care professionals can find this information.

We are Alzheimer's Society. We are a vital source of support and a powerful force for change for everyone affected by dementia. We provide help and hope.

If you have any concerns about Alzheimer's disease or any other form of dementia, go to **alzheimers.org.uk** or call our **Dementia Connect support line** on **0333 150 3456**. (Interpreters are available in any language. Calls may be recorded or monitored for training and evaluation purposes.)

Please do not provide information you are not comfortable with others knowing. Professionals should tell you how they will use the information you provide. If they don't, ask them – it's your right to know.

Download this leaflet or order copies online at **alzheimers.org.uk/thisisme** or call **0300 303 5933**.

To give feedback on **This is me** please email **publications@alzheimers.org.uk**

© Alzheimer's Society, 2022
First edition 2010, revised 2013
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Next review due: March 2022

Dedicated to the memory of Ken Ridley, a much valued member of the Northumberland Acute Care and Dementia Group.

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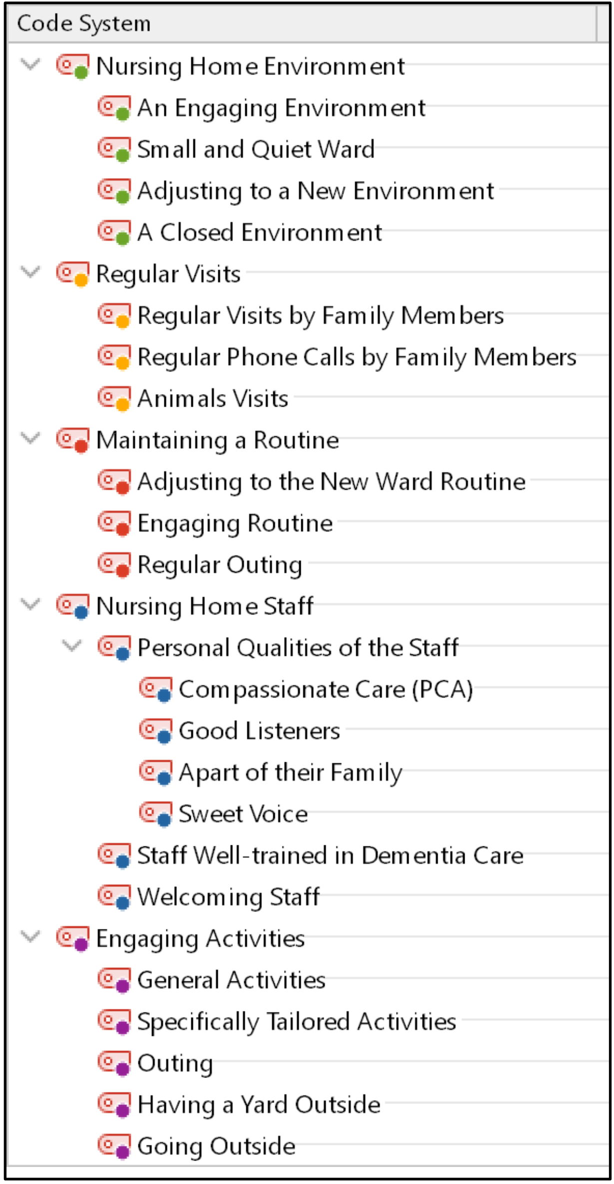
Appendix 15: The Coding Schema



Appendix 16: The Code Matrix Browser for the Resultant Categories and Sub-categories