

**QUALITY OF LIFE AND OCCUPATION FOR PEOPLE WITH
DEMENTIA: THE PERCEPTION OF CAREGIVERS**

by

Corné Kotzé

Dissertation submitted in fulfilment of the requirements for the
MAGISTER DEGREE IN OCCUPATIONAL THERAPY

Faculty of Health Sciences
University of the Free State

Bloemfontein

(240 Credits)

JULY 2012

Supervisor: Dr. S.H.J. Du Toit
Co-supervisor: Dr. S.M. van Heerden

DECLARATION

I certify that the dissertation hereby submitted by me for the Master's degree at the University of the Free State is my independent effort and had not previously been submitted for a degree at another university/faculty. I furthermore waive copyright of the dissertation in favour of the University of the Free State.

Corné Kotzé

SUMMARY

Advanced dementia is a very complex condition and requires that caregivers be equipped to administer care successfully. Therefore, quality of life (QoL) for persons with dementia in long-term care facilities relies heavily on the knowledge, skills and attitudes of caregivers who spend the majority of time with these residents. Although various professional bodies all over the world encourage person-centred care, (i.e. promoting the focus on the resident with dementia as a unique individual), most residential care facilities in the South African context still measure QoL as a list of completed tasks at the end of the day. Therefore, the caregivers' understanding and application of a person-centred care approach needed careful consideration. Due to the fact that consultant occupational therapists who designed individualised person-centred care programs for residents with dementia depends on the caregivers to implement these programs, a study was undertaken to describe and explore caregivers' perceptions of QoL, person-centred care and occupational engagement for residents with dementia.

A triangulation, mixed methods design was applied with a comprehensive sample of full-time caregivers employed at a residential care home (RCH) in Bloemfontein. The researcher specifically chose this approach with interview schedules (qualitative findings) and structured questionnaires (quantitative results). Qualitative findings were compared and contrasted with quantitative results in order to verify similarities and to identify discrepancies between the two data sets. Literature was also consulted to support similarities and discrepancies. The mixed methods triangulation design, therefore, contributed to the trustworthiness of the study.

Results and findings indicated that personal and organisational factors had a major impact on the perspectives of the caregivers. The caregivers were mostly conditioned to operate within an approach associated with meeting the physiological needs of the residents and addressed individualised care as a list of separate chores associated with each resident. One of the reasons supporting a more physiological approach is the organisational culture found

in units where care is provided for persons with dementia. It was also evident that if person-centred care could be experienced by caregivers as receivers (employees of an organisation), it might enable them to embrace the personal perspectives and needs of each resident individually.

Personal factors that impacted the perspectives of the caregivers were their home circumstances, the general public opinion and the relationship between them and the family of residents. It appeared that stress factors associated with their home circumstances further aggravated the burden of care at work, negatively impacting person-centred care. The general public opinion was led by ageism, which emphasised the low status of their job as caregivers. Lastly, the relationship between the caregivers and family of the residents was guided by misunderstandings, unrealistic expectations and role confusion between these two stakeholders. The caregivers were guided by the priorities of the family which were, similar to those of the organisation, focused on physiological care associated with the traditional model, rather than person-centred care.

The value of the study is that it indicated that a culture change towards care would be beneficial to the organisation at every level. A move away from the traditional medical-focused care approach could provide new opportunities for growth and development. This implies that the personhood and dignity of every employee and resident could be promoted, leading to a life worth living.

OPSOMMING

Gevorderde demensie is 'n hoogs komplekse toestand wat vereis dat versorgers genoegsaam toegerus moet wees om sorg suksesvol toe te dien. Lewensgehalte vir diegene met demensie in langtermynversorgingsinstansies berus dus grootliks op die kennis, vaardighede en houdings van versorgers wat meestal by hierdie inwoners is. Hoewel verskeie professionele rade wêreldwyd persoongerigte sorg (met die klem op die persoon met demensie as 'n unieke individu) aanmoedig, beskou die meeste residensiële versorgingsinstansies in Suid-Afrika steeds lewensgehalte as 'n lys voltooide take aan die einde van 'n dag. Versorgers se begrip en toepassing van 'n persoongerigte sorgbenadering het hiervolgens dus oorweging vereis. Aangesien raadgewende arbeidsterapeute wat individuele, persoongerigte sorgprogramme vir inwoners met demensie ontwerp, van versorgers afhanklik is om die programme te implementeer, is 'n studie onderneem om versorgers se persepsies rakende lewensgehalte, persoongerigte sorg en die werksbetrokkenheid van inwoners met demensie te ondersoek.

'n Gemengde triangulasie metode is toegepas op 'n omvattende steekproef voltydse versorgers in diens van 'n residensiële versorgingsinstansie in Bloemfontein. Die navorser het spesifiek hierdie benadering met onderhoudskedules (kwalitatiewe bevindinge) en gestruktureerde vraelyste (kwantitatiewe resultate) gekies. Kwalitatiewe bevindinge is met kwantitatiewe resultate vergelyk om ooreenkomste tussen die twee stelle data te bevestig en verskille te identifiseer. Die ontwerp het dus tot die betroubaarheid van die studie bygedra.

Die resultate en bevindinge dui daarop dat persoonlike en organisatoriese faktore 'n wesentlike invloed op die perspektiewe van die versorgers het. Die versorgers is grootliks gekondisioneer om 'n benadering te volg wat daarop gerig is om aan die fisiologiese behoeftes van die inwoners te voldoen en sorg te beskou as 'n lys afsonderlike take ten opsigte van elke inwoner. Een van die redes vir 'n oorwegend fisiologiese benadering is die

organisatoriese kultuur in eenhede waar sorg voorsien word aan persone met demensie. Dit blyk dat indien persoongerigte sorg deur versorgers as ontvangers (werknemers van 'n maatskappy) ervaar kan word, dit hulle dalk in staat kan stel om die persoonlike perspektiewe en behoeftes van elke individuele inwoner aan te gryp.

Persoonlike faktore wat die perspektiewe van die versorgers beïnvloed het, sluit in hulle huislike omstandighede, die algemene openbare mening en die verhouding tussen hulle en die inwoners se gesin of familie. Dit blyk dat stres tuis die versorg-las by die werk vererger en persoongerigte sorg negatief beïnvloed. Die algemene openbare mening is deur ouderdomsdiskriminasie gevorm en beklemtoon die lae status van die versorgers se werk. Die verhouding tussen die versorgers en die inwoners se gesin/familie is deur misverstande, onrealistiese verwagtinge en rolverwarring tussen die twee groepe belanghebbendes versuur. Die versorgers is gerig deur die prioriteite van die familie – wat ooreenstem met die organisasie se fokus op fisiologiese sorg, wat weer met die tradisionele model eerder as persoongerigte sorg verband hou.

Die waarde van die studie is daarin geleë dat dit aandui dat 'n kultuurverandering ten opsigte van sorg op alle vlakke van die organisasie voordelig sal wees. 'n Skuif vanaf die tradisionele, mediesgerigte sorgbenadering kan nuwe groei- en ontwikkelingsmoontlikhede inhou. Dit beteken dat die individualiteit en waardigheid van elke werknemer en inwoner verbeter kan word en volwaardige, kwaliteit lewens tot gevolg kan hê.

TABLE OF CONTENTS

	Page
LIST OF ACRONYMS	i
LIST OF FIGURES	ii
LIST OF TABLES	iii
ACKNOWLEDGEMENTS	vii
PREFACE	x
CONCEPT OF CLARIFICATION	xii
<u>CHAPTER1: INTRODUCTION AND ORIENTATION</u>	
1.1 INTRODUCTION AND BACKGROUND	1
1.2 PROBLEM STATEMENT	5
1.3 AIM	7
1.3.1 OBJECTIVES	7
1.4 METHODOLOGY	7
1.5 ETHICS	9
1.6 VALUE OF THE STUDY	9
1.7 CHAPTER LAYOUT	10
1.8 SUMMARY	11
<u>CHAPTER 2: LITERATURE REVIEW</u>	
2.1 INTRODUCTION	12
2.2 CULTURE CHANGE	13
2.2.1 ORGANISATIONAL TRANSFORMATION IN A RCH	14
2.2.1.1 Ethics and the Law	16

2.2.1.2 The role of the caregivers in the organisation	22
2.2.1.3 Diversity	24
2.2.2 PHYSICAL TRANSFORMATION	26
2.2.3 PERSONAL TRANSFORMATION	27
2.2.3.1 Personhood of the caregivers	28
2.2.3.2 Residents	29
2.4 SUMMARY	33
<u>CHAPTER 3: METHODOLOGY</u>	
3.1 INTRODUCTION	35
3.2 RESEARCH DESIGN	35
3.2.1 RATIONALE FOR APPLYING A MIXED METHODS APPROACH	36
3.2.2 SELECTING A SPECIFIC MIXED METHODS DESIGN	37
3.2.3 RESEARCH PROCESS	39
3.3 RESEARCH POPULATION	39
3.3.1 SELECTION CRITERIA	40
3.3.1.1 Inclusion Criteria	40
3.3.1.2 Exclusion Criteria	40
3.3.2 SAMPLING	40
3.4 SECTION A: QUALITATIVE APPROACH	41
3.4.1 STUDY DESIGN	41
3.4.2 MEASURING TECHNIQUES	42
3.4.2.1 Interview schedule	42
3.4.2.2 Participant observation	42
3.4.3 MEASURING INSTRUMENT	43

3.4.4 DATA COLLECTION PROCEDURE	44
3.4.4.1 Data Analysis	47
3.4.4.2 Data Management	47
3.4.4.3 Reading and Memoing	47
3.4.4.4 Describing, Classifying and Interpreting	47
3.4.4.5 Representing and visualising	49
3.4.5 DATA QUALITY CONTROL	49
3.4.5.1 Credibility	49
3.4.5.2 Dependability	50
3.4.5.3 Confirmability	51
3.4.5.4 Transferability	51
3.5 SECTION B: QUANTITATIVE APPROACH	51
3.5.1 STUDY DESIGN	51
3.5.2 MEASURING INSTRUMENT	52
3.5.3 DATA COLLECTION PROCEDURE	58
3.5.4 DATA ANALYSIS	58
3.5.5 DATA QUALITY CONTROL	58
3.5.5.1 Reliability	58
3.5.5.2 Validity	59
3.6 TRACEABLE VARIABILITY	61
3.7 PILOT STUDY	63
3.8 ETHICAL CONSIDERATIONS	64
3.9 SUMMARY	66
<u>CHAPTER 4: PRESENTATION AND INTERPRETATION OF THE RESULTS AND FINDINGS</u>	
4.1 INTRODUCTION	67

4.2 SECTION A: VIEWING THE SCU IN CONTEXT	71
4.3 SECTION B: STRESS OF THE CAREGIVERS	78
4.3.1 THEME 1: ROLE AS EMPLOYEE WITHIN THE	78
4.3.1.1 Nature of the job	79
4.3.1.2 Work schedule and workload	87
4.3.1.3 Training	95
4.3.2 THEME 2: WORK ENVIRONMENT INFLUENCES	98
4.3.2.1 The organisation	99
4.3.2.2 Family of the residents	109
4.3.2.3 Public opinion	114
4.3.3 THEME 3: ROLES OUTSIDE OF WORK	115
4.3.3.1 Home circumstances	115
4.3.4 THEME 4: STRESS MANAGEMENT SKILLS	120
4.4 SECTION C: PERCEPTIONS ASSOCIATED WITH QOL, PERSON-CENTRED CARE AND OCCUPATIONAL ENGAGEMENT	122
4.4.1 THEME 5: THE CAREGIVER ROLE	122
4.4.1.1 Priorities of caregivers, the organisation and family	123
4.4.1.2 Independence	130
4.4.1.3 Activity participation	152
4.4.1.4 The resident's ability to experience positive emotions	160
4.4.1.5 The resident as a unique individual	165
4.5 PERCEIVED ASSOCIATIONS BETWEEN QoL AND THE CONCEPTS OF OCCUPATIONAL ENGAGEMENT AND PERSON-CENTRED CARE	188
4.5.1 LINK BETWEEN QoL AND OCCUPATIONAL	189

ENGAGEMENT	
4.5.2 LINK BETWEEN QoL AND PERSON-CENTRED CARE	191
4.6 SUMMARY	192
<u>CHAPTER 5: CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS</u>	
5.1 INTRODUCTION	193
5.2 CONCLUSIONS	193
5.2.1 OBJECTIVE 1	194
5.2.1.1 Personal Factors	194
5.2.1.2 Organisational factors	195
5.2.1.3 Physical factors	196
5.2.2 OBJECTIVE 2	197
5.3 RECOMMENDATIONS	198
5.3.1 GENERAL RECOMMENDATIONS	198
5.3.2 RECOMMENDATIONS FOR FURTHER RESEARCH	200
5.4 LIMITATIONS OF THE STUDY	201
5.5 CLOSURE	201
6. LIST OF REFERENCES	203
7. ADDENDA	222
ADDENDUM A: Information Document (English)	223
ADDENDUM B: Information Document – (Afrikaans)	228
ADDENDUM C: Information Document (Sesotho)	233
ADDENDUM D: Information Document (Tswana)	237
ADDENDUM E: Consent Form – Residential Care	241

Homes(English)	
ADDENDUM F: Residential Care Homes (Afrikaans)	245
ADDENDUM G: Consent form – Participants (English)	249
ADDENDUM H: Consent form – Participants (Afrikaans)	252
ADDENDUM I: Consent form – Participants (Sesotho)	255
ADDENDUM J: Consent Form – Participants (Tswana)	258
ADDENDUM K: Probing Questions	261
ADDENDUM L: Interview Schedule (Objective A & B)	263
ADDENDUM M: Case study	278

LIST OF ACRONYMS

Special Care Unit	SCU
Quality of Life	QoL
Occupational Therapy	OT
Residential Care Home	RCH
Residential Care Homes	RCH's

LIST OF FIGURES

	Page
Figure 2.1: Continuum of culture change	14
Figure 3.1: Visual diagram of the mixed methods procedures	38
Figure 4.1: Home language of the caregivers	73
Figure 4.2: Home languages of the residents	74
Figure 4.3: Link between QoL and occupational engagement	191
Figure 5.1: Influencing factors on caregivers' perceptions	194
Figure 5.2: Possible factors linking QoL, person-centred care and occupational engagement	197

LIST OF TABLES

	Page
Table 2.1: Adapted Table of Moral Theories	19
Table 3.1: Medical model vs. person-centred care approach	56
Table 4.1: Qualitative data: Themes and Categories	70
Table 4.2: Ages of the caregivers (n=8)	72
Table 4.3: Ages of the residents (n=21)	72
Table 4.4: Factors determining behaviour towards residents of different cultures (n=8)	74
Table 4.5: Factors determining residents' behaviour towards participants of different cultures (n=8)	75
Table 4.6: Months of experience working with people with dementia (n=8)	77
Table 4.7: Burden of care of the organisation (n=8)	81
Table 4.8: Impact of burden of care (n = 8)	85
Table 4.9: Giving time to eat independently or feeding the resident in a slow manner vs. feeding the resident quickly to save time (n=8)	89
Table 4.10: Example of the shifts of one caregiver in a four week period (n = 1)	92
Table 4.11: Travelling methods (n = 8)	93
Table 4.12: Formal education (n = 8)	95
Table 4.13: Influence of nursing staff on the caregivers' application of independence (n=8)	108
Table 4.14: Influence of the manager on the caregivers' application of independence (n=8)	109
Table 4.15: The family's priorities for the residents (n=8)	112

Table 4.16: Caregivers' perceptions about the family's priorities for the residents: the importance of person-centred care (n=8)	112
Table 4.17: Number of dependents per caregiver (n=8)	116
Table 4.18: Financial provision for dependents (n=8)	117
Table 4.19: Caregivers' perceptions about the importance of person-centred care for the residents (n=8)	124
Table 4.20: Caregivers' perceptions about the need of the residents for emotional contact vs. not needing emotional contact (n=8)	124
Table 4.21: Most important needs of the residents according to the caregivers (n=8)	125
Table 4.22: Caregivers' perceptions about management's priorities for the residents: the importance of person-centred care (n=8)	126
Table 4.23: Caregivers' opinion of what managements' priorities for the residents are (n=8)	127
Table 4.24: Link between enjoyment and independence(n=8)	131
Table 4.25: Consequences of facilitating independence (n=8)	134
Table 4.26: Ability of the residents to actively participate in activities of daily living (n=8)	139
Table 4.27: Washing the residents vs. independent washing (n=8)	139
Table 4.28: Caregivers' perceptions about the ability of the residents to be independent (n=8)	140
Table 4.29: Giving the chance to choose vs. making choices for the residents with regard to walking around (n=8)	142

Table 4.30: Caregivers' perceptions about a link between activity participation and enjoyment vs. not forming a link between these aspects (n=8)	155
Table 4.31: QoL in relation to life stages (n=8)	161
Table 4.32: Caregivers' perceptions about the ability of the residents to experience enjoyment	163
Table 4.33: Caregivers' perceptions about the residents' ability to experience pride vs. not being able to experience pride (n=8)	164
Table 4.34: Caregivers' perceptions about the residents' individuality vs. universalism (1) (n=8)	167
Table 4.35: Caregivers' perception about the individuality of the residents vs. universalism (n=8)	167
Table 4.36: Caregivers' perceptions about preferences that do still exist vs. do not exist anymore (n=8)	167
Table 4.37: Caregivers' perceptions about the need to know the previous occupation of the resident vs. not seeing the purpose of knowing the previous occupation (n=8)	171
Table 4.38: Caregivers' perception about the need to know the previous food preferences of the resident vs. not seeing the purpose of knowing the previous food preferences (n=8)	172
Table 4.39: Caregivers' perceptions about the need to understand pre-morbid personality vs. not seeing the purpose of knowing the pre-morbid personality (n=8)	173
Table 4.40: Caregivers' perceptions about communication with residents on different levels of functioning (n=8)	184
Table 4.41: Caregivers' application of validation vs. reality orientation or reinforcement of delusions and hallucinations of the resident (n=8)	186
Table 4.42: QoL and occupation according to the person-	188

centred care and traditional model approach (n=8)	
Table 4.43: The means procedure of the link between QoL and person-centred care (n=8)	191
Table A: Kitwood's psychological needs of people living with dementia	283

ACKNOWLEDGEMENTS

I would like to extend a special “Thank You” to the following:

Thank you, Lord, for using me as your instrument, keeping all your promises and for providing me with endurance beyond measure. All the honour and glory belongs to You.

Marlene, everyone who knows me can testify that I wouldn't have made it without you. Thank you for looking after me and picking me up time after time. Thank you for your selflessness and sacrifices and for covering for me whenever you could.

To the best parents in the world, Hein and Adri Kotzé, thank you for all your love and support. I know that a parent can only be as happy as their least happy (or most stressed) child. Thank you for being on board and for accompanying me through all my ups and downs. Thank you for being so proud of me, no matter what.

To my older sister, Liezel, thank you for being such a good example and for “helping” in any way you could. You saved me many times. To my younger sister, Adéle, thank you for always having a joke and that you forced me to laugh when I didn't want to. To my three brothers - Niel for always showing me the lighter side of life and Heinrich for your tenderness and caring ways. Petrus, thank you for your support, selflessness and loyalty.

Thank you to my other family, Tannie Priscilla, Lynette, Jacques, Charmain and Louise for your support.

I have a long list of friends (that would not fit on any page) who I would like to thank for their continuous support. Each of you knows who you are. I have missed spending time with all of you.

To my colleagues, Veda, Rialda, Marina, Lyndall and Mateboho who have supported me through my four years of study and to Jess, Elfie, Ané and Debs, four recent additions to our staff, for supporting me through the last few months.

Dr. Sanet du Toit, my supervisor, mentor and friend. We share more than a career path, we share a passion and we share life. Thank you for everything that you have taught me, personally and professionally. I know there are lots more to come. I will never be able to repay you.

Dr. Rita van Heerden, co-supervisor, for the remarkable precision with which you led me through this research process and for the life lessons that I learned through this experience.

Special thanks to the Alzheimer Association of South Africa for the financial contribution to this study.

Thank you to Jacques Raubenheimer from the Department of Biostatistics for your expertise and patience and to Deirdré van Jaarsveld for your guidance on the issue of diversity.

To Juanita Swanepoel and Mia Vermaak who worked very hard in helping to analyse the qualitative data for this study in due time. Thank you for sharing your insight and expert knowledge with me. To Lerato, thank you for providing clear communication in the interviews and enabling me to understand the caregivers more clearly. Also, thank you for your perseverance and patience when interviews had to be held late at night in the midst of your studies. Thank you to everyone who helped me to transcribe the interviews. Luna, thank you for the special care with which you edited this work.

I would like to especially thank the management of the residential care facilities for opening your facilities to this research project. A most special thank you goes to all of the caregivers for allowing me into their hearts and

circumstances and for helping me to understand...

PREFACE

My grandmother was diagnosed with dementia at the age of 72. I was 19 years old at the time and it was my first encounter with dementia. I did not understand the disease or the implications thereof. My grandfather took care of her throughout the course of the disease. As the disease progressed, my grandmother lost her independence, but so did my grandfather. Although the family tried to give my grandfather more freedom, the burden of care was immense. He was determined to keep her at home. After two years, he experienced severe emotional burn-out and my father and grandfather visited a RCH in Bloemfontein to have my grandmother admitted to the SCU. Before she could be admitted to the SCU, she was admitted to hospital, where she died two years after being diagnosed.

During the final year of my occupational therapy (OT) studies, our research group started our research project at the same RCH where my grandmother would have been admitted. The research was part of an action research project driven by Dr. Sanet du Toit, senior lecturer at the University of the Free State. The purpose of the project was to introduce person-centred care in the SCU. The person-centred care programme was an approach focussed on individualism, independence and occupation. I became really intrigued with the disease of dementia and fell in love with the people in the SCU. In my final year, during the execution of the research study followed by clinical practice for six weeks, I spent a considerable amount of time in the SCU. I worked very closely with the residents, sisters and caregivers. All the while I wondered how my grandmother would have experienced the SCU. I left the SCU at the end of my clinical practice, having developed the first individual programmes for four of the residents. I was inspired.

As a qualified occupational therapist in my year of community service for the Department of Health, I kept in touch with Dr. Du Toit, who became my mentor and friend. I also kept in touch with the RCH and the action

research project that my research group was part of. At the beginning of my second year as a qualified occupational therapist, I enrolled at the University of the Free State to complete my Master's degree by building on the same action research project that I was involved in at undergraduate level. I also started working at a district hospital in Bloemfontein and I was very enthusiastic when the same RCH was allocated as one of the community areas I had to attend to. I returned to the RCH with a very enthusiastic attitude, only to find that there did not seem to be any change towards person-centred care after one year. Ever since, I observed projects and training attempts which seemed to have no impact on the circumstances in the SCU. I also had to deal with negative emotions regarding occurrences in the SCU.

It is clear that my personal, as well as professional, experience could have caused some prejudice that could have impacted on this study. Although at the age of 29, I am still very young and inexperienced, I have grown personally and professionally since my very first professional encounter with dementia care. I learned that neither people, nor a situation can be judged by appearances; I learned that the power and influence of diversity should never be underestimated. I learned that you will never have all the answers, but most of all I learned that every person should be allowed and empowered to LIVE, in the fullest sense of the word, everyday of their lives.

My sole purpose is to make a difference in the SCU, for the caregivers just as much as for the residents. My endeavour is to understand with empathy and not to criticise. I decided to change the names of the two RCH's to protect the identity of the institutions, the caregivers and residents involved in this study. The RCH that was the focus of the study will be referred to as Greenacres RCH and the RCH that assisted with the pilot study will be referred to as The Resting Place RCH.

CONCEPT CLARIFICATION

DEMENTIA

In the most recent DSM V Criteria, the term dementia has been changed to 'major neurodegenerative disease', but due to the fact that the new term has not yet been introduced to non-medical professions, the researcher will refer to the term dementia throughout the text (American Psychiatric Association 2012:online)

Milwain (2009:23) defined dementia as a syndrome of intellectual decline, of which memory plus one or more cognitive function is damaged, affecting the person's functionality. According to Kitwood (Baldwin & Capstick 2007:11) dementia remains a difficult diagnosis to make and when considered from a person-centered perspective would be a configuration of five factors: Dementia = Personality + Biography + Health + Neurological factors + Psychological factors.

CAREGIVER

Caregivers are paid carers. They provide care at institutions for elderly people (Davies, Aveyard & Norman 2006:506).

The caregivers at the residential care home (RCH) involved in this research do not qualify as nurses as they had no training towards a nursing qualification (Olivier 2009). Thus, for the purpose of this study, the term caregivers will refer specifically to the nursing staff that have received no training as nurses and are working in the special care unit (SCU) at the RCH.

SPECIAL CARE UNIT

A Facility providing specialized 24-hour care for the residents as needed. This SCU utilised during the research also provides 24-hour care and is a unit and it was a unit within the extended RCH (Olivier 2009; Reed 1999:167). Thus, through the course of this study, a SCU should be understood as a facility that provides specialized, 24-hour care to residents.

OCCUPATIONAL ENGAGEMENT

Occupational engagement refers to collections of activities in everyday life, which has value due to individual characteristics and culture, and completely engages time, attention and environment by the application of basic abilities, motivation and objectives to enable the fulfilment of roles (Perrin, May & Anderson 2008:30; Trombly 2002:256-257; Law, Steinwender & Leclair 1998:83).

For persons with advanced dementia one should also recognise that occupational engagement may relate to only the ability to complete components or aspects of an activity independently. Therefore the essence of meaningful engagement focuses more on the 'doing' rather than completing an activity (Eden Alternative 2010b:20). Therefore, for the purpose of this study, occupational engagement is considered as aspects of activity participation and independence.

OCCUPATIONAL JUSTICE

Occupational justice refers to the right of every human being to be enabled to occupational engagement and to be protected from occupational deprivation. Occupational justice leads to quality of life and is part of the human rights that lead to human dignity when occupational justice is applied (Van der Merwe

2010:18; Wilcock 1998:346).

QUALITY OF LIFE

Quality of life equals maximal independence and engagement in activity, thus the enjoyment of participating in activities of daily living enhanced by person-centred care (Baldwin & Capstick 2007:152,233; Eden Alternative 2010b:289). For the purpose of this study, quality of life is enhanced by maximal independence, engagement in activity and person-centred care (through consideration of the individual needs of the residents) and is displayed through the experience of positive emotions.

WELL-BEING

According to the Economic and Social Research Council (2007:online) well-being is a condition of existing with other people where goals that are meaningful to the person are achieved, the needs of the person are provided for and QoL is present. Therefore, the assumption for this study is that well-being leads to QoL.

PERSONHOOD

Through the course of this study, personhood will be seen as an individual's unchanging definition of the self. It is the essence of who the person is. Personhood also determines how a person is treated and wants to be treated by others and has a close connection with human rights and human dignity (Baldwin & Capstick 2007:174).

PERSON-CENTRED CARE

Person-centred care is given when the caregiver has insight into life history and is considering the client's tastes, preferences, beliefs and is enhancing independence. People with dementia are dependent on their caregivers to provide the type of care that will enhance their well-being (Baldwin & Capstick 2007:89-90,223; Innes, Macpherson & McCabe 2006:i).

REALITY ASSURANCE

Reality assurance is similar to reality orientation, (i.e. a technique used to heighten awareness of the reality towards place, time, other people and the situation). In contrast to reality orientation, information is provided to the residents rather than asked from them. This technique is done with the purpose of enhancing reality orientation, without stressing the fact that a person is not orientated to reality (Du Toit 2005:30-34).

For the purpose of this study, reality assurance will be used and not reality orientation. No response or improvement is expected of the client. The only goal is to reduce anxiety and preserve dignity (Du Toit 2005:38-46).

CULTURAL COMPETENCE

Although there are similar definitions of cultural competence, no universal definition exists (Campinha-Bacote & Kardong-Edgren 2008:38). Andrews (2003:15) gives an adequate definition for the purpose of this study: Cultural competence represents the strive of the health care professional to operate efficiently within the cultural framework of a person, a family or society from another cultural background.

DIVERSITY

Diversity is the difference between groups of people. These differences can include any of the following and more: religion, language, physical size, gender, sexual orientation, age, disability (physical or mental), political orientation, socio-economic status, occupational status, geographical location, education, prior health experiences ethnicity, race, and national origin (Campinha-Bacote 2003:online, Lum 2000:3, Kai, Spencer, Wilkes & Gill 1999:616).

This work is a testimony of the Lord's strength and his equal love for us all, just as we are, young and old, healthy or ill. It shows that we are saved, not because of who we are, or how we perform, but because of what he has done for us. We should love all people as He loves us – unconditionally

CHAPTER 1

INTRODUCTION AND ORIENTATION

1.1 INTRODUCTION AND BACKGROUND

Throughout the world, organisations such as The Pioneer Network (2011:online), University of Bradford (well-known for Dementia Care Mapping) (2012:online) and the Eden Alternative (2009:online) are in the developing process of changing and improving care for people with dementia with the focus on person-centred care. The development of the concept of person-centred care is an ongoing process that has not been completed yet. Kitwood (2000:8-10) advocates a culture change from the 'old culture' of dementia care to the 'new culture' referring to person-centred care.

According to Baldwin and Capstick (2007:89-90,223) as well as Innes *et al.* (2006:i), people with dementia are dependent on their caregivers to provide the type of care that will enhance their quality of life (QoL). This means that person-centred care is given when the caregiver has insight in life history and is considering the client's tastes, preferences, beliefs and enhancing independence. Many authors agree that person-centred care is key to QoL (Baldwin & Capstick 2007:89-90,233; Davies *et al.* 2006:492; Hoe, Katona, Roch & Livingston 2005:134).

Currently in South Africa, a more traditional approach, (embedded in the medical model and focusing mainly on physical care as opposed to person-centred care and independence), is followed at the majority of Residential Care Homes (RCH's). The websites of the national bodies, Dementia South Africa (2009:online) and Alzheimer South Africa (2000-2012:online) appear to highlight the impact of the pathology of dementia and the process of decline from the first to the last phase of the disease. This approach may contribute to the fact that the caregivers, who are trained by these national bodies, present more focus on

administering medically-associated care needs as the disease progresses. Therefore, training specific to dementia appears not promoting person-centred care and QoL as a point of departure. This is the frame of reference that the caregivers of the people with dementia experience in the South African context (Du Toit & Surr 2011:48).

With physical well-being an important aspect of dementia care, the family members admitting their loved ones to RCH's also emphasise that quality of medical and physical care are of great importance when choosing the most suitable RCH, leaving person-centred care and QoL out of the picture (Du Toit & Surr 2011:48-49).

William Thomas, the founder of the Eden Alternative, emphasises in the Eden Alternative Training Manual that the medical model, although used with all the good intentions in the world, cannot combat three of the most prominent problems in dementia care: loneliness, helplessness and boredom (Eden Alternative 2010b:2). Thomas (1996:1) also states that staff and management at RCH's are confused about the meaning of care, thus more attention is given to medical and physical care than to the prevention of loneliness, helplessness and boredom. He also emphasises that these problems should be addressed with commitment to people with dementia and changing views of institutions to improve QoL.

An immense part of person-centred care is also to create a home for the residents and shying away from the popular perception that the RCH is a *facility* or *institution*. A systematic change should be brought upon the RCH to provide a home for the residents (Power 2010:17). As Thomas (1996:13) emphasises:

“Longterm care is supposed to be about ‘homeness’ about leading a life worth living.”

Anyone that enters an RCH, whether it is to work or to visit, should do so from the perspective that they are entering the home of elderly people, not a workplace or a medical facility (Thomas 1996:11). Personal preferences and

beliefs should be considered and respected (Baldwin & Capstick 2007:89-90,233).

The other stepping stone that goes hand in hand with person-centred care to enhance QoL in dementia is occupational engagement. Hasselkus and Murray (2007:9) argued that occupational engagement is a source for improvement of QoL. This connection between occupational engagement and QoL supports a basic belief of the occupational therapy (OT) profession that every person has the right to occupational justice and that he/she should be protected from occupational deprivation (Townsend & Wilcock 2004:80; Wilcock 1998:346). Not only does participation in meaningful occupational engagement lead to QoL, but it is a basic human right that leads to human dignity when a person experiences occupational justice (Van der Merwe 2010:18). Thus, occupational engagement and person-centred care is the means through which OT could advance QoL, as human dignity pertains to a right of every able and disabled person.

Although the researcher is working in a hospital with an inevitably strong focus on the medical model, the researcher believes in the approach of occupation and person-centred care that leads to QoL. This belief is incorporated by the researcher at Greenacres Residential Care Home (RCH), which is part of the outreach areas of the hospital. The approach of occupation and person-centred care to reach QoL falls within the core beliefs of OT that a person should be viewed as a holistic individual with the aim to promote QoL and occupational engagement (Christiansen & Baum 2005:524). Therefore, this approach was implemented at Greenacres RCH.

Greenacres RCH in Bloemfontein provides a home to 20 residents suffering from dementia. These residents are in need of 24-hour care and stay in the Special Care Unit (SCU). As part of the person-centred care approach, individual care programmes were compiled for these residents. All the staff, as well as the families of the residents at Greenacres RCH, need to work together in order to satisfy the physical and emotional needs stipulated in the person-centred care programmes of the residents (Du Toit 2009) whilst keeping

personhood intact (Baldwin & Capstick 2007:310). Although this diverse group of people (e.g. occupational therapy students, professional nurses, family, volunteers, friends and caregivers) are involved in the lives of these residents, the caregivers and the professional nurses working in the SCU are the most influential, because of the time spent in their presence while taking care of them. The caregivers have the most direct contact with the residents and are in the predominant position to have an impact on their lives, and it is their responsibility to see to the physical and emotional needs of the residents. The goal of QoL through person-centred care and occupational engagement is essential to the transformation at Greenacres RCH and cannot be met without the caregivers. The reality is that occupational therapists are dependent on the caregivers due to their vital role in the achievement of QoL (Du Toit 2009) and extensive teaching and learning need to be done with caregivers, in order to maximise the quality of care in dementia (Baldwin & Capstick 2007:135, 224).

Alzheimer South Africa (2000-2012:online) is the leading national body providing training in the Free State and as previously stated, the focus of this training for caregivers include the pathology of dementia and the progressive decline that people with dementia undergo. The standard procedure at Greenacres includes training from Alzheimer South Africa for the caregivers who work in the SCU. The consulting occupational therapist and the OT students continually do additional training with all of the caregivers included in this study, associated with their person-centred care input (Du Toit 2009).

The effects of the training were determined by the implementation of a Dementia Care Mapping evaluation in February 2010 and October 2010. The results showed that in spite of the informal training attempts mentioned above, hardly any of these caregivers showed an improvement in their attitude, knowledge or skill that could impact QoL of the people with dementia in the SCU (Du Toit 2011). Adhering to the medical model they see to it that the residents take their medication, are well fed, hydrated, clean and safe. All residents are treated the same with no consideration for individual differences. It appears as if independence is not encouraged, as most of the tasks are done for the residents by the caregivers (Du Toit 2011).

The information from literature as well as the information obtained from professionals working in the SCU at Greenacres prompted the researcher to explore the caregivers as individuals - their circumstances, their perspectives and their emotions - to find reasons for the ineffective promotion of QoL and seeking greater understanding of the problem from the perspective of the caregivers. For example, three potential aspects that the researcher considered was a possible lack of person-centred care perspective in the organisation (Power 2010:17; Thomas 1996:11) that the caregivers as holistic human beings, living in a stressful world apart from the institution, were misunderstood; and that caregivers and trained staff like occupational therapists, perceived QoL and occupational engagement for people with dementia from different worldviews:

“You think the only people who are people, are the people who
look and think like you, but if you walk the footsteps of a
stranger, you’ll learn the things you never knew, you never
knew.”

(Menken & Schwartz 1994: lyrics)

1.2 PROBLEM STATEMENT

Person-centred care programmes were individually designed to enhance the QoL of the residents with dementia at Greenacres RCH. The purpose of these programmes was to integrate the strong focus on the medical model with a focus on QoL through person-centred care. The programmes contained person-specific activities, as well as person-centred strategies for the appropriate handling of the resident.

The person-centred care programmes were meant for the use of everyone who came into contact with the residents, especially those who spent the most time with the residents, in this case the caregivers. Without the help from the

caregivers, optimal QoL could not be met and the transformation from a *facility* to a *home* could not be achieved.

All of the caregivers had been exposed to and involved in this process of person-centred care since 2006. They had been engaged in the process by the OT students during their fieldwork education (which provided unique potential for the area but also interesting challenges because the service only operated during fieldwork placement periods) and the process had been modelled to them by the students and consultant occupational therapist working in the area. These strategies included, for example, the preferences of the residents concerning eating at a set table, washing with their favourite soap or drinking their tea like they always preferred to do and just like they would have done if they were in their own homes.

Although most of the nine caregivers were perceived as very dedicated to their work, training attempts were unsuccessful and according to the results of the Dementia Care Mapping it was observed that they did not apply what they had been taught, even though it was explained to them that the application of these strategies would even make the management of the residents easier (Du Toit 2011).

The reasons for the perceived incomprehension of the caregivers were unknown and the course of this study led to two research questions:

Question 1: What are the caregivers' pre-conceived ideas regarding person-centred care, occupational engagement and QoL for people with dementia?

Question 2: Is there a link for caregivers between person-centred care, occupational engagement and QoL for people with dementia?

1.3 AIM

The aim of the study was to describe the caregivers' pre-conceived ideas of and explore and understand the caregivers' perception of QoL, person-centred care and occupational engagement for the people with dementia, in need of 24-hour care.

1.3.1 OBJECTIVES

- To describe the caregivers' pre-conceived ideas of occupational engagement, person-centred care and QoL for people with dementia.
- To explore and understand the caregivers' perception of a potential link between occupational engagement, person-centred care and QoL for people with dementia.

1.4 METHODOLOGY

To reach the abovementioned aim and objectives, the researcher used a triangulation, mixed methods study design. The researcher followed the process and steps to design a mixed methods study as described by Ivankova, Creswell and Plano Clark in Maree (2007:256-283). The motivation for the use of a mixed methods study, the specific mixed methods design as well as the full seven steps that were used to design this study are discussed in detail in Chapter 3.

It was evident that a mixed methods design was needed to obtain an in-depth understanding and to reach both objectives of the study. The researcher chose the triangulation design based on the objectives, timing and the stage of the integration of the data (Ivankova *et al.* 2007:278).

The researcher used a structured interview questionnaire that contained specific questions on occupational engagement, person-centred care and QoL to collect quantitative data that produced numerical data that were converted into tables. The researcher used an interview schedule with follow-up questions and probing techniques to collect qualitative data that produced transcripts and field notes. Although the quantitative and qualitative data were collected during the same session, two data sets were produced that were analysed separately and afterwards integrated for comparison and interpretation. This process is true to the triangulation mixed methodology design (Ivankova *et al.* 2007:268)

The interviews were conducted during working hours and lasted more or less an hour and a half with a break and refreshments in between. A translator was present at the interviews and assisted with language difficulties when indicated. The interviews were recorded as audiovisual material, transcribed and member-checked. Participant observation was used to verify verbal and non-verbal messages of the participants. The transcripts represented the qualitative data (Greeff 2011:330,344-347,349,351-353; Ivankova *et al.* 2007:272; Rubin & Rubin 1995:126-127,150,210).

The quantitative data were analysed by the Department of Biostatistics, University of the Free State. Qualitative data were analysed by the researcher with the help of two co-coders who were chosen due to their recent involvement and expertise in qualitative data analysis, in order to enhance trustworthiness (Polit & Beck 2006:333).

Prior to the use of the measuring instrument with the study population, the data were tested with four participants in a pilot study. The participants that were used for the pilot study were not part of the study population. The purpose of the pilot study was to determine the comprehensibility of the structured interview questionnaire and the interview schedule and also to determine whether the two measurement instruments served the purpose of collecting the applicable data (Strydom 2011d:240-243). The pilot study also provided the researcher the opportunity to practise interview skills.

The collection of qualitative and quantitative data in a triangulation mixed methodology allowed the development of an inclusive report to reach the aim of this study (Ivankova et al. 2007:268).

1.5 ETHICS

Consent for the execution of the study was obtained from the Ethics Committee of the Faculty of Health Sciences of the University of the Free State after the research proposal was submitted for approval (ETOVS NR 169/2010). The researcher also obtained written consent from the managers of both the homes for the execution of the study and the pilot study. There was no risk or harm involved for the participants (Strydom 2011a:115,117,126).

The participants gave informed consent for participation in the study and all information was treated confidentially. The participants were informed of their right to withdraw at any time during the execution of the study without penalty. No remuneration was offered for participation in the study. The data were handled with respect and integrity. The institutions and participants would receive feedback on the result of the study and they were also informed that the research results would be published in an accredited journal for scientific purposes (Strydom 2011a:116-117,126).

1.6 VALUE OF THE STUDY

The vision and mission of the OT programme at Greenacres RCH was to give optimal care to every resident, regardless of their pathology or prognosis. The person-centred care approach followed by the OT students in the SCU, mainly by means of small-scale research projects, needed multi-disciplinary effort to ensure sustainability. This was especially true for the caregivers working in the SCU, who had the most direct contact and spent the most time with the residents. Therefore, they held the key to optimal QoL through person-centred

care. They held the key to transform institutionalised care and provide a home for the residents. With a greater understanding of caregivers' interpretation of what person-centred care implies for them, the OT programme could be adapted to ensure better co-operation between all team members. This would address QoL for all persons living and working in the SCU.

The study was designed to enable other South African organisations in similar settings and with similar circumstances to implement the research and to identify the cause of the lack of understanding between the caregivers and occupational therapy and the problems within the organisation that prohibits the facilitation of person-centred care.

Therefore, this study focuses on promoting an understanding between specifically the OT team and the caregivers. The researcher attempted to understand person-centred care, occupational engagement and QoL from the worldviews of the caregivers in order to promote its application in the future.

1.7 CHAPTER LAYOUT

The following represents a summary of each chapter in this dissertation:

Chapter 1: Introduction and Orientation, serves as an orientation to the reader with regard to the background of the study and the course of the dissertation. Chapter 1 describes the origin of the study and presents the problem that gave rise to the study. The aim and objectives are indicated in this chapter together with a summary of the research methodology. An overview of the ethical aspects of the study as well as the value of the study is included. The chapter concludes with the chapter layout that serves as an orientation to the dissertation.

Chapter 2: Literature Review, offers a discussion on the three components of the study, which are the residents, caregivers and lastly, the environment.

Chapter 3: Research Methodology, firstly offers a discussion of the mixed methodology triangulation method that formed the scientific base of this study, followed by the quantitative and qualitative methodology, each with their unique components.

Chapter 4 offers the *Presentation and Interpretation of the Results and Findings* gained from this research study.

Chapter 5: The last chapter offers the *Conclusions, Recommendations and Limitations* applicable to this study.

1.8 SUMMARY

In Chapter 1, the researcher aimed to orientate the reader to the study by means of a general overview. The chapter introduced problems associated with dementia and the importance of QoL, occupational engagement, person-centred care and caregivers for people with dementia.

It is evident that the current focus of the RCH on the medical model intensifies the loneliness, helplessness and boredom experienced by residents despite attempts by OT to promote person-centred care. It appears as if a lack of understanding between the caregivers and OTs may be due to the fact that there is a different perception of QoL, person-centred care and occupational engagement for people with dementia.

As the reader is now familiar with the background of the study, Chapter 2 continues with a literature review regarding QoL and person-centred care, residents with dementia, the RCH as an institution and the caregivers as part of this institutional setup.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

In the previous chapter, an introduction and a general overview of the study were given. In Chapter 2, the literature study provides a background of the recent developments in the care culture of RCH's. The researcher determined from the literature that a culture change is starting to develop throughout certain RCH's in South Africa and internationally, although it has not been officially implemented everywhere. And even in the RCH's where it has been implemented, maintaining a care culture is an on-going process (Calkins 2011:45; Eden Alternative 2010b:138).

Therefore, the literature review focuses on the care culture in long-term care facilities, taking into consideration the overall values, beliefs and attitudes of the organisation (Bell & Troxel 2011:13; Calkins 2011:42; Eden Alternative 2010b:25). It will commence with a discussion on culture change and the culture change continuum, which consists of three transformational stages (Calkins 2011:42; Eden Alternative 2011:20): organisational transformation, physical transformation and personal transformation in conjunction with the influence thereof on the resident living with dementia. This philosophy of the Eden Alternative will form the structure of the literature review.

Firstly, a discussion will be given on the organisational transformation of the RCH in terms of the attitudes, beliefs and values underlying culture change. The role of the caregivers in terms of their perspectives, beliefs, circumstances, personhood and sensitivity to diversity as well as the influence of ethics and the law pertaining to them will also be discussed.

Secondly, the physical transformation of care facilities will be discussed in terms of the institutional model versus a home environment. Lastly, personal transformation will be discussed in terms of the caregivers as well as the residents, focusing on the person-centred care model vs. the traditional model.

Campinha-Bacote (2002), Christiansen and Baum (2005), Eden Alternative's Haleigh's Almanac (2010b) and Eden Alternative Associate Manual (2011), Kitwood (2000), a compilation of Kitwood's work by Baldwin and Capstick (2007), Power (2010) and Thomas (1996) are the main selected references and provided a specific background and frame of reference for QoL and person-centred care for the focus in Chapter 2.

In Addendum M, a case study is presented to illustrate the influence of the transformation and person-centred care on a person with dementia. This case study is based on the Person-Environment-Occupation-Performance (PEOP) model (Christiansen & Baum 2005:254) and Kitwood's psychological needs of people living with dementia (cited by Brooker & Surr: 2005: 27-32).

Although the population at Greenacres was not limited to people living with dementia and many of the concepts are applicable to elderly people in general, the focus of this literature review will be on people with dementia, who will be referred to as the residents.

2.2 CULTURE CHANGE

As previously mentioned, a culture change is taking place in dementia care. This means that the overall values, beliefs and attitudes of organisations are changing to accommodate person-centred care (Bell & Troxel 2011:13; Calkins 2011:42; Eden Alternative 2010b:25). The point of departure of this change process is the traditional model of care and the end vision is the person-centred care model (Eden Alternative 2010b:138) as illustrated in figure 2.1.

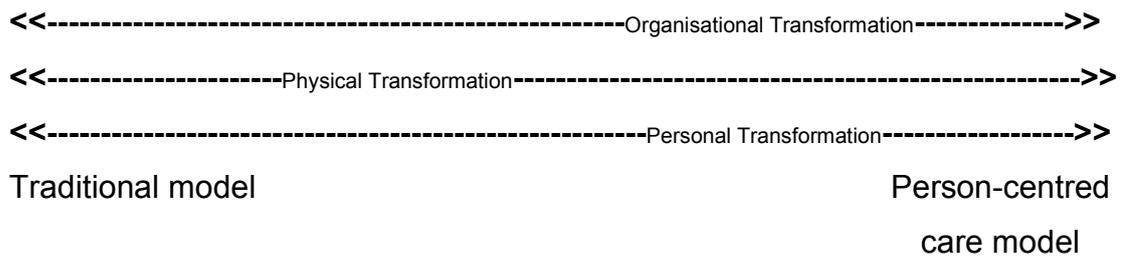


Figure 2.1: Continuum of culture change

In Figure 2.1, the process of culture change is indicated as a continuum. This implies that the process of culture change is a journey and that RCH's can be on different places on the continuum. Different aspects of the same RCH can also be at different places on the continuum, e.g. organisational and personal transformation can be at a later stage than physical transformation, meaning that the care attitudes have changed, but the physical changes are still to follow (Eden Alternative 2010b:6,9-31).

Organisational transformation focuses on the differences between the institutional model and a person-centred care model brought on by a change in the culture of the RCH, the role of the caregivers and ethics and the law to illustrate the influence of organisational culture on the resident with dementia.

2.2.1 ORGANISATIONAL TRANSFORMATION IN A RESIDENTIAL CARE HOME

Kitwood (2000:7) proposes two foundational principles regarding a culture. The first is that within a culture it is the institution that determines social power, principles for behaviour, values and beliefs. Secondly, he proposes, that when people are absorbed within a culture, it follows that they will take on the guiding behaviour of the culture.

Therefore, if an organisation is not focused on person-centred care, the result will be that person-centred principles will not be part of the organisational

culture. The system should change first before the thoughts of the individual will change. If they are not encouraged to apply any of these principles, it will only be 'nice-to-have' knowledge, which is not promoted and sustained by the institution (Du Toit 2009). Power (2010:17) states that caregivers are part of an organisation and he agrees with Thomas (1996:11) that the problem, therefore, does not lie with individuals, but with the way the RCH is systematised.

Thomas (1996:11) states that most RCH's have more in common with a hospital than with an actual home. Anyone that enters an RCH, whether it is to work or to visit, should do so from the perspective that they are entering a home, not a workplace or a facility.

According to the Eden Alternative (2010b:23,42,158) and Kitwood (2000:8-10) in the traditional model, the residents in RCH's are referred to as patients and the central focus is on their medical conditions with the doctor, professional nurses and therapists as the main role players with a top-down approach to management and the workload divided between the different departments. It is an environment where the residents wait for the caregivers to provide routine care that is cost effective. It is clear that in this task-oriented environment, the personhood of the residents is neglected and not much attention is given to their individual needs (Eden Alternative 2010b:23,42,158; Kitwood 2000:8-10). The problem with this approach is that it cannot cure the three most prominent problems amongst elderly people residing in care facilities, namely loneliness, helplessness and boredom. In the Eden Alternative (Eden Alternative 2010b:8), these three problems are referred to as *the three plagues of the human spirit* and will from now on be referred to by using the same term. Due to the loss of abilities, the *three plagues* are more severe for people with dementia. According to Christiansen and Baum (2005:136,169) and Cutler and Kane (2004:13), a loss of basic abilities and thus activity performance can cause people with a specific debilitating condition to become deprived in terms of occupation and prone to a situation of sensory deprivation. Therefore, they are at risk of suffering from occupational deprivation and occupational injustice, because of the absence of

participation in meaningful activities, which in turn leads to decreased QoL (Wilcock 1998:346).

In contrast to the medical model, the Eden Alternative (2010b:158) suggests an approach where staff members are employed for a specific group of people and where there are no definite differences in the roles of different staff members. It is suggested that decisions are made in conjunction with the staff and residents with the needs of the residents as the main priority. The staff members in that specific group report to each other and the residents, not to the management of the RCH. In this approach, the 'patients' are referred to as residents and they are the main role players in a homelike environment where caregivers facilitate the independence and growth of the residents. In this environment, the personhood of the residents is preserved; they are free to make choices; their preferences and individuality are the main focus; and medical treatment is only a supportive function when needed. The residents get the opportunity to give as well as to receive care. Caregivers know the life stories of the residents. The main aim of this approach is to combat the *three plagues*. The Eden Alternative philosophy enhances QoL and is supported by Baldwin and Capstick (2007:89-90,223) and Innes *et al.* (2006:i). It follows from the above that the culture of the organisation sets the pace for the type of care that the residents receive.

2.2.1.1 Ethics and the Law

According to the Certified Eden Associate Training Workbook (Eden Alternative 2010b:25) a code of ethics is defined as the rules and regulations that guide the actions of the members of an organisation. This set of rules is determined by the organisation.

As previously discussed, people with dementia suffer the loss of abilities. They are vulnerable to unethical behaviour and therefore, ethics and the law are important aspects for discussion.

- **The Law**

The objectives of the South African Older Persons Act (South Africa 2006:8) emphasise the importance of QoL:

“All proceedings, actions or decisions in a matter concerning an older person must:

- (a) respect, protect, promote and fulfil the older person’s rights, the best interests of the older person and the rights and principles set out in this Act, subject to any lawful limitation;
- (b) respect the older person’s inherent dignity;
- (c) treat the older person fairly and equitably; and
- (d) protect the older person from unfair discrimination on any ground, including on the grounds of the health status or disability of the older person.”

These general principles of the act indicate that it is the right of every resident to be in a state of optimal QoL and to be treated with dignity and fairness. At the top of the agenda should be equal rights and the absence of discrimination.

The law provides a set of rules that every staff member and even members of the public should adhere to. These principles give a workable guideline for lawful behaviour, but even within these principles, ethical dilemmas could still occur. In order to provide the person with dementia with maximum QoL and in order to behave in an ethical manner, it is crucial to take ethical factors into account.

- **Ethical principles and dilemmas**

*There is no death of the spirit, there is a very serious impairment of cognitive functions. It is wrong to equate cognitive impairment and death of the spirit
(Blanchard 2006:12).*

Ethics in dementia care is a highly controversial subject. According to Volicer (2006:89) the objective of dementia care should be to preserve QoL as much as possible in spite of the decline associated with the disease. Strubel and Samacoits (2006: 109) are of the opinion that a human being is of very high value to society and that the value does not change due to the health status of the person. In accordance with this opinion, Bender (2009:19) also suggests that a person should be valued for the contribution they have made throughout their lives and not for their capacity at any given time. The ninth principle of Eden Alternative (2010b:28) indicates that *human life should never be separated from human growth*. Therefore, residents are still able to grow until the end of their lives and should be helped to grow according to their needs. Dignity is of the utmost importance and is dependent on the way that the caregivers and family view the person (Strubel & Samacoits 2006: 109).

An organisation can be classified into one of two categories according to the way they perceive the residents with whom they work. The kind of organisation that views the person with dementia as an important individual who can still contribute to society, is the kind of organisation that can be positive about the care they provide and are able to work towards the goal of QoL of the person with dementia. On the other hand, the kind of organisation that views the person with dementia as frail and burdensome will generally be pessimistic about the QoL of the person who is being cared for (Milwain 2009:14). The Eden Alternative Training Notes (Eden Alternative 2012:4) and Hughes and Baldwin (2006: 87) also argue that our actions reflect on our inner nature and thoughts, and therefore we act according to our thoughts and feelings. Thus, ethical behaviour starts with our thoughts regarding the person who is being cared for.

Ethical decisions are made every day when a staff member has to decide between right and wrong, and these decisions are guided by moral theories (Hughes & Baldwin 2006: 16). As previously mentioned, people with dementia are vulnerable to unethical behaviour and the staff members at Greenacres were mostly uninformed or ignorant about ethical guidelines. These factors are problematic in the facilitation of person-centred care (Baldwin & Capstick 2007:224).

Categories of moral theories are adapted and summarised in Table 2.1 (Hughes & Baldwin 2006: 16-27, 88, 106):

Table 2.1: Adapted Table of Moral Theories

THEORY	PROTOCOL FOR DECISION-MAKING
Consequentialism	The person decides whether an action is ethical or not, by considering the consequences of the action.
Deontological (duty-based) ethics	The person decides depending on whether the action is their duty or not
Principlism	<p>The person decides whether an action is ethical by applying ethical principles</p> <p>Autonomy: Protecting independence, letting the person choose for his/herself</p> <p>Beneficence: Doing good to the person</p> <p>Non-maleficence: Avoiding harmful actions towards the person</p> <p>Justice: Treating people fairly</p> <p>More can be added:</p> <p>Fidelity: Always telling the truth</p> <p>Confidentiality: Keeping information regarding the person you care for, private</p>

Subjective moral theories	The person decides whether an action is ethically based on his/her own feelings
Objective moral theories	The person decides whether an action is ethically based on shared ideals (e.g. social acceptability)
Perspectivism	Making an ethical decision based on the perspectives of the individuals who are involved in the case
Narrative ethics	Firstly understanding the life story of the person involved, followed by making the ethical decision.
Virtue ethics	Making a moral decision based on our perspectives of what a righteous person would do.

The moral theory named perspectivism suggests that an ethical decision should be made, based on the perspectives of the individuals who are involved in the case: An ethical decision cannot be made when the points of view of those who have a legitimate interest in the case have not been considered. Contrary to this theory, people with dementia have so far mostly not been consulted when an ethical dilemma occurs (Hughes & Baldwin 2006:83).

Nobody has the right to make the assumption that a person with dementia is not able to make decisions and in order to understand the person with dementia, we should make the effort to gain an empathic understanding of their worldviews and perspectives on situations and relationships and the meaning that it holds for them. Therefore, caregivers need to know and understand the life story of the person (narrative ethics) to make ethical decisions. No person can be disconnected from their associations with the world, their history and their relationships (Eden Alternative 2011:10; Hughes & Baldwin 2006: 39-41,46,62).

These theories are not always a solid guideline for making moral decisions. For example, sometimes the principles in the principlism theory contradict one another, like the issue of feeding people with dementia when they refuse to be fed. Autonomy and non-maleficence come into conflict, leaving the caregiver with an ethical dilemma (Hughes & Baldwin 2006: 24). These ethical

dilemmas could become very difficult, especially in the case of dementia, where a great percentage of the residents cannot communicate effectively as language, comprehension of others and expression of self is impaired. Usually the person with dementia retains the ability to express emotion, emphasising the importance of building close relationships and learning about the past experiences of the client to bring meaning to caregiving (Strubel & Samacoits 2006:107, 109).

- **Relationships**

A caregiver will make a decision regarding a person with dementia based on the type of relationship they have. Ethical behaviour is thus greatly dependent on healthy relationships (Hughes & Baldwin 2006:76, 79).

The caregiver should have a general understanding of exactly what the resident is experiencing in a certain situation and therefore it is essential for caregivers to know the resident's life story. This relationship requires understanding and empathy, leading to personhood being maintained. The problem that arises in dementia care is that an understanding of the person seems to be more difficult to obtain as the disease progresses, making it all the more important to just "be with" the person to form an understanding and build a relationship (Eden Alternative 2011:10; Hughes & Baldwin 2006:82).

- **Education**

Firstly, it is essential to determine whether the education and training given to the caregivers are ethically appropriate and whether their practice is in line with moral principles. Caregivers need to be equipped to handle challenges of care within a highly vulnerable population. When a caregiver moves away from the standard pattern of practice, it is important to investigate the reason for the different method. If it is only for the convenience of the caregiver, with no regard for dignity and safety, it becomes an ethical concern. Continuous training should take place to inform caregivers of changes in the ethical frame of reference that is used when giving care to people with dementia. Educators

should have an extensive knowledge of ethical principles and should be open to advanced knowledge as well as rectification (Eden Alternative 2010b:33; Hughes & Baldwin 2006:124-126,130).

In making ethical decisions, the situation should be viewed in-depth and with the required insight. That is the complexity of reality. There is no fool-proof moral theory, only weighing up different perspectives and applications (Hughes & Baldwin 2006:133). Therefore, ethical decisions represent a challenge facing the caregivers of people with dementia and the emphasis should be on their relationship with the residents and the knowledge of their life stories as the basis for making ethical decisions.

2.2.1.2 The role of the caregivers in the organisation

Baldwin and Capstick (2007:223;312) emphasise that all people are dependent on one another. Moreover, people are dependent on each other to experience well-being. According to the Eden Alternative (2010b:230) the main aim of a RCH should be to eliminate loneliness, helplessness and boredom through warm relationships with others. Thus, people with dementia are dependent on their caregivers to provide the type of care that will enhance their well-being as they are the people who are in contact with the residents for 24 hours per day. Therefore, it was important for the researcher to look at the role of the caregivers and what is expected of them.

To eliminate loneliness, the first priority of the caregivers should be to learn the names and life stories of each resident to provide them with the opportunity to connect with other human beings (Eden Alternative 2010b:10). The caregivers are expected to log into the individual experiences of the client's personal world, often without input from the client. Therefore, it is essential to know the background of the residents (Davies *et al.* 2006:504), which is often difficult at Greenacres due to the diverse population.

According to Perrin *et al.* (2008:67-68), the most important skill of the caregiver is to establish an attachment between him/herself and the resident. To reach this objective, it is required of the caregivers to be sensitive to the meaning of the signals that the residents give, providing a balance between comforting and challenging the resident. The emotions of the caregiver should be unconcealed and he/she should be comfortable enough to provide close physical contact with the resident. It is also expected of the caregiver to playfully facilitate the resident to engage with the environment.

The feelings of helplessness of the residents can be eliminated by giving them not only the opportunity to receive care, but to also give care. This implies that the caregiver should facilitate situations where the resident has the chance to give time, effort or emotional care to the community or individual people to help the resident to grow (Eden Alternative 2010b:15). Helplessness can also be eliminated by facilitating independence. This is a very challenging and essential skill for caregivers; to know when to help the client with a task and when to stand back in order to enhance the independence of the person. When a situation is a challenge, growth takes place. When the ability of a person to grow is encouraged, QoL is enhanced (Cutler & Kane 2004:13; Ebersole, Hess & Luggen 2004:586; Power 2010:22; Volicer 2006:91).

To combat boredom, the caregivers have to facilitate spontaneity and out of the ordinary daily happenings that eliminate the strict, task-driven, everyday routine. Risk goes hand in hand with this approach, but risk is a part of life that keeps life interesting (Eden Alternative 2010b:18).

Due to the lack of these skills, Hughes and Baldwin (2006:125) stress the importance of education, training and experience in conjunction with the individual life story of each client to enhance person-centred care. According to Power (2010:18) educational changes will facilitate a change in the application of care strategies and provide a new perspective to caregivers. To change the perspectives of the caregivers, it is important to establish a knowledge base on their frames of reference, beliefs and perspective. According to the Eden Alternative (2011:20), the starting point to facilitate

change is for the organisation to undergo a culture change from the traditional model to the person-centred care model.

2.2.1.3 Diversity

To fully understand another human being, one has to understand the life story as well as the context and background in which the life story takes place (Eden Alternative 2010b:13). As was pointed out above, at Greenacres, this is a challenge due to the diverse population.

Diversity is the difference between groups of people. To recap, these differences can include any of the following and more: religion, language, physical size, gender, sexual orientation, age, disability (physical or mental), political orientation, socio-economic status, occupational status, geographical location, education, prior health experiences, ethnicity, race, national origin and individual backgrounds (Campinha-Bacote 2003:online; Kai *et al.* 1999:616; Lum 2000:3).

From this range of factors that determine the diversity of people, it follows that residents cannot simply be classified into groups. The ability of a health professional to understand all the factors that are part of an individual's life plays a vital role in the relationship between the caregiver and the resident (Hughes & Baldwin 2006: 82). Residents cannot be treated alike. Their individuality should always be taken into account, for no two human beings are the same. Each person is unique and everyone has the need to be treated in a unique way. Although there might be similarities, one does not find two people who think and feel exactly the same. At Greenacres RCH, it is not only the employees and the residents that differ from one another. Differences also exist between residents as well as between employees as separate entities. The concept of person-centred care implies that the caregiver enhances the human dignity of the person with dementia by considering the client's personal history, preferences, tastes and beliefs.

For caregivers to appreciate diversity, it is essential to become aware of one's own issues of labelling and prejudice towards people who are different from the health professional or caregiver, as these views have a great influence on health care (Kai *et al.* 1999:616,618; Milwain 2009:14).

In the opinion of the researcher, the concept of cultural competence does not only apply to race, but to all of the factors contributing to diversity. The issue of diversity will be discussed along consideration of The Process of Cultural Competence in the Delivery of Healthcare Services model (Campinha-Bacote & Kardong-Edgren 2008:141-148).

The model suggests that being competent in dealing with diversity is not a process with an end. It focuses on a person *becoming* competent rather than *being* competent. This process consists of integrated constructs identified as desire, awareness, knowledge, skill and encounters. The caregiver has to engage with each of these constructs to become more competent in dealing with diversity. Connecting to one of these constructs, regardless the sequence of practice will develop the equilibrium of all five constructs (Campinha-Bacote 2002:183).

The first construct is awareness of diversity, which implies an individual has to dig deeper into the self to investigate one's own values and views. This also involves ones' professional background and the acknowledgement of ones' own suppositions, partialities and prejudices. If caregivers want to communicate successfully in a diverse community, it is of great importance to become aware of their own stance regarding their attitudes towards diversity. They should also be ready to deal with the unknown cultural behaviours of residents (Campinha-Bacote 2002:182; Kai *et al.* 1999:618).

The second construct is knowledge of diversity, which is based on education concerning diversity. When a health professional focuses on becoming more knowledgeable, he or she will automatically gain insight in the worldview and health-related values of a client that determines the way he or she thinks and acts in the health care setting (Campinha-Bacote 2002:182).

Skill in terms of diversity is the third construct and refers to the capability to perform an exact assessment based on data applicable to the client (Campinha-Bacote 2002:182).

The fourth construct is the occurrence of the caregiver participating in encounters and relations with diverse residents and implies encounters with diversity. This process will filter and/or change the health professionals' beliefs regarding diversity and thus eliminate stereotyping (Campinha-Bacote 2002:182).

The final construct, desire, is the wish of the health professional to *want to* become competent in dealing with diversity and engage in the integrated constructs represented in the model (Campinha-Bacote 2002:182). It consists of caring and love, sacrifice, social justice, humility, compassion and sacred encounters (Campinha-Bacote & Kardong-Edgren 2008:143). In support of this theory, Brown (2008:16) states that the central part of becoming competent in dealing with diversity is the acknowledgment of ones' own lack of knowledge, and the enthusiasm to learn more.

The question that arises is whether occupational therapists are expecting caregivers to be competent in dealing with diversity, without the knowledge proposed by the five constructs. Do occupational therapists and the residents consider the diversity of each and every one of the caregivers and *vice versa*? The researcher should be perceptive of the caregivers' as well as her own awareness of diversity. All of these constructs of diversity are beneficial for person-centred care, and thus QoL. Without a certain sense of diversity, the transformation from *facility* to *home* cannot be established as individual needs will not be understood.

2.2.2 PHYSICAL TRANSFORMATION

According to the Eden Alternative (2011:20) the physical environment should also change from the traditional model to the person-centred care model. In

the traditional model, the nursing station is surrounded by long corridors leading to big blocks of rooms that are shared by residents. This construction offers little privacy for residents. There is a communal dining hall and television room and the never-ending sound of bells from residents' rooms.

On the contrary, the care homes built within the Eden Alternative (2011:20-21) framework are small, warm homes, with private spaces and are decorated by the residents themselves. The atmosphere is welcoming and plants, animals and children are part of the everyday lives of the residents. The residents have control over their environment. In a study by Kane, Lum, Cutler, Degenholtz and Yu (2007:1-8) the Eden Alternative houses maintained the independence of the residents for a longer period of time; depression occurred less; and QoL measures improved as opposed to a traditional RCH.

2.2.3 PERSONAL TRANSFORMATION

Integrated with the transformation of the organisation and the physical transformation, individuals within the RCH should also undergo transformation. In the traditional RCH, there are set boundaries with regard to the job descriptions of the staff and residents are not addressed using their names. The safety of the resident is the highest priority when choosing activities and the abilities of the residents are undermined. The residents are not left with any choices. In the person-centred care model, job descriptions overlap, and the residents choose how they want to be addressed. The caregivers focus on the abilities rather than the inabilities of the residents. For personal transformation to take place, the personhood of the caregivers as well as of the residents needs to be considered (Eden Alternative 2011:22-23; Kitwood 2000:8-10).

2.2.3.1 Personhood of the caregivers

With all of the focus on person-centred care for residents with dementia, it is of the utmost importance to note that person-centred care goes both ways. If the concept of diversity is embraced, the preferences, tastes and beliefs of the caregivers should, thus, also be considered (Baldwin & Capstick 2007:89-90,223; Innes *et al.* 2006:i).

The golden rule of the Eden Alternative states that caregivers will treat the residents in the same way as they are treated by management, therefore also indicating that the culture change should start with the organisation and how it is managed (Eden Alternative 2010a:33). If a caregiver is treated in a task-oriented, clinical manner, that is the way the caregiver will treat the residents, but if she is treated in a person-centred, caring way, she will treat the residents similarly. Therefore it is extremely important for the organisation to know the life story and background of the caregivers and to identify and meet their individual psychological needs. In the old culture, however, the caregivers are seen as 'servants of the organisation' and therefore, their psychological needs are not considered or met. The new culture proposes that respect for the personhood, human dignity, individuality; personality and preferences of the caregivers should be as much on the foreground as that of the residents (Eden Alternative 2010b:119; Kitwood 2000:9-10).

Traditionally, the belief was that effective dementia care had no room for the emotions of the caregiver. Within PCC, however, caregivers are encouraged to be in contact with their emotions and to use their negative and positive emotions for advancing the care setting (Kitwood 2000:10). According to Baldwin and Capstick (2007:323) and the Family Caregiver Alliance (2006:online) one of the most important factors that impacts the caregivers is that the work of caregiving is emotionally strenuous and can lead to severe frustration, and when emotional resources are exhausted, it results in 'burnout' or 'compassion fatigue' (Lauria, Clark, Hermann & Stearns 2001:223-224). Therefore, the organisation should make it possible for each caregiver to be open to their emotions as a part of person-centred care.

2.2.3.2 Residents

The residents concerned in this study are elderly people who live in residential care settings due to the impact of dementia. It was necessary for the researcher to take into account the unique qualities of the elderly as well as the implications of dementia; therefore, both aging and dementia are discussed.

- **The aging process**

The residents in an RCH are in the final stages of life. Physiology (physical changes), the psychosocial component of life (emotional challenges) and cognition (cognitive changes) are the three factors that determine changes that take place during the aging process. 'Successful' aging is indicated when the changes that occur are only caused by the aging process without any interference of disease, the environment or an unhealthy lifestyle. 'Usual' aging refers to the aging process that is influenced by disease, the environment and an unhealthy lifestyle (Lewis 2003:47; Holstege & Riekse 2003:88).

Although physical changes across the life span of each individual are unique, certain similarities do occur. Most cases show a decline in the sensory, muscular and skeletal systems. Digestive and urinary functions slow down, lungs lose elasticity and problems with constipation and the immune system occur (Lewis 2003:39, 47-76; Holstege & Riekse 2003:88-89).

Apart from these physical challenges, the elderly person has to deal with emotional challenges caused mostly by loss of respect from the community, loss of the meaning of their work, as well as loss of health, intimacy, a future and control. They also experience a loss of their family and friends from the same generation (Holstege & Riekse 2003:184-187). On a positive note, Lewis (2003:177) adds that reminiscence about experiences could lead to feelings of inner peace, self-actualisation and acceptance of the last phase of life, which is also a considerable part of the aging process.

The cognitive decline that takes place with healthy aging includes a decrease of cells and fibres in the central nervous system. Previously, decline in memory was thought of as a part of 'usual' aging when in fact, the only ability that is lost during the healthy aging process is the speed of memory retrieval (Holstege & Riekse 2003:159).

Not everyone is blessed with a 'successful' aging process. In a 2008 prevalence survey, it was estimated that 30 million people lived with dementia at the time. This is a number that is rising every seven seconds and by 2050, the estimated number of people who will be living with dementia will be over 100 million (Alzheimer's Disease International 2008:1).

- **The person with dementia**

In the old culture, people with dementia are perceived as a group of people who have lost their individuality and personality traits, while the new culture of dementia states that dementia is only another type of disease with the range of disability depending on the care quality. Therefore, a person with dementia is neither half empty nor half full, but remains a whole person until the day he/she dies (Power 2010:42). Every person with dementia stays a unique individual with unique experiences (Kitwood 2000:8).

It is necessary for the reader to realise that the impact of dementia stretches far beyond the visible physical symptoms of dementia. There is also the factor of the person with dementia's reaction to the transformation in the brain and the human being's experience as a person suffering from dementia that we are blind to (Power 2010:13).

Bearing in mind that the experience of the person with dementia should not be ignored and although Kitwood (2000:9-10) suggests that the focus must be on the abilities of people with dementia, rather than their inabilities, it is nonetheless essential to be familiar with the pathological factors influencing everyday life of the person with dementia - which contributes to further

loneliness, helplessness and boredom. Therefore, only a short summary will be given of the symptoms of dementia.

- Symptoms of dementia

Although it is still in the revision process, the DSM V (American Psychiatric Association 2012:online) gives criteria for the diagnosis of dementia, which include a decline in cognitive function and that it interferes with independence in activities of daily living. Disturbance with regard to executive functioning, language, visual perception and emotional intelligence may also occur. The person usually has a decreased ability to focus his attention and to learn.

Literature also indicates that dementia is a progressive disease and although Holstege and Riekse (2003:168) and Perrin *et al.* (2008:4) report on the different stages of dementia, Bell and McGregor (2000:12) report on the risks of adopting a 'stage theory' relating to the disease. A stage theory relates to the view of dementia as a progressive disease which causes decline through a certain number of pre-determined stages, ending in a malfunctioned state prior to death. These two authors warn against this simplistic perspective due to the fact that a stage theory ignores individual differences, dehumanises the person and stipulates the discouraging prospect of unavoidable decline. The caution with which they handle stage theory is in accordance with the person-centred care perspective indicating that all individuals are unique and should be treated differently and according to their needs (Eden Alternative 2010b:42); therefore each person living with dementia should be treated by person-centred care principles regardless of the symptoms of the stage of dementia that they are in. Through the experience of working with persons with dementia, Bell and McGregor (2000:12) have seen enough evidence to be confident of the fact that every person with dementia is a unique individual. They also stress the fact that, contrary to traditional belief, people with dementia still possess the core personality traits that preserve them as the person that they are. Although damage to the brain tissue is permanent, people with dementia should still be viewed as people with potential. Perrin *et al.* (2008:7) stress that the person with dementia, which is a mental disability,

should be perceived similarly to a person with a physical disability. The degree of disability is defined largely by the quality of the support structure that is in place to compensate for the disability.

- Medical treatment and other role players

Dementia presents with direct damage to the brain tissue. The medication that can be prescribed cannot restore the damage to the brain, but increases the levels of the neurotransmitter acetylcholine which, in turn, enhances communication between nerve cells. Therefore, the literature indicates that the progress is being made in the direction of relieving the symptoms of dementia, but a cure has not yet been found (Perrin *et al.* 2008:6-7). According to Kitwood (2000:9) the old culture of dementia focuses on medical research to find a cure for dementia, and institutions that function in this frame of mind believe that without a cure nothing can be done to promote QoL of these people. The reality in the person-centred care model is that positive change can be facilitated every day through effective caring that is person-centred.

While further research is necessary to turn the pathology around, Power (2010:21,27) and The Eden Alternative (2010b:23) report that the everyday focus of the traditional model is medical care and especially the use of medication in the form of antipsychotic drugs. Power (2010:27) points out that antipsychotic drugs have a positive effect in less than 20% of the cases. Yet, these drugs are used for symptomatic treatment of behavioural problems every day around the world in dementia care, often leaving the users sedated and restricting activity involvement.

On the contrary, the philosophy of the Eden Alternative (2012:4) and Kitwood (2000:10) holds that the behaviour of residents is a reflection of their attitudes, which in turn reflects their beliefs and values. When this process is taken into account, all problem behaviour can be counteracted by knowing the beliefs and values of the residents and knowing their attitudes. If their needs in terms of their attitudes, beliefs and values can be met, the problem behaviour will

disappear. It is important for the caregiver to look beyond medication to determine if the problem behaviour can be turned around by providing meaningful companionship to eliminate loneliness; giving them a chance to give care and to be independent to combat helplessness; and by creating unexpected events or happenings to eliminate boredom. The *three plagues* are often the cause of behavioural problems in that they restrict independence, participation and QoL (Christiansen & Baum, 2005:524; Eden Alternative 2010a:21-23). Quality of life is a doing-word and for the people with dementia QoL should be made possible by the environmental structure and the people entering that environment (Power 2010:17; Thomas 1996:1,11).

According to Baldwin and Capstick (2007:178,223-224,226,310) it is evident that person-centred care leads to a higher QoL as well as improved well-being. In fact, person-centred care is a powerful tool for establishing QoL and combating loneliness, helplessness and boredom – the main challenges in RCH's all over the world (Eden Alternative 2010b:2).

2.4 SUMMARY

Through the course of this chapter it was once again made clear that transformation needs to take place so that loneliness, helplessness and boredom are replaced with person-centred care and QoL. This transformation should replace a *facility* with a *home*. It was made evident that person-centred care, occupation, an understanding of diversity as well as ethical behaviour are all attributes of a well-trained caregiver and ensure the provision of optimal QoL to people with dementia.

Unfortunately, the absence of these required ethical attributes in caregivers are noted and the researcher has found no answers for these limitations at Greenacres RCH. In order to establish transformation, the researcher needs an understanding of a vital element in the process: the caregiver. The methodology for this study aims to determine the perception of the caregivers

regarding person-centred care that leads to QoL and will be discussed in *Chapter 3, Research Methodology*.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION

In Chapter 2, the literature discussed provided an overview of the theory regarding the key concepts of this study. The conclusion was made that optimal QoL appears to rely on person-centred care, occupational engagement, an understanding of dementia, well-trained caregivers, awareness of diversity and ethical and professional behaviour.

The aim of this chapter is to inform the reader of the scientific approach that was followed to reach the aim of the study. Included is a discussion of the triangulation mixed methods design that was chosen to reach the objectives of the study along with a description of the research population and sampling. This is followed by two sections to describe the qualitative and quantitative approaches according to the study design, measuring techniques, measuring instruments, the data collection procedure, management of the data, as well as data quality control. The study design is followed by a description of the pilot study, traceable variability and ethical aspects. The science of research is underlined in this chapter along with the preservation of the personhood of the caregivers. The reader should note that the individuality and personhood of the caregivers guided the choices made with regard to the study design, as well as the practical arrangements.

3.2 RESEARCH DESIGN

The researcher concluded that a mixed methods triangulation design was to be implemented to comprehensively answer the aim and objectives of the study (cf. 1.3; p7). The mixed methods theory with seven steps as suggested by

Ivankova *et al.* (2007:256-283) was followed after an extensive review of the literature. These steps are to:

1. Determine whether mixed methods is the best approach to address the research problem.
2. Identify a rationale for applying a mixed methods approach.
3. Select a mixed methods design.
4. Write a mixed methods purpose statement.
5. Develop research questions.
6. Choose the data to collect.
7. Draw a visual diagram of the mixed methods procedures.

The rationale for a mixed method study is discussed next, followed by the reasons for selecting the specific mixed method of triangulation. The completed process (step 7) is portrayed in a diagram (cf. Figure 3.1; p38) which guides the description of the research process from the data collection phase to reaching the conclusions regarding the objectives of the study.

3.2.1 RATIONALE FOR APPLYING A MIXED METHODS APPROACH

Considering the fact that the caregivers did receive some in-service training, it was expected that they should have had a certain degree of knowledge of the concepts relating to person-centred care, occupational engagement and QoL. However, they did not appear to be applying this knowledge of person-centred care in the SCU. Therefore, it was evident that there was a discrepancy between their knowledge and the application thereof. Although the qualitative approach predominantly supported the inquiry into the caregivers' perceptions, the quantitative data was needed to compare and verify the qualitative findings. By confirming or contradicting the qualitative findings, the source of the discrepancy between the knowledge of the caregivers and their application thereof could be identified and explored further against current literature (Ivankova *et al.* 2007:276). Therefore, the combination of the qualitative and

quantitative approaches and supporting published literature enhanced the trustworthiness of the study (cf. 3.4.5.1; p49).

In the researcher's opinion numerical data only would not have supported the aim of describing, exploring and attempting to understand the perceptions of the caregivers. A platform from which the caregivers could voice views and explain their circumstances and behaviour (as they were the experts on how they perceived concepts) was a means through which the researcher could obtain accurate information.

3.2.2 SELECTING A SPECIFIC MIXED METHODS DESIGN

At the time of selecting a mixed methods design, it was important to consider the objectives of the study (cf. 3.2.1; p36), the sequential or simultaneous collection and analysis of both data sets and the phase during which the two sets of data are integrated (Ivankova *et al.* 2007:265-270,277).

Therefore, the timing of the collection of both data sets was considered to select the specific mixed methods design. In the case of this study both qualitative and quantitative data sets were collected in the same session, which is an indication of a triangulation design. The two data sets were analysed separately (Ivankova *et al.* 2007:268-269,277).

The qualitative findings and quantitative results were integrated and compared during the interpretation phase of the study, also implying that the triangulation method was the most suitable to reach the aim of this study (Ivankova, *et al.* 2007:268-269,277).

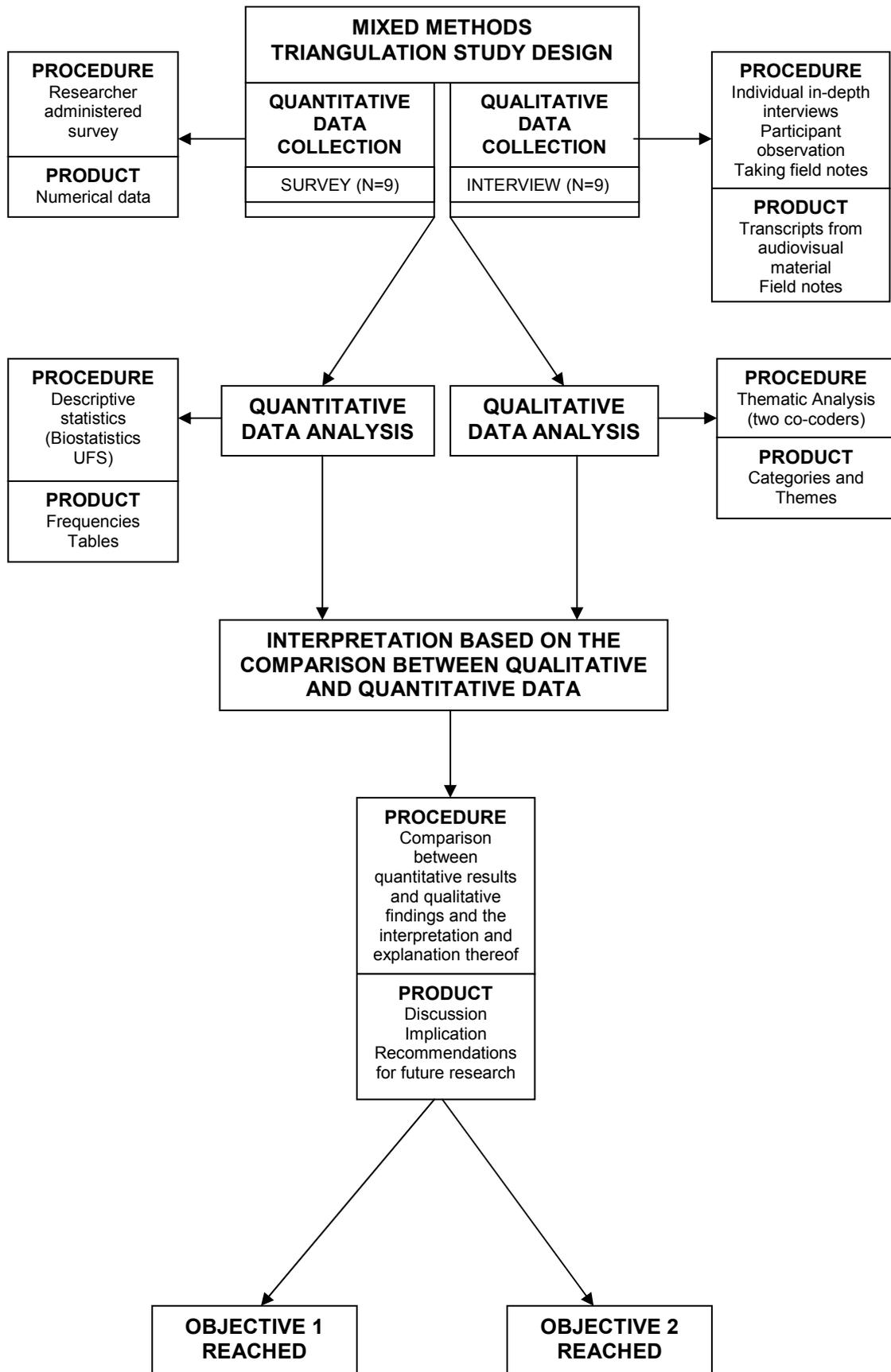


Figure 3.1: Diagram of the mixed methods procedures

3.2.3 RESEARCH PROCESS (Figure 3.1)

The qualitative and quantitative data collection occurred during the same session. To collect in-depth qualitative data from the caregivers, the completed quantitative data were used as a semi-structured interview schedule with follow-up questions and probing techniques. The outcome of the semi-structured interview schedule produced a set of qualitative data in the form of transcripts and field notes and offered categories and themes after analysis.

To collect quantitative data from nine caregivers, the researcher used a structured interview questionnaire. The outcome of the structured interview questionnaire was a set of quantitative numerical data and produced frequencies that were converted into tables after the analysis.

The researcher compared the qualitative data set to the quantitative data set to reach both objectives.

3.3 RESEARCH POPULATION

The research population consisted of nine female, Sesotho and Tswana speaking caregivers (from now on referred to as the participants) working at Greenacres RCH, and between the ages of 30 and 46. Although some of them matriculated, they did not undergo any formal training specifically for the work expected of them (Olivier 2009).

These participants cared for a population that consisted of mainly Afrikaans and English speaking residents between the ages of 40 and 96. Two Sesotho speaking residents also resided in the SCU at the time of the study (Olivier 2009).

3.3.1 SELECTION CRITERIA

The sample included participants from the SCU at Greenacres RCH who complied with the inclusion criteria.

3.3.1.1 Inclusion Criteria

- Employees who worked with and cared for the specified residents at the time of the execution of the study.
- Employees who had no formal tertiary education.
- Individuals who were employed on a permanent basis by Greenacres RCH.

3.3.1.2 Exclusion Criteria

- Nursing students who were placed in the SCU on a temporary basis to do clinical work. For some of these students, the SCU was their first encounter with people with dementia, and they did not have the experience that was needed to answer the questionnaires.
- Employees who were unwilling to participate in the study.

3.3.2 SAMPLING

Strydom (2011c:222-223) defines sampling as strategies to extract a portion of a population. Considering the qualitative focus of the study, the sample was determined according to the requirements of the study to reach the point of saturation of the data (Strydom & Delpont 2011:391).

True to the preservation of personhood, none of the participants who adhered to the inclusion criteria could be excluded if they gave informed consent as the researcher regarded the perspectives and frames of references of each and every caregiver as valuable. Therefore, all nine caregivers who worked in the

SCU at Greenacres RCH were included in the study. Per definition, purposive sampling was done as the researcher chose the sample according to the needs of the study. Purposive sampling uses all the resources available regardless of the level of saturation and was therefore more applicable to this study in order to give each of the participants a chance to voice their perspectives (Strydom 2011c:232,234). Although sequential sampling was also considered due to its similarity to purposive sampling, the factor of saturation had to be considered. Sequential sampling indicates that saturation should be assessed throughout the data collection process indicating when the collection of data should stop due to saturation of the data. During this study no new information came to light after the fifth interview and the last four participants mainly confirmed and elaborated previous findings. After the data had been collected, the audio-visual material from one of the interviews was lost due to damage to the tape and therefore, the qualitative and quantitative data obtained from that specific participant was removed from the study. From this point forward, the sample will be referred to as a total of eight participants.

3.4 SECTION A: QUALITATIVE APPROACH

In Section B the qualitative approach of the study is discussed.

3.4.1 STUDY DESIGN

The qualitative data was collected by the use of an interview schedule as part of the triangulation mixed methods design to obtain in-depth data in order to reach both objectives of the study (Ivankova *et al.* 2007:256-283).

3.4.2 MEASURING TECHNIQUES

A semi-structured interview schedule and participant observation were used in an attempt to gain a deeper understanding of the participants' perspectives.

3.4.2.1 Interview schedule

A one to one interview with the use of a semi-structured interview schedule was the main technique to collect the qualitative data of the study. Individual interviews were chosen to once again guard the personhood of the participants by protecting their privacy and to give them freedom of speech, without offending the other participants or being judged by them. This choice of interviewing also aided the researcher in gaining an understanding of the perspectives of each participant as opposed to a group perspective with the danger of only one or two strong perspectives surfacing that could have caused measurement errors. Probing techniques were used when necessary and gave the participants the opportunity to elaborate on their answers and even express matters that the researcher did not think of. Probing also allowed more in-depth data and a more detailed understanding of the perception of the participants. Follow-up questions were also asked during the interview for clarification of the probes, but could not be planned ahead as it depended on the initial answer of the participant. Follow-up questions were also guided by the individual personalities of the participants (Greeff 2011:344-346,349,351-353; Rubin & Rubin 1995:150,210).

3.4.2.2 Participant observation

Participant observation was used during the interview and the researcher recorded audiovisual material and took field notes of impressions, such as the body language portrayed by the participants (Greeff 2011:330,372; Strydom 2011:330b).

The transcripts from the audiovisual recordings as well as the field notes were used to confirm the information given by the participants to be reliable or to identify possible discrepancies between verbal and non-verbal messages of the participants.

3.4.3 MEASURING INSTRUMENT

The completed quantitative instrument (cf. 3.5; p51) was used for semi-structured interview purposes (cf. 3.2.3; p39) along with the following questions as part of the interview schedule:

Section D: Question 32-35. With these questions the researcher determined the perception of the participants regarding the names of the residents and how to address them.

Section E: Question 37 aided the researcher in determining whether the participant fully understood question 36 by asking for an example.

Also included in Addendum K, is a list of questions that were used after the quantitative questions and probed the participants to elaborate on the answers that were given in Section B, C, D, E and F. These questions showed the participant that the researcher was paying attention and that her answers mattered (Rubin & Rubin 1995:148).

The researcher had to ensure the most accurate interpretations of questions and answers. The accuracy was enhanced by a set of probing techniques, which is a combination from Greeff (2011:345-346), as well as Rubin and Rubin (1995:210):

- Asking for clarification when the researcher asked the participant to clarify certain concepts.
- The researcher asked the participant to elaborate.

- Repeating: the researcher repeated the part of a sentence which she wanted the participant to elaborate on.
- Encouragement: the researcher attempted to boost the participant in order to obtain more information.
- Showing understanding: the researcher showed the participant that she understood what she was saying and gave her time to finish her comments.
- Paraphrasing: the researcher paraphrased the words of the participant in order to gain a deeper understanding.
- Reflection: the researcher reflected back on an important comment from the participant, to give her a chance to elaborate.
- The researcher asked direct questions to obtain further details.
- Experience probes were used when the researcher wanted to know if the participant experienced an event herself or if she only heard about it from others.
- Evidence probes were used when the researcher wanted evidence to confirm what the participant was saying.
- Slant probes were used when the researcher suspected any bias towards a certain person or topic.

The most useful probing techniques were asking for clarification, asking the participant to elaborate, showing understanding, paraphrasing, direct questions and evidence probes.

3.4.4 DATA COLLECTION PROCEDURE

Although qualitative and quantitative data collection followed different procedures, the collection of these two data sets occurred simultaneously (in one session) and therefore, the data collection procedures of both sets of data are discussed together.

Each participant was invited to meet the researcher at a local church in Bloemfontein where the study was explained to them. Permission was obtained

from the management of Greenacres RCH to do the interviews during working hours, but it was specifically arranged to take the participants away from their work place to create a relaxed atmosphere. Three participants at a time were working the day shift and two during the night shift and were transported individually from Greenacres to the church. There was a private room in the church that the researcher had access to. The reason for the use of the church was that the private room was very quiet and furnished with couches that created a relaxed, non-threatening atmosphere, away from the workplace. The time and place was arranged prior to the interview and was again confirmed on the day before the interview (Greeff 2011:350).

The participant was greeted in a friendly and sincere manner. She was invited to sit comfortably and a beverage of choice was served. This was done in order to also 'preserve' the personhood of the participant and to alleviate any anxiety that the participants might have felt (Baldwin & Capstick 2007:138).

Although understanding and speaking Afrikaans was not the first language of the participants, fluency in Afrikaans was a condition for their employment at Greenacres RCH (Olivier 2009). Therefore, the interviews were conducted in Afrikaans in order to enhance communication between the researcher and the participant. A first-year OT student was used as translator to alleviate any language difficulties (c.f. 3.5.5.1). She was fluent in Sesotho, Tswana and Afrikaans and had excellent language skills. Her level of education and knowledge of the principles of translation were used during the interviews. The translator was present in the room during the interviews, but was used as little as possible. Direct communication between the participant and researcher were encouraged to enhance the researcher's experience of the emotional expressions of the participant (Greeff 2011:347).

The interviews were started by stating the purpose of the study again as well as the function of the structured interview questionnaire and semi-structured interview schedule as part of the study. The participant was informed that the interview would take more or less an hour and a half and that cake will be served during a short break halfway through the session. The participant was

also informed that all data would remain confidential, only to be used for educational purposes. Time was then given to the participant to read the information document in the language of her choice and she was asked to sign the consent form if she agreed to participate. The researcher also asked permission to record audio-visual material and take field notes of observations and insights. The participant was made aware of the fact that she had the right to withdraw at any time (Strydom 2011a:128).

During the interview, the researcher asked the quantitative questions from the structured interview questionnaire. Once the answers were given, she used the quantitative questions and answers as a semi-structured interview schedule along with probes and follow-up questions to obtain the qualitative data. The interviewer showed sincere interest in the answers of the participant, combined with the application of active listening principles to emphasise to the participants the importance of their experience (Greeff 2011:343-346).

After the quantitative and qualitative data were collected, the interviewer gave an opportunity for questions, emphasised contact details of the interviewer and thanked the participant. She also asked the participant what her thoughts and feelings on the interview were to determine whether she needed to be debriefed. None of the participants showed any signs that debriefing was necessary. When the participant left the room, the interviewer as well as the translator wrote down their thoughts on the events during the interview, in the form of field notes.

After the interview, the participant was transported back to Greenacres RCH where the sister in charge saw that she had no verbal contact with the other two participants before their interviews were completed, in order to avoid participant influence.

3.4.4.1 Data Analysis

The process of data analysis was described using a variety of authors (Creswell 2007; Polit & Beck 2006; Rubin & Rubin 1995; Saldana 2009) and consisted of data management, reading and memoing, describing, classifying and interpreting, and representing and visualising.

3.4.4.2 Data Management

The researcher watched the audiovisual material and recorded any emotional responses and/or any discrepancies between the body language of the participants and the answers that were given. The aim was for the coders to fully understand the data and the context. The data from the field notes and audiovisual material was merged, transcribed and typed into a computer producing integrated transcripts. Each caregiver was presented with a copy of her separate transcript to confirm that it was a correct portrayal of the interview (Creswell 2007:150-151,152,154,163; Polit & Beck 2006:332-337; 398). These transcripts were handed to the co-coders for independent analysis.

3.4.4.3 Reading and Memoing

The researcher and co-coders read through every completed interview schedule several times to be familiarised with its content and wrote memorandums of ideas and concepts in the margins. In an attempt to exclude bias, neither of the co-coders had in-depth insight into the study or the setup at Greenacres RCH (Creswell 2007:151; Rubin & Rubin 1995:228).

3.4.4.4 Describing, Classifying and Interpreting

The actual process of analysing the data is described as an integration of information from the sources of Creswell (2012:237-238).

After the data sets were read thoroughly and the coders were familiarised with the content, the following process was followed:

- Verbatim were underlined in the script of the data
- These verbatim were sorted by codes which were written in the right hand column that was created for coding on each page.
- The codes were indicated on a separate diagram
- The intention was not for the codes to be expressions of words only, but could have been anything, e.g. emotional responses or pauses in a conversation.
- When new concepts were added to the codes list, the coders started again at the beginning to determine if the code did previously occur.
- The codes were clustered into categories.
- The categories were then clustered into themes.
- The coders also marked the responses of participants who spoke from first-hand experience to determine which pieces of data bore the most weight.
- The data in each theme was examined and directly interpreted in order to explain the issues under investigation. This step is called theorising, where clarification of the data is obtained (c.f. Chapter 4).

Saldana (2009:46-138) describes different methods of coding and advises the researcher to choose the methods applicable to the specific study. The researcher identified the following methods for use in this study:

- Attribute coding: referring to descriptive data in the form of demographics at the beginning of the data set (2009:55).
- Descriptive coding: allows the analyst to indicate the topic of a piece of data (2009:70).
- In vivo coding: subtracting a word or phrase directly from the data (2009:74).
- Emotion coding: coding the emotions of participants (2009:86).
- Values coding: coding the values, attitudes and beliefs of the participant (2009:89).

3.4.4.5 Representing and visualising

The data was thoroughly discussed according to the volume and meaning thereof (Creswell 2007:148) and was also compared to the quantitative data to reach the second objective. The last step was to re-contextualise the combination of qualitative and quantitative data in order to determine whether there is a link between the data and established theories in literature (Polit & Beck 2006:399; Rubin & Rubin 1995:228-229).

3.4.5 DATA QUALITY CONTROL

Polit and Beck (2006:332-337) refer to the four criteria of Lincoln and Guba named credibility, dependability, confirmability and transferability. The procedures with regard to trustworthiness are described according to this.

3.4.5.1 Credibility

- Prolonged engagement

Adequate time was spent in the interview to obtain intensive data from the participants. A literature study was done on the situation of the participants. Although all of the participants were fluent in Afrikaans, a translator was available to eliminate any language barriers that occurred.

- Persistent observation

The researcher did an extensive literature study on occupational engagement as well as QoL and the interview schedule was designed according to these factors.

- Triangulation

Investigator triangulation was utilised as the two co-coders assisted the researcher in analysing and interpreting the data from the interviews as well as the observational data.

Methodological triangulation (Ivankova *et al.* 2007:268; Padgett 1998:97) was utilised and both qualitative and quantitative methods of study were followed. The qualitative and quantitative responses were compared to determine the relationship thereof.

In order to utilise data source triangulation, all participants were interviewed as well as observed, each with her different perception to reach this objective. Data was retrieved from audiovisual material and field notes from the interviews. This technique enabled the researcher to determine whether there were any contradictions between participants' verbal and non-verbal messages.

- External checks: Peer debriefing and member checks

After the completion of the interviews, a session was held with the two study leaders to debrief and discuss the events during the interviews and to discover different features of the investigation. The transcripts were presented to all participants to confirm the credibility thereof.

- Searching for disconfirming evidence

Due to the comprehensive sample, all of the participants' perspectives were taken into account, including the contradictory perspectives.

- Researcher credibility

The qualifications of the researcher and study leaders were added to the research report to provide proof of their credibility.

3.4.5.2 Dependability

- Stepwise replication

The researcher and two co-coders analysed the data separately and confirmed with each other until they agreed on the results. The two co-coders were two occupational therapists who were chosen on account of their recent research experience, as well as their experience working with caregivers.

- Inquiry audit

When the results were established, a fourth expert and study leader, Dr. Sanet du Toit reviewed the data to confirm that the categorisation of the data was effective and reflected completely on the transcripts.

3.4.5.3 Confirmability

The confirmability of the study was established by the use of an inquiry audit (cf. 3.5.5.2; p59).

3.4.5.4 Transferability

- Thick description

In order to establish whether the study could be executed in another setting, the research report included a comprehensive portrayal of the setting in which the research took place. This also allows the reader to apply the results to different, but similar settings.

3.5 SECTION B: QUANTITATIVE APPROACH

In this section, the quantitative approach of the study is discussed.

3.5.1 STUDY DESIGN

The quantitative data was collected by the use of a structured interview questionnaire as part of the triangulation mixed methods design to determine the number of times that the same answer was given to a specific question as previously discussed (Ivankova *et al.* 2007:256-283).

3.5.2 MEASURING INSTRUMENT

The structured interview questionnaire consisted of a set of preset questions (Addendum L) arranged in the most logical sequence.

The literature study was used as a guide to assemble the questions and ensured that every subject of the topic was included. The researcher attempted to compile questions as impartial, to the point, easily comprehensible and as focused as possible (Greeff 2011:343).

Hypothetical questions or questions requiring the use of knowledge or memory were avoided in the design of the structured interview questionnaire. The researcher wanted the participants to be at ease and therefore threatening questions and assumptions were circumvented as far as possible (Maree & Pietersen 2007:160).

The questions were formulated to include concepts that are directly linked to QoL, occupational engagement and person-centred care of people with dementia.

Section A of the semi-structured interview schedule started with demographical questions to alleviate any anxiety that the participant might have felt (Maree & Pietersen 2007:160). The demographical questions aided the researcher in obtaining background information and comprehensively describing the population and their personal and working circumstances. It was extremely valuable to the researcher to gain an understanding of the background of each participant, as well as the levels of stress under which the participants were expected to perform at work and in their daily lives. The researcher did not enforce these questions on the participants and they were made aware that they had the choice not to answer the questions.

The questions in section B were focussed on the perception of the participants relating specifically to the SCU, the residents and the families of the residents. The options of these questions were ranked by the participants. After placing

the options in the correct order, they also had to indicate whether the option occurred always (1), sometimes (2) or never (3). These values were multiplied by the initial ranking position that the participant indicated. Therefore, the lower the ranking value, the higher the rank for all of the questions in Section B.

Section C also consisted of questions with different options and the participants were allowed to choose one of the answers. Section D was purely qualitative and part of the semi-structured interview schedule. The questions were answered in the participant's own words and were therefore not part of the quantitative data collection (cf. 3.5.3; p58).

Section E contained only one quantitative question (question 36) to determine whether the participant believed that a person-centred approach was followed in the SCU. If the participant believed that a person-centred approach was followed, she was asked to give an example – which was also part of the semi-structured interview schedule (cf. 3.5.3; p58).

The interview then proceeded to the final section, Section F with specific, single, unbiased questions in words that were familiar to the participant (Maree & Pietersen 2007:160-161). The questions grouped into Section F were aimed at determining whether the participants viewed the person-centred care, occupational engagement and QoL of the residents according to the person-centred approach or the traditional model without the person-centred approach. Each question had two or three options of which one or two represented the person-centred approach.

The options of each question that represented the person-centred care approach were arranged in a specific randomised pattern that prevented the participants from choosing only the first or the last option given and encouraged them to think before giving an answer (Raubenheimer 2009).

The following represents a map of all the quantitative questions that were included in the structured interview questionnaire (refer to Addendum L). Also

included in this map is the reasoning in support of the inclusion of specific questions.

Section A contained questions with regard to demographical information (to understand the personal and working circumstances of each participant).

Section B: As previously discussed, all the questions in Section B had options that were ranked according to importance (the full question with the options is included in Addendum L). After that, each option was also rated by the following scale:

- 1 = Altyd (Always)
- 2 = Partykeer (Sometimes)
- 3 = Glad nie (Never)

The following is an indication of the question followed by the aim of the question in this section:

21. Watter aktiwiteit/deel van die aktiwiteit sal die inwoners aan kan deelneem sonder dat die versorgers/personeel alles vir hulle hoef te doen?/*What activities/part of the activity will the residents be able to participate in without being totally dependent on the caregivers?*

Question 21 determined the perception of the participants regarding the potential of the residents to perform specific activities.

22. Hoekom dink jy doen die versorgers tans alles vir die inwoners in die eenheid?/*Why is it that the caregivers are presently doing everything for the residents in the unit?*

Question 22 gave an indication of the factors that influenced the application of person-centred care regarding occupation and QoL.

23. Hoekom dink jy probeer die versorgers selde verskillende maniere vir dit wat hulle elke dag met die inwoners moet doen?/*Why is it that the caregivers rarely try new methods for the tasks done with the residents every day?*

Question 23 determined the factors that prohibited the participants from showing initiative regarding occupation and QoL.

24. Wat dink jy is belangrik vir die inwoners?/*What do you think is important to the residents?*

Question 24 determined the participants' perception of the needs of the residents.

25. Wat dink jy is belangrik vir die bestuur van die tehuis vir die inwoners?/*What do you think is important to the management of the facility for the residents?*

Question 25 gave an indication of the participants' perception of the priorities favoured by the management and staff of Greenacres RCH.

26. Wat dink jy is belangrik vir die familie van die inwoners (vir die inwoners)?/*What do you think is important to the family of the residents (for the residents)?*

Question 26 determined the participant's perception of the needs of the families of the residents.

27. Watter mense kan hulle lewens die meeste geniet?/*What category of people can enjoy life the most?*

Question 27 determined the participants' perception of age and its relationship to QoL.

28. Wie is die meeste verantwoordelik daarvoor dat die inwoners die lewe geniet en self deelneem aan take?/*Who is most responsible for the residents to enjoy their lives and to facilitate independent activity participation?*

Question 28 indicated the participants' perception of their own and the residents' responsibilities towards person-centred care.

Section C: The first question in section C determined the consequences of making contact with the residents. The researcher reasoned that it could be the

case that the participants tried to keep their contact as short and simplistic as possible, if they were physically or emotionally abused by the residents or if they did not see any results after their person-centred input. Question 30 determined the participants' perception of their own awareness of diversity and question 31 determined the participants' perceptions of the awareness of the residents towards diversity.

Section E: Question 36 aimed to determine the perception of the participants about their own as well as the other participants' compliance towards person-centred care.

Section F: Table 3.1 indicates the category for every question.

Table 3.1: Traditional model vs. person-centred care approach

QoL (Person-centred care)		OCCUPATIONAL ENGAGEMENT (Person-centred care)	
Independence	38 39 40 41 42 43 44 45 48 61 62	Independence	38 39 40 41 42 43 44 45 48 61 62
Activity participation	61	Activity participation	61
Positive emotions	45 46 48 61 62		
Individuality	39 40 41 47 50 52 53 54 57 58 59 61		
Emotional connection	49 51 54		
Validation	60		

Table 3.1 offers a presentation of the questions relating to the approach followed by the participants. Question 45, for example, related to independence and enjoyment, which referred back to QoL as well as independence and sense of achievement, which referred back to occupation (cf. concept clarification; xii). When the participant responded according to the person-centred approach, which will be 'a' for question 45, she received a mark for the question. If she chose option 'b', she did not receive a mark. Afterwards, every mark was plotted to see what percentage of the questions she answered according to the person-centred approach and what percentage she answered according to physical care without the person-centred approach. The median value (the

value in the middle of a list of values ranked in order) was used instead of the mean (average) value because of the small sample size (n=8) to exclude the impact of outliers (extremely high or extremely low values) (Cohen, Manion & Morrison 2007:502-503, 513; Raubenheimer 2012).

Some of the questions mentioned in the table had an alternate purpose. The following is an indication of these questions and the aspect which they aimed to determine:

Question 42 and 43 determined the perspective of the participants towards the authority of the nurse in charge and specifically the manager of Greenacres RCH, which could have had an effect on the actions of the participant regarding person-centred care.

Question 44 determined whether the participants viewed residents as people who still had a certain degree of potential. If the participants did not believe that the residents still had a certain degree of potential, they would not have complied with the person-centred principles.

Question 54, 55 and 56 determined the perception of the participants regarding the needs of the residents, the family of the residents as well as the management of Greenacres RCH. This could also have had an influence on the perceptions and actions of the participants regarding person-centred care, if they tried to satisfy a certain party who had the same or a different opinion as that of the participant.

The questions in Section B triangulated with the questions in Section F as similar themes emerged from the two sections:

- Independence
- Participant's perception of the needs of:
 - the resident
 - the family
 - the management of Greenacres

- Participants' perception of their own and the staff members' responsibility towards person-centred care.

3.5.3 DATA COLLECTION PROCEDURE

The qualitative data and quantitative data were collected in the same session (cf. 3.4.4; p43).

3.5.4 DATA ANALYSIS

Most of the data were represented as simple frequency tables, or as cross-tables. For the ranked items of Section B, the ranks were determined as follows: The ranks as given by the participants were weighted (through simple multiplication) by their evaluation of the importance of the item. Since the ranking indicated that the lower the absolute value of the rank, the more important it was (e.g., the option ranked 1 was the most important), and the evaluation of frequency followed the same trend (e.g. 1 indicated always, and 3 never) (cf. 3.5.2; p52), the lower the weighted rank, the more important that option was deemed, and vice versa. Finally, the items were sorted according to their weighted rank.

3.5.5 DATA QUALITY CONTROL

Reliability and validity is discussed as data quality control of a quantitative nature.

3.5.5.1 Reliability

The reliability refers to the consistency of the scheduled interview questionnaire (Delport & Roestenburg 2011:177). To increase the reliability of the interviews,

the researcher clearly defined the variables (cf. concept clarification; xii). The researcher used precise questions that were to the point. Specific questions were used to measure each variable and a pilot study was done prior to the execution of the study to test the reliability of the interviews (Neuman & Kreuger 2003: 179-180). Due to training as part of the undergraduate OT degree the researcher was qualified to carry out the interviews herself.

It was not possible to determine the reliability of most of the interview schedule statistically, because of the nature of the items and the small study sample. For Section F, however, an alpha-coefficient of 0.69 was calculated. This value is acceptable as reliability can vary between the values of 0 and 1. The higher the value, the more reliable the section is (Raubenheimer 2011).

3.5.5.2 Validity

The validity of the interview schedule used in this study referred to the degree to which this instrument indeed measured the variables described in the two objectives. The term 'variables' refer to the participants' perceptions of person-centred care, occupational engagement and QoL (Delpont & Roestenburg 2011:172-173).

- **Content Validity**

In order to measure content validity, it was important to establish whether the content of the structured interview questionnaire indeed measured the variables. The questions included in this instrument were determined by the use of a thorough literature study to ensure that all the aspects underlining person-centred care, occupational engagement and QoL were included. The pilot study contributed to the content validity. Triangulation of the data was used between Section B and Section F of the structured interview questionnaire as similar themes emerged from the two sections (Delpont & Roestenburg 2011:173).

- **Face Validity**

According to Delpont and Roestenburg (2011:173-174) in this instance the question that needed to be asked was: Did it seem as if the structured interview questionnaire relates to the variables?

All the questions that were included were directly linked to person-centred care, occupational engagement and QoL and/or to establish a link between the two concepts.

- **Criterion-Related Validity**

This type of validity refers to the connection between the data and a peripheral criterion (Delpont & Roestenburg 2011:174; Polit & Beck, 2006: 329).

After all of the interviews were completed, the researcher gave each of the participants a copy of her specific data and they all agreed that they were in agreement with the data. Unfortunately, one of the participants died at the time and therefore could not confirm that the data was correct. The quantitative and qualitative data were also compared as part of the mixed methods triangulation design and therefore strengthening criterion-related validity.

- **Construct Validity**

Construct validity seeks to determine whether the questionnaire in reality measures the variables. This is a statistical concept that could not be measured in this study (Delpont & Roestenburg 2011:174; Polit & Beck 2006:330; Raubenheimer 2012).

3.6 TRACEABLE VARIABILITY

According to Burns and Grove (2004:369) measurement errors are the factors that influence the data to differ from the reality.

Although all of the participants were fluent in Afrikaans, the majority's first language was Sesotho and in some cases, Tswana.

This variable was controlled by the presence of a translator during the interviews. The interpreter was trained before the pilot study. The researcher explained the aim and background of the study to her as well as the reason for the interviews. She was expected to interpret exactly what the researcher and participants were saying (if needed during the interview) and not to add any words or summarise the spoken words. She was not allowed to make assumptions or include anything that was not said by the researcher or the participant. She was assessed during the pilot study and was given the opportunity to ask questions. All verbal communication was in Afrikaans and the translator was only used to enhance the quality of the information obtained. The researcher was aware that the expression of emotions could possibly be influenced or inhibited by the fact that participants did not communicate in their mother tongue. This fact was taken into account throughout the execution of the study. The researcher was also aware that the language barrier influenced personhood and a person-centred approach during the interviews. The researcher explained the reason for the use of Afrikaans during the interviews to the participants.

Although the researcher was not directly involved in the training of the participants, she was working in the SCU with OT students at the time of the study. This could have caused the participants to perceive the position of OT as more powerful than their position as caregivers. This could have influenced their willingness to be honest and also cause the Hawthorne effect (Burns & Grove 2005:35). This effect might have influenced the attitudes of the

participants and caused them to feel that they should have answered the questions according to what they thought the researcher wanted to hear.

The purpose of the study was explained to the participants so that they could have a better understanding of the reasons for the questions. They knew that the researcher was not criticising them, but was trying to understand their perspectives and situations, find a way to enhance the communication between OT and the participants as well as to involve them in therapy, specifically the person-specific programmes. It was emphasised that the participants were the experts and that the researcher was dependent on them to complete the study and obtain accurate information. The researcher explained to them that their participation and honesty could promote their work satisfaction and that their duties could be accomplished with greater ease if they were honest and willing to share information. It was thus important for the researcher to explain that the data would be treated as confidential at all times. The co-coders were informed of instances where the Hawthorn effect was present and was therefore incorporated likewise in the data analysis process.

The participants were also informed that their specific expertise in this field would assist the researcher so as to motivate them to be honest and willing to share information.

The concept of bracketing was used to raise the awareness of the researcher of her own perceptions in order to keep them from influencing the data. The researcher wrote her own worldviews and perspectives in a book and kept it on hand during the interviews, in case she needed to be reminded in order to avoid any prejudice influencing the data (Merleau-Ponty, cited by Beck 1994:500).

It was possible for the researcher to make assumptions based on her own beliefs and worldview that may not be accurate. Therefore, the translator was requested to act as a critical friend to heighten the awareness of the researcher when such an event occurred.

3.7 PILOT STUDY

A pilot study was conducted with four caregivers from The Resting Place RCH. These participants were also working with residents suffering from dementia. The pilot study was not executed at Greenacres RCH to avoid repetition of the questions. Thus, the data from the pilot study was not included in the results of the study. The aim of the pilot study was to determine the comprehensibility of the structured interview questionnaire and the interview schedule. It also indicated whether the questions were clear enough and unbiased and to determine if the data was generated by the use of the specific questions (Strydom 2011d:240-243).

The researcher had to make the following adaptations for problems that occurred during the pilot study:

- Section B and Section F were swapped to start with the questions providing the most information first. This decision decreased the time spent on one semi-structured interview.
- The researcher also decided to make cards for Section B and Section C so as to provide participants with a visual aid when answering these questions. To further ease the process of answering the questions in Section B, the options were cut out individually so that the participant placed them in order of importance.
- Question 10, 11 and 16 were changed due to incorrect coding.
- Another option was added to give the participants the option to indicate whether they were rotating between day and night shift.
- Question 20 was added to determine the extent of their experience.
- Four questions were removed as they were already answered by the content of other questions.
- Another option was added to question 40 for the participants to be able to indicate whether it was important for the residents to choose when they wanted to walk around.

- Another option was added to question 41 and 42 for the participants to be able to indicate that they would feed the resident at a slow pace.
- Language corrections were made in questions 49 and 53.

3.8 ETHICAL CONSIDERATIONS

The researcher had obtained informed consent from The Resting Place RCH for the execution of the pilot study as well as Greenacres RCH for the execution of the study, during working hours. The results were made known to the managers of both The Resting Place RCH and Greenacres RCH. They were also informed that the results would be published (Strydom 2011a:117,126).

Participants were selected based on the prerequisites of the study and the researcher attempted to treat each one equally and in a just manner (Polit & Beck 2006:90-91).

All of the participants had been given the opportunity to provide informed consent to participate in the study by the use of an information document as well as a consent form which was signed by each prospective participants. These documents were made available in Tswana, Sesotho, Afrikaans and English and gave the participants the opportunity to choose their language of preference. It was of great importance that the participants knew exactly what the research entailed and what was expected of them. They were also well informed about the requirements relating to time and effort on their part as well as the potential benefits resulting from the study. There was no risk of harm for the participants involved. None of the participants were deceived as to the purpose or process of the study and no information was withheld from any participant (Polit & Beck 2006:89-90; Strydom 2011a:115,117-119).

The interviews were recorded on video to enable the researcher to observe non-verbal behaviour of the participants. They were informed of this and had the opportunity to give informed consent.

The study was designed to be discontinued or modified at any time in the process, if it appeared that the researcher or participants were uncomfortable with any aspects of the research process. Although the participants were not anonymous to the researcher, confidentiality was ensured to protect them from exploitation by any means by assigning a number to each participant. No names were mentioned (Polit & Beck 2006:87-88; Strydom 2011a:120). Data was lost when one of the interview tapes was damaged, but confidentiality of this participant was not compromised even though her input could not be utilised. The participants were also informed that the results of the study would be published on completion, without revealing their personal identities. Therefore the names in the text of were changed to protect the privacy of the residents and the participants.

Demographical information was asked in order to gain a deeper understanding of the participants' working and home environment and circumstances. The importance was explained to the participants, but they were made aware that they had the option not to answer these questions.

As the purpose of the study was to gain a deeper understanding of the thoughts of the participants and the reasons for their behaviour, no judgements based on culture or any other aspect of the participants were made by any person involved in the study. The researcher as well as the translator noted their views and prejudices in an attempt to avoid possible judgement and presumptions (Merleau-Ponty, cited by Beck 1994:500). After each interview, participants were given the opportunity to share their thoughts and feelings on the situation. This gave the researcher the opportunity to detect any need for a debriefing session that would be arranged, had it been necessary, in accordance to these needs (Strydom 2011a:122).

In the event of misconduct in the SCU being reported by one of the participants during the interviews, the researcher would have discussed the situation with the parties involved until an agreement was reached to either correct their behaviour or to report the misconduct to management.

The protocol of the study was evaluated by expert and evaluation committees to ensure that the research was ethical and effective. The research proposal was presented to and approved by the Ethics Committee of the Faculty of Health Sciences of the University of the Free State (ETOVS NR 169/2010). The competence of the researcher was promoted by direct supervision of experienced study leaders who both hold Ph.D. qualifications (Strydom 2011a:123-124,126-127).

For the benefit of the reader, the research findings were written in a final comprehensive report. The researcher hoped to publish the findings in an accredited journal and did not aim to manipulate findings to fit any hypothesis as no pre-set hypothesis was presented (Strydom 2011a:126).

3.9 SUMMARY

This chapter was a focused description of the research methodology that was used for this study. The choice of methodology was based on the best pathway to reach the objectives with specific emphasis on the maintenance of the personhood of the participants. The maintenance of personhood formed the basis of the entire study and the personhood of the participants was regarded as equally important to the personhood of people with dementia.

In Chapter 4, the results of the study are discussed with qualitative and quantitative components.

CHAPTER 4

PRESENTATION AND INTERPRETATION OF THE RESULTS AND FINDINGS

4.1 INTRODUCTION

As discussed in Chapter 3, a structured interview questionnaire and a semi-structured interview schedule were used to obtain quantitative results and qualitative findings respectively. The combination of these results is a portrayal of the two objectives of the study; namely, to explore the caregivers' view of occupation and QoL of people with dementia and to explore whether the caregivers potentially link occupation and QoL for people with dementia.

Qualitative data analysis was directed by integrating guidelines from Creswell (2012:237-238) and Polit and Beck (2006:401). The analysed data were grouped into themes and categories which are discussed in this section. Quantitative data were analysed by the Department of Biostatistics of the University of the Free State and is portrayed in tables.

In this interpretation stage of the study it is important to remember that the mixed method design of triangulation was chosen as a framework for the study. This design was chosen based on the timing of the collection of qualitative and quantitative data sets and because of the intent to compare and integrate the data in the interpretation stage of the study (cf. 3.2.3; p39) (Ivankova *et al.* 2007:265-270,277).

Creswell (2012:220) stipulates that in the data collection phase of a triangulation study, the qualitative and quantitative data are collected as separate entities. However the results and interpretation thereof are best presented as a unit. The combination of the qualitative findings and the quantitative results in the research report allows one to effectively compare the

discrepancies and similarities. Therefore, this chapter offers a combined description of the qualitative findings and the quantitative results. Due to the strong qualitative component of the study, the qualitative themes and categories form the framework for the discussion as indicated in Table 4.1. Given the small sample size, and the sample-size-sensitive nature of the tests used, it would be extremely difficult to find statistically significant results in the analysis of the quantitative data (Raubenheimer 2012). The quantitative data are thus presented to support, verify and contrast the qualitative findings. This provides a more in-depth understanding of the results and findings. The quantitative data are therefore integrated within the qualitative themes and categories and presented in tables. Throughout the discussion, the researcher referred back to the tables to indicate the links between the qualitative findings and quantitative results. The researcher used various sources of literature to confirm or contradict the data and the interpretations thereof.

It is important at this stage to describe the context of the South African legislation system and the influence thereof on residential elderly care. The South African Older Persons Act as described in Chapter 2 (cf. 2.2.1.1; p16) includes all of the basic care principles such as hygiene, medical care and dignity that should be adhered to by each RCH to be registered under this law (South Africa 2006:16). Unfortunately, to this day legislation is not effectively enforced in South Africa (Ferreira 2012:26,29) and therefore, something that should be regarded as the given circumstances (i.e. to be clean and well fed), cannot be taken for granted in the South African context. In this chapter, the researcher often indicates that the focus should be more directed to the tasks associated with person-centred care rather than medical care and the physiological needs of the residents. It may, therefore, appear that the researcher focuses more on the psychological needs of the residents, but this is due to the fact that physical care should be in place and not a primary focus. Culture change means that all of the needs of the residents should be taken into consideration, not only the tangible needs, but also the emotional needs. This means that the focus should not be on the speed and effectiveness of a task, but every task that is done with the residents should be viewed as an opportunity for interaction and a shared experience. When the residents' needs

are considered holistically, they will not feel like this resident who was quoted in a report by Dannefer and Stein, cited by Fagan (2003:133):

I just feel like a nobody . . . they are very nice to me . . . it's always clean. . . Life for me, as far as being comfortable, couldn't be better, you know, if I just wanted to sit around and do nothing. I'm told what to do and when to do it. I'm very well fed and I'm comfortable, but that's not living.

Another important factor to take note of is that the leadership style in Greenacres points to an autocratic, top-down management structure with the caregivers at the bottom of this system. It was not a system of consensus management associated with person-centred care that indicates shared responsibility and takes the caregivers' opinions into account (Castle & Decker 2011:631,638-639; Eden Alternative 2010b:25,30; Fagan 2003:138). Although the autocratic system is in direct contrast with person-centred care (Eden Alternative 2010b:25,30; Fagan 2003:138), this was the reality at Greenacres RCH. Being their direct supervisors, the professional nurses were the only superiors with whom the caregivers came into contact. Therefore, the caregivers viewed management of the organisation and the professional nurse as the same entity and when the professional nurse was indicated, she in fact represented management (for the caregivers). The researcher was aware that the professional nurses were also only employees under the management of the RCH and were therefore also driven by the organisational culture to which she was exposed.

Table 4.1 Qualitative data: Themes and Categories

SECTION A: VIEWING THE SCU IN CONTEXT		
	THEMES	CATEGORIES
SECTION B: CAREGIVER STRESS ASSOCIATED WITH BURDEN OF CARE	1. ROLE AS EMPLOYEE WITHIN THE ORGANISATION	1.1 Nature of the job 1.2 Work schedule and workload 1.3 Training
	2. WORK ENVIRONMENT INFLUENCES	2.1 Management of the RCH 2.2 Family of the residents 2.3 Public opinion
	3. ROLES OUTSIDE OF WORK	3.1 Home circumstances
	4. STRESS MANAGEMENT SKILLS	4.1 Coping with stress
SECTION C: PERCEPTIONS ASSOCIATED WITH QOL, PERSON- CENTRED CARE AND OCCUPATIONAL ENGAGEMENT	5. THE CAREGIVER ROLE	5.1 Priorities of caregivers, the organisation and the family 5.2 Independence 5.3 Activity participation 5.4 The resident's ability to experience enjoyment/positive emotions 5.5 The resident as a unique individual

Chapter 4 is presented in three sections. Section A offers background regarding the diversity of the population of caregivers and residents who lived in the SCU at Greenacres. This section endeavours to provide a greater understanding about context within the SCU, explaining who the caregivers and who the residents were and what factors should be considered relating to their situation, before the results are discussed further.

In Section B, Theme 1-4 of the qualitative findings are discussed. The focus of the section relates to the stress experienced by the caregivers. The focus falls specifically on the mental and physical well-being of the caregivers and the influence thereof on both their work and home circumstances and vice versa. The section also supports the background information in Section A. Only by creating a better understanding of the caregivers and their lives as a point of

departure would it be possible to contemplate their perceptions of QoL and activity participation in Section C.

Section C discusses Theme 5 and closes in on the findings relevant to the caregivers' perceptions of QoL, person-centred care and occupational engagement for the residents for whom they care. Following on the picture created of the organisational and home circumstances in Sections A and B, Section C illuminates findings relating directly to the organisation, the caregiver and the residents living with dementia. The three sections are followed by a discussion of the perceived associations between QoL and the concepts of occupational engagement and person-centred care.

4.2 SECTION A: VIEWING THE SCU IN CONTEXT

The participants will be referred to as caregivers from this point onwards to preserve the personhood of the caregivers in correspondence to the qualitative nature of the study. Please note that the interviews were conducted in Afrikaans and therefore the quotes were written in Afrikaans in this chapter to give a direct portrayal of the perceptions of the caregivers.

Section A is a description of two populations. The age, sex and cultural diversity of both populations were considered.

Eight (n=8) female caregivers who participated in the study were a comprehensive sample of all permanent caregivers at the facility. They were chosen based on the principles of purposive sampling (cf. 3.3.2; p40) as well as the selection criteria (cf. 3.3.1; p40). The number of residents at the time of the study was 21.

Table 4.2: Ages of the caregivers (n=8)

Age	Frequency	%
29	1	12.5%
30	1	12.5%
34	1	12.5%
36	2	25%
37	1	12.5%
42	1	12.5%
46	1	12.5%

The caregivers were between the ages of 29 and 46 as indicated in Table 4.2, with the majority (75%) of the caregivers between the ages of 29 and 37 and 25% between the ages of 42 and 46.

Table 4.3: Ages of the residents (n=21)

AGE	FREQUENCY	PERCENTAGE
40-49	1	4.76%
50-59	2	9.52%
60-69	4	19.04%
70-79	3	14.29%
80-89	8	38.10%
90-99	3	14.29%

The ages of the residents are indicated in Table 4.3 and were between 47 and 95 with 85.71% of the residents above the age of 60.

The ages of the caregivers place all of them within the boundaries of early and middle adulthood while the ages of the residents place the majority within the boundaries of elderlyhood. Table 4.2 and Table 4.3 indicate that there are major age differences between the caregivers and the residents contributing to the diverse population (Campinha-Bacote 2003:online; Lum 2000:3).

No male caregivers were employed at the SCU of Greenacres RCH, while four of the 21 residents were male. De Vugt, Stevens, Aalten, Lousberg, Jaspers, Winkens, Jolles and Verhey (2004:90) found that female caregivers are more focused on the emotions of the residents, which are in line with person-centred care, while male caregivers are more focused on the task at hand. Although this is the case, Campinha-Bacote (2003:online) and Lum (2000:3) list gender differences as a factor contributing to diversity which in turn complicates the

tasks associated with care and therefore this factor could have had a negative impact as it could have been easier for male residents to relate to male caregivers and vice versa.

The caregivers represented diverse cultural backgrounds as six (75%) of the caregivers' home language was Sesotho, one caregiver's home language (12.5%) was Tswana and one caregivers' home language (12.5%) was Xhosa as shown in Figure 4.1. At the time of the execution of the study, there were 21 residents in total. Nineteen of these residents' home language was Afrikaans, and only two of the residents' home language was Sesotho (cf. 3.3; p39) as indicated in Figure 4.2.

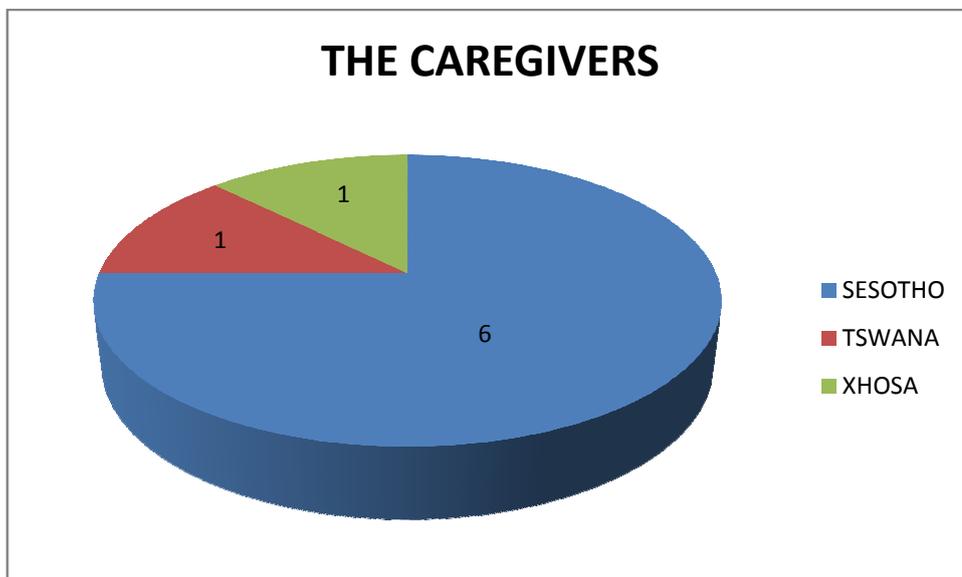


Figure 4.1: Home language of the caregivers

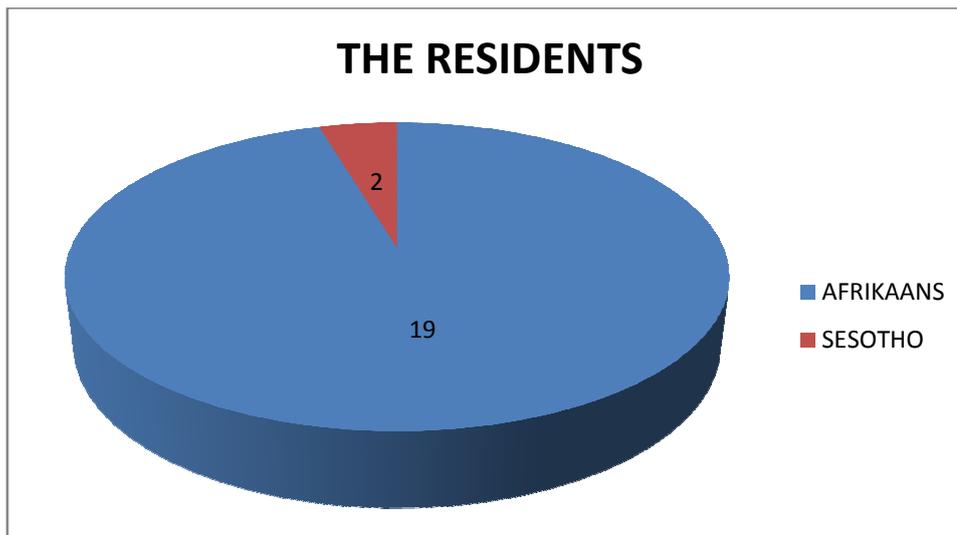


Figure 4.2: Home languages of the residents

When Figure 4.1 and Figure 4.2 are viewed in comparison, it is evident that the SCU at Greenacres have a rich cultural diversity. The possible impact of cultural differences is portrayed in Table 4.4 and Table 4.5. One could argue that cultural differences should be less of a problem when you are competent in handling these differences (Campinha-Bacote 2003:online), but the following evidence shows that cultural competence is a skill yet to be mastered in the SCU.

Table 4.4: Factors determining behaviour towards residents of different cultures (n=8)

Factors	Frequency	%
Caregivers are not aware of cultural differences and think that everyone is the same as their own culture	1	12.50%
Caregivers are aware of cultural differences, but still feel that everyone should think like they do	0	0%
Caregivers are aware of cultural differences, but do not know what to do about it.	1	12.50%
Caregivers are aware of cultural differences and know how to treat a resident from another culture, but did not get the chance to practise	0	0%
Caregivers know how to treat residents from different cultures and they do apply it accordingly	6	75%

Caregivers showed a heightened awareness of cultural sensitivity. Pertaining to the skill of the caregivers to handle cultural differences, Table 4.4 indicates that

six (75%) of the caregivers were of the opinion that they had the knowledge and skill to handle residents according to their different cultures,

‘Byvoorbeeld met die blanke inwoners sal met ‘n mes en vurk eet waar Mnr. Mancoe hou nie van ‘n vurk en by die tafel sit nie, hy eet lekker met ‘n lepel en voordat hulle eet wil hulle bid en ons laat hulle toe om dit te doen.’

Other qualitative findings indicated that in some instances principles were applied supporting their own cultural beliefs (Makhotla 2012), for example how to show respect to an older person,

‘Omdat die inwoners ouer is ons nou respek ons hulle deur ouma te roep.’

Table 4.5: Factors determining residents’ behaviour towards caregivers of different cultures (n=8)

Factors	Frequency	%
Residents are not aware of cultural differences and think that everyone is the same as their own culture	1	12.50%
Residents are aware of cultural differences, but still feel that everyone should think like they do	4	50%
Residents are aware of cultural differences, but do not know what to do about it.	1	12.50%
Residents are aware of cultural differences and know how to treat a resident from another culture, but did not get the chance to practise	1	12.50%
Residents know how to treat residents from different cultures and they do apply it accordingly	1	12.50%

There is little indication that residents were culturally sensitive. According to Table 4.5 four of the caregivers (50%) were of the opinion that the residents were aware of cultural differences, but they (the residents) thought that everyone should think like they do. For the rest of the options given (as shown in Table 4.5) there was no consensus amongst the caregivers. This could be because the caregivers were referring to different residents when they answered this question or that they understood the impact of dementia on the cognitive functioning of the residents. It is evident from this data that the

second option weighed the heaviest. The caregivers were of the opinion that the residents were aware of cultural differences in the SCU, but they were not as such sensitive towards these differences. The residents' attitude and associated actions could be due to their cognitive inability to judge and interpret situations and also it appeared to be linked to the fact that they grew up in the era of *apartheid*, where racism against e.g. the Sesotho culture were much more explicit and acceptable than in modern times (Mtose 2011:337). Qualitative findings indicated that residents were of the impression that the caregivers should adapt to their frame of mind,

'... partykeer sal jy kry dat die inwoners sal raaksien dat ons van 'n ander, uhm ... kultuurgroep is, maar nogsteeds ons sleg behandel soos voorheen en ons nogsteeds soos ousies noem of kaffer of wat ookal.'

'Ja hulle noem ons daai name. Party, paar van hulle sê ons is die bobbejane.'

It is evident from the above findings that cultural insensitivity is a factor that could cause a lot of stress when considering the employee and resident populations in the SCU. Without other work stressors taken into account, the lack of cultural sensitivity exhibited by residents in combination with differences in age and sex, already poses a stressful working environment for the caregivers. The residents and caregivers show lack of intellectual and emotional insight in cultural backgrounds that are different from their own, therefore increasing the burden and decreasing effective communication and the efficiency of care (Campinha-Bacote 2002:181; Seeleman, Suurmond & Stronks 2009:229).

Therefore, even though the focus of this study is not to unravel complicated issues associated with cultural diversity, the potential influence of discrimination experienced by the caregivers should still be considered. The experience of discrimination and prejudice could evoke anger and/or depression in caregivers and therefore remains an important issue to take cognisance of.

'Ek voel baie sleg, partykeer dit voel ek kan hom met my hande (makes fists) ... jy sien?'

Table 4.6 indicates that only two of the caregivers had worked in the SCU for less than one year and two had worked there between two and three years. Thus, during the last 2.3 years, four of the eight caregivers had had to be replaced, indicating a high turnover rate and potentially this could be accounted for as low job satisfaction. When the working experience of the other half of the caregivers is considered, the opposite is true. Three caregivers had worked between six and seven years and one had worked for 16 years as a caregiver in dementia care, which is a long time to be working in this stressful working environment.

Table 4.6: Months of experience working with people with dementia (n=8)

Months of experience working with people with dementia	Frequency	%
3	1	12.50
6	1	12.50
24 (2 years)	1	12.50
28 (2.3 years)	1	12.50
72 (6 years)	2	25.00
84 (7 years)	1	12.50
192 (16 years)	1	12.50

It therefore appears that the caregivers with longer working experience became more tolerant towards the comments of the residents. Zimmerman, Williams, Reed, Boustani, Preisser, Heck and Sloane (2005:103) report that work stress reduces after two years of working with residents with dementia, which indicates an adaptive response from the caregivers. This adaptive response could be associated with cultural competence (cf. 2.2.1.3; p24). However, this is a loaded term and includes the following constructs: desire, awareness, knowledge, skill and encounters. Being culturally competent is therefore a process and to expect the caregivers to be culturally competent is unrealistic. Therefore, it can be said that to expect the caregivers to be *culturally responsive* will be more appropriate, referring to a sense of cultural sensitivity (Iwama 2004:1; Munoz 2007:274). Therefore, the caregivers deserve credit for

developing cultural responsiveness along with insight into the disease seeing that they were aware of the cultural differences, but chose to ignore these issues due to the symptoms of the disease. Although the occurrence of abuse caused low morale, it appeared as if it was expected and accepted by most of the caregivers, because they believed it to be part of behaviour associated with dementia. The caregivers' passive acceptance was evident in the fact that they appeared not to treat the residents any differently and loved and liked them despite the abuse:

"... want partykeer dan sal hulle teruggaan na wat gebeur het (apartheid) en vir ons name noem, maar ons vat dit nie persoonlik op nie, want dis die Alzheimer pasiënte."

"... ons geleer hoe tree die mense op met Alzheimer so ons is lief vir almal al doen hulle dalk slegte goed of noem ons name."

4.3 SECTION B: STRESS OF THE CAREGIVERS

Since it was already established that the diverse situation in the SCU caused stress, it is also important to look at the additional factors that influenced the caregivers' burden of care relating to their role as employees of the organisation (Theme 1), other work environment influences (Theme 2) in addition to roles outside of their work situation (Theme 3) and their skills to manage the stress that they experienced (Theme 4).

There are different causes that could lead to the work stress of the caregivers. Besides a seemingly *disagreeable work environment*, a variety of stress factors could lead to poor mental and physical well-being and could be intensified by the stress experienced at home. In Section B, these stress factors are discussed to illuminate the background, circumstances and other foundational factors which could potentially influence the perceptions of the caregivers that

are discussed in Section C. A greater awareness of the circumstances of the caregivers could assist with creating an understanding of the QoL and activity involvement they pursue inside and outside of work. This awareness could then assist in exploring influences on the caregivers' perception of what QoL and activity participation of the residents with dementia should entail and will therefore directly affect the objectives of the study.

4.3.1 THEME 1: ROLE AS EMPLOYEE WITHIN THE ORGANISATION

Theme 1 consists of the perceptions of the caregivers regarding their role as employees of the organisation and the associated burden of care. Three categories support this theme: The nature of the job, work schedule and workload, and training. This theme is important to illustrate the stress caused by the the intrinsic nature of the job, the working circumstances of the caregivers and how it is intensified by the associated burden of care.

4.3.1.1 Nature of the job

In Section A the context in the SCU was indicated to intensify the stress of the caregivers. Therefore, it is now important to discuss the intrinsic factors relating to the nature of the caregivers' job to emphasise the most important role players and the mental and physical burden that rests upon them as caregivers and to further illuminate how the job characteristics influence their burden of care.

- **Most important role players**

The qualitative evidence pointed to three role players in providing care for the residents: the professional nurse, the caregivers and the family.

Caregivers reported that the professional nurse (referred to by the caregivers as 'the sister') was a very important care provider for the residents. Although the professional nurse was prepared to take the responsibility of managing the

SCU, her role was not to provide direct care to the residents as was the case with the caregivers.

“Die suster is die hoof, né. Dis sy wat sy gaan kyk, sy gaan seker maak of die mense hulle, hulle is reg.”

“Die suster sal net ‘n klein rukkie in kom en dan weer uit gaan. Ons is die meeste van die tyd by die inwoners en vir hulle bad, eet en aantrek.”

The caregivers reported the family to be afraid of the residents, spending less time and giving of care and therefore increasing the burden of care for the caregivers.

“Party van die kinders bly net so twee minute dan loop hulle. Dis asof hulle bang is.”

“Ja die ander mense hulle het baie jare by ons gebly, die ander ... paar van hulle ons ken nie die familie nie.”

From the following excerpt it appeared that the caregivers perceived the burden of care equal to the amount of time spent with the residents. Therefore, the caregivers reported that every role player in the multi-disciplinary team was important in caring for the resident, but the caregivers were the most responsible due to the amount of time spent with residents, therefore intensifying the burden of care.

“Dis altyd, want ons altyd daar mos vir hulle. Ons is elke dag daar om hulle te sorg.”

“Ek dink altyd want ons is mos elke dag daarso.”

Although being the key care providers for the residents heightened their levels of stress, the caregivers were ambivalent between the intensified burden of care

and the pride they experienced associated with their role as key caregivers. The caregivers were of the opinion that this important role had a positive influence on the bond that the residents formed with them. This perspective could increase their burden in the work situation or be perceived as enhancing their status in the organisation.

Navorsers: *“So jy sê julle is die belangrikste? Julle is die meeste verantwoordelik?”*

Deelnemer: *“Mmm.”*

“... want ons altyd daar mos vir hulle. Ons is altyd daar om hulle te sorg.”

“Ons is die meeste van die tyd by die inwoners en vir hulle bad, eet en aantrek. So ontwikkel daai emosionele kontak.”

Table 4.7 Burden of care of the organisation (n=8)

Ranking		Rank value
1	The caregivers	1.8
2	The professional nurse	2.1
3	The resident himself	4.1
4	Occupational therapist	4.5
5	Closest family	5.3
6	Friends	5.8
7	Volunteers	5.8
8	Extended family	6.8
9	Other (preacher and management)	7.3

The quantitative data in Table 4.7 correlates with this qualitative data and indicates that the caregivers were of the opinion that they were the role players who were most responsible for the QoL of the people with dementia. The professional nurse had the second most important role and the nearest family were perceived to be the fifth (out of of nine) priority caregivers for the residents. It is important for the reader to note that the researcher will refer back to Table 4.7 through the course of this chapter to discuss the remaining role players as they link with the qualitative findings.

According to Park (2010:139) caregivers are the people who provide the most 'direct care' and need the most support to manage difficult behaviour of the people with dementia. He also states that the sources of stress for caregivers and nurses differ in the sense that caregivers experience more stress related to direct resident care and nurses experience stress related to limited resources. In a study by Engstrom, Skytt and Nilsson (2011:739), it was also found that this kind of informal power situated in the role of the caregiver is related to heightened levels of stress. Therefore, the conclusion can be made that although it also gave them a higher status and sense of accomplishment within the organisation, the caregivers experienced more stress due to the high demands of being the main role players in the lives of the residents with dementia. As one caregiver stated,

"Hulle gee vir ons baie stres daar."

- **Emotional burden**

The emotional burden that the caregivers experienced was related to both boredom and the role conflict caused by the deaths of residents in the SCU.

The caregivers reported that the repetitious nature of the tasks led to boredom. This was a factor that caused stress and intensified the burden of care.

"Ja, jy doen die werke een ding elke dag. Jy word moeg van daai."

"Nie te veel werk nie, maar een ding te veel gedoen."

Literature supports the opinion that care could be monotonous, but also how person-centred care could impact such situations positively. Repetitiveness of the job certainly had a negative influence on work stress (Ahmad, Zia-ur-Rehman & Rashid 2011:513), but job satisfaction can be greatly enhanced by the application of person-centred care and especially emotional contact with the residents (Power 2010:97):

“Ek dink dis lekker om saam met iemand te gesels. En ... jy kan voel jy ... dis lekker as jy heelyd gesels met mense, want jy voel jy kan ontspan en hoef nie net alleen te sit.”

Something that inhibited this emotional contact was that, although the caregivers expected the death of residents and accepted it as part of their job, they reported that due to the often occurrence of death in the SCU they experienced intense emotional pain and therefore avoided emotional contact and building close relationships with the residents.

“Want daai een maak my nie dat ek sleg voel nie. Dis deel van my werk.”

“Ek voel maar dis mos die ander oupa, Oupa van der Merwe, daai oupa ek was baie baie lief vir daai oupa ... die dag toe die oupa ... oe ek was so hartseer, maar ek het gebid dat daai ding kan verbygaan.”

“Party van hierdie mense gaan vinnig dood soos die een oupa het net twee weke by ons gebly toe is hy oorlede. Dit speel ‘n rol dat ons nie te geheg moet raak aan hulle nie.”

Although this was the case, one of the caregivers recognised that a person doing the job of a caregiver needed to have compassion for the residents,

“Nou as jy nie hart het vir dit nie, jy mag nie daar werk nie.”

This indicated that she knew that she had to be compassionate, but it appeared as if she has built a resistance to protect her from emotional distress. This discrepancy between the compassionate care caregivers wanted to give to the residents and their natural instinct to protect themselves emotionally caused role conflict.

Table 4.8 is a combined table between the reasons for not taking initiative with the residents when engaging with daily tasks and routines (Column 1) and the reasons for not facilitating independence during the same situations (Column 2). These two questions were combined in Table 4.8 to indicate the impact of the burden of care. The options of these questions were ranked by the participants. After placing the options in the correct order, they also had to indicate whether the option occurred always (1), sometimes (2) or never (3) (cf. 3.5.2; p52). These values were multiplied with the initial ranking position that the participant indicated. Therefore, the lower the numerical ranking value, the higher the importance for the options given with these questions. Throughout the course of this chapter, the researcher will refer back to Table 4.8 to indicate how the rest of these quantitative results link with the qualitative findings. Therefore, the quantitative evidence in Table 4.8 confirms that the caregivers perceived exposure to death as the most important impact on the burden of care that prohibited the caregivers from taking initiative when they worked with the residents, because they did not want to expose themselves to the risk of spending too much time and effort on the residents and forming a relationship with them.

Table 4.8: Impact of burden of care (n = 8):

Column 1 Reasons for not taking initiative		Column 2 Reasons for not facilitating independence	
1. Caregivers have been exposed to death too many times and do not want to become attached to the residents	0.5	1. The caregivers are afraid to try new methods when working with the residents	2.0
2. Too much conflict within the multi-disciplinary team	0.5	2. Caregivers did not get the chance to practise the facilitation of independence	2.1
3. RCH does not give the opportunity to the caregivers to be creative. They have to do only what is expected of them	0.9	3. The residents are old and weak and do not have the ability to be independent	2.9
4. Caregiver are not paid enough	0.9	4. Workload is too heavy. The caregivers are tired	3.1
5. The memory of the residents is maintained better when the caregivers do not disrupt the routine	1.0	5. Emotional and physical abuse from the residents	3.4
6. Job of the caregiver has little status – caregivers do as little as possible as long as they avoid being in trouble	1.5	6. Caregivers do not know how to analyse tasks	3.5
7. The caregivers do not like some of the residents	1.5	7. Too much stress	3.6
8. The residents are supposed to adapt to the caregivers	1.8	8. Too little time	4.5
9. The caregivers do not know enough about the lives and interests of the residents	2.6		
10. Physical and emotional abuse from the residents	3.0		

Although Mitchell, Teno, Kiely, Shaffer, Jones, Prigerson, Volicer, Givens and Hamel (2009:1529) indicate that dementia is regarded as a terminal illness. Doka (2010:20) as well as Boerner, Schulz and Horowitz (2004:673) indicate that even when death is an expected outcome, caregivers experience grief and loss with the death of a resident. There is even a possibility that caregivers can grieve the loss of the caregiver role when the care recipient is not there anymore. Therefore, the closer the relationships between the caregivers and the residents, the more extreme the experience of emotional loss would be for the caregiver (Boerner *et al.* 2004:673). A caregiver at the Eden Alternative Associate Training (2012:6) explains that she forms very strong bonds with the residents. She grieves about her loss when residents pass away and reports

that, at first, she does not want to make contact with the new residents that move into the late residents' room, but then quickly comes to love them as well.

Various authors [i.e. Moyle, Murfield and Griffiths (2010:4), Park (2010:136), Verbeek, Zwakhalen, Van Rossum, Kempen and Hamers (2011:6)] confirm that the most important attributes of a caregiver who works with people with dementia are a positive outlook toward the elderly person with dementia, patience; empathy; and a person-centred approach. Therefore, the caregivers know the attributes needed to do the job, but do not show these attributes to avoid close relations with residents for the reason of the possible death of the resident (Kada, Nygaard, Mukesh & Geitung 2009:2386). Furthermore, emotional isolation from residents causes low job satisfaction and aimlessness (Hung & Chaudhury 2011:9,11; Moyle *et al.* 2010:4). Therefore, literature supports that the caregivers appeared to be in conflict between building a relationship with the residents and protecting themselves from the emotional trauma associated with the death of the residents contributing to the emotional burden.

- **Physical burden**

Adding to the emotional burden caused by the nature of the job, the caregivers reported physical consequences due to work-related stress as mostly being tired and having back problems.

Deelnemer: *"Oe my rug is seer!"*

Navorser: *"Is hy seer?"*

Deelnemer: *"Mmm en daai mense hulle maak ons klaar."*

The conclusion can be made that the physical handling of the residents increased the stress levels and burden of the caregivers, because they were either not properly trained to effectively handle the residents while protecting their own bodies, or they did not implement training. A lack of assistive devices like hoists could also have an impact as manual handling would be without the support of specialised equipment. Literature confirms that residential care

home staff are disadvantaged due to physically demanding tasks performed without proper training and/or equipment e.g. transferring bedridden residents (Hasson & Arnetz 2007:475, Cornman-Levy, Gitlin, Corcoran & Schinfeld 2001:54).

4.3.1.2 Work schedule and workload

Through the course of this chapter, the context in the SCU was illuminated whereafter the researcher felt the need to describe the nature of the job expected of the caregivers within this context. Now it is important to inform the reader of the workload and work schedule that surrounded this context and the nature of the job. The workload and work schedule of the caregivers appeared to be major factors contributing to the burden of care experienced by the caregivers and caused immense stress at work.

- **Workload**

The heightened workload that was associated with the job of the caregivers in the SCU was caused not only by the volume of work, but also by an insufficient number of staff members. The ratio of caregivers to residents was 1:2,33. This had a negative effect on the facilitation of independence of the residents. The experienced burden caused by the heavy workload was intensified by and is discussed in relation to the salary level of the caregivers.

The caregivers were of the opinion that they suffered under a very high workload caused by the understaffed facility and insufficient time to perform their daily duties. The caregivers were of the opinion that the SCU needed more caregivers, but the RCH could not afford more caregivers due to financial constraints:

“Dis partykeer so dat ons nie eers alles kan klaarmaak nie ...”

“Want as ons vra ons soek die ander een (caregiver) dan sê Sr. Pretorius¹ sy het nie geld om vir die ander een te betaal nie.

The high workload of the caregivers had a negative influence on the facilitation of independent task participation and emotional care for people with dementia and therefore compromised person-centred care. The facilitation of independence was only applied when it did not influence the normal unit routine. Therefore, time constraints encouraged dependence.

“I can’t wait for her to try to do something, because I can see I am running out of time.”

“Dan kry ons nie tyd om vir die inwoner kans te gee dat hulle kan self die goeters doen nie. Dan moet ons alles vinnig klaar maak.”

“As hulle huil as ons sien hulle voel nie lekker nie maar partykeer het jy nie tyd nie, jy sien hom maar huil daarso.”

The quantitative evidence that supports the overall perception of the caregivers that their workload was too high is indicated in Table 4.8 (Column 2) as a factor that impacts the burden of care. This table illuminates that being tired from the heavy workload was the fourth (out of eight listed) priority reason why independence was not encouraged compared to time constraints (this was not considered as important at all as it was listed as last choice for the eight that could be chosen). Therefore, even though a high workload was acknowledged, it was not a priority reason for discouraging independence.

Although the caregivers admitted to not always encouraging independence of the residents, the quantitative evidence in Table 4.9 indicates that 100% of them agreed that independence and patience with the residents was a priority.

¹ Please remember that the names of individuals have been changed

Table 4.9: Giving time to eat independently or feeding the resident in a slow manner vs. feeding the resident quickly to save time (n=8)

Response	Frequency	%
Time allowed to be fed slowly or to eat independently	8	100%
Quicker and better control of nutritional intake	0	0%

Therefore, the caregivers were of the opinion that the facilitation of independence was important, but was neglected due to the heavy workload, causing work stress for the caregivers.

There was no legislation in South Africa at the time of the study to indicate what the ratio should be, but at the time of the study there were facilities with a ratio of 1:12 caregivers to residents. This was the highest ratio experienced by the researcher and was much higher when compared to the ratio at Greenacres. According to literature that supports these findings, restricted funds in a facility limit the numbers on the staff establishment (Du Toit & Surr 2011:49). Lack of managerial support and the failure of the organisation to recognise the restrictions in the working environment could result in the caregivers working with the residents in a hasty manner and therefore appearing to be unkind (Hung & Chaudhury 2011:5-6). More evidence (Ahmad *et al.* 2011:512,514-515; Cooper & Marshall 1976:12; Faragher, Cooper & Cartwright 2004:193) confirms that a workload that is unrealistic in relation to the time allowed for the job causes pressure and heightens work stress, adding to poor performance. The poor performance also results in a lack of person-centred care. Literature also confirms that although residents can be facilitated to perform tasks independently, the majority of the residents may not be allowed the opportunity. The tasks are done by the caregivers who are often in a hurry, limiting the opportunity for the residents to participate (Du Toit & Surr 2011:51,53; Hung & Chaudhury 2011:5). According to Power (2010:52) time limits discourage person-centred care and make task completion a bigger priority than the residents themselves.

Of all the caregivers, only the one with six years experience was of the opinion that they had enough time in a shift to complete their daily tasks and was therefore not overwhelmed by the workload.

Deelnemer: *“Die tyd is baie, want dis 7 tot 7. Ja, dis ...”*

Navorser: *“Kry jy al jou werk gedoen dan?”*

Deelnemer: *“Ja.”*

This caregiver was also looking after her grandmother with dementia, her brother and sister and her own two children. She did not have any support. It is possible that she was so used to rushing to get all her tasks done at home that she experienced the SCU as a slower-paced environment where she had help from and companionship with the other caregivers (Dahlin, Kelly & Moen 2006:22-23). She expressed the fun that she had with her colleague:

*“Ons gaan ... dit was ek en Selina. Ons is net mal mos.
Selina is so mal soos ek. Ja.”*

Literature indicates that it is possible that a caregiver can be more relaxed at work than at home because of the companionship they received from other caregivers that reduced work stress (Ahmad *et al.* 2011:511; Dahlin *et al.* 2006:22-23). This experience was supported by a caregiver who was of the opinion that good communication between caregivers added to successful task completion during a shift. Therefore, these findings also indicate that companionship at work could reduce work stress.

*“Nou dan sê die ander skof, ek en Maria as ons op diens is,
die goeters loop, jy sien? Alles is reg, want ons ons praat met
mekaar saam met Maria.”*

Kitwood (1997:111) is of the opinion that the person-centred care approach of this caregiver is prone to add to job satisfaction and therefore alleviate work and personal stress by giving her a sense of control over her work, because work

stress influences the stress experienced at home (Ahmad *et al.* Rashid 2011:515-516).

Although so far during the course of this theme, it is clear that the caregivers experienced an immense burden of care caused by the nature of their work and their workload, they received the same salaries as the caregivers working in the other corridors without residents with dementia.

“... want ek weet nie hoekom moet ek daarso gaan en hard gaan werk verniet ... Jy werk net hard vir niks.”

“Die werk wat ons doen is anders en moeiliker as die ander gange, maar ons word nogsteeds dieselfde as hulle betaal ...”

The quantitative data showed that the caregivers rated salary constraints as the fourth most important reason in Table 4.8 (Column 1) (i.e. the fourth priority from ten suggested reasons) why they did not try new methods or take initiative when working with the residents. This indicated that it was not a priority reason, but that the low salary was acknowledged as a factor that prohibits initiative and therefore person-centred care. Apart from this serious stress factor, the salaries that they received further intensified the burden of care that they experienced.

Confirming literature agrees that caregivers are generally discontented with the remuneration that they receive for a job that requires skilfulness and dedication (Chenoweth, Jeon, Merlyn & Brodaty 2010:165). This contributes to high work stress and adds to the seemingly *disagreeable work environment* (Ahmad *et al.* 2011:517; Cooper & Marshall 1976:12; Faragher *et al.* 2004:193).

- **Work schedule**

The work schedule is determined by the number of hours and shifts that the caregivers were expected to work and is viewed against their travel arrangements, which also added to their burden of care.

The work schedule and shifts of one of the caregivers is set out in the Table 4.10:

Table 4.10: Example of the shifts of one caregiver in a four week period (n = 1)

Week 1		Week 2		Week 2		Week 2	
Monday	07:00-19:00	Monday	Off	Monday	07:00-19:00	Monday	Off
Tuesday	07:00-19:00	Tuesday	Off	Tuesday	07:00-19:00	Tuesday	Off
Wednesday	Off	Wednesday	07:00-19:00	Wednesday	Off	Wednesday	07:00-19:00
Thursday	Off	Thursday	07:00-19:00	Thursday	Off	Thursday	07:00-19:00
Friday	19:00-07:00	Friday	Off	Friday	07:00-19:00	Friday	Off
Saturday	19:00-07:00	Saturday	Off	Saturday	07:00-19:00	Saturday	Off
Sunday	19:00-07:00	Sunday	Off	Sunday	19:00-07:00	Sunday	Off
Total	60	Total Hours	24	Total Hours	60	Total Hours	24

Table 4.10 indicates that the caregivers worked 60 hours for one week and then 24 hours the next week. According to the South African Labour Law, 45 hours is the maximum threshold for hours worked in a week. If a worker exceeds 45 hours, the worker should be paid overtime (Claassen 2012:online). However, the Basic Conditions of Employment Act (Du Plessis, Fouché & Van Wyk 2001:37) states that a compressed work week is possible when an arrangement is made between a shift worker and the employer. This means that the employee can work up to five shifts of 12 hours per week as long as the average of the total hours per week does not exceed 45 hours (Du Plessis *et al.* 2001:37). The manager of Greenacres made an arrangement with the caregivers that the hours are calculated monthly to ensure that they were paid overtime when they worked more than 173 hours per month. Therefore, the average hours that the caregivers worked per week were 39, whereafter they were paid overtime. This is well within the boundaries of the legal overtime payment when an employee exceeds 45 hours per week. Therefore it can be concluded that the organisation is covered legally and that a legal issue cannot cause stress and add to the burden of the caregivers. Shift work, however, and the long hours per shift was tiresome and caused emotional stress, which intensified the burden of care.

Although the research of Bambra, Whitehead, Sowden, Akers and Petticrew (2008:764) suggest that a compressed work week could enhance the balance between the job and social life, findings by Shen and Dicker (2008:402) focused on the negative consequences of shift work. They found that shift work has a number of negative implications, such as fatigue resulting from a lack of sleep resulting in poor quality of their work, and therefore could have had an influence on person-centred care.

The caregivers were allowed to indicate whether they preferred to work day and/or night shifts and chose this according to their preference. Seven caregivers rotated between day and night shift, while the caregiver with 16 years working experience only worked during the day. Her children were older, contributed to the household and were at work or at school during the day. The researcher came to the conclusion that the caregivers with younger dependents chose to alternate between day and night shifts to be able to care for their dependents on a more regular basis.

Literature indicates that night shifts caused less disruption to a household than working only by day, because mothers compromised their sleep to be able to run the household and look after their children by day (Abdalkader & Hayajneh 2008:77; Barton 1994:453) but impeded restorative occupation due to unbalanced occupational behaviour (Pierce 2001:252) and therefore more work stress accrued (Ahmad *et al.* 2011:515).

The two factors that intensified this burden of care was their time of travel and their travelling methods. Four of the caregivers made use of both a bus and a taxi as travelling method, while four others made use of a taxi only. Both buses and taxis are very unreliable transport methods in terms of punctuality and availability.

Table 4.11: Travelling methods (n = 8)

Travelling method	Frequency	%
Both bus and taxi	4	50%
Taxi	4	50%

Although not corroborated by qualitative data, the researcher concludes that transport added to the stress of the caregivers, because they had no guarantee that they would be on time for work, although they started travelling long in advance to be at work by the start of their shifts.

Focusing on travelling time, it was determined that the caregivers all resided in and around the Bloemfontein area and travelled between seven and 70 km to work every day. To be on time for work, the caregivers had to rise between two hours and three hours and 20 minutes prior to work, depending on the travelling distance. Therefore, the earliest time that a caregiver had to arise was at 03:40 to start the 07:00 shift. The distances and time of travelling to and from work resulted in extremely long working days, especially for 12 hour shifts. In the opinion of the researcher, this unbalanced day programme could add to job dissatisfaction.

“Nee, ek kan nie rus nie, mos ek het ... mos ek het kinders, ek moet die wasgoed was. Ek moet ...”

Pierce (1998:490; 2001:252) indicates that the appeal of activities lies within three subjective dimensions: pleasure, productivity and restoration. In the situation of the caregivers, the focus among these three dimensions was directed mostly on productivity. In a 12 hour working day, the sphere of productivity was covered, but when travelling time and their duties towards their dependents at home were considered, they definitely had less than 7 hours sleep, which neglected the sphere of restoration. They also had hardly any time for activities which were enjoyable to them, which could heighten work stress (Ahmad *et al.* 2011:517). Even on their off days, they had to run their households (cf. 4.3.3.1; p115), leaving little time for restoration and pleasure.

It was evident from this category that the caregivers' work schedule added to the burden of care and that the travelling methods and time of travel intensified their stress levels.

4.3.1.3 Training

The level of education and the training the caregivers received had to be examined to indicate whether they were properly equipped for the job that was expected of them as well as the high demands thereof. Therefore, background on their formal educational levels is given, followed by a discussion on the job-specific training that they received.

- **Formal educational level**

Five of the caregivers working in the SCU at Greenacres RCH (62.5%) matriculated, two (25%) completed Grade 11 and one (12.5%) completed Grade 7. No post-school training was engaged in.

Table 4.12: Formal education (n = 8)

Grade Completed	Frequency	%
Grade 12	5	62.5%
Grade 11	2	25%
Grade 7	1	12.5%

From Table 4.12 it is evident that only five of the eight caregivers (62.5%) reached the optimal level at secondary level. The caregivers did not have any post-school (i.e. specialised training/diploma) qualifications for the job. Taking this into consideration, it can be concluded that the caregivers had an educational disadvantage to perform this complicated job of caregiving.

- **In-service training**

Taking a look at the job-specific, once-off, in-service training sessions it appears not to have equipped the caregivers to perform their duties effectively, which added to the burden of care. The following discussion aims to provide a picture of the perceptions of the caregivers towards their job requirements as well as their perceptions about the feasibility of the training and the practical application of the knowledge pertaining to the in-service training they received.

The causes of stress that the caregivers indicated included inadequacy to perform the job. They reported that their job was difficult and they experienced insecurity in the handling of residents which caused stress.

“Kyk soos ons by die eenheid ons werk met die mense wat moeilik is en swak”

“Want ons werk met moeilike pasiënte.”

“Ja jy kry die stres, want die eerste ding is (counts on her fingers) doen jy die regte, doen jy nie die regte nie.”

The quantitative evidence in Table 4.8 (Column 2) indicates that further insecurities were felt by the caregivers relating to the practice of facilitating independence. Therefore, they experienced strong feelings of inadequacy apparently related to the fact they felt they were insufficiently trained to do their job. These feelings of inadequacy led to increased work stress; thus, exposure to increased training opportunities could be a start for counteracting feelings of inadequacy.

Research confirmed that deficient knowledge and perceived inadequate training could be a source of stress for the caregivers and that dementia training is one of the best ways to reduce stress for caregivers working with people with dementia (Chenoweth *et al.* 2010:156-167; Park 2010:136).

Apart from feeling inadequately trained to do their jobs, the caregivers indicated that training was not always feasible. There was a perceived discrepancy between learned information and the expectations of the person-centred care programme and the feasibility thereof.

“Die wat ek nie doen nie is as die boek sê as die inwoners was in die bad, moet ons as hulle nie wil bad nie moet jy ook uittrek en saam met die inwoner in die bad klim sodat die inwoners kan sien jy wil bad, maar ons kan dit nie doen nie.”

“Ons probeer om daar by eenheid te doen. Ons kan nie alles doen nie want partykeer die boek (training) sê so en jy kan nie alles by die boek (training) volg nie want daai mense regtig hulle is difficult.”

One of the caregivers who felt very strongly about the lack of feasibility of the training also contradicted her own statements by indicating that the training was valuable to provide the knowledge. She therefore valued the knowledge, but did not apply this knowledge practically.

“... by die Alzheimer opleiding het ons geleer hoe tree die mense op met Alzheimer.”

When the caregivers do not view what is expected of them as feasible, causing lack of power over their job which adds to work stress (Ahmad *et al.* 2011:516) and limits job satisfaction (Van den Pol-Grevelink, Jukema & Smits 2012:227). Ayalon, Arian, Bornfeld and Beard (2009:124) as well as Hung and Chaudhury (2011:11) comment that training is required and essential for all caregivers to obtain insight into residents with dementia and their behaviour in order to provide person-centred care. Furthermore, Zimmerman *et al.* (2005:103) report that trained caregivers are more prone to provide person-centred care. Therefore, the conclusion can be made that although the caregivers received training, they did not apply these principles practically.

Some caregivers believed that they did apply what they have learnt at the training in terms of person-centred care.

“Sr. Pretorius, partykeer sy, sy gee vir ons die opleiding. En ons gaan en ons, ons doen dit.”

Although this was their perceptions, their focus was not on person-centred care, but on the everyday routine and their application of these principles was dependent on and restricted by the routine.

“Ja ek dink ons doen almal alles. Ons het ‘n roetine vir elke dag en daai roetine bevat als wat ons geleer het en moet doen vir die pasiënte.”

Deelnemer: *“Die ander, die ander dag ons is net moeg of die tyd is min.”*

Navorsers: *“Hmm, okay?”*

Deelnemer: *“So ons doen, ons doen vir hulle dat ons kan tjaila.”*

Therefore, it can be concluded that the caregivers believed that they applied the principles that they learned at the training. These principles, however, was not directed at person-centred care, but was dependent on the routine within the SCU. The strict adherence to the routine is in complete contrast with the person-centred care philosophy stating that the boredom of a routine should be counteracted by spontaneity (Eden Alternative 2010b:18).

Throughout Theme 1 it became evident that the role of the caregivers within the organisation pointed towards an intensively increased burden of care in terms of the nature of the job, their workload and work schedule and the training that they received. In Theme 2 the focus will be on the influences caused by the work environment.

4.3.2 THEME 2: WORK ENVIRONMENT INFLUENCES

Theme 2 consists of the perceptions of the caregivers regarding the factors that influence their working environment. This theme is divided into the following three categories: the organisation, the family of the residents and public opinion. Theme 2 illustrates the influence of these factors on the caregivers and the burden of care that they experienced.

4.3.2.1 The organisation

As previously discussed (cf. 2.2.1; p14), the culture in a RCH is determined by the organisation itself and all of the employees are driven by this organisational culture. Therefore, it is critical to discuss the factors that influenced the relationship between the organisation and the caregivers. These factors were a task-focused organisation, recognition and feedback to employees, the opportunity for caregivers to take initiative, conflict in the workplace and power of authority. These factors not only influenced the relationship between the organisation and the caregivers, but also impacted on the burden of care experienced by the caregivers.

- **Task-focused organisation**

Considering the routine and regimes followed in the SCU, the caregivers identified both advantages and disadvantages. It is important to take note that not only a certain sequence of tasks was followed, but the tasks were also associated with certain times of the day, causing more stress in terms of time constraints (i.e. tasks associated with oral hygiene should take place between breakfast and tea time). The researcher noted within certain settings in a RCH, the time constraints to do certain tasks (i.e. brushing the teeth of the residents) resulted in methods to spare time, but which violated the residents' dignity (i.e. using the same toothbrush for more than one resident).

However, in the caregivers' opinion there were advantages and disadvantages to a fixed routine. The first advantage was that the caregivers were of the opinion that the residents experienced less memory problems within a fixed routine compared to when there was no fixed routine or when they were exposed to new activities. For example, the actual events in the SCU depict that the residents were bathed at 04:00 in the morning, while this was not part of their routines before accessing the RCH. Therefore, the caregivers did not take the residents' history and previous regimes into account, causing a negative impact on the memory of the residents, as discussed in Theme 6 (cf. 4.4.1.5; p165).

“Die ander rede is dat ons wil nie hê die pasiënte te veel moet blootgestel word aan verskillende goed nie, dat hulle meer kan onthou as hulle dieselfde roetine elke dag gebruik.”

“Ek dink die inwoners is al gewoond aan hulle roetine. Dis hoekom ons dit nie verander nie.”

The quantitative data in Table 4.8 (Column 1) displays the reasons why the caregivers did not use their initiative in the performance of daily tasks with the residents. The fifth most important reason was that the memory of the residents was better preserved when a fixed routine was followed. Although this reason was ranked very low (fifth out of ten), the fact that they recognised the routine as a reason for not taking initiative, was important and confirms the qualitative evidence regarding their beliefs that a routine maintained the memory of the residents and was therefore advantageous for the residents. Therefore, the conclusion can be made that the caregivers believed in these two advantages of a routine, causing them to follow this routine – which contradicts person-centred care.

Literature appears to favour a relaxed regime to support a more home-like environment for residents. For literature accessed, only Kada *et al.* (2009:2386) found that 93.1% of the caregivers were of the opinion that a firm routine is very important in dementia care as it may enhance memory. Harmer and Orrel (2008:553) confirm that a routine can be favourable to enforce meaningful activities, but stresses that it can also be harmful to residents, causing more boredom – which should be counteracted with spontaneity (Eden Alternative 2010b:18). Harmer and Orrel (2008:553) and Power (2010:52) also indicate that a routine caters more for the needs of the caregivers and organisation instead of the residents and therefore, these routines and regimes often violated residents in a RCH. In the opinion of the researcher the strict routine on the unit mostly fulfilled the needs of the organisation, showing less regard to the needs of the residents and therefore held little advantage for the residents.

The above findings were further expanded by caregivers' opinions on the disadvantages of a routine. The caregivers explicitly indicated that the routine restricted them in their work. It is evident that the caregivers were restricted by the routine expected by the professional nurses.

“As jy soontoe gaan om te gaan werk, kry jy sekere uhm ... volgorde wat jy moet volg.”

“Miskien hy is moeg, né, hy slaap op die stoel. Ek moet vir haar bietjie opstaan dat hy wakker maak dat hy kan drink, hy kan eet of drink.”

The caregivers also reported that the strict routine that was followed in the SCU was unrealistic, especially in terms of the time that the residents were expected to wake up in the morning.

“Want hulle word so vroeg wakker gemaak, so vier uur wakker om te was, en dan moet hulle wag vir agt uur om te eet.”

“Die pasiënte is moeg in die oggend omdat hulle weet dat hulle nog eintlik moes geslaap het.”

In support of these disadvantages listed by the caregivers, Power (2010:52) states that the general culture in RCH's enforced by the organisation is task-focused and the main influence on the caregivers. According to Kitwood (2000:7) it is the organisation that determines the principles for behaviour. Therefore, if an organisation is not focused on person-centred care, the result will be that person-centred principles will not be part of the organisational culture and the caregivers will follow with behaviour relevant to the dominating culture. The expected behaviour within the culture will therefore become a habit to all of the caregivers, not because they follow each other's lead, but because they follow the values and beliefs of the organisation (Eden Alternative 2011:20). Therefore, although the caregivers were restricted by the unrealistic routine, it was a part of the organisational culture with which they

had to comply. This occurrence restricted the control that the caregivers had over their job and therefore increased the burden of care (Ahmad *et al.* 2011:515-516). Verbeek *et al.* (2011:7) actually recommends that staff working in small care facilities should experience more independence and freedom in deciding the day schedule. They should be allowed to plan the day according to the individual preferences of the residents, causing the work to be less challenging and strenuous. They could then enjoy the personal touch that they are allowed to give. Consequently, not only could a strict routine be harmful to the caregivers, but also to the residents. Hung and Chaudhury (2011:6) report that an unrealistic, inflexible routine that restrict residents' needs from being satisfied take away their control over their actions and leave them powerless and aggressive.

Therefore, the conclusion can be made that the organisation facilitated a strict and unrealistic routine in the SCU for which the caregivers could identify two advantages, but moreover this routine increased the burden on the caregivers as they had to comply with something with which they sometimes did not agree with.

- **Recognition and feedback from superiors**

It appeared that in the SCU it was very important for the caregivers to receive positive feedback from superiors and to avoid situations where their behaviour could elicit negative feedback. It was especially important for the caregivers to receive positive feedback from the professional nurse. Therefore, the autocratic management system within the traditional model is clear in this context.

Navorser: "*Dan hoe voel jy dan as sy dit vir jou kom se: 'Baie dankie?'*"

Deelnemer: "*Baie bly.*"

Due to the autocratic management system, the conclusion can be made that positive feedback was of great importance to the caregivers. According to Hung and Chaudhury (2011:11) it is of great importance for the residential care facility

to recognise the caregivers by making them feel appreciated and by providing positive feedback. Literature indicates that caregivers who receive more positive feedback experience lower levels of stress (Abualrub & Al-Zaru 2008:233; Albertsen, Rugulies, Garde & Burr 2010:87-88).

It also appeared that the caregivers' main motivation for doing their work correctly was to impress the professional nurse and to avoid getting into trouble. Adhering to a strict regime associated with list of chores that focuses mainly on the physical health of the residents does not address the well-being of residents comprehensively. Thus, caregivers were forced to operate within the task-focused boundaries of the organisation (to work precisely and accurately) and therefore the personhood and psychological welfare, as the very essence of person-centred care, are easily neglected.

“Suster gaan mos ook daar rondtes doen kom kyk en die rondtes doen om te kyk of het jy werk presies.”

Organisations where physical and medical care of residents is merely the foundation on which to build person-centred care strategies are in stark contrast to organisations where procedures associated with physical care dominate the care focus. When nursing care rather than comprehensive caregiving are inherent to the organisational structure, caregivers may not be commended for promoting individual dignity and participation of residents, but clinical work tasks could easily cause stress symptoms and therefore increase the burden of care (Albertsen *et al.* 2010:87-88).

It is therefore evident that the need of the caregivers to receive positive feedback and to avoid negative feedback, kept them complying only to the physical care standards set by the organisation, and so adhering to the traditional model of nursing care.

- **Need and opportunity to take initiative**

This discussion regarding the need to take initiative illuminates the discrepancy between the willingness of the caregivers to take initiative versus following the lead of the organisation. Another focus point is that the caregivers also showed discrepant perceptions about the opportunity granted to them to take initiative within the organisation.

Concerning the need and willingness to take initiative, it was evident that the caregivers were willing to initiate new methods when they felt that they were skilled to do it.

“Ons het op ‘n kursus gegaan waar ons geleer het hoe om met mense met Alzheimer te werk en ek self kan ook met nuwe dinge kom as ek sien dit sal die pasiënt help.”

“Met dies wat kan kan jy nuwe goed probeer soos byvoorbeeld om hulle te vat en um dan vir een van die inwoners te vat en te sê “kom ons gaan was gou die koppies, ons gaan nou vir julle koel drank ingooi” maar net met die wat kan.”

Another view was that it was easier when someone else initiated new methods that could be followed.

“... dis beter as iemand anders kom en sê: ‘O, ek sien julle doen elke dag so’. As iemand anders kom dan sê: ‘Kom kom ons probeer so maak’, dan doen ons dit.”

Therefore, some caregivers felt able and skilled to assess a situation and initiate new methods, but for others it was not that easy.

According to literature, the organisational culture guides the behaviour of the caregivers and all of the employees and therefore the caregivers operate within the boundaries of the culture and although there will be small attempts, they will

not be prone to take initiative (Eden Alternative 2011:20). Therefore, if the organisational culture at Greenacres did not change, the small efforts of the caregivers to take initiative would not be sustainable against the force of the organisation.

Some statements regarding the perception of the caregivers about the opportunity to take initiative were positive and others were negative. Some caregivers reported that there was an opportunity to take initiative within the organisation.

Navorsers: *“So dink jy hulle (management) sal dat julle dit anders doen as, as ...”*

Deelnemer: *“Ek dink hulle sal.”*

The majority of comments illuminated the fact that the overall perceptions of the caregivers were directed towards the lack of opportunity within the organisation to take initiative. There were four aspects that demanded the attention of the researcher. The first was that although the professional nurse allowed the caregivers to take initiative and do activities according to their own methods, the condition was that the caregivers had to take responsibility for the risks (i.e. the risk of falling or other injury) that were involved, causing them to be scared to take initiative. Therefore, the caregivers did not take initiative because they felt that the organisation did not encourage them to do so.

“Sy sê toe sy daar in die eenheid gaan werk het het sy goed so gekry, hulle het daai maniere gebruik en elke keer as jy met ‘n idee vorendag kom dan sal hulle vir jou sê wat as die pasient nou seerkry dan gaan dit op jou wees. So dan doen jy dit nie.”

It also appeared that the professional nurses got upset when the caregivers wanted to take initiative, also indicating a lack of support from the organisation to generate new ideas.

“As die suster vir ons iets vra om te doen en ek wys sê nou maar vir die suster omdat ek ‘n familielid het met dementia. Ek verstaan sekere goed van dementia, dan sal die suster kwaad word net omdat ek iets gesê het wat teen haar idee is, net oor die feit dat sy die suster is.”

The following excerpt indicates an instance where a caregiver experienced negative emotions when the professional nurse dismissed her ideas.

Deelnemer: *“Ek voel sleg.”*

Navorsers: *“Hoe sal jy graag wil hê moet dit wees?”*

Deelnemer: *“Ek sal daarvan hou as die suster sal verstaan dat ek ook iets weet van dementia en dat my idees ook goed sal wees vir die pasiënt.”*

Lastly, in addition to the lack of support from the organisation to take initiative, the caregivers mentioned a CCTV camera that was used in the SCU to monitor them. They were scared of the camera and to try new methods for which they could be criticised. From this opinion of the caregivers it is also evident that there was a misconception of the use of the camera as it could potentially also protect them when unjust claims were made.

“Ja as daar fout is dan gaan Sr. Pienaar daar by die kamera en kyk vir jou.”

The quantitative data further confirm this in Table 4.8 (Column 1) and indicates that the third most important reason (out of ten listed) for not taking initiative was that caregivers felt they were not granted the opportunity at Greenacres to be creative and to try new things. They only had to do what was expected of them (mostly according to the medical care perspective). In Table 4.8 (Column 2) the caregivers indicated that the most important reason that they did not encourage independence was that they were afraid to try new methods with the residents that could be criticised by the organisation. The overall perceptions of the caregivers were that they were not granted the opportunity to take initiative.

According to Hung and Chaudhury (2011:6) it is crucial for the organisation to support the caregivers effectively. The research of Castle and Decker (2011:631,638-639) shows that consensus management (which implies that the caregivers' opinions and ideas are taken into account) is more effective in quality assurance than any other leadership style. Consensus management is the management style which is most compatible with person-centred care, because the individual needs of the residents are a priority, while an autocratic management style is in contrast to person-centred care (Eden Alternative 2010b:25,30; Fagan 2003:138). Power (2010:52) agrees that the organisational structure in a RCH often undermines and belittles the insight of the caregivers. It should be the role of the professional nursing staff to provide mentorship and encourage the caregivers (Kada *et al.* 2009:2390). Chenoweth *et al.* (2010:164) emphasise the importance of facilitating learning of the caregivers in an environment where they are respected and not criticised.

- **Conflict**

The caregivers reported that there was no conflict between the members of the multi-disciplinary team in the SCU,

Navorsers: *“Is daar, is daar bakleiery met die susters en die multi-dissiplinêre span?”*

Deelnemer: *“Huh uh, nee.”*

“Daar is nie sulke bakleiery nie.”

The quantitative data in Table 4.8 (Column 1) proved to be discrepant with this statement. This table indicates that the second most important reason that the caregivers did not take initiative was because of conflict situations between the team members in the SCU. It also appeared that they were frequently criticised. With the qualitative and discrepant quantitative data taken into account, the conclusion can be made that the caregivers did not want to admit that there was sometimes conflict between them and the professional nurses.

By denying these conflict situations, the caregivers might have evaded the topic as they did not want to put the SCU in a negative light.

Literature (Almost, Doran, McGillis Hall & Spence Laschinger 2010: 989) confirms that conflict in the workplace is unavoidable and therefore, if a person denies this, they may not be open to the learning and growth opportunities provided by conflict.

- **The power of authority**

All the factors of the task-focused organisation, the lack of opportunity to take initiative and especially the strong need of the caregivers to avoid negative feedback create the impression that the caregivers would view the dominant influence on their daily routines as the organisation's managerial structure. Instead, caregivers reported that their first priority in the day-to-day dealings were the residents.

“Nee, ek sal eers die tande borsel, want ek is daar oor ouma, nie vir Sr. Pienaar nie.”

“Nee, ek moet ... ek sal eers die tande borsel, dan ek sal by suster gaan, ja.”

“Nee, ek sal die tande borsel, want ek is daar oor ouma, nie vir Sr. Cronje nie.”

In accordance with the qualitative data, the caregivers indicated, as reflected in Table 4.13 and Table 4.14 that the residents were their first priority.

Table 4.13: Influence of nursing staff on the caregivers' application of independence (n=8)

Response	Frequency	%
Not influenced by authority	8	100%
Influenced by authority	0	0%

Table 4.14: Influence of the manager on the caregivers' application of independence (n=8)

Response	Frequency	%
Not influenced by the authority of the manager	6	75%
Influenced by the authority of the manager	2	25%

Although this evidence indicates that the caregivers are more directed to the needs of the residents than the needs of the organisation, it might be fair to say that this qualitative and quantitative data might not be a true reflection when viewed against the discussions of the task-focused organisation, lack of opportunity to take initiative and need of the caregivers to avoid negative feedback. When viewed in the light that the culture of an organisation, which is determined by the organisation itself (Kitwood 2000:7; Eden Alternative 2011:20), it is difficult to believe that the caregivers did prioritise the needs of the residents above the needs of the organisation.

This category highlighted that the unrealistic routine, lack of positive feedback and the lack of opportunity to take initiative increased the burden of care. The caregivers were not open to the admittance of conflict situations within the SCU and wanted the researcher to view the SCU in a positive light.

4.3.2.2 Family of the residents

This category aims to describe the family of the residents as an external influence and offers a discussion of the relationship between the caregivers and the family. Therefore, this category discusses the unrealistic expectations of the family towards the caregivers and vice versa that potentially could cause misunderstandings

- **Unrealistic expectations of the family**

Misunderstandings and unrealistic expectations of the family focused mainly on two areas. The first was the high demands of the family with which the

caregivers had to comply and the second was that the caregivers felt that the family blamed them when residents passed away.

It became evident that the family complained and gave orders to the caregivers without having regard for the circumstances in the SCU. They had to fulfil the requests of the family to avoid being in trouble and therefore this was a strong cause of stress for the caregivers. Secondly, the caregivers were of the opinion that the family blamed the death of the residents on the caregivers, which also caused stress and made the caregivers feel unappreciated and useless.

Navorsers: *“Wanneer kom jy in die moeilikheid?”*

Deelemer: *“Die ander uh ... pasiënt se kinders hulle. Dis hoekom ek sê miskien hulle verstaan nie wat gaan aan daarso ...”*

“... kla as die persoon dood gaan, ene sê ons doen nie ons werk nie.”

“... jy sal jou beste doen om iemand te help, en dan sal hulle nog steeds kla by die suster en dit laat jou voel of jy niks werd is nie. Niks reg doen nie.”

Edberg, Bird, Richards, Woods, Keeley and Davis-Quarrell (2008:238) confirm that the family often have a limited knowledge and understanding of dementia and therefore also of the circumstances within a SCU. This is the cause for them often blaming the caregivers for factors that are out of their control or unreasonable (Edberg *et al.* 2008:238). The unrealistic demands of the family cause work stress for the caregivers and apart from having a lack of control over their work, this also caused them to feel unappreciated (Park 2010:137). In a caring environment where a person-centred care approach dominates, the family should be part of the care approach and involved in many aspects of the day to day running, activities presented and decision making of a unit. When family do not feel they have a role, they often act as ‘protectors’ of the residents

in a negative capacity because they are outsiders and not involved enough to also take responsibility for the QoL of staff and residents (Tobin 2000:15).

- **Unrealistic expectation of the caregivers**

But it is not only family members who have unrealistic expectations. The use of restraint is one factor where caregivers were unable to relate enough to the situation of family members. The caregivers expected the family to understand why the residents were being restrained and to comply with this procedure.

One of the main causes of conflict between the family and the caregivers was the issue of restraint. The caregivers reported that they restrained the residents with the consent of the professional nurse to keep them safe, but that the family was against the use of restraints. According to the qualitative evidence, it was definitely important for the caregivers that the residents sit still and be restrained to keep them safe.

“Want hulle (the family) baklei as hulle kry ons sit hulle by die tafel wat hulle in die stoel hou. Hulle soek nie daai tafel eintlik nie.”

“Ek sal nie sê by die susters nie, die susters hulle verstaan, maar as hulle sê die familie soek nie daai (restraint).”

“Partykeer ons los vir hulle, hulle gaan uit daarso, hulle sal val daar buite. Ons het nie tyd om hulle te kyk daar buite nie.”

“As suster sien iemand miskien loop rond, dan sy gaan sê: ‘Brenda, jy moet agter by haar loop, want ons is bang sy gaan val, sy gaan seerkry.’ Ja. Nou hulle moet stil sit.”

The quantitative evidence in Table 4.15 indicates that the caregivers perceived sitting still as a low priority for the family of the residents (the fifth of out of eight

priorities listed) and supported the notion that the family did not view the need for residents to sit still as a priority.

Table 4.15: The family's priorities for the residents (n=8)

Ranking		Rank value
1	To be clean and hygienic	1.0
2	To have enough to eat and drink	2.0
3	To receive emotional contact	3.0
4	To participate in activities	3.4
5	To sit still	3.9
6	To be independent	3.9
7	To rest	4.5
8	To make choices	4.5

More quantitative evidence in Table 4.16 shows that the caregivers indicated the person-centred care model to be priority to the family and confirms that the family would be against restraint if they wanted the personhood of their loved ones to be preserved.

Table 4.16: Caregivers' perceptions about the family's priorities for the residents: the importance of person-centred care (n=8)

Response	Frequency	%
Person-centred care	8	100%
Medical care	0	0%

Therefore, the family wanted to preserve the personhood of the residents and were against restraint, but the caregivers justified their use of restraints as a safety precaution. This discrepancy caused conflict and stress between these two parties, increasing the burden of care for the caregivers.

Restraints are in direct violation of a person's human rights and most countries take legal action against care facilities that still use this e.g. UK (United Kingdom 2005:6-7). Du Toit and Surr (2011:53) confirm that residents in South Africa are often restrained, which restricts their ability to participate in activities that are meaningful to them. Ayalon *et al.* (2009:120) report that caregivers use restraint of the residents more often than the nursing staff. Aggressive residents (Nakahira, Moyle, Creedy & Hitomi 2008:7-8) and residents who are prone to getting hurt have a better chance to be restrained than other residents

(Edberg *et al.* 2008:240). As previously discussed, the Eden Alternative (2012:4) philosophy stipulates that behaviour is based on the attitudes, beliefs and values of the residents; therefore, by considering their life stories, perceived problem behaviour will disappear without the use of restraint. This literature is also supported by Dementia Care Australia (2012:online), which indicates that behavioural problems are actually stress reactions of the residents. These reactions occur due to the way they are handled within the RCH and therefore perceived behavioural problems will from this point onwards be referred to as stress reactions.

- **Misunderstanding**

To fully understand the different interpretations of the actions of another human being, one needs to understand the context of the life story of that human being (Eden Alternative 2010b:13). A misunderstanding that occurred on the part of the caregivers was that they felt criticised when the family brought food as gifts for the residents. The caregivers perceived this to be an act of the family to feed the residents (implying that they were not well fed), although the family showed their love practically by the use of gifts. The family perceived this action as caring while the caregivers experienced the action as critique.

“Hulle, hulle weet mos hulle kry vrugte elke dag. Hulle eet, maar hulle bring die ander kos.”

According to Hung and Chaudhury (2011:3) caregivers confirm that family bring extra food as gifts. Because caregivers and residents are often from different cultural groups, one should remember that the type of gift might cause confusion as it is not viewed the same by different cultures (Campinha-Bacote 2002:182; Kai *et al.* 1999:618).

This category indicates that there was role conflict between the caregivers and the families of the residents with the cause being misunderstanding and unrealistic expectations from both parties. Boise and White (2004:15-18) indicate that conflict between family and caregivers can easily result from the

family's participation in direct caregiving, but that it is very important to involve the family in the care-giving process for the benefit of the resident and person-centred care.

4.3.2.3 Public opinion

In this category, the caregivers highlighted that public opinion influenced the status of the job and also the attitudes and the feelings of pride that they experienced in their work.

It was illuminated by the caregivers that the opinion of the public was that caregiving in a hospital deserved a higher status than working at an old age home.

“As jy in ‘n hospitaal werk as dit ‘n belangrike werk is maar as jy by ‘n ouetehuis werk sien hulle dit as nie belangrik nie.”

Although this resulted in caregivers being embarrassed by their job,

“Hulle sê nee, jy’s, jy’s ... jy’s jonk, hoekom werk jy by die ouetehuis? Hulle maak jou nie moeg nie? Ja. So, so ... so ons kry skaam.”

They admitted that they would have been proud of the job that they are doing had it not been for the opinion of others.

Navorser: *“En as dit nie vir die mense was nie, sou jy nogsteeds skaamgekry het dat jy daar werk?”*

Deelnemer (laughing): *“Nee.”*

Navorser: *“So is jy, is jy trots dat jy daar werk?”*

Deelnemer: *“Ja.”*

Therefore, it is evident that the public did not have high regard for the very important job that the caregivers were doing, causing them to feel embarrassed.

According to Priebe (2004:81-82) as well as Biernacki (2009:14), mental health and well-being is not an appealing field to be working in. Countries in Europe do not attract staff with any qualifications in the field. Although this often is the case, Kitwood (1997:111) is of the opinion that increased opportunities towards training in dementia care will lend status to the profession. Therefore, the caregivers should be trained professionally to successfully perform their job and to earn the job status in the community that they deserve for their hard work.

In summary of Theme 2, it was pointed out that there were more factors that caused heightened work stress and therefore an increased burden of care. The work environment influences relating to the organisational culture, the discrepant views between the families and the caregivers and the public's low regard for the job of the caregivers were all factors that lead to an increased burden of care. Theme 3 is a discussion on the caregivers' roles outside of the work area.

4.3.3 THEME 3: ROLES OUTSIDE OF WORK

Theme 3 is a discussion of the roles outside of work and is combined into only one category: the home circumstances of the caregivers. It is important to have an understanding of their home circumstances so as to determine the potential influence thereof on their work circumstances and vice versa.

4.3.3.1 Home circumstances

The factors that were taken into account regarding the home circumstances of the caregivers were the number of people that were dependent on them and the influence of their dependents on their working circumstances.

- **Provision for dependents**

It follows from Category 1 of Theme 1 (cf. 4.3.1.2; p87) that the caregivers were generally discontented with the salary that they received. Therefore, it is important to discuss the influence of the salary constraints on their home circumstances. Initially, background is provided regarding the number of dependents that the caregivers had to provide for, followed by the qualitative and quantitative evidence of the caregivers' perception regarding their salary.

To provide the background, the quantitative evidence in Table 4.17 indicates that the caregivers had children who were dependents as well as other dependents ranging from mothers, mothers-in-law, brothers and sisters and grandmothers. The children were only indicated in the table if they were still living with and were still dependent on the caregiver.

Table 4.17: Number of dependents per caregiver (n=8)

Number of children	Number of other dependents	Frequency	%
2	3	1	12.5%
2	0	1	12.5%
2	0	1	12.5%
1	0	1	12.5%
3	0	1	12.5%
1	2	1	12.5%
2	0	1	12.5%
2	1	1	12.5%

All of the caregivers had children, the number of children ranging between one and three. Three of the caregivers took care of additional dependents. The number of these dependents also ranged between one and three per caregiver. The most dependents were five per caregiver (two children, three other family members).

It was evident from the qualitative evidence that the caregivers were not satisfied with the salary that they received.

“Altyd ek het die rede as die kinders vir my goeters vra: ‘Oe volgende maand’, maar dan volgende maand het ek die ander

problem Nou wat maak dit vir die kinders? Ek lieg vir die kinders.”

The quantitative evidence in Table 4.18 confirms that the residents were not content with their salary levels as none (0%) of them were able to provide for their dependents on their own and only five of the caregivers (62.5%) revealed that the income of all the family members were still not enough to provide for the dependents.

Table 4.18: Financial provision for dependents (n=8)

Provision for dependents (caregivers' income only)			Provision for dependents (combined household income)		
	Frequency	%		Frequency	%
Able to provide	0	0%	Able to provide	2	37.5%
Not able to provide	8	100%	Not able to provide	5	62.5%

Therefore it is evident that the consequences of the salary constraints were not limited to only the caregivers, but also impacted on their home circumstances and their dependents. This caused financial stress, which increased the burden of care.

Literature confirms (Ahmad *et al.* 2011:517; Chenoweth *et al.* 2010:165; Cooper & Marshall 1976:12; Faragher *et al.* 2004:193) that increased burden of care at home negatively influences caregivers' attitudes towards their work, which again heightens the burden of care.

- **Influence of the dependents on work circumstances**

There seemed to be discrepant opinions amongst the caregivers with regard to the influence that their dependents had on their work circumstances. Some had a negative perspective and some were positive.

The negative view related to their burden at home and their unbalanced lifestyle. Apart from caring for the residents during the day, the caregivers had

the responsibility at home to care of their dependents, leaving no time for themselves. Their unbalanced day and stress at home definitely impacted their lives and their work stress negatively.

“Hmm, partykeer as jy kom by die huis, nê, jy het baie goeters daar by die huis. Nou as jy by die werk kom jy het stres.”

“En die huis ook as jy by die huis kom ... jy is so moeg vir alles.”

Literature confirms (Pierce 1998:490; Pierce 2001:252), that it is important to have a balanced day programme to experience optimal QoL and this day should consist of activities for restoration, productivity and pleasure. Less restorative and pleasurable occupation due to unbalanced occupational behaviour (Pierce 2001:252) causes more work stress (Ahmad *et al.* 2011:515).

Although the time spent caring for their dependents could be a reason for increased stress levels at work, the dependents of the caregivers also proved to have a positive influence on their work situation. One caregiver had a family member with a disability and two caregivers had family members who were living with dementia. These three caregivers believed that they had more insight to analyse tasks and enforce positive emotions.

Ek weet hoe, because of my child. Ek weet hoe. Ek weet hoe omdat my kind so is en ek aktiwiteite vir hom moet opdeel.”

“Nee, die anders, hulle verstaan dit nie. Ek, ek het ... my ouma is ook ‘n dementia. Ja, ek verstaan hoe...”

The only literature that could be found to support this evidence was research by Farran, Fogg, McCan, Etkina, Dong and Barnes (2011:518) who report that caregivers develop skills according to the specific symptoms of the people with dementia that they care for.

- **Influence of work satisfaction on home circumstances**

The caregivers reported one factor that illuminated a positive influence between work and personal stress. Although most caregivers were influenced by their stress, *Selina* (who was also a caregiver to her grandmother with dementia) was of the opinion that being at work and interacting with the residents offered an escape from her home circumstances.

“Dis nie soveel stres, want as jy met stres van huis af kom en jy gaan werk toe dan om met die pasiënte te interact en te lag, dit maak jou eintlik beter en vergeet van al daai goed.”

It was evident that this caregiver’s role at work reduced her stress at home, especially when she communicated and used humour with the residents (evidence of person-centred care). It can therefore be concluded that when the caregiver used a person-centred approach, her stress at home was reduced. And therefore, her work circumstances had a positive effect on the stress that she experienced at home.

Although Edberg *et al.* (2008:238) report that it is problematic for the caregivers to separate home and work stress in dementia care, Karatepe and Uludag (2008:39) are of the opinion that the relationship between family roles and work roles people engage in, may have a positive effect on their emotions and therefore alleviate work stress as well as stress at home. Therefore, these two sets of circumstances kept influencing the other either in a positive or negative way and added to or reduced the stress levels that the caregivers had to endure.

To conclude this category relating to the home circumstances of the caregivers, it was evident that there were positive and negative factors. The stress that the caregivers experienced was caused by the fact that they were not able to provide for their dependents with the salary that they received. Furthermore, their unbalanced day programme that was caused by work and home circumstances also increased the burden of care. For some caregivers, the

work environment offered an escape from the burden experienced at home and alleviated the stress that they experienced at home. The caregivers who had dependents living with dementia or other disabilities felt more experienced and skilled to handle the residents living with dementia. Therefore, it had a positive influence on the working circumstances.

4.3.4 THEME 4: STRESS MANAGEMENT SKILLS

Throughout the course of Section B it became very clear that the caregivers experienced work stress as well as stress factors at home which increased the burden of care. The next step is thus to understand the caregiver's perception regarding their skills to manage their stress.

Some caregivers believed that they were not allowed to experience work stress, and therefore, suppressed their negative emotions. They tended to keep negative emotions to themselves in an attempt to control their stress levels at work due to the professional situation.

“Nou as jy daar werk, jy mag nie stres het nie...”

“Mmm en jy mag niks sê nie, jy moenie antwoord nie, jy moet net stilbly.”

“Gaan net bietjie uit die plek, bietjie asem gaan skep, as jy weer terugkom, dan is jy weer reg.”

The caregivers were of the opinion that 'mental health' leave was an accepted way to address work stress and that the professional nurse encouraged absence from work when the caregivers experienced stress which resulted in regular absenteeism.

“Nee, die suster sê ook as jy voel jy is baie moeg, bel net dan kom jy nie werk toe nie.”

“Ek sê partykeer want soos vandag hulle was mos twee by die eenheid, nou die ander een het nie opgedaag nie, nou jy sien?”

One of the caregivers reported a lack of opportunity in the SCU to express their negative emotions and felt relief after sharing her thoughts and feelings with the researcher.

“... maar dis ‘n lekker kans om te deel, sodat jy nie so met alles hoef te sit nie, maar daar (SCU) ons sit maar.”

Although the caregivers reported several ways that they tried to alleviate their stress levels, they did not specifically identify aspects relating to the knowledge or skills to manage their stress effectively. The excerpts above indicate that the caregivers used ineffective methods to handle their stress: suppression and absenteeism. These were the only methods that they appeared to know and tried to use, but due to the ineffective nature thereof, this increased their stress levels, which in turn increased the burden of care. It also became clear that they felt were not encouraged in the SCU to share their emotions.

Literature supports the fact that caregivers working in an SCU are under immense stress (Zimmerman *et al.* 2005:103). According to Gillespie, Barger, Yugo, Conley and Ritter (2011:576-577) the suppression of negative emotions, when caring for the elderly, is associated with dissatisfaction in the job and when the caregivers talk about their negative emotions it could possibly relieve stress more effectively. Therefore, the organisation should provide an opportunity for the caregivers to express their negative emotions to alleviate their stress levels. Cooke, McNally, Mulligan, Harrison and Newman (2001:132) report that to improve psychological well-being, social interaction and cognitive stimulation are an important part of intervention and therefore, taking leave to relieve caregiver burden and to improve psychological well-being could be a very short-term solution. Therefore, considering the high levels of work stress of the caregivers and their perceived inability to manage their work stress

effectively, it would be to the organisation's advantage to promote mastering of these skills

4.4 SECTION C: PERCEPTIONS ASSOCIATED WITH QOL, PERSON-CENTRED CARE AND OCCUPATIONAL ENGAGEMENT

In Sections A and B it became evident that the context in the SCU, the role as employee within an organisation, work environment influences and caregiver roles outside of work were all factors working together to cause immense stress for the caregivers. Now that the background and their circumstances have been explained, the description of the caregivers' perceptions relating to their caregiver role (Theme 5) is described. As indicated in Table 4.1, this section focuses on (a) describing the caregivers' pre-conceived ideas of occupational engagement, person-centred care and QoL for people with dementia and (b) exploring and understanding the caregivers' perception of a potential link between occupational engagement, person-centred care and QoL for people with dementia.

4.4.1 THEME 5: THE CAREGIVER ROLE

Aspects that predominantly could have an influence on the perceptions of the caregivers were associated with their role of providing care and their interpretations of what the organisation and family members expected them to focus on. Furthermore, the perceptions of the caregivers relating to the resident with dementia, their participation in activity, the residents' ability to experience positive emotions, independence and the resident as a unique individual are discussed.

4.4.1.1 Priorities of caregivers, the organisation and family

This first category of Theme 5 takes a closer look at the priority needs of the residents according to the caregivers, the organisation and the family. Although tasks associated with physiological care are important in a SCU, only a person-centred care approach could prevent the three plagues of loneliness, helplessness and boredom (which are the main problems for elders) from robbing the residents of their QoL (Eden Alternative 2010b:2; Fagan 2003:129). All three of these stakeholders perceived person-centred care as a tool to enhance care, but their priorities were tasks associated with medical care.

- **Needs according to the caregivers**

From the sets of qualitative and quantitative evidence, it could easily appear to the reader that the caregivers' main focus is upon person-centred care, but when contrasting quantitative evidence, a different perspective comes to light.

Within the qualitative findings the caregivers highlighted three particular needs of the residents. All of these are needs to be fulfilled by a person-centred approach. The first perception was that the residents wanted to do things in their own way.

“Ek kyk nou so, want hulle hou nie soos jy moet sê: ‘Kom ons doen dit’, dan sê: ‘Nee, huh uh, ek wil nie, by die huis ek doen so.’”

Secondly, they experienced that the residents became angry and were emotionally hurt when they were treated in a hasty manner.

“Huh uh, nee ek sal rustig hierso tande borsel, want vinnig jy gaan hom seer maak en bietjie kwaad maak.”

And thirdly the caregivers felt that emotional care is very important to the resident.

“Ek sê: ‘Kom, kom, kom gee vir my die drukkies’. Dan kom gee my die drukkies. Na dan gaan ons loop en sing by die gang dan is dit baie lekker vir haar.”

Confirming the qualitative evidence above, the quantitative evidence in Table 4.19 and Table 4.20 suggest that person-centred care was important to the caregivers. Additionally, Table 4.19 indicated that seven caregivers (87.5%) were of the opinion that the residents were in need of person-centred care and only one caregiver (12.5%) reported that the focus should be on tasks associated only with physical well-being.

Table 4.19: Caregivers’ perceptions about the importance of person-centred care for the residents (n=8)

Response	Frequency	%
Person-centred care is important	7	87.5%
Only medical care is important	1	12.5%

In Table 4.20 it is indicated that all of the caregivers were of the opinion that the residents liked to give and receive hugs, to laugh and to make conversation, suggesting that elements of a person-centred care approach were important.

Table 4.20: Caregivers’ perceptions about the need of the residents for emotional contact vs. not needing emotional contact (n=8)

Response	Frequency	%
Residents need emotional contact	8	100%
Physical care is the only priority in care homes	0	0%

However, Table 4.21 contradicts all of the abovementioned results and findings, as it provides evidence that the caregivers were of the opinion that the most important needs for the residents were to be clean and hygienic and secondly to have enough to eat and to drink. Clearly the focus here is on the physiological needs of the residents and is supported by a purely medical approach to care. The other options related to a person-centred care approach i.e. to receive emotional contact, independence, choices and activity participation (Baldwin &

Capstick 2007:89-90,223; Innes *et al.* 2006:i; Bell & Troxel 2011:4) were lower on the list and were therefore not top priority according to the caregivers.

Table 4.21: Most important needs of the residents according to the caregivers (n=8)

Ranking		Rank value
1	To be clean and hygienic	2.0
2	To have enough to eat and drink	2.4
3	To receive emotional contact	2.6
4	To rest	3.4
5	To be independent (to be provided with an opportunity to do for one self)	4.3
6	To make choices	4.4
7	To participate in activities	5.0
8	To sit still	7.0

The two main priorities of the caregivers for the residents were therefore focused on hygiene and feeding, meaning that their focus was not upon person-centred care, but rather on needs associated with the medical model alone.

“... so it is my duty to see ... that she is safe and clean, neat.”

Literature confirms that, although physical as well as the mentioned emotional needs were essential in the SCU (Hung & Chaudhury 2011:9; Kada *et al.* 2009:2386), physical care was more important to the caregivers than person-centred care (Harmer & Orrel 2008:555; Van Beek & Gerritsen 2010:1278). This conclusion was also illuminated in the way the caregivers practically applied care in the SCU. This ambivalent approach to care was confirmed in a study by Du Toit and Surr (2011:51) that indicated that just as affection is given to residents, they are also subject to *outpacing* (when care and input is too quick for the resident to respond to or participate), *withholding* (when staff do not respond to requests from residents), *intimidation* (when residents are verbally threatened by staff members) and *mockery* (when residents are made fun of). According to Hung and Chaudhury (2011:5), when they are exposed to these task-oriented relations between them and the caregivers, residents with dementia experience extreme negative emotions implying that this task-focused approach could be harmful to the residents.

- **Needs according to the organisation**

Along with the caregivers' priorities, the organisation's priorities also indicated person-centred care to be important, but it was also not a priority for them above tasks associated with physiological needs.

The caregivers indicated that emotional contact with the residents was important to the professional nurses and therefore that the residents' emotional needs were considered. This indicated that elements of the person-centred care approach were important to the organisation.

“Ek weet altyd as sy (professional nurse) inkom, sy gaan by hulle, groet hulle, gee vir hulle drukkie.”

“Hulle (professional nurse) gee hulle, hulle drukkies, hulle gesels met hulle.”

“Hy (professional nurse) wil hulle gelukkig hou.”

Confirming evidence in Table 4.22 indicates that person-centred care was important above the provision of medical care alone as seven caregivers' (87.5%) perception was that the person-centred care model was most important to the the organisation of the RCH. Only one caregiver (12.5%) indicated that only medical care was the most important to the the organisation.

Table 4.22: Caregivers' perceptions about the organisation's priorities for the residents: the importance of person-centred care (n=8)

Response	Frequency	%
Person-centred care	7	87.5%
Only medical care	1	12.5%

Although it appears that the organisation was of the opinion that a person-centred approach should be followed, the quantitative evidence in Table 4.23 indicates that the medical model was more important to the organisation than person-centred care. According to caregivers, the organisation's three main

priorities (which are basic physiological needs and therefore associated with the medical model) were: firstly to be clean and hygienic, secondly to have enough to eat and to drink and thirdly to get enough rest. The priorities associated with person-centred care i.e. independence and activity participation were listed last.

Table 4.23: Caregivers' opinion of what the organisations' priorities for the residents are (n=8)

Ranking		Rank value
1	To be clean and hygienic	1.5
2	To have enough to eat and drink	1.6
3	To rest	1.9
4	To make choices	3.3
5	To receive emotional contact	3.5
6	To sit still	4.0
7	To be independent	4.0
8	To participate in activities	5.1

It also came to light during the qualitative enquiry that proper feeding and hygiene were very important to the organisation confirming the evidence in Table 4.23. The professional nurses came to inspect (cf. 4.3.2.1; p99) if these tasks were done properly.

“As hulle nie wil eet soos die kos, ons maak vir hulle die vloeistowwe, jy sien? Ons los net nie vir die mense soos sy self se: “Suster daai een wil nie eet nie, ons moet nog ander planne maak dat die ouma kan iets in die maag kry.”

“En die susters sal elke oggend inkom om te kom kyk of almal skoon is.”

The qualitative and quantitative evidence show that the priority of the organisation was focused on hygiene and physical care. Although Van Beek and Gerritsen (2010:1278) found that these factors associated with the medical model are not as important to nursing staff as person-centred care, Du Toit and Surr (2011:49), indicate that the organisation in facilities often neglects the right of the residents to participate in meaningful activities when they are physically cared for. Physical care chores could easily be turned into opportunities for

engagement and independence in aspects of their daily activities. Therefore the conclusion can be made that although aspects of a person-centred approach (such as emotional contact) was important to the organisation, tasks associated with the medical model were the main priority. Considering that staff report feelings of hopelessness without support from the organisation (Hung & Chaudhury 2011:6,11; Jeon, Luscombe, Chenoweth, Stein-Parbury, Brodaty, King & Haas 2011:10) it is the role of the organisation to enforce a review of the foundational beliefs of the facility to bring forth a culture and structural change towards person-centred care.

- **Needs according to the family**

The third stakeholders are the family whose perspective (according to the caregivers) was in congruence with the perspective of the organisation and the caregivers. The caregivers reported person-centred care to also be important, but with tasks associated with the medical model to be the main focus and priority.

The caregivers reported that a person-centred care approach was important to the family.

*“Hulle is miskien hulle is, is ... is hulle ma of hulle is hulle pa.
Hulle moet daai drukkies kry, daai liefde, hulle moet dit kry.”*

*“... hulle gaan saam met Wilma stap en sing en dis baie lekker
vir Wilma. Nou jy kan sien Wilma was altyd lief om te sing.”*

Confirming this qualitative evidence, all of the caregivers reported as shown in Table 4.16 that a person-centred care approach through physical contact and favourite activities was more important to the family than the medical model without person-centred care. The importance thereof was illustrated by the family spending quality time with the residents, although some caregivers report that family members do not visit often (Park 2010:137) while family contact is important and meaningful for the residents (Boise & White 2004:15).

Although person-centred care and especially emotional contact was important to the family, Table 4.15 indicated the priorities of the family to be hygiene and proper feeding. The needs associated with person-centred care were therefore not priorities above tasks associated with the medical model.

Confirming qualitative evidence showed that the caregivers were of the opinion that the family were more focused on the medical model than person-centred care. The aspects of the medical model that were of importance to them are indicated in brackets.

“Want as die familie kom dan kry hulle die ma is vuil of ... dan baklei sy.” (hygiene)

“... as Yolandi inkom, sy kry die ouma hy sit by die stoel en slaap..dan word sy kwaad. As ons sien die ouma is moeg ons sit haar maar bietjie by die bed.” (rest)

“Dis belangrik vir die familie dat daar ‘n formele struktuur is.” (structure)

“Want hulle (family) is bang hulle kry seer as hulle te veel rondloop.” (safety)

This qualitative and quantitative evidence is confirmed by studies by Ducharme and Geldmacher (2011:1334) and Natan (2008:198) which indicate that the family are more directed towards the medical model than person-centred care. Research (Ducharme & Geldmacher 2011:1334; Kellett, Moyle, McAllister, King & Gallagher 2010:1708,1713) states that the task-focused framework of the organisation tends to leave the impression that the tasks associated with the primary care role of the family are no longer needed. Therefore, the family expect the organisation to provide the care associated with the medical model more than person-centred care.

Considering the above findings as well as supportive literature in this category the researcher realised that the caregivers' perceptions of their own, the organisation and the family's perceptions of the needs of the residents differed immensely from the expectations created by a person-centred care approach. Although the caregivers reported that person-centred care was important for all three of these stakeholders, it was not reported to be the priorities of providing care for the residents. The focus of all three stakeholders was on tasks associated with physiological well-being. Following these views of the three stakeholders, Natan (2008:198) found that the key priorities of the residents themselves were directed towards person-centred care. These needs were to be independent, trust between them and the caregivers and visits with the family.

4.4.1.2 Independence

The caregivers' perceptions regarding the independence of the residents living with dementia were based on two factors and will be described as such. The two factors are firstly, the value of independence and secondly, the restrictions towards the facilitation of independence.

- **Value**

It was evident from the qualitative and quantitative data that the caregivers acknowledged the value of independence for the residents. The three advantages that they identified were self-actualisation and dignity, enjoyment and the maintenance of abilities.

Firstly, the caregivers identified self-actualisation and dignity. They reported that there were residents in the SCU who expressed thankfulness towards the caregivers when they gave them the opportunity to be independent, which facilitated a sense of achievement and enhanced dignity.

“... want ek sien Susan hou daarvan om goed self te doen dan gee ek haar daai kans: “Susantjie, hier is die waslap en die seep gesmeer, was net jou boude gou.” Dan was sy en sê baie dankie en as ek loop sê sy weer: ‘Baie dankie, hoor’. Sy waardeer dit.”

The second value of independence that the caregivers identified was the need of the residents to be independent. Although the caregivers indicated that the declining abilities restricted independent task performance, they agreed that when independence was facilitated, the residents experienced enjoyment.

Navorsers: *“Dink jy die inwoners sal die lewe meer geniet as hulle take vir hulle self kan doen, soos om self gesig te was?”*

Deelnemer: *“Hulle wil dit graag doen.”*

Deelnemer: *“... Susan sy voel mos die ander dag sy kan vir haar was of self aantrek, sy wil nie dat ons vir haar help nie, jy sien?”*

Navorsers: *“Dan is dit vir haar lekker.”*

Deelnemer: *“Ja, dan is dit vir haar lekker.”*

These qualitative findings are confirmed by the evidence in Table 4.24. The results show that the majority (87.5%) of the caregivers recognised the enjoyment that resulted from independence and therefore they made a positive link between occupation and enjoyment, which is a determinant of QoL.

Table 4.24: Link between enjoyment and independence (n=8)

Response	Frequency	%
Residents enjoy independence	7	87.5%
Residents prefer that care is administered to them	1	12.5%

Keeping in mind that the caregivers were of the opinion that the declining abilities of the residents restricted independence (cf. 4.4.1.2; p130), the caregivers realised that independence should be facilitated to maintain the

current remaining abilities of the residents. If they were not granted the opportunity to be independent, they would lose the ability.

“As ons haar voer gaan ons haar aanmoedig op te hou self eet. Sy gaan gewoon raak dat mense haar altyd moet voer.”

It was evident that the caregivers indicated that a sense of achievement, enjoyment and the maintenance of abilities were advantages resulting from the opportunity to do tasks independently.

Literature (Luttenberger, Donath, Uter & Graessel 2012:838) confirms that the opportunity to be independent leads to an improvement in the mood of the residents, decreased regression of abilities. It is also reported that less stress reactions were observed among residents who were given the chance to be independent. Law (2012:41) also confirms the conclusion and perception of the caregivers that independence and dignity goes hand in hand.

- **Restrictions**

Although the caregivers showed some degree of insight into the advantages of independence, they did not facilitate independence continuously. In this part of the category, the restrictions towards the facilitation of independence are discussed. The first restriction that the caregivers identified was the heavy workload which referred to the volume of work and time constraints which restricted the facilitation of independence. This restriction is discussed earlier in this chapter (cf. 4.3.1.2; p87). The second restriction was the stress reactions of the residents which created an obstacle to the application of person-centred care (facilitation of independence). A very prominent restriction on independence that the caregivers indicated was the inability of the residents to be independent due to their declining abilities. This restriction was combined with the stress that the caregivers experienced due to the poor quality of task performance by the residents and the fear of negative emotions caused by unsuccessful task performance by the residents. Five more restrictions were mentioned by the caregivers that are also discussed in this category. These

restrictions refer to the safety of the residents, poor motivation of the residents, poor knowledge and skill of the caregivers to analyse activities and to facilitate independence, the influence of the organisation and the influence of the family on the facilitation of independence.

- Stress reactions

The caregivers' appeared to know the burden of care associated with the stress reactions of the residents that were observed through changing values and difficulty to handle the residents. This part is a discussion of the qualitative data along with the confirming and the contrasting quantitative evidence of the caregivers' perception regarding the stress reactions of the residents and person-centred care.

Firstly, the qualitative evidence indicated that the caregivers were of the opinion that due to dementia, residents' values changed.

“En as hulle vloek voor hulle kinders sal hulle verbaas wees en sê: ‘Ek ken my pa nie so nie, my pa het dit nooit gedoen nie, hy was ‘n kerk person.’”

The focus of the caregivers on the challenging behaviour had negative consequences for person-centred care. The caregivers were of the opinion that the residents became more difficult to handle than the other residents. With this occurrence they admitted to not have the skill to facilitate independence with these residents who were more difficult to handle.

“... hulle is so moeilik, jy weet mos.”

“Ek kan glad nie met hom nie, want hy wil nie saam werk nie. As hy so knyp dan knyp hy vas.”

Therefore, it can be concluded that independence was not facilitated when the residents showed stress reactions.

The quantitative data that supports these qualitative findings is indicated in Table 4.25 showing the three groups of consequences of facilitating independence. Three (37.5%) of the caregivers indicated that they believed that stress reactions were the consequence of facilitating independence. Therefore, it is clear that stress reactions were one of the main consequences of facilitating independence. The other two aspects of consequences were lack of motivation (25%) and the inability of the residents (37.5%).

It is once again important to note that the complete table is not discussed in this category, but that the applicable factors will be referred to further into the discussion of the chapter.

Table 4.25: Consequences of facilitating independence (n=8)

	Consequence	Frequency	%	Total %
Lack of motivation	The resident did not try to do anything	2	25%	25%
Inability	The resident tried to participate but could not succeed	2	25%	37.5%
	The resident could only do some of the steps, the rest had to be done by the caregiver	1	12.5%	
Stress Reactions	The resident hit the caregiver	2	25%	37.5%
	The resident yelled at the caregiver	1	12.5%	

In Table 4.8 (Column 1 & 2) the evidence contradicts the course of the discussion so far. Table 4.8 (Column 1) indicates that stress reactions (experienced by the caregivers as abuse) of the residents was the tenth and least important reason for not taking initiative and trying new methods with the residents. In Table 4.8 the caregivers indicated that stress reactions (also experienced by the caregivers as abuse) from the residents (4.2) were a low priority (fifth out of eight) reason for not encouraging independence. It is clear

from Table 4.8 that the stress reactions of the residents were not a priority reason for not facilitating independence and taking initiative. Therefore, the stress reactions of the residents did create an obstacle towards the application of person-centred care (facilitation of independence and taking initiative), although it was not the main reason. As discussed in Section A (cf. 4.2; p71) these reactions from residents were believed not to be deliberate, but part of the progression of dementia as a disease.

Literature confirms that stress reactions are expected from people with dementia who are living in RCH's, increasing the need for highly qualified staff members to be able to appropriately handle this behaviour (Isaksson, Graneheim, Astrom & Karlsson 2011:573; Margallo-Lana, Swann, O'Brien, Fairbairn, Reichelt, Potkins, Mynt & Ballard, 2001:41; Selbaek, Kirkevold & Engedal 2006:848). Literature also indicates that caregivers accept stress reactions as a part of the disease and therefore, a part of the job (Levin, Beauchamp, Hewitt, Misner & Reynolds 2003:34). This acceptance of stress reactions implies that they are not looking for solutions to the problem.

It is evident from literature that stress reactions of the residents causes low morale and stress for the caregivers, but can be counteracted by the provision of adequate support by the organisation as well as in-depth knowledge of dementia care (Astrom, Karlsson, Sandvide, Bucht, Eisemann, Norberg & Saveman 2004:413; Isaksson *et al.* 2011:577; Jeon *et al.* 2011:2; Park 2010:136; Miyamoto, Tachimori & Ito 2010:250). The occurrence of low morale causes low job satisfaction and the caregivers would not do anything outside of their job descriptions, hindering person-centred care.

The Eden Alternative (2012:4) and Dementia Care Australia (2012:online) support counteracting the problem and suggest that caregivers do not need to accept these stress reactions as a part of the job. They offer a solution which implies that the root of problem behaviour (e.g. aggression) associated with people living with dementia is unfulfilled needs of the residents. The stress reactions that they have are actually a way to express the stress that they experience and a way to communicate their unfulfilled needs. According to the

Eden Alternative (2012:4) behaviour is based on attitudes, values and beliefs and if the needs of the residents are met, stress reactions will disappear. Therefore, the caregiver should be familiar with the individual needs of the resident in order to fulfil them and to decrease problem behaviour (Kovach, Noonan, Schlidt & Wells 2005:136; Zeller, Dassen, Kok, Needham & Halfens 2009:6). This challenge offers a great opportunity for caregivers to develop personally by identifying the source of the stress reaction instead of focusing on the reaction itself (Dementia Care Australia 2012:online).

- Declining abilities

A very prominent perspective that came to light was the perceptions of the caregivers that the residents were old and weak and had no ability to perform any tasks. The focus of the caregivers was therefore on the decline of the physical and mental abilities of the residents with dementia that they cared for, rather than on the remaining abilities and the maintenance thereof. This focus on the inabilities of the residents caused a lack of opportunity for the residents to be independent.

“... they are having Alzheimer, they can't think for themselves, they can't think straight, we know that, so we do our best to ...we know that they are not okay, some of them they are mentally disturbed, they can't think straight. We help them because it is our duty and we have to.”

“Miskien die bene is ... hmm, wat moet ek se ... hulle is stokstyf, ne, hulle sal nie meer so ... soos ons ... ons, ons is jonk. Hulle, hulle kan nie.”

“Uhm, want, uhm jy weet mos die Alzheimer hulle word nie beter, hulle word elke dag bietjie swakker, maar ons probeer vir hulle te help.”

The problem with independence, according to the caregivers, was the poor quality of the tasks when residents tried to do something independently. The caregivers were of the opinion that if they facilitated independence of the residents, it increased their stress levels.

“Partykeer as hulle hulleself aantrek, dan sit hulle dit agterstevoor aan.”

“Partykeer, nie altyd nie, want hulle sal dit kan kam maar ons help daarvoor want hulle kan dit nie ordentlik kam nie.”

Navorsers: *“As julle dan alles vir hulle doen, dan is julle stres minder, verstaan ek jou reg?”*

Deelnemer: *“Ja.”*

“Ek wil sê hulle ... hulle gaan nie verstaan. As ons sê: ‘Ouma, doen dit, doen so’, hulle sal nie.”

Another belief that emerged from the data was that it was worse for a weak resident to try and not succeed, than to be helped from the start. The caregiver attempted to illuminate the weaknesses of the resident and her goal was rather to avoid negative emotions.

“Uhm ... hulle hulle kan, maar ek sê hulle raak gou kwaad as hulle nie iets kan doen nie. Of miskien hulle bêre die sleutel daar (showing with hands), hulle weet nie eers, oe dan raak hulle so bietjie aggressief, jy moet hom bietjie gelukkig maak en vir hom help.”

The Eden Alternative Associate Training (2012:6) confirms that residents sometimes do not try to participate in activities because they are feared, which increases helplessness.

Although independence was mostly not facilitated by the caregivers, they did not prohibit independent task performance when initiated by the residents.

“As ‘n pasiënt met iets wil help sal ons haar toelaat en haar nie laat voel sy is ‘n pasiënt in die eenheid nie. Ons sal haar los dat sy saam stap en vir die ander pasiënte kos gee.”

It was evident from the qualitative results that the caregivers were of the opinion that the inabilities of the residents restricted independent task performance. The poor quality of the tasks performed by the residents and the fear of failure and associated negative emotions for the resident caused heightened stress levels for the caregivers. The caregivers did not prohibit independence when initiated by the residents.

The quantitative results that are parallel to these qualitative findings consist of six sets of results portrayed in tables. Firstly, the three sets of results that contradict these qualitative findings are discussed whereafter the two sets of results that confirm these findings follow. One set of results portrays discrepant information and is presented last.

The confirming evidence in Table 4.26 displays a prioritised list of the activities that the caregivers thought to be most frequently done independently by the residents. The values (1=always, 2= sometimes, 3=never) (cf. 3.5.2; p52) were multiplied by the initial ranking position that the caregiver indicated. Therefore, the lower the ranking value, the higher the position of the activity.

These activities were in the first place, making the bed; in the second place was using the toilet; the third activity was brushing teeth; washing their hair was in the fourth place, just before shaving in the fifth place. Brushing hair was in sixth place followed by eating and drinking, washing and dressing in the last place. This table stresses that although the qualitative evidence indicated that the residents were not able to perform tasks independently, they had the ability to perform steps of the listed tasks.

Table 4.26: Ability of the residents to actively participate in activities of daily living (n=8)

Ranking		Rank value
1	Making the bed	0.5
2	Using the toilet	0.7
3	Brushing teeth	1.0
4	Washing hair	1.1
5	Shaving	1.5
6	Brushing hair	1.8
7	Eating and drinking	2.8
8	Washing	2.8
9	Dressing	2.9

More evidence that contradicts the qualitative evidence is portrayed in Table 4.7 which indicates that the caregivers were of the opinion that the residents themselves were the third most important role player in the establishment of QoL. This suggests that the residents had the ability to take responsibility for their QoL, which is in direct contrast with their view of people with dementia as people who were old, weak and unable to do things.

The last set of quantitative evidence that contradicts the qualitative findings is displayed in Table 4.27 which indicates that five (62.5%) reported that they did offer the residents the opportunity to be independent, implying that they were of the opinion that the residents had the ability to participate in independent task performance.

Table 4.27: Washing the residents vs. independent washing (n=8)

Response	Frequency	%
Helping them to wash themselves	5	62.50%
Focus on the standard of hygiene	3	37.50%

Therefore, the contradicting quantitative evidence suggests that residents were able to perform certain tasks (or steps of tasks) independently, that they were important role players in enhancing their QoL and that, therefore the majority of the caregivers did offer them the chance to be independent.

The first set of quantitative evidence that confirms the qualitative evidence is displayed in Table 4.8 (Column 2) which indicates the perceived reasons for not

encouraging independence. This table correlates with the qualitative data and indicates that the third (out of eight) most important reason was that the caregivers perceived the residents as old and weak without the ability to be independent, implying that they had to 'do for' the residents.

The second and last set of quantitative results that confirm the qualitative findings are indicated in Table 4.25 which shows that 25% of the caregivers experienced that the residents tried to do activities, but could not succeed and 12.5% of the caregivers indicated that the residents always had to be helped to do the steps of the activities. Therefore 37.5% of the caregivers indicated that the cause of restricted independence was the inability of the residents.

Therefore, the quantitative evidence that confirms the qualitative evidence suggests that the caregivers were of the opinion that the inability of the residents forced the caregivers to do tasks for them and not with them.

It is evident that the qualitative and quantitative evidence is in contrast, as are the different sets of quantitative evidence. Table 4.28 is a portrayal of the discrepant opinions of the caregivers regarding the ability of the residents to be independent and indicates that 50% of the caregivers were of the opinion that people with dementia did have the ability to be independent, while 50% of the caregivers said the opposite.

Table 4.28: Caregivers' perceptions about the ability of the residents to be independent (n=8)

Response	Frequency	%
Residents do have the ability to be independent	4	50%
Residents need constant support	4	50%

Therefore, considering the overall discrepancy in evidence, the researcher came to the conclusion that the caregivers were taught by the OT that independence was important and should be applied in person-centred care, but that it was not as such expected or enforced by the organisation. These discrepancies imply that the caregivers did not believe in the value of independence they were taught and that their attitude reflected that they could

not credit the value of the training they received as feasible (cf. 4.3.1.3; p95). It appeared that they knew that they were supposed to apply independence and therefore they answered the questions according to what they thought the right answer was according to the researcher, but their focus remained on the weaknesses of the residents. Therefore, without the application of the person-centred care approach, this burden of care will not decrease.

It was also evident from the literature that society views dependence and aging as parallel and and this resulted in a common belief of the elderly being a burden to others (Power 2010:122) and causing stress for direct caregivers (Park 2010:135). In a research study conducted by Kada *et al.* (2009:2386-2388) it is evident that caregivers perceive the residents as people with little potential; that they are ill and in need of care and that the residents have many characteristics in common with children, focusing on the weaknesses of the residents. Du Toit and Surr (2011:49,52) report that residents observed during Dementia Care Mapping research in South Africa are subject to objectification, which means that they are treated like 'a dead lump of matter' rather than being specifically involved by the caregivers in the task at hand and the natural decline of these residents with dementia could be enhanced by inadequate opportunities to be independent and take part in daily activities. Furthermore, the Eden Alternative (Eden Alternative 2010b:28; Fagan 2003:139) philosophy states that a person-centred perspective focuses on each person's ability to grow and experience satisfaction in the moment, which contradicts the caregivers' perspective in this category.

- Safety of the residents

The caregivers were of the opinion that one of their main priorities were to keep the residents safe and comfortable at all costs. This perception diverted caregivers from addressing any needs for independence the residents may have had. It appeared that the caregivers believed that by helping residents and consequently sacrificing independence, they were reducing risks of injury. They also admitted using restrictions (cf. 4.3.2.2; p109) in the form of tray tables to keep the residents from walking around unsupervised.

“... want dis belangrik vir die pasiënte om te sit as ons besig is by hulle stoele en die tafels sodat hulle nie uitval nie, maar as ons daar is by hulle, hulle kan maar loop want ons kyk altyd vir hulle.”

“No, I think as I have said I should take care of them so it is my duty to see if everything is okay with that patient, she don't get hurt or she is safe and clean, neat.”

The quantitative data in Table 4.21 confirms the qualitative findings and show that the caregivers ranked sitting still as the least important need that the residents had, therefore implying that they knew that the residents did not want to sit still, but that they had to be passive for their own safety.

In contrast to this evidence, Table 4.29 indicates that five (62.50%) of the caregivers were of the opinion that they gave the residents the chance to choose when they wanted to walk around.

Table 4.29: Giving the chance to choose vs. making choices for the residents with regard to walking around (n=8)

Response	Frequency	%
Giving the residents the opportunity to choose	5	62.50%
Choosing for the residents	3	37.50%

This discrepancy between the evidence could be the result of cognitive knowledge that was not put into practice, meaning that the caregivers recognised what they have learned in person-centred care training, but failed to apply these principles in practice.

Watts (2011:37) confirms that the application of knowledge is a process that happens over a period of time and a combination of formal training (including effective guidance from a mentor) and learning through trial and error. Therefore, the knowledge that the caregivers received were not applied due to an apparent lack of these opportunities.

Ayalon *et al.* (2009:120-121) found that caregivers believe more than any other profession that supervision and seclusion are important in providing effective care to people with dementia. Harmer and Orrel (2008:552) support the view that safety is a very high priority for caregivers. Data from Dementia Care Mapping research in South Africa presented evidence that the caregivers used tray tables as restrictions for up to six or more hours per day, which caused little opportunity for independence (Du Toit & Surr 2011:53). The effect of this approach according to Hung and Chaudhury (2011:10) is that residents feel powerless and disrespected as human beings. Therefore, the focus of care should be on the person as a '*human being*' with the focus on person-centred care to preserve the personhood of people with dementia (Du Toit & Surr 2011:53) rather than practices that encourage helplessness.

- Lack of motivation of the residents

The next restriction for discussion in this category is the lack of motivation of the residents. The caregivers were of the opinion that the residents did not want to be independent. They stated that they got a negative or passive reaction when trying to facilitate independence, because the residents were so used to being cared for.

*"Hulle sit maar net. En die anders wat kan praat hulle sal sê:
'Nee, ek wil nie'".*

More qualitative evidence indicated that the caregivers noticed that residents initiated independent task performance and therefore implied that the residents were motivated towards independence.

*"... maar hy, hulle wil besig, sy besig, sy wil alles reg maak die
stoele daar vat en daar sit."*

*"She said she was a teacher and caterer, so she can do some
dishes or clean up."*

The quantitative data in Table 4.21 indicates that the caregivers did recognise the need of the residents to be independent, but this need was ranked as a low priority (fifth out of eight) thereby stipulating that the caregivers felt this need was not a priority for the residents.

The qualitative and quantitative evidence suggest that the caregivers did recognise the need of some of the residents to be independent. These residents, however, were limited to those who still had the ability to initiate tasks independently. Also, the perceived lack of motivation could possibly be explained by the loss of ability of the residents and the lack of knowledge and skill of the caregivers to facilitate independence.

Literature by Du Toit and Surr (2011:53) clarify that limited activity participation could be due to the loss of abilities preventing the residents to participate in activities without independence being facilitated by the caregivers. The caregivers, however, perceive the loss of ability as the residents' negative attitude towards independence.

- Poor knowledge and skill of techniques

Another restriction discussed in this category is the lack of knowledge and skill of the caregivers to be able to facilitate independence. The following evidence suggested that the caregivers were not aware of any techniques to enhance independence.

Navorser: *“Maar doen die versorgers dit?”*

Deelnemer: *“Ja.”*

Navorser: *“Kan jy vir my ‘n voorbeeld gee?”*

Deelnemer: *“Ek weet nie.”*

“Ons het nie die kans gekry om opleiding te kry oor hoe om pasiënte te help om self take aan te rig nie, hulle leer ons net oor die siekte.”

“Ek wil sê hulle ... hulle gaan nie verstaan. As ons sê: ‘Ouma, doen dit, doen so’, hulle sal nie.”

Although some of the caregivers were of the opinion that they did not have the skill to facilitate independence, others made use of the effective techniques of physical prompting, touch and vision to encourage residents to be independent.

“Ek gee, sit in die hand dan drink sy self van die water.”

“En dan die hare kam. As hulle sien net die hareborsel dan vat...” (illustrates brushing action).

“Is altyd, want as hy net die water hier so by die kop, hy was.”
(illustrates washing action)

Therefore, the qualitative evidence indicates that some of the caregivers were uncertain of techniques to facilitate independence and because not all of them had the knowledge it could therefore be concluded that the facilitation of independence was not encouraged by the organisation and that more training was needed.

Du Toit and Surr (2011:54) also indicate that caregivers are not equipped to apply the principles of person-centered care. If the caregivers can learn these skills, the residents will have more opportunities to achieve success, which in turn will enhance their QoL (Chung 2004:29-30).

- Poor knowledge and skill of activity analysis

The qualitative evidence implied that the caregivers were aware of different levels of functioning among residents and they accommodated individual cases. The caregivers also said that some residents were able to perform certain steps of activities.

“Die ander een hulle kan, maar die ander een jy weet mos, hulle kan niks nie.”

“Hulle is nog nie so swak nie. Nou hulle kan iets vir hulle self doen.”

Caregivers were aware that a resident’s function and reactions could fluctuate on a daily basis.

“Maar later in die dag sal sy sekere van die stappe self doen soos dan sal die patient self haar rok op lig of so.”

“Ouma van der Merwe is partykeer moeilik maar die ander dag dan kan sy die regte goeters met jou praat dan kan jy sien...”

Navorsers: *“Dink jy dit is vir hulle altyd belangrik om drukkie te kry en te lag en gesels of partykeer?”*

Deelnemer: *“Partykeer.”*

Navorsers: *“Hoekom sê jy partykeer?”*

Deelnemer: *“Partykeer, ja ander dag dan is hulle happy en ander dag oe nee hulle stel nie meer belang nie.”*

Therefore, the conclusion can be made that the caregivers were aware of individual differences between the residents as well as day to day differences in the functioning of the same resident.

Literature (Clare, Marková, Roth & Morris 2011:940) confirms that levels of awareness can fluctuate in a certain time span. Moreover, Chung (2004:30) indicates that different levels of cognitive functioning are a cause of different levels of occupational functioning in residents. Therefore, residents with less cognitive impairment could potentially participate in more activities; because their communication skills and motivation are still relatively intact. Considering the different levels of functioning, The Eden Alternative (2012:8) reports that lower-functioning residents are underestimated and could often do more than

they are allowed to do and could still grow while they are alive as life and growth cannot be separated.

It was clear from the previous conclusion that the caregivers were aware of different levels of functioning among residents as well as day-to-day differences in the same residents. Therefore, it is important that the caregivers should have the basic knowledge and skill to analyse activities according to the functional needs of the residents. From the following evidence it appeared that the caregivers did not understand the concept or the method of activity analysis; they saw the activity as a whole.

“Ee, ee, sy hoor nie as jy vir haar sê: ‘Was’ of so nie.”

*“O, hulle kan nie want miskien jy gee vir haar die skottel:
'Uhm, Ouma, hier is die water, hier is jou waslappie, Ouma
kan nou begin, uh, lekker was.’ Dan hy sal net so kyk dan...”*

*“Soos as jy iemand kry wat swak is, as ‘n mens sien vir haar
help om te was. Jy kan ... jy gaan nie weet, of jy gaan nie
verstaan hoe kan jy dit makliker doen. Vir hy en jousef.”*

In addition, the caregivers thought that they were able to analyse tasks, but that it was not always effective.

*“Ons kan dit partykeer doen soos om iemand se brood te sny
en ons kan dit daar sit dat die pasiënt dit eet, maar dis nie ‘n
waarborg dat as ons die persoon los om te eet, sy dit gaan eet
nie, want altyd as ons teruggaan, dan eet die persoon nie.”*

Therefore it was evident that the caregivers did not fully comprehend the concept of activity analysis and could not apply the skill effectively.

The quantitative evidence that confirms the qualitative statement can be found in Table 4.26 where it is stipulated that the caregivers did recognise that some

of the residents were able to do some of the activities. It appears as if they ranked the activities only if the residents were able to do it independently, without the caregivers enforcing independence and without the caregivers helping them. It appeared that they did not fully understand that tasks can be analysed into certain steps.

Further quantitative evidence In Table 4.8 (Column 2) indicated that a reason for not encouraging independence was that they did not have the knowledge of activity analysis. This was a very low priority (sixth out of eight), but nonetheless, the caregivers did indicate that their inadequate knowledge of activity analysis was one of the reasons that they did not facilitate independence of the residents.

In a study by Brodaty, Gresham and Luscombe (2007:140,143) it was found that caregiver training programmes which include activity analysis as part of the intervention postponed institutionalisation of people living with dementia. However, according to evidence from a study by Du Toit and Surr (2011:53) caregivers have trouble planning activities for residents and therefore they do not encourage residents to participate in activities.

It is, therefore, evident that the caregivers were aware that residents functioned at different levels and that certain residents were able to do different tasks compared to others. They were also aware that residents' function and reactions could fluctuate on a daily basis; therefore, it was important that activities needed to be adapted, even from day to day, but the caregivers did not have the knowledge or skill to analyse activities effectively. This lack of knowledge and skill restricted the facilitation of independence.

Another opinion of the caregivers was that they contributed towards independence by 'teaching' residents through demonstration and therefore still by 'doing for', not by giving the residents the chance to do the task independently. This added to the conclusion that the caregivers lacked skill and knowledge to facilitate independence.

“Ons help hom te eet. Die ander een sy vat die lepel net so, as sy moet by die mond sit, sy kan nie. Sy los die kos, sy mors. Jy moet vir haar leer.”

These qualitative data are supported by the quantitative data (cf. Table 4.8 Column 2; p85). The caregivers ranked their perception that the residents were old and weak as the third (out of eight) most important reason for not encouraging independence, therefore also implying that they had to ‘do for’ the residents.

According to Du Toit and Surr (2011:54) caregivers lack the skill to incorporate person-centred care and therefore, a person-centred care approach should be used to handle staff so they can experience the benefit thereof and start applying it within the SCU. If the caregivers could learn these skills, the residents may have more opportunities to achieve success, which will enhance their QoL (Chung 2004:29-30).

- The influence of the organisation

The attitude of the organisation regarding the facilitation of independence of the residents implied that the caregivers also had different perceptions. Firstly, according to the caregivers, the professional nurse encouraged independence according to the ability of the resident, although the caregivers were more concerned for the safety of the residents (as previously discussed as part of this category).

“Ja ... Hulle kan mos nie, ons sê vir die suster hulle kan nie dan sê die suster: ‘Los hulle dat hulle so en so doen, los vir hulle’. Dan sê ons: ‘Maar suster ons is bang’. Partykeer ons los vir hulle, hulle gaan uit daarso, hulle sal val daar buite.”

“Maar ons in die verpleeg, ons sê vir die suster ons kan nie daai mense los as hulle iets wil doen nie, want ons sien mos,

die verpleeg sien mos, nou die pasiënte is nou swak sy kan nie iets doen nie.”

Other opinions were that the professional nurse encouraged dependence and safety, not independence.

“Dan sy (professional nurse) gaan se: ‘Maria, jy moet agter by haar loop, want ons is bang sy gaan val, sy gaan seerkry.’”

“Hulle, die ander (professional nurse)...hulle sê vir ons ons mag dit nie net vir hulle los en net doen hulleself. Ja.”

It appeared that the organisation experienced independence as time consuming and sacrificed independence to save time.

“Want die suster sal sê, as sy miskien iets vir haar self doen, sy vat lank sy en ... ons moet haar help gou.”

This qualitative evidence is supported by the quantitative evidence in Table 4.23 which indicates that the facilitation of independence was only the seventh priority out of the eight listed priorities for the the organisation of Greenacres.

Therefore, the conclusion could be made that the professional nurses did not enforce the facilitation of independence consistently as independence was not a high priority for them. When they did encourage the caregivers to facilitate independence, the protective instinct of the caregivers and their focus on the weakness of the residents instead of the remaining abilities overshadowed the opinion of the professional nurse.

According to literature (Eden Alternative 2011:20; Fagan 2003:133; Kitwood 2000:7), the organisation decides on the aspects of importance and forms a culture surrounding these chosen aspects. Independence cannot only be encouraged by the organisation, but needs to be part of the culture of care and to be consistently enforced for the whole organisation and the caregivers to

consistently apply these principles. It will then become a habit for the organisation and the caregivers.

- The influence of the family

The last restriction on the facilitation of independence was the caregivers' perception of the opinions of the families. Some caregivers perceived the family as encouraging independence according to the ability and reality orientation of the resident.

Ja, but as die, die ding weer kom, hulle (family) weet, die ding weer kom ... sy kan dit self doen ... net partykeer."

According to the caregivers, the family did not encourage independence for residents with advanced dementia.

Navorsers: *"En sê nou die swak inwoners, is dit vir hulle familie belangrik?"*

Deelnemer: *"Huh uh."*

Navorsers: *"Nooit belangrik nie?"*

Deelnemer: *"Nee, dis onse werk om hulle te help. Want hulle kan ook nie vir daai een help nie."*

The caregivers perceived the expectations of the family who did encourage independence of the residents to be unrealistic about the abilities of the residents.

"Hulle verstaan nie, ek dink hulle verstaan nie wat gaan aan, die ander sê hulle wil, miskien ... as jy haar voer hulle wil dat sy haarself voer, maar jy is die een wat met sy ma werk jy ken sy gaan nie voer, sy gaan net die kos so (shaking hands back and forth) maak."

Therefore the qualitative evidence indicates that the family on the whole did not encourage independence and when the exception occurred the caregivers focused on the weaknesses of the residents resulting in what they perceived to be unrealistic expectations of the family.

The quantitative evidence according to Table 4.15 indicates that independence was the sixth most important priority (out of eight) for the family of the residents. Therefore, although the lack of encouragement from the family was a restriction for the caregivers in facilitating independence, the focus of the caregivers on the weaknesses of the residents once again also restricted independence.

Literature (Du Toit & Surr 2011:49; Park (2010:137) indicates contrasting opinions regarding the attitude of the family towards independence. While Park (2010:137) confirms that family members find it difficult to come to terms with the mental decline that is associated with dementia and therefore have unrealistic expectations, Du Toit and Surr (2011:49) are of the opinion that the family often underestimate the ability of the resident to participate in activities and to be independent.

In this category the value and restrictions of independence were discussed. It was illuminated that although the caregivers had limited insight into the advantages of independence, they did recognise a sense of achievement and dignity, enjoyment and the maintenance of remaining abilities that resulted from the facilitation of independence. Although the caregivers realised these advantages, there were restrictions on independence that prohibited them from the facilitation thereof. These restrictions caused very limited facilitation of independence (if any).

4.4.1.3 Activity participation

This category focuses on the perceptions of the caregivers regarding activity participation. The fields that will be discussed are the caregivers' comprehension of the concept of activity; their insight into the advantages of

activity participation; and the factors influencing the facilitation of activity participation for residents with dementia.

- **Concept of activity participation**

During the data analysis, the concept of activities came to light when it was noted that the caregivers did not have a deep understanding of what the term *activity* entails. Caregivers perceived activities only as exercise, games and dancing, not any activities that relate to normal household routines.

“Ons moet elke dag ons moet vir hulle speel met hulle, miskien die musiek dat ons bietjie dans met hulle. Wat hulle kan. Ja.”

“It (activities) is part of training, hulle moet soos ek het gesê hulle moet bietjie oefening maak, hulle kan nie stilsit altyd, hulle mag nie.”

It is evident that the caregivers' perception of activities was limited to recreational activities and did not include activities of daily living; therefore, the concept of activity participation in this category (cf. 4.4.1.3; p152) will refer only to recreational and leisure activities.

The literature according to Harmer and Orrel (2008:555) found that caregivers' concept of activities was different throughout residential care facilities. Du Toit and Surr (2011:53) also report that care facilities observed in South Africa do not incorporate activities of daily living on a daily basis for residents, such as laying the table. This could be because the caregivers view these functional tasks as part of their work role and not the role of the residents (Harmer & Orrel 2008:555).

- **Advantages of activity participation**

The caregivers showed insight into some of the advantages of activity participation. These are divided into physical and psychological advantages.

The insight of the caregivers was directed towards the physical advantages of keeping the residents active and the dangers of inactivity. The caregivers kept the residents active to prevent pressure sore development. They understood that the residents got stiff due to inactivity (i.e. when they sat still the whole day) and it also made the physical handling and transfers difficult for the caregivers.

“Through it (being active) we are preventing pressure sores.”

“Ja ... want jy weet as hulle so die hele dag so sit kom ek sê vir jou die waarheid, hulle raak styf. Dan is hulle bietjie moeilik vir ons.”

The caregivers also showed some insight into the psychological advantages of activity participation. In their opinion the residents' memory was stimulated, they hurt themselves less and showed less inappropriate behaviour. The caregivers also indicated that the residents enjoyed activity participation.

“... 'n mens kan sien hoe hulle onthou hoe hulle dit gedoen het in die verlede.”

“Want hulle gaan nie hulleself meer so seermaak en goed doen wat nie reg is nie.” (when they participate in activities)

“Sy sing net elke dag, as sy sing jy kan sien sy is bly.”

“Hulle hou baie van dans. En hulle klap by die (clapping her hands) musiek. Jy kan sien hulle word ... hulle hou van musiek en te speel met die balle.”

The qualitative findings above are confirmed in Table 4.30 which indicates that all of the caregivers (100%) agreed that residents with dementia enjoyed the act of participating in activities.

Table 4.30: Caregivers' perceptions about a link between activity participation and enjoyment vs. not forming a link between these aspects (n=8)

Response	Frequency	%
People with dementia will enjoy life more if they are occupied with activities that interest them	8	100%
People with dementia will not enjoy life more if they are occupied with activities that interest them	0	0%

Therefore, the conclusion can be made that the caregivers could identify the physical and psychological advantages of activity participation.

The literature confirms that the physical and psychological benefits of activity participation for residents with dementia are numerous (Chung, Ellis-Hill & Coleman 2008:378). It has proven to lessen stress reactions when the residents' individuality and life story are taken into account to meet their occupational needs (Eden Alternative 2012:7). Activities provide opportunity for success and enjoyment and decrease the development of unnecessary disability, adding to general well-being (Chung 2004:30).

Caregivers at the Eden Alternative Associate Training (2012:7) also show insight into the enjoyment residents experience when they participate in meaningful occupation. Kada *et al.* (2009:2386) report that caregivers emphasise the importance of motivating and pleasant activities for residents with dementia.

- **Factors influencing the facilitation of activity participation**

It was evident that the caregivers recognised the advantages of activity participation for the residents, but it was also clear from the qualitative and quantitative evidence that there were factors that negatively influenced the facilitation activity participation. These factors were the organisational priorities,

the families' priorities, convenience, skill and the caregivers' perception of their job description.

Firstly, the discussion of the organisation's influence on activity participation of the residents is discussed. It was previously stated that the culture of the organisation determined the behaviour and actions of the caregivers (cf. 2.2.1; p14). Apart from activity participation being very low on the caregivers' priority list, activity participation was not enforced by the organisation. Therefore, the reason for this occurrence could be that the professional nurses not only neglected to encourage activity participation, but that they did the direct opposite to ensure peace and quiet.

Navorsers: *"Dan om deel te neem aan aktiwiteite, is dit vir die susters belangrik?"*

Deelnemer: *"Nie altyd, want hy soek net die stilte en die bietjie rus, rus."*

Although activity participation was greatly neglected by the organisation as part of their culture and therefore influenced the caregivers' views, it did seem as if the facilitation of activity participation was sometimes incorporated in the SCU.

"Soos die bal en die musiek, suster De Beer is lief vir die musiek. Sy dans daarso saam met hulle."

According to the quantitative evidence in Table 4.22 the caregivers sometimes recognised that person-centred care was more important to the organisation than only tasks associated with physiological needs. This indicated that activity participation as a part of person-centred care should also be important, but in Table 4.23 contrasting evidence indicated that activity participation was indicated as the least important priority of the organisation from a list of eight priorities.

Therefore, even though the professional nurses did sometimes facilitate activity participation, it was the least important priority on their list. This indicates that

they did not see this as a part of the main tasks that they had to perform in a day, but rather as an extra task that they did when they had spare time.

This conclusion is supported by the literature that states that although activity participation is less of a priority for the organisation, it is evident that it is facilitated, but even then the type of activities are more focused on the maintenance of physical than mental skills (Harmer & Orrel 2008:555), which is another indicator of a medical model focus. In relation to this, Chung (2004:29) and Pulsford (1997:704) agree that residents in RCH's are physically taken care of, but their right to activity participation is neglected.

Another external factor that needed to be considered was the family. The overall perceptions of the caregivers regarding the importance of activity participation for the family were that they wanted the residents to participate in activities, because inactivity weakened them.

“Ja, want jy kan sien miskien as hulle ons kom kry ons doen die speletjies met hulle, dan sien o jitte hulle (the family) is regtigwaar happy.”

“Hulle sê hierdie stilte maak hulle ma's swak en swak elke dag.”

In contrast to this, the qualitative evidence in Table 4.15 indicates that the fourth (out of eight) most important need listed needs for the family was the encouragement of activity involvement of the residents. Therefore, although activity participation was a need of the family, it was not part of the priorities, which were also focused on the medical model more than the person-centred care model.

The literature confirms that inactivity weakened the resident (Harmer & Orrel 2008:553). Boise and White (2004:15) also confirm that activities are important to the family and are sometimes initiated by them and that the family should be consulted to determine the needs of the residents with regard to activity

involvement to ensure that the residents are not forced to do activities that they no longer enjoy. Although activity participation was important to the family, literature also confirms that the family are more directed towards medical care than person-centred care. (Ducharme & Geldmacher 2011:1334).

The third factor that influenced the facilitation of activity participation was the skills of the caregivers. When caregivers did initiate activity, but could not get residents to comply when they wanted to move them, the caregivers admitted that they sometimes forced the residents to stand up and participate in activities.

“Partykeer wil hulle glad nie iets doen nie, hulle wil net sit, en dan moet ons hulle forseer om iets te doen, maar dan wil hulle nogsteeds nie.”

It is evident that the caregivers did not have the skill to initiate activity participation through person-centred care because it appears that they forced the residents to participate.

Literature confirms and indicates that caregivers do not have the skill to carefully structure and grade activities to interest the residents and therefore the residents spend more of their time in a state of inactivity or engaged in activities that provide little opportunity to experience enjoyment or success (Chung 2004:29-30).

The fourth and last factor that influenced the facilitation of activity participation for the residents was that the caregivers were of the opinion that it was not part of their job description, but depended on the OT. Therefore activity participation was only applied when convenient or mostly initiated by the residents.

“... en dan sal ons dit doen wat van ons word verwag om net ons werk te doen en dan sal die arbeidsterapeute ons betrek in sekere van die aktiwiteite.”

“You can see that she is doing it very nice so I think it is okay to know.”

“As hulle sien die skottel was is daar so, hy sal sê iemand hy wil die skottel was.”

The qualitative evidence is confirmed in Table 4.21 where it is indicated that participation in activities was the seventh (of eight) priority on the needs list of the residents and therefore a very low priority. Therefore it can be concluded that the facilitation of activity participation was very low on the priority list of the caregivers due to the fact that they did not perceive it to be part of their job description and thus only facilitated when convenient or when it happened spontaneously.

More confirmation is found according to Du Toit and Surr (2011:53) who indicate that RCH's have limited activity involvement amongst the residents, because the caregivers do not facilitate activity participation due to the low priority thereof (Van Beek & Gerritsen 2010:1278). Power (2010:52) also confirmed the low priority of activity participation for the caregivers and therefore states that they are prone to isolate the tasks that their job entails and perceive anything other than these tasks as an added burden. In addition to this Anderson, Taha and Hosier (2009:70) report that the focus on tasks associated with physiological needs may be explained by the high demands on the caregivers in terms of the workload and causes a neglect of person-centred care and results in enhanced dependence.

This phenomenon makes it extremely difficult to change the culture of care and to implement person-centred care where the priority focus is on the individual human being and not on a list of tasks that need to be completed (Power 2010:52), but the Eden Alternative (2010b:20) states that all staff, from the cleaner to the manager of the RCH, should be involved in person-centred care and therefore the facilitation of activity participation.

In the discussion of this category it came to light that the caregivers did not understand that the word activity includes activities of daily living and not only

games and recreational activities. Therefore the category was discussed against the background of recreational activities and not activities of daily living. It came to light that the caregivers showed insight into some of the physical and psychological advantages of activity participation, but still they did not as such encourage this due to the low priority thereof for them, the family and the organisation (which created the culture in the SCU) and the fact that they did not view it as part of their job descriptions. In this category the value and restrictions of independence were discussed.

4.4.1.4 The resident's ability to experience positive emotions

This category relates to the caregivers perception of the residents' ability to experience positive emotions and is divided into the two emotions of enjoyment and pride.

- **Enjoyment**

It is clear that there was a discrepancy in the perceptions of the caregivers regarding the ability of elderly people in general to enjoy life, but there was a unanimous opinion that the residents' with dementia could not experience enjoyment at all.

Some caregivers were of the opinion that elderly people (without dementia) in general were able to experience enjoyment in elderlyhood.

"... the bejaardes because they have seen life, they had a chance to live a long time. They know everything, even their old age they still enjoy. It is not all of them which are having dementia. Some of them they are okay and are also enjoying life."

“Ok as jy bejaardes is, jy’t ... omdat jy al jou lewe geleef het moet jy besef wat jy gedoen het, is gedoen en jy moet geniet wat jy nou het.”

In contrast, other caregivers stated that elderly people in general were dependent and not respected – especially by their children – and therefore could not enjoy life.

“Oumense kan glad nie die lewe geniet nie omdat hulle soveel disrespek kry van die kinders af. Veral in die swart gemeenskap wat die kinders hulle vloek en so en dis veral kleinkinders wat hulle oumas en oupas disrespect.”

It is evident from the excerpts above that some of the caregivers were of the opinion that elderly people (excluding people with dementia) were able to experience the positive emotion of enjoyment. Other caregivers felt that enjoyment was not possible for them, because of the disrespect from their children and grandchildren. To clarify this discrepancy, Table 4.31 indicate that the caregivers were of the opinion that elderly people enjoyed their lives less once aged than in other stages of life. The caregivers were of the opinion that teenagers had the highest QoL, followed by adults and children. Therefore, elderly people had the lowest QoL and therefore experienced emotions of enjoyment less than in any other life stage.

Table 4.31: QoL in relation to life stages (n=8)

Ranking		Rank value
1	Teenagers	1.6
2	Adults	3.3
3	Children	3.5
4	Elderly	5.8

The conclusion that can be made was that although some caregivers were positive towards the enjoyment of life for these people, their opinion was that the elderly experienced less enjoyment than in any other phase of life.

Therefore, being an elderly person was already a disadvantage in the opinion of the caregivers and was an obstacle to the application of person-centred care.

The literature (Harmer & Orrel 2008:555) confirms that elderly people generally suffered more from a lack of motivation than in other life stages, but Power (2010:119-120) states that enjoyment is still possible for people in their last phase of life. The caregivers' perceptions that lack of positive emotions in old age and the disrespect shown by the children is explained by discrimination against the elderly and people with dementia which occurs in South Africa (South Africa 2006:8). According to Hung and Chaudhury (2011:7) a resident emphasises the impact of being treated without respect. Her opinion is that the elderly should be treated with honour regardless of their life stage and situations. She reports feeling humiliated by the caregivers' attitudes toward her. In accordance with this, Power (2010:122) reports that society views dependence as a negative outcome of the aging process and stipulated that this perspective is built on the myth that dependent elderly are a burden and that they need to be institutionalised to solve the problem, robbing them of their personhood. The myth is elaborated by the implication that elderly persons are dependent on caregivers in institutions to provide care without any elements of person-centred care (Power 2010:122). This view causes the institution and therefore also the caregivers to create minimum opportunity for the residents to be involved in their own life processes (Du Toit & Surr 2011:53).

It was evident from the previous conclusion that the caregivers were of the opinion that elderly people without dementia were able to enjoy life, but less than in other stages of life. Therefore, the conclusion can be made that they were also of the opinion that the residents with dementia did not have the ability to experience enjoyment. The caregivers stated that the reason for the inability to experience enjoyment (for the people with dementia) was the decline of functionality that occurred. This also indicated that the focus for the caregivers was on the weaknesses of the residents rather than the remaining abilities.

“Ja, partykeer weet jy as hulle so oud en hulle sien hulle kan nie meer die goeters reg doen nie, dan sê hulle: ‘O, ek kan maar eerder doodgaan.’ Sulke goete.”

“Ek dink dis net die mense (young people) wat die lewe kan geniet, die oumense kan nie, want hulle kan niks doen en niks verstaan nie.”

From the qualitative evidence it was clear that the caregivers were of the opinion that elderly people still had the ability to enjoy their lives, but not people with dementia, because of the decline in functionality.

This conclusion, however, is contradicted in Table 4.32 which indicates a discrepancy between the qualitative and quantitative data as five (62.5%) of the caregivers indicated that the residents were able to experience enjoyment and three of the caregivers (37.5%) were of the opinion that the residents’ experiences were overall dominated by the signs and symptoms of dementia.

Table 4.32: Caregivers’ perceptions about the ability of the residents to experience enjoyment

Response	Frequency	%
Residents were still able to enjoy life	5	62.5%
Residents’ experiences were overall dominated by the signs and symptoms of dementia	3	37.5%

According to the qualitative evidence, the caregivers were of the opinion that the residents were not able to enjoy life, but the discrepant quantitative data indicates that the majority of the caregivers were of the opinion that the residents were able to enjoy life. Therefore it can be concluded that there was a discrepancy in the opinions of the caregivers that could not be accounted for. This means that, because there is no consensus, the belief that residents are able to enjoy life is not enforced by the organisation. If it was enforced by the organisation, all of the caregivers would have been of the opinion that the residents had the ability to experience enjoyment. Therefore, enjoyment was

not facilitated by the caregivers, because the organisation did not enforce it by providing knowledge to the caregivers.

According to literature (Harmer & Orrel 2008:555) residents with dementia did experience general negativity and a lack of motivation, which had a negative influence on their experience of positive emotions, but Power (2010:119-120) indicates that endorphins are still released in the brain of a person with dementia causing positive emotions as a result of positive happenings or memories. These positive happenings and memories should be facilitated. According to the Eden Alternative (2010b:13-18), positive emotions of belonging, achievement and excitement could be facilitated when the three plagues of loneliness, helplessness and boredom are counteracted.

- **Pride**

The caregivers were of the opinion that residents with dementia still had the ability to experience pride.

“As sy iets gedoen het vir haarself of iets klaargemaak het sal sy die hele dag trots voel en opgewonde wees en gelukkig wees.”

The quantitative evidence in Table 4.33 supports the qualitative data and is an indication that all of the caregivers were of the opinion that the residents were still able to experience the positive emotion of pride when they achieved success. The caregivers experienced these events positively.

Table 4.33: Caregivers' perceptions about the residents' ability to experience pride vs. not being able to experience pride (n=8)

Response	Frequency	%
Residents are still able to experience pride	8	100%
Residents' experiences are overall dominated by the signs and symptoms of dementia	0	0%

Therefore it can be concluded that the caregivers' opinion was that the residents were able to experience pride when they achieved success.

Literature (Hung & Chaudhury 2011:10) also confirms that caregivers suggest one of the sources of positive emotions (such as pride) to be the adaptation of activities to make independence possible. At the Eden Alternative Associate Training held in Bloemfontein (2012:6) participants reported that residents feel proud when they take part in meaningful occupation.

In this category the caregivers' opinion regarding positive emotions were displayed. In general, the caregivers were negative regarding the residents' ability to experience enjoyment due to their regressing abilities. However, all of the caregivers were positive about the experience of the emotion of pride and therefore made the link between occupation and QoL by saying that the residents experienced the emotion of pride when they achieved success during facilitated activity participation. The discrepant attitudes of the caregivers toward the two emotions could be an indication that they perceived the emotion of enjoyment in the passive state of the residents (in which they mostly remained) and they observed the emotion of pride when the residents were engaged in occupation which needed to be facilitated. This discrepancy, therefore, strengthens the conclusion that the caregivers made a link between activity participation and QoL.

4.4.1.5 The resident as a unique individual

Category 5 of Theme 5 relates to the perceptions of caregivers regarding the resident as a unique individual. The first part of this category relates to the knowledge of the caregivers regarding the pre-morbid life of the residents and their perspective of the importance thereof. Secondly, the caregivers' perspective regarding the provision of choices for the residents is discussed, followed by the communication skills of the residents and the relationships between the caregivers and the residents.

- **Individuality and preferences**

The first category of Theme 5 focuses on the perceptions of the caregivers regarding the importance of knowledge and preferences of the residents and whether they were equipped to apply this knowledge. Firstly, the caregivers' positive and negative perceptions towards individual preferences are discussed followed by the benefits of considering the individuality of the residents.

- Perceptions about individual preferences

It appeared that there was a discrepancy between the caregivers' opinions regarding the existence of individual preferences and whether these individual needs of the residents were met in the SCU. Therefore, the caregivers' perception about the existence of individual preferences is discussed, followed by their perception about the practice in the SCU.

Positive and negative perceptions about the existence of individual preferences of the residents were reported. Some of the caregivers were of the opinion that preferences of the residents still existed.

“Die anders wil glad nie suiker hê nie, die anders hou van die soet tee.”

Other opinions were that the residents did not have individual preferences anymore, because either they could not remember anymore or they became used to the fact that these preferences were not taken into account anymore.

Navorser: *“Dink jy die inwoners hou nogsteeds van dieselfde goeters nou as wat hulle van gehou het voor hulle siek geword het?”*

Deelnemer: *“Ek dink nie so nie, want hulle kan niks onthou nie.”*

“*Ek dink hulle hou daarvan (the same amount of milk and sugar in their tea) omdat hulle al gewoon is aan dit.*”

This discrepant qualitative evidence could be explained when compared to three sets of quantitative results indicating that the majority of the caregivers were of the opinion that individual preferences still existed for the residents.

In Table 4.34, Table 4.35 and Table 4.36 it is indicated that the majority of the caregivers acknowledged individual preferences of the residents.

Table 4.34: Caregivers’ perceptions about the residents’ individuality vs. universalism (1) (n=8)

Response	Frequency	%
Do not know	1	12.5%
Residents have different preferences	5	62.5%
Residents do not have different preferences	2	25%

Table 4.35: Caregivers’ perception about the individuality of the residents vs. universalism (2) (n=8)

Response	Frequency	%
Residents do have individual needs	5	62.5%
Residents are all the same	3	37.5%

Table 4.36 Caregivers’ perceptions about preferences that do still exist vs. do not exist anymore (n=8)

Response	Frequency	%
Preferences still exist	7	87.5%
Preferences do not exist anymore	1	12.5%

Therefore, although some of the qualitative evidence suggested that some caregivers did not perceive the residents to have individual preferences, the majority of the caregivers were of the opinion that the individual preferences still existed.

Literature indicates that the preferences of residents with dementia still exist (Edberg *et al.* 2008:239; Eden Alternative 2012:7; Hung & Chaudhury 2011:7). Furthermore Edberg *et al.* (2008:239) report that caregivers frequently have

limited knowledge of the pre-morbid personalities and life history of the residents. They are left with the person with dementia to understand the individual nature of the person, which is complicated by communication difficulties between the caregiver and the resident.

Considering the perception of the majority of the caregivers that the preferences of the residents still existed, the next step is to discuss the practice within the SCU. Firstly, the caregivers' knowledge of these individual preferences is discussed, followed by their consideration and application thereof. Overall, it was found that the preferences of the residents were not a priority.

It appeared that, although the abilities of the residents were communicated to caregivers, the individual preferences of the residents were not communicated to the caregivers by the family or the professional nurses. Therefore, the caregivers learned these preferences by watching the residents.

“Hulle sê net: ‘Daar is ouma van Wyk’. Dis al what we know, sy is ouma van Wyk. Ons weet nie waar kom sy, wat gaan aan met haar, dat jy ... miskien weet, okay kom ons gaan sy like die sy like nie dit. Sy kan haarself voer, sy kan haar self was of sy kan nie. Dis al.”

“Jy sal altyd sien deur die take wat hulle sal doen in die ouetehuis en hoe die oumense hulleself besig hou, so jy kan sien waarvan hulle hou.”

It became evident that the caregivers had a lack of knowledge regarding the preferences in the SCU. This issue lead to poor consideration of these principles. The caregivers reported that preferences of the residents were not taken into account, except when the residents specifically asked for their needs to be met.

“Ek weet nie want ons maak net dieselfde (tea) vir hulle almal.”

“Ons verander dit (tea) net as hulle kla.”

“Dis nie almal mos maar Susan en die anders soos ouma van der Merwe sy se: ‘Nee ek wil nie die hê nie’. Dan vra ons haar: ‘Wat soek jy?’ Dan ons bel by die kombuis.”

From the qualitative evidence it is clear that the knowledge of individual preferences of the residents was not a priority of the organisation as such, but that the caregivers took initiative to understand these preferences. The quantitative evidence that supports these findings is portrayed in Table 4.8 (Column 1) which indicates that the ninth (out of ten) priority reason for not taking initiative was that the caregivers did not know the preferences and pre-morbid personalities of the residents. Although it was not a priority reason, the caregivers did recognise the problem of deficient knowledge of the preferences and pre-morbid life of the residents. Therefore, the conclusion can be made that although some caregivers made the effort to gain knowledge, the organisation was not set up (i.e. by obtaining written background as part of applications) for consideration of individual preferences of the residents and caused poor caregiver knowledge and restricted person-centred care.

Literature that contradicted the effort made by the caregivers found that caregivers do not make the effort to enquire about the preferences of the residents (Hung & Chaudhury 2011:7) and therefore the knowledge of the caregivers is limited (Edberg *et al.* 2008:239). Furthermore, Anderson *et al.* (2009:73-74) emphasises the importance of care that takes personal preferences into account, but that there is a lack of knowledge among caregivers regarding these preferences. According to Du Toit and Surr (2011:54) apart from the knowledge, caregivers also lack the skill to incorporate individual preferences. They suggest that the individual preferences of the caregivers as part of a complete person-centred care approach should be used with the caregivers so that they can experience the benefit thereof and start to apply it within the SCU. Therefore, a change within the organisation will enhance the accommodation of individual preferences and person-centred care.

- Benefits of considering individual preferences

In the discussion in this category so far, the caregivers admitted that generally they did not incorporate the individual preferences of the residents in the daily programme when the residents did not specifically ask for their needs to be met. It also became evident that the caregivers associated four benefits with individual preferences of the residents.

The first benefit was the maintenance of memory. The caregivers reported that that knowing the resident guided them to be more appropriate in their handling of the residents. For example, when caregivers gave residents tasks associated with their pre-morbid lives it appeared to maintain memory.

“Ek hou daarvan, want jy, ‘n mens kan sien hoe hulle onthou hoe hulle dit gedoen het in die verlede.”

Literature confirms that the people with dementia, who had made adaptations to their careers, could still continue with these tasks. Therefore, memory of and skills associated with the tasks were maintained for as long as possible (Swann 2012:196).

Another opinion implied that the perspective of the caregivers was influenced by the history or previous career of the resident. The previous career of the residents could increase the residents' status and tasks were given in accordance to this.

“Want een van die inwoners se vrou het altyd vir ons gesê dat haar man ‘n dokter was en mense goed behandel en in ag geneem het.”

“Because other can touch and do some things with their hands, like Susan, she said she was a teacher and caterer, so she can do some dishes or clean up. You can see that she is doing it very nice so I think it's okay to know.”

It was clear that the majority of the caregivers realised the benefit of knowing the previous career of the residents, but one of the caregivers did not share this view and therefore did not have insight in the value knowledge of the pre-morbid life of the residents.

“Vir my kant ek dink dis nie belangrik nie want wat gaan ek maak as sy vir my sê ek was ‘n onderwyseres of so.”

This qualitative findings supported by the quantitative results in Table 4.37 show that seven (87.5%) of the caregivers recognised the need and importance of knowing the previous career of the residents so tasks could be given in accordance.

Table 4.37: Caregivers’ perceptions about the need to know the previous occupation of the resident vs. not seeing the purpose of knowing the previous occupation (n=8)

Response	Frequency	%
It is important to know the residents’ previous occupation	7	87.5%
It is not important to know the residents’ previous occupation	1	12.5%

Literature that supports this qualitative and quantitative evidence is found in literature by Boise and White (2004:15) and Hung and Chaudhury (2011:5). They report that knowledge of a resident’s previous career helps the caregivers understand the resident’s behaviour and experiences.

The third and fourth benefits, identified by the caregivers, of considering the individual preferences of the residents (specifically the use of their favourite food) are that it can be used to stimulate positive emotions for the residents when they were upset and the second is to persuade the resident to comply with the task at hand.

“Want as die inwoner kwaai is of ontsteld is, dan as dit daar is in die kombuis dat ek dit kan gaan haal en vir hom gee, dalk laat dit hom beter voel.”

“Dis dan makliker om hulle kos te eet bevoorbeeld as jy van koek gehou het dan kan jy sê jy sal nie koek kry as jy nie jou kos sal eet nie.”

The quantitative results supporting these qualitative findings is portrayed in Table 4.38 indicating that all of the caregivers were of the opinion that it was important to know the food preferences of the residents.

Table 4.38: Caregivers’ perception about the need to know the previous food preferences of the resident vs. not seeing the purpose of knowing the previous food preferences (n=8)

Response	Frequency	%
It is important to know previous food preferences	8	100%
It is not important to know previous food preferences	0	0%

Kitwood, cited by Brooker and Surr (2005:27-32) propose that the psychological needs of residents with dementia should be met by honesty and considering their needs. The opposite of this honesty is referred to as treachery and means that the resident is manipulated to do the task desired by the caregiver. Instead of meeting the needs of the residents, their needs are being undermined by the use of treachery (cf. Addendum M; p278). In a study by Hung and Chaudhury (2011:7) residents report that they feel patronised when the caregivers offer a reward when they eat all their food or when the reward is withheld when they do not eat all of their food.

It is evident from this category that the caregivers generally did not incorporate individual preferences into the daily lives of the residents, except when the residents specifically asked for something or if it held some kind of benefit for the residents or caregivers in that specific situation. It was also evident that the benefit should be visible with immediate effect.

The quantitative evidence in Table 4.39 is in direct contrast to the qualitative evidence. The results portrayed in this table indicate that eight (100%) of the caregivers were of the opinion that knowledge of the pre-morbid life and individual preferences was important in the SCU.

Table 4.39: Caregivers' perceptions about the need to understand pre-morbid personality vs. not seeing the purpose of knowing the pre-morbid personality (n=8)

Response	Frequency	%
It is important to have an understanding of the residents' pre-morbid personality	8	100%
It is not important to have an understanding of the residents' pre-morbid personality	0	0%

This contrasting qualitative and quantitative evidence suggests that the caregivers did acknowledge the importance of an individualistic approach, because that is what they learned from the OT. The practical application thereof, however, was hindered by a lack of knowledge about the specific needs of the residents, the skill to incorporate these individual needs and the lack of enforcement by the organisation to gain this information and practise these skills.

The literature that supports this conclusion suggests that the benefits of considering individual preferences is that the residents feel loved, cared for and valued. It also enhances the relationship between the caregivers and the residents and preserves the personhood and individuality of the residents (Anderson *et al.* 2009:70; Hung & Chaudhury 2011:7-8,11). Despite the importance of this, Anderson *et al.* (2009:72) report that a significant amount of caregivers do not know any personal information about the residents in their care.

In this category it was evident that insight into individual preferences was not a priority. The organisation did not enforce gaining knowledge of the preferences of the residents and practising these skills. Some of the caregivers were of the opinion that the residents lost their individualism and were not able to remember their preferences and therefore it was not important. Other opinions proved that the caregivers had limited insight in the importance of considering the individual needs of the residents. Therefore, the individual needs of the residents were mostly not met, except when the caregivers could see the benefit thereof immediately.

- **Choices**

This category is a discussion of the caregivers' perceptions relating to choices. It focuses on the importance of choices, the ability of the residents to make choices, the perceived advantages and disadvantages of providing the residents with the opportunity to make choices and the caregivers' view of the perceptions of the organisation and the family of the provision of choices for the residents and the influence thereof.

- Ability

The qualitative findings gave an indication of the discrepant views of the caregivers' regarding the ability of the residents to make choices. It was established that they were of the opinion that the residents did not have the ability to make choices, because the choices that they made were not appropriate in the eyes of the caregivers.

“Sometimes residents make the wrong choices.”

“Swak inwoners kry nie kans om te kies nie, kan nie reguit dink nie.”

Another opinion was that the residents were only able to make choices when they were oriented to reality.

*“Op goeie dae, wanneer hulle mooi dink, sal hulle kan kies:
'Ek wil dit aantrek en nie dit nie.’”*

More evidence suggests that the caregivers were uncertain about the ability of the residents to choose, causing them to choose for the residents.

*“Want ek sal partykeer nie weet wanneer die pasiënt sal self
kan kies nie, so dan kies ek maar altyd.”*

It was evident from the quantitative findings that the caregivers did not believe that the residents had the ability to choose. Some reported directly that they did not have the ability, others were uncertain and some allowed choices on the condition that the resident should be oriented to reality.

The following quantitative evidence contradicts the qualitative evidence. According to Table 4.29, five (62.5%) of the caregivers reported that they gave the residents a chance to choose and therefore realised the importance of choices. Therefore, although there were inconsistencies in the beliefs of the caregivers regarding the ability of the residents to choose, the majority of the caregivers reported that they did give the residents the chance to choose.

Table 4.29 shows contradicting evidence that could possibly be explained by the assumption that, when the question leading to the results in the table was asked, the caregivers had in mind a resident who were more aware of their surroundings. Therefore, the specific resident was given the chance to choose, but residents who were not oriented to reality were not given the chance and the answer was generalised to account for all the residents in the SCU.

The quantitative evidence in Table 4.21, however, supports the qualitative findings and indicates that the chance to choose was only the sixth (out of eight) priority need of the residents according to the caregivers. Therefore, they did not view the provision of choices for the residents as a priority.

The results of a study by Kada *et al.* (2009:2386) confirms that caregivers of residents with dementia did not believe that the residents have the ability to make choices for themselves, and therefore they did not give them the opportunity to choose, because they made inappropriate choices according to the caregivers (Hung & Chaudhury 2011:7).

- Advantages

The caregivers reported one advantage of providing the residents with the opportunity to choose. They believed that residents should be allowed to make

choices regarding the things that were important to them to avoid negative reactions.

“Man ek wil daai rok aantrek’ en jy sê: ‘Nee, jy gaan nie daai rok aantrek nie, jy gaan daai rok aantrek.’ Dan maak jy hom heeltemal, vir die dag kwaad.”

“Want soos ek, ek wil nie dat iemand sê vir my wat moet ek doen, ek wil vir myself kies.”

These qualitative findings indicate that the caregivers had a certain degree of insight in the emotions of the residents and the influence of choices to stimulate positive emotions and avoid negative emotions.

Kada *et al.* (2009:2386) confirms that only 19.6% of the caregivers who were a part of their study are of the opinion that it is important to provide choices in the daily lives of the residents while Sloane, Hoeffler, Mitchell, McKenzie, Barrick, Rader, Stewart, Talerico, Rasin, Zink and Koch (2004:1796, 1800), confirm the importance of the provision of choices. They also claim that the provision of choices decreases aggressive behaviour of residents.

- The influence of the organisation

According to the caregivers, choices were not encouraged by the organisation. Some of the caregivers reported that the professional nurse encouraged choices, but according to another excerpt, the caregivers reported inconsistent facilitation of choices from the professional nurse.

“Uhm ... Hulle (professional nurses) dink hulle (residents) verstaan dit nie wat doen hulle. Ons moet dit doen vir hulle.”

“Die ander een, ee, die ander pasiënte. Sy sê altyd: “Los vir haar, as sy wil iets doen, los vir haar”.

“Partykeer, sy wil hê ons moet vir Susan los dat sy kies as sy kan, maar ander dag sê sy: ‘Nee man’. Jy sien?”

The qualitative evidence indicates that organisational practice did not consistently encourage the provision of choices for the residents. In Table 4.23 the qualitative findings is confirmed showing that the caregivers were of the opinion that the enforcement of choices was a low (fourth of eight) priority for the organisation.

According to Haleigh’s Almanac (Eden Alternative 2010b:75) and The Pioneer Network (Fagan 2003:133), the RCH’s that operate within the institutional model do not enforce the provision of choices for the residents, while it opens up possibilities to decrease the experience of negative emotions and stress reactions (Sloane *et al.* 2004:1796, 1800).

- The influence of the family

In relation to the organisation, the caregivers also reported inconsistent perceptions of the importance of choices for the family of the residents. Some caregivers reported that the provision of choices was encouraged by the family while some of the caregivers reported that choices were not important to the family.

“Miskien as, as hulle kom, nê, hulle sal bel en vra: ‘Mammie, wil jy sweetie of sap hê?’”

“Miskien hulle kinders sal vir hulle sê hulle moet hulle los as hulle self klere wil kies.”

Navorsers: *“Om keuses te maak? Is dit partykeer belangrik vir die familie of altyd belangrik?”*

Deelnemer: *“Dis nie altyd belangrik nie.”*

Navorsers: *“Partykeer?”*

Deelnemer: *“Mmm.”*

Navorser: *“Hoekom sê jy so?”*

Deelnemer: *“Want hierdie mense paar van hulle hulle kan nie goeters vir hulleself doen of ... nou hoe kan hulle keuse maak.”*

Therefore it is evident that the caregivers did not experience consistent encouragement from the family of the provision of choices for the residents.

In accordance with the qualitative data the caregivers indicated in Table 4.15 that choices were the least important priority of the family for the residents.

Literature (Boise & White 2004:16) confirms that choices are not a priority for the family and that they do not always allow the resident to choose. They often insist on the type of care that is sometimes hurtful to the residents e.g. regular combing of the hair while the action is hurtful to them. They choose the type of care according to their needs and not necessarily according to the needs of the residents (Boise & White 2004:16).

In this category, the overall perception of the caregivers was that the residents should be granted the opportunity to choose if they had the ability. Residents who were less oriented to reality than others were not given the chance to make choices because the caregivers were of the opinion that they made inappropriate choices. Although they could identify one advantage of the provision of choices (avoiding negative emotions) choices was not a priority for the caregivers. Choices were not consistently enforced by the family or the organisation and were therefore not a priority for them.

- **Communication**

This category refers to the perceptions of the caregivers regarding communication with the residents. Three topics that came out in the findings were the manner in which they addressed the residents, the way that they communicated with less responsive residents and their perception regarding validation as a technique to enhance communication.

- Manner of addressing the residents

It was evident that the caregivers chose different ways to address the residents and different reasons for these choices. Some of these ways were effective, but most were ineffective with regard to person-centred care.

The caregivers, who seemed to be equipped to effectively communicate with the residents, applying person-centred care, addressed them by the name that elicited the best response.

“As ek partykeer sê Mnr, dan antwoord hy nie, maar as ek sê: ‘Oupa van Wyk, hoe gaan dit, Oupa van Wyk?’ Hy antwoord: ‘O baie goed’. Jy sien sy kan antwoord. Ek sien as ek so met die oupa praat die oupa word nie bly nie, maar as ek sê oupa...”

The evidence also implies that the caregivers addressed the residents by name to make them feel like the caregiver knew them personally.

“Partykeer as jy die inwoners op hulle name roep dan voel dit vir die pasiënte dat jy hulle ken op ‘n persoonlike vlak.”

More opinions indicated that the caregivers acknowledged the residents’ need for emotional contact and communication and were of the opinion that effective communication could lead to better compliance from the residents.

“Ek dink dis lekker om saam met iemand te gesels. En... jy kan voel jy ... dis lekker as jy heeltyd gesels met mense, want jy voel jy kan ontspan en hoef nie net alleen te sit.”

“... weier om die pille by Mandy te drink dan sê sy: ‘Martha, jy weet hoe moet jy Wilma te werk gaan’. Dan begin ek: ‘Wilma, kom drukkies, my skat en ‘n soentjie.’ As ek klaar vir haar daai goeters gemaak het dan gaan drink sy die pilletjies.”

Therefore, the caregivers who acknowledged the effectiveness of individualised communication, agreed that when the residents were treated according to their individual characteristics and preferences, the responses of the residents were more appropriate, they felt like they belonged and they were easier to handle.

The literature (Bell & Troxel 2011:4; Eden Alternative 2010b:13,88; Fagan 2003:131) confirms that using the preferred names of the residents plays a key role in the building of relationships between them and the caregivers. It gives the resident a sense of belonging. Moreover, Kada *et al.* (2009:2386) report that caregivers realise the importance for them to have a personal relationship with residents with dementia and the positive emotions of the caregivers and the residents that result from that. This statement is supported by two more studies where caregivers report to enjoy emotional contact with the residents (Clarke, Hanson & Ross 2003:73; Moyle *et al.* 2010:4). According to Kada *et al.* (2009:2386) caregivers are of the opinion that residents are more satisfied when they feel that they are understood, confirming the abovementioned conclusion.

Although some of the caregivers understood the positive effects of addressing the residents by their preferred names, other caregivers used less effective ways or even ways that added to the disorientation of the residents. It is clear from the following excerpts that the caregivers chose a certain way of addressing the residents to show respect for the residents.

Deelnemer: *“Nee, Mev. Wilma Pretorius.”*

Navorser: *“Hoekom noem jy haar so?”*

Deelnemer: *“Ek dink mos nie lekker as ek kan sê: ‘Wilma’. Ek weet die Wilma is haar naam maar ... Wilma is mos nie my portuur nie.”*

“Laat sy kan verstaan ek praat saam met Wilma and I just want to respect her so I say ‘Ouma.’”

Although the intention of the caregivers was to show respect for the residents, this occurrence often disoriented the residents more. The long term memory of the residents is usually more intact than the short term memory and therefore it is likely that they do not remember being called “Ouma”, because they were only addressed like that in the later stage of their lives. This only caused more confusion on the part of the resident.

Matzo and Sherman (2004:120) confirm that dementia usually begins with short-term memory loss, which progresses to long-term memory loss at a later stage. Although Kada *et al.* (2009:2386) report that caregivers are of the opinion that residents should always be treated with respect, Du Toit and Surr (2011:51) emphasise that the way in which respect is shown does not as such address the individual needs of the residents.

Most of the caregivers addressed the residents as “patients” during the interviews, implying that they perceived the RCH not as a home for the residents, but as a nursing care facility dealing with specific conditions experienced by residents.

“... dis mos ‘n pasiënt.”

“Ek moet klaarmaak met die pasiënte...”

“... dis die Alzheimer pasiënte”

The quantitative evidence that supports these qualitative findings is displayed in Table 4.21 which indicates that the caregivers were more focused on tasks associated with the physiological rather than the mental and emotional needs and therefore it makes sense to conclude that the caregivers viewed the institution as a facility and not a home, implying that the residents were viewed as patients.

Literature by Du Toit and Surr (2011:51) and Thomas (1996:11) confirms that most RCH's have more in common with a hospital with patients than with an

actual home and in these facilities the physical care is more important to the caregivers than the individual needs of the residents.

Some of the caregivers only followed the lead of the other caregivers or what they were used to doing, because of the mental capacity of the residents and the perceptions of the caregivers that the residents could not understand anything. Caregivers sometimes forgot the names of the residents which caused them to address the residents by their surnames.

Deelnemer: *“Oupa van Zyl.”*

Navorser: *“Okay, hoekom noem jy hom so?”*

Deelnemer: *“Want Oupa verstaan niks.”*

“Ons vergeet partykeer hulle name omdat daar so baie inwoners is, so dan sê ons net ‘Oupa’. Veral die nuwe opname.”

“Die anders noem hom Pieter. Ek is dalk net gewoond om hom so te noem.”

These caregivers did not consider the individual preferences of the residents and therefore, they were not focused on person-centred care. The caregivers were focused on the inability of the residents to understand instead of the possible positive outcomes of addressing the residents by their preferred names.

Du Toit and Surr (2011:51) report that caregivers do not necessarily address residents by their preferred name, but by their surnames. The residents are often subject to infantilisation meaning that they are treated like children. Power (2010:98) proposes a technique of *“first person narrative”* to counteract this perspective when working with people with dementia. The technique entails that the caregivers should write the care plans of the residents in the first person, bringing the life story and individual preferences to the foreground, and creating a perspective of the residents as human beings living in their home in-

stead of patients living in an institution. Anyone that enters an RCH, whether it is to work or to visit, should do so from the perspective that they are entering the home of the elderly, not a workplace and not a facility (Thomas 1996:11)

It was evident that there was a discrepancy in the ways in which the caregivers addressed the residents. Most of the caregivers did not have insight into the positive effects of considering the preferences of the residents and therefore did not apply these principles.

- Less responsive residents

This part of the category relates to the caregivers' perceptions regarding communication with less responsive residents. It was evident that, although they felt that orientating the less responsive residents to the task at hand was important, they found it difficult to communicate with these residents and therefore failed to do so.

The caregivers were of the opinion that they were in the habit of communicating with residents who did not communicate. Their reason for this was that the residents could still hear and react although they did not have the ability to speak. They also showed insight by highlighting that orientating the resident to the activity was very important to avoid aggravation and stress of the residents.

“Elke keer, jy kom nie net in en vat nie, jy moet eers sê al sy nie antwoord nie, jy moet eers vir die ouma groet en vir haar se: ‘Ouma, ek gaan dit en dit vandag doen by jou, sien?’ Jy kan nie net vat by haar. Ek moet altyd met haar praat, al sy nie antwoord nie.”

“Ja, want al kan sy nie praat nie maar ek dink sy hoor. Soos ander oumatjie daar onder, ouma Pieterse as sy, kan nie praat nie, maar partykeer as jy sê: ‘Goeie more ouma, hoe gaan dit?’ Dan sien jy die ogietjies sy kyk rond.”

“Ag Ouma nee man, kom ons loop maar net so bietjie.’ Dan staan sy op, maar as jy net kom (pulling translator by the arm to demonstrate), dan begin hy bietjie aggressive.”

Although some of the caregivers had insight in the advantages of communicating with the less responsive residents, others were of the opinion that these residents were approached less frequently or handled differently because of the difficulty of communication.

“Ek sal meer kommunikeer en kontak maak met die een wat lag en gesels as met een wat net stil sit.”

As jy inkom by die deur en iemand, nê, skree net so, jy weet nie wat soek sy. As jy vra vir haar, sy kan nie vir jou antwoord nie. Want ons verstaan hulle nie, partykeer hulle kan nie sê wat is die fout.

There was an obvious discrepancy and inconsistency between the perceptions of the different caregivers. The quantitative evidence in Table 4.40 also indicates a discrepancy and confirms that 50% of the caregivers were of the opinion that the less responsive residents should be talked to and be orientated to the activity while the other half of the caregivers felt that it was difficult to communicate with the residents.

Table 4.40: Caregivers’ perceptions about communication with residents on different levels of functioning (n=8)

Response	Frequency	%
Lower functioning residents are still talked to and orientated to the activity	4	50%
Deterioration due to dementia impedes communication	4	50%

This confirmed discrepancy between the opinions of the caregivers and the fact that not all of the caregivers viewed communication with less responsive residents as important indicates that communication with less responsive residents was not enforced by the organisation.

The data accumulated by Du Toit and Surr (2011:53) supports the notion that the caregivers do not communicate with the residents who are not able to talk to them. Hung and Chaudhury (2011:6) as well as Kada *et al.* (2009:2386) found that caregivers think that communication with residents is useless and a waste of time because of their memory problems and seeing that they could not understand the caregivers. Du Toit and Surr (2011:52) report that residents are often subject to objectification (not involving them in the activity at hand, but doing the task 'to' them) when they are not involved in the activity that the caregiver is doing to them, which causes increased helplessness and could result in stress reactions. From the view of the resident, they often feel lonely and neglected when the caregivers do not make contact with them (Hung & Chaundhury 2011:9) and therefore the residents should be approached in a less intimidating way and instead of being told what to do, they should be given choices about how and what they want to do (Eden Alternative 2010b:75-76; Fagan 2003:133). According to Fruhauf, Jarrott and Lambert-Shute (2004:47) caregivers should be provided with training to communicate effectively with the residents to enhance communication between residents and caregivers. Du Toit and Surr (2011:53) are also of the opinion that if the caregivers knew the positive influence their communication had on the residents, their attitudes would change.

- Validation

Caregivers did not understand the concept of validation. Reality orientation and reinforcement of delusions and hallucinations of the resident were used more often than validation. The caregivers reported that they reinforced delusions to avoid conflict and negative emotions of the residents. Therefore, they did not have the insight in the positive effect of validation.

“Ja, ons ... die boek (training) sê ons mag nie vir hulle lieg nie en vir hulle sê: ‘Ons is by die trein’. Maar as sy sê: ‘Ons gaan by Bloemfontein, ons is by die trein, julle vir my sê as ons by die Bloemfontein stasie, julle moet vir my sê, ek wil afklim’. Nou ons gaan saam met die ding en sê vir haar: ‘Okay, ons

sal vir jou sê as ons in Bloemfontein kom.’ Al sê die boek vir ons ons moet dit nie doen nie.”

“Ek dink want dan gaan ek die Mev. se hart seermaak as ek vir haar die healtyd sê dis nie ‘n trein nie, dis ‘n ouetehuis.”

“Soos bv. Mev. van der Merwe, volgens haar weet sy alles en sy vertel altyd vir ons goed en ons mag haar nie sê as sy verkeerd is nie want sy moet altyd reg wees, die pasiënt kom altyd eerste so dan moet ons aanpas by haar stories en maak asof wat sy vir ons sê die regte ding is.”

The quantitative data is in correlation with the qualitative data as shown in Table 4.41 which indicates that only one (12.5%) of the caregivers used validation.

Table 4.41: Caregivers’ application of validation vs. reality orientation or reinforcement of delusions and hallucinations of the resident (n=8)

Response	Frequency	%
Application of validation	1	12.5%
Application of reality orientation or reinforcement of delusions and hallucinations of the resident	7	87.5%

According to Cohen-Mansfield, Jensen, Resnick and Norris (2011:10) validation therapy requires time and can most effectively be used with residents who are still able to communicate verbally. The benefits of validation are that the residents feel that their emotions are important and they experience a moment of being close to the caregiver (Hung & Chaudhury 2011:8). Douglas, James and Ballard (2004:173) comment on the purpose of reality orientation as a method in the treatment of memory loss, but that it is not effective in the case of dementia care and that validation was developed as an improved technique to use with people with dementia.

In this category it was apparent that most of the caregivers addressed the residents from their own frame of reference using terms such as ‘ouma’ to show respect. They were careless regarding the way they addressed residents

because, according to the caregivers, the residents did not have the mental capacity to understand the way in which they were addressed. Residents were often classified and referred to as patients, highlighting the medical model approach that was followed by the caregivers. Communication was mostly dependent on the ability of the resident to communicate on the level of the caregiver. Caregivers who had more knowledge of communication with the residents reported that the residents were more compliant when they were addressed by their preferred names. These caregivers enjoyed having relationships with the residents and were aware of the value of communication with compassion for the residents. It also appeared that there was a discrepancy between the perceptions of the residents regarding communication with less responsive residents. This indicates that communication with these residents was not enforced by the organisation. Although validation is a very important and valuable skill in preserving the personhood of people with dementia, the caregivers did not show insight in the value thereof.

To summarise Theme 5 it became evident that the priority of three stakeholders (caregivers, organisation and the family of the residents) were based on meeting the physiological needs of the residents rather than practising person-centred care. The caregivers had limited insight into the advantages of independence and activity participation and identified numerous restrictions on independence. It was established that the caregivers was negative about the ability of the residents to experience enjoyment, but positive about the experience of pride. It was established that utilising the unique qualities of the residents in person-centred care was not a priority for the three stakeholders and was therefore not encouraged.

4.5 PERCEIVED ASSOCIATIONS BETWEEN QoL AND THE CONCEPTS OF OCCUPATIONAL ENGAGEMENT AND PERSON-CENTRED CARE

The majority of the findings discussed explored and gave insight into the caregivers' perceptions of person-centred care, occupational engagement and QoL. Their perceived link of these concepts was also highlighted but is viewed more comprehensively in Table 4.42.

Table 4.42: QoL and occupation according to person-centred care versus a more traditional approach (n=8)

QoL (Person-centred care approach)				Occupation (Person-centred care approach)			
Definition	No.	%	Median	Definition	No.	%	Median
Independence	38	62.5	87.5	Independence	38	62.5	87.5
	39	62.5			39	62.5	
	40	62.5			40	62.5	
	43	75			43	75	
	44	75			44	75	
	45	87.5			45	87.5	
	41	100			41	100	
	42	100			42	100	
	48	100			48	100	
	61	100			61	100	
62	100	62	100				
Activity Participation	61	100	100	Activity Participation	61	100	100
Positive emotions	46	62.5	100				
	45	87.5					
	48	100					
	61	100					
	62	100					
Individuality	52	50	87.5				
	39	62.5					
	40	62.5					
	50	62.5					
	53	62.5					
	45	87.5					
	47	87.5					
	54	87.5					
	56	87.5					
	58	87.5					
	41	100					
	55	100					
	57	100					
	59	100					
61	100						
Emotional connection	54	87.5	100				
	56	87.5					
	49	100					
	51	100					
	55	100					
Validation	60	12.5	12.5				

Table 4.42 shows different aspects that comprise QoL, person-centred care and occupational engagement as was defined in the initial concept clarification (cf. xii). The (%) column represents the percentage of caregivers that answered the question in the (No) column according to the person-centred care model. For example when one looks at question 38 this means that 62.5% of the caregivers' answers support a person-centred care viewpoint, which implies that 37.5% of the answers supported a traditional physical approach to care. As Question 38 contained aspects of independence that related to both QoL and occupational engagement it is therefore included in both of these columns.

The table as a whole was divided into sections for independence, activity participation, positive emotions, individuality, emotional connection and validation. For these sections the median value was used instead of the average value because of the small sample size (n=8) (cf. 3.5.2; p52). The median column for independence, for example, indicates that a median value of 87.5% of the perceptions about independence supported a person-centred care approach. Other median values indicated emotional connection, activity participation and positive emotions which were the highest with 100% while validation was the lowest at 12.5%. Individuality was at 87.5%. The correlation between these sections was used to discuss the link between QoL and the concepts of occupational engagement and person-centred care.

4.5.1 LINK BETWEEN QoL AND OCCUPATIONAL ENGAGEMENT

The two factors leading to occupational engagement assessed in this study are independence and activity participation. The next two sections will show the link between independence and QoL as well as activity participation and QoL.

- **The link between independence and QoL**

Due to the high median value for independence at 87.5%, the statement can be made that, based on the quantitative results, the caregivers made a link between QoL and occupational engagement in 87.5% of the answers.

It is important to highlight two questions in Table 4.42; question 48 (cf. Table 4.33; p164); and question 62 (cf. Table 4.24; p131) as they identified the direct link that the caregivers made between QoL (positive emotions) and independence.

The qualitative findings that confirm this quantitative evidence are found in this chapter (cf. 4.4.1.2; p130) indicating that the caregivers identified the benefits of independence as self-actualisation and dignity, enjoyment and the maintenance of abilities. This indicates that the caregivers did identify a link between independence (occupational engagement) and the benefits identified that could lead to QoL.

- **Link between activity participation and QoL**

Another question from Table 4.42 that needs to be highlighted is question 61 (cf. Table 4.30; p155) that indicates that 100% (eight) of the caregivers were of the opinion that the residents enjoyed activity participation.

The qualitative data confirming the importance of activity participation (cf. 4.4.1.3; p152) indicates that the caregivers identified the benefits as less stress reactions and enjoyment. They also indicated the experience of pride as a benefit of activity participation (cf. 4.4.1.4; p160). Therefore, they made a link between the experience of positive emotions (QoL) and activity participation.

Therefore, considering that both independence and activity participation as parts of occupational engagement were linked to QoL (as indicated in Figure 4.3), it can be concluded that the caregivers did identify a link between occupational engagement and QoL.

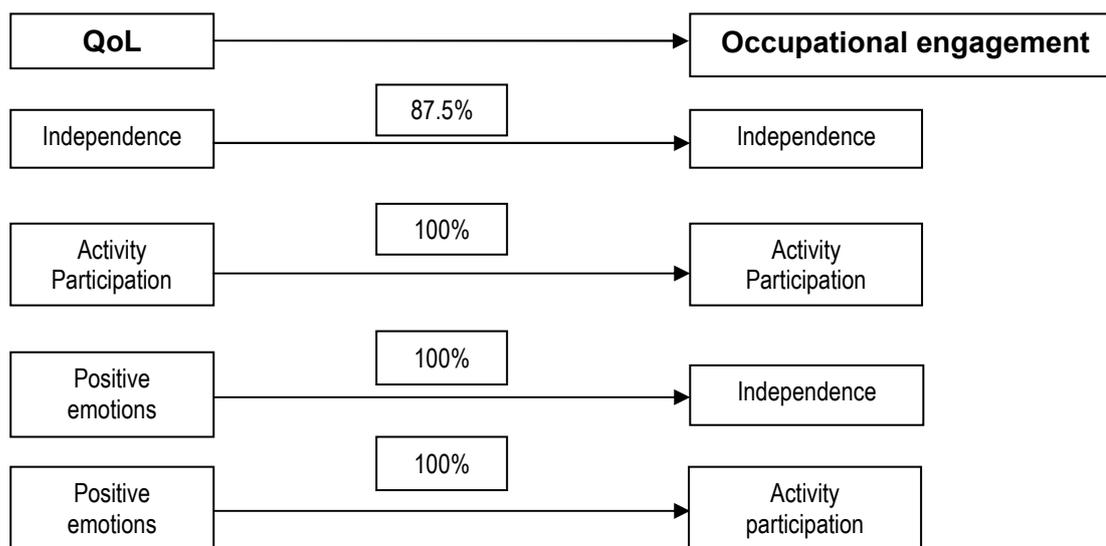


Figure 4.3: Link between QoL and occupational engagement

4.5.2 LINK BETWEEN QoL AND PERSON-CENTRED CARE

The link that the caregivers made between QoL and person-centred care was calculated statistically from the data derived from Section F and is portrayed in Table 4.43.

Table 4.43: The means procedure of the link between QoL and person-centred care (n=8):

Total questions (Section F)	Minimum	Maximum	Median	Mean	Standard deviation
25	15.000	24.000	18.000	19.125	2.800

The table above indicates that the caregiver who scored the lowest answered 15 of the 25 questions according to the person-centred care approach. The caregiver, who had the highest score, answered 24 questions according to the person-centred care approach. The average (mean) value among the caregivers was 19.125, but because of the small sample, the focus is on the median value at 18. This means that 18 out of 25 (72%) was the score of the

caregiver who scored in the middle of the listed scores ranked in order (cf. 3.5.2; p52). The median value, therefore, indicates that the caregivers made a 72% link between QoL and person-centred care, which is above average.

The standard deviation refers to the spreading of the scores of each separate caregiver. This low standard deviation of 2.8 means that the scores of the separate caregivers were deviated with a value of 2.8 from the median, indicating that the scores were clustered together and that there were no outliers (an extremely high or low value that influences the data) involved (Cohen *et al.* 2007:512-513).

Therefore, the conclusion can be made that the caregivers appeared to identify a link between QoL, person-centred care and occupational engagement, even though they did not as such embrace it as part of their care practice

4.6 SUMMARY

It is evident from this chapter that the caregivers had an understanding of QoL, occupational engagement and person-centred care that went beyond that of the traditional care model. It appeared, however, from the comparison between the qualitative findings and quantitative results that there was a discrepancy between the caregivers' knowledge of person-centred care and their application thereof. The main reason for their lack of application appeared to be due to the organisational culture that focused on the traditional care model rather than person-centred care.

CHAPTER 5

CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS

5.1 INTRODUCTION

Chapter 4 was a portrayal of the results and findings of this study. The qualitative findings and quantitative results were compared with literature to reach the conclusions which are set out in this chapter.

Recommendations are made regarding proposed strategies to incorporate person-centred care within a RCH as well as recommendations for future research. Alongside the recommendations, the limitations of the study are discussed, leading to the closure of the study.

5.2 CONCLUSIONS

This study was designed to meet the following aim:

To describe the caregivers' pre-conceived ideas of and explore and understand the caregivers' perception of QoL, person-centred care and occupational engagement for people with dementia, in need of 24-hour care.

The objectives of the study were:

- To describe the caregivers' pre-conceived ideas of occupational engagement, person-centred care and QoL for people with dementia.

- To explore and understand the caregivers' perception of a potential link between occupational engagement, person-centred care and QoL for people with dementia.

5.2.1 OBJECTIVE 1

The conclusions of this study pertaining to the first objective are discussed according to the personal, organisational and physical factors (cf. Chapter 2; p12). The researcher combined all the potential influences that may have impacted on the perceptions of the caregivers and visually portrayed these in Figure 5.1:

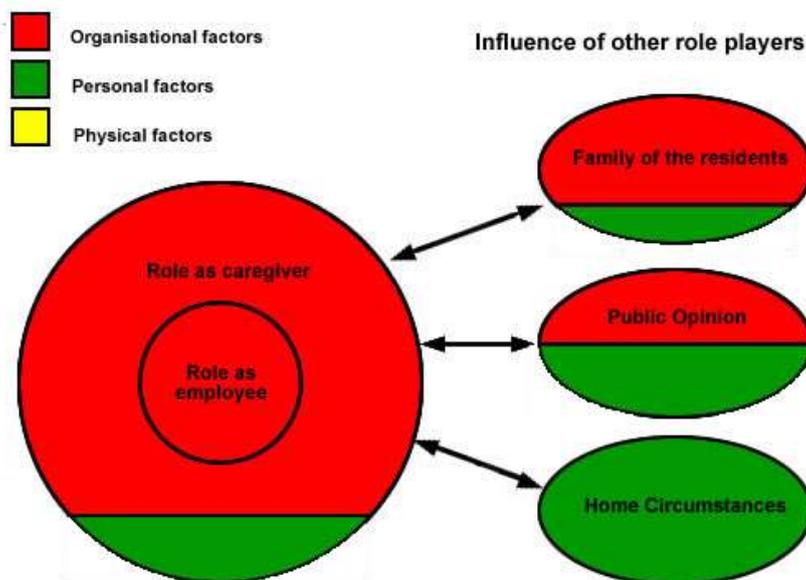


Figure 5.1: Influencing factors on caregivers' perceptions

5.2.1.1 Personal Factors

It appeared that the perceptions of the caregivers regarding QoL, person-centred care and occupational engagement were minimally guided by their personal characteristics (e.g. culture). However, it was mostly the home

circumstances of the caregivers that added to their burden of care. Fatigue because of long shifts and extensive travelling time to get to work resulted in a task-orientated focus and doing only what was within their job descriptions, therefore neglecting person-centred care.

It seems as if other role players that influenced the caregivers' perception were the family of the residents and general public opinion. The relationship between the caregivers and the family of the residents was influenced by misunderstandings and unrealistic expectations between these two stakeholders. It appears that the fact that family members had to relinquish their status as main carer resulted in a heightened focus on tasks associated with physiological needs – those aspects visible during a short visit. The caregivers who wanted to meet the needs of the family were also focused on meeting the physiological needs of the residents and therefore could more easily neglect psychological needs associated with person-centred care.

Ageism is rife in a society where status is associated with the level of a person's financial contributions. Caregivers were, therefore, in a situation where they worked with a part of the population who neither generated an income (therefore seen as a burden) nor were respected due to their high level of physical and emotional dependence. Thus, giving care to residents with dementia was a job with little importance in the opinion of the public and caused embarrassment to the caregivers. This factor caused poor motivation and caregivers only did their work according to their job descriptions which, for them, did not include QoL, person-centred care and occupational engagement.

5.2.1.2 Organisational factors

The SCU at Greenacres was an environment that caused stress for the caregivers in terms of the diversity and lack of cultural sensitivity between the different populations of residents and caregivers. Furthermore, a heightened burden of care was seemingly aggravated not only by the nature of the job, poor knowledge and skill (associated with limited training opportunities), a heavy

workload and work schedule, but also the apparent lack of stress management skills caregivers at Greenacres possessed. It would only be natural that caregivers in these circumstances would view person-centred care as an extra burden on top of their normal workload. The conclusion can be made that their perceptions of person-centred care, occupational engagement and QoL were primarily guided by organisational factors which promoted a task-focused as opposed to resident-focused approach. The organisational leadership structure where each layer of the management is the prime authority and has to take responsibility results in the caregivers as the bottom layer who are expected only to follow the lead and perform their tasks within the regime's structure.

As the family of the residents were not specifically included in the care plan of the organisation they could not experience inclusion and their historical role was replaced by that of the caregivers. Therefore, role confusion and misunderstandings between these two parties increased and diminished potential input from a variety of sources that could contribute towards person-centred care, occupational engagement and ultimately an enhanced QoL for all involved (i.e. residents, caregivers and family members).

5.2.1.3 Physical factors

While numerous physical changes have been implemented in the SCU (e.g. multi-sensory garden, multi-sensory wall panels, memory boxes), none of these physical resources were mentioned during data collection. This indicated the possibility that the caregivers did not comprehend the therapeutic value of these physical resources. It also appears as if these resources were not acknowledged as part of the care plan promoted by the organisation. Perhaps these physical resources were viewed merely as 'nice extras' as they were not utilised by the caregivers and therefore not directly associated with QoL, person-centred care or occupational engagement.

5.2.2 OBJECTIVE 2

The overall philosophy of OT, the Ten Principles of the Eden Alternative explained throughout the document of Haleigh's Almanac (Eden Alternative 2010b) and Kitwood's positive person work (Baldwin & Capstick 2007:17-19) promote the fact that person-centred care and occupational engagement are vital for obtaining optimal QoL. Illustrated in Figure 5.2 is an adapted visual portrayal of Maslow's Hierarchy of basic needs (1954:15-31) in association with the Eden Alternative philosophy (Eden Alternative 2011:6). Starting at the bottom are physiological needs and the need for safety and security. These needs are addressed by the traditional model and on their own do not facilitate optimal QoL. The higher needs on the hierarchy are parallel to person-centred care and associated with occupational engagement and therefore, when these needs are addressed, the resident should experience optimal QoL.

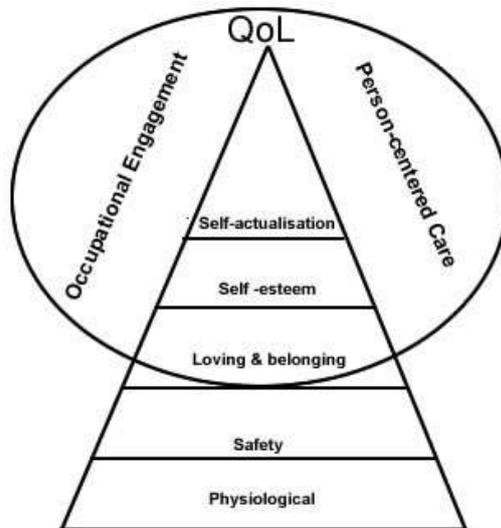


Figure 5.2: Possible factors linking QoL, person-centred care and occupational engagement

Findings indicate that caregivers seemed to identify a link between the elements of QoL, person-centred care and occupational engagement (cf. 4.5; p188) and in many instances; the caregivers appeared to be aware of the advantages thereof. Despite this link and apparent awareness caregivers seemed to think

that person-centred care and occupational engagement were not expected of them by the organisation, and therefore they apparently neglected to apply the associated principles. Although they identified a link, it seems as if they did not perceive occupational engagement and person-centred care to be essential to achieve QoL. Their focus was on meeting the physiological needs of the residents and that this level of care, in their view, was enough to obtain QoL.

5.3 RECOMMENDATIONS

Recommendations in general as well as recommendations for further research derived from the conclusion of the study.

5.3.1 GENERAL RECOMMENDATIONS

The recommendations are made in the endeavour to promote culture change for care organisations and are also discussed within the parameters of personal, organisational and physical factors.

- **Personal factors**

The home circumstances of the caregivers cannot be changed from within an organisation, but the organisation should be sensitive to the issues facing the caregivers on a daily basis at home. Training opportunities could enhance stress management skills in order to alleviate the emotional burden that rests upon caregivers.

- **Organisational factors**

A culture change in order to establish a predominant person-centred care focus within the organisation would require training specific to person-centred care for all staff members who come into contact with the residents (from the cleaners,

gardeners all the way to the directors at top management level). If the physiological needs of the residents are met on a daily basis, the focus of the organisation would shift to providing person-centred care and enhancing QoL for the residents. This culture change should be guided by the organisation and is the only route to influencing the perspectives of the caregivers, the family and the public in order to overcome the stigmatisation associated with dementia.

Only when a culture change is implemented would the organisation begin to experience that this approach does not cost extra money and does not necessarily take extra time. On the contrary, time management will be more effective as the residents could become more independent in aspects of their care and depend less on the caregivers.

Every role player is important in the lives of the residents with dementia and therefore consensus management should be implemented within the organisation (rather than the autocratic leadership structure), so as to facilitate the involvement of all (professional nurses, caregivers, the residents and the family of the residents) in the care plan. The family should especially be involved in the care plan (i.e. supplying information regarding the background, preferences and previous routines of the resident) to provide person-centred care alongside the caregivers. This will eliminate role confusion between them and the caregivers.

The organisation should facilitate a high level of cultural sensitivity between all of the stakeholders within the organisation. This will reduce the caregivers' heightened stress levels due to diversity within the SCU. Cultural sensitivity is also very important when providing person-centred care. The organisation should develop a high regard for the life story and personhood of the caregivers. Without this factor, the caregivers will not have high regard for the life story and personhood of the residents and will not take their preferences into account in the care plan. The degree to which the caregivers experience person-centred care will be the degree to which they administer person-centred care to the residents.

The low job status of the caregivers and their feelings of incompetence should be changed from within the organisation through building on the knowledge and skills pertaining to person-centred care to grant them confidence in their job and in the community. The building of this understanding of person-centred care and applying the principles associated with this approach could lessen the stress of the caregivers, and may even gradually change the public opinion so that eventually a higher status would be awarded to the job of giving care to residents with dementia.

- **Physical factors**

The overall organisational approach should encourage utilisation of the physical changes already made within the SCU to facilitate person-centred care.

5.3.2 RECOMMENDATIONS FOR FURTHER RESEARCH

A similar study should be done on the perceptions of the management and the rest of the staff at Greenacres RCH to determine their perceptions towards QoL, person-centred care and occupational engagement for residents with dementia. Consideration then should be given to the content and structure of short (but regular) training sessions that would enhance the knowledge, skills and attitude of all staff at the RCH. Furthermore, an analysis should be done on the current physical structure of the building to identify more potential changes to the environment by involving the caregivers so that they could contribute towards changes that would promote person-centred care and enhance QoL. Research should be conducted to determine the best strategy to implement the identified changes that are needed at Greenacres.

Moving beyond Greenacres, focus groups or a nominal group technique with caregivers from across organisations could assist with determining broader trends associated with person-centred care. On a provincial level, the research should be conducted at the sister facilities of Greenacres to compare the results and to determine the similarity and differences thereof. The study

should be duplicated and implemented in other facilities (e.g. moving away from church organisations to another non-governmental organisation) to compare the results.

5.4 LIMITATIONS OF THE STUDY

The language barrier and the use of a translator during the interviews diminished the opportunity to capture emotional expression between the caregivers and the researcher.

The language barrier also resulted in lengthy interviews and some of the verbatim used in this dissertation did undergo translation (i.e. from Sesotho to Afrikaans). Despite the translation of the data, the meaning remained unchanged (cf.3.6; p61).

After the data collection phase of the study, the audiovisual material from one of the interviews was lost due to damage to the tape. This interview could not be repeated as it would have eliminated the spontaneous, unbiased response from the caregiver. Therefore, the actual sample of nine caregivers was reduced to eight. This limitation did not influence the saturation of the data (cf. 3.3.2; p40).

5.5 CLOSURE

The overall aim of the study and the different objectives were reached. In the institutional model, the focus falls on meeting the basic needs on Maslow's Hierarchy without high regard for the needs of love and belonging, self-esteem and self-actualisation, which would be addressed by implementing person-centred care. It was encouraging to realise that person-centred care as an approach for persons with dementia is something caregivers did consider even though they struggled to apply it in practice. Greenacres RCH is in the privileged position that with some planning and little effort overall, the limited

institutional perspective could be redirected so that the organisation as a whole would embrace person-centred care. By creating an organisation that considers the personhood and dignity of every employee and every resident, all working and living at this RCH would have the opportunity to have experienced a purposeful life.

6. LIST OF REFERENCES

Abdalkader, R.H., Hayajneh, F.A. (2008). Effect of night shift on nurses working in intensive care units at Jordan University Hospital. *European Journal of Scientific Research*. Volume 23. Number 1:70-86.

Abualrub, R.F., Al-Zaru, I.M. (2008). Job stress, recognition, job performance and intention to stay at work among Jordanian hospital nurses. *Journal of Nursing Management*. Volume 16:227–236.

Ahmad, A., Zia-ur-Rehman, M., Rashid, M. (2011). Assessing the characteristics of work-related stress in public sector organizations. *Interdisciplinary Journal of Contemporary Research in Business*. Volume 2. Number 10:511-523.

Albertsen, K., Rugulies, R., Garde, A.H., Burr, H. (2010). The effect of the work environment and performance-based self-esteem on cognitive stress symptoms among Danish knowledge workers. *Scandinavian Journal of Public Health*. Volume 38: 81-89.

Almost, J., Doran, D.M., McGillis Hall, L., Spence Laschinger, H.K. (2010). Antecedents and consequences of intra-group conflict among nurses. *Journal of Nursing Management*. Volume 18: 981–992.

Alzheimer's Disease International (2008). *The prevalence of dementia worldwide*. London: Alzheimer's Disease International. Total pages:2.

Alzheimer South Africa. (2000-2012). *Home page*. [online]. Available from: <http://www.alzheimers.org.za/> accessed on 24 November 2011.

American Psychiatric Association (2012). *Diagnostic and statistical manual of mental disorders*. [online]. Available from: <http://www.dsm5.org/proposedrevision/pages/proposedrevision.aspx?rid=419> accessed on 12 March 2012.

Anderson, K.A., Taha, R.D., Hosier, A.F. (2009). Know thy residents: An exploration of long-term care nursing staff's knowledge. *Research in Gerontological Nursing*. Volume. 2. Number 1: 69-76.

Andrews, M.M. (2003). Culturally competent nursing care. In: Andrews, M.M., Boyle, J.S. *Transcultural concepts in nursing care*. Fourth Edition. Philadelphia: Lippincott Williams & Wilkins. Total pages:431.

Astrom, S., Karlsson, S., Sandvide, A., Bucht, G, Eisemann, M., Norberg, A., Saveman, B. (2004). Staff's experience of and the management of violent incidents in elderly care. *Scandinavian Journal of Caring Sciences*. Volume 18:410–416.

Ayalon, L., Arean, P., Bornfeld, H., Beard, R. (2009). Long term care staff beliefs about evidence based practices for the management of dementia and agitation. *International Journal of Geriatric Psychiatry*. Volume 24:118-124.

Baldwin, C., Capstick, A. (ed). (2007). *Tom Kitwood on dementia: a reader and critical commentary*. New York: Open University Press, McGraw Hill Education. Total pages:352.

Bambra, C., Whitehead, M., Sowden, A., Akers, J., Petticrew, M. (2008). Reviewed work: "A hard day's night?" The effects of compressed working week interventions on the health and worklife balance of shift workers: a systematic review. *Journal of Epidemiology and Community Health*. Volume 62. Number 9:764-777.

Barton, J. (1994). Choosing to work at night: a moderating influence on individual tolerance to shift work. *Journal of Applied Psychology*. Volume 79. Number 3: 449-454.

Beck, C.T. (1994). Phenomenology: its use in nursing research. *International Journal of Nursing Studies*. Volume 31 number 6:499-510.

Bell, J., McGregor, I. (2000). A challenge to stage theories of dementia. In: Kitwood, T., Benson, S. (ed.). *The new culture of dementia care*. London: Hawker Publications. Total pages:80.

Bell, V., Troxel, D. (2011). *An overview of: The Best Friends™ approach to Alzheimer's Care*. Health Professions Press. Total pages:22.

Bender, M. (2009). Britain 2009: No country for old men, or old women? *Journal of Dementia Care*. Volume 17. Number 5:19-20.

Biernacki, C. (2009). I believe, therefore I care. *Journal of Dementia Care*. Volume 17. Number 1:14-15.

Blanchard, F. (2006). "We have to fight against the idea that Alzheimer's disease is death of the spirit". *Supporting and Caring for People with Dementia throughout End of Life*. Number 2:10-16.

Boerner, K., Schulz, R., Horowitz, A. (2004). Positive aspects of caregiving and adaptation to bereavement. *Psychology and Aging*. Volume 19. Number 4:668–675.

Boise, L., White, D. (2004). The family's role in person-centered care: practice considerations. *Journal of Psychosocial Nursing*. Volume 42. Number 5:12-20.

Brodaty, H., Gresham, M., Luscombe, G. (2007) The Prince Henry hospital dementia caregivers' training programme. *Revista Română De Psihiatrie*. Seria A lii-A, Volume Ix, Number 2-3:140-146.

Brooker, D., Surr, C. (2005). *Dementia care mapping: principles and practice*. Chichester: John Wiley & Sons, Ltd. Total pages:156.

Brown, L.S. (2008). *Cultural competence in trauma therapy: beyond the flashback*. Washington DC: American Psychological Association. Total pages:289.

Burns, N., Grove, S.K. (2005). *The practise of nursing research: conduct, critique, and utilization*. Missouri: Elsevier Saunders. Total pages:780.

Calkins, M.P. (2011). Ten senior living design innovations: a look at the most significant changes in senior living design over the past decade. *Long-term Living*. 60th Anniversary Special. March:41-45.

Campinha-Bacote, J. (2002). The process of cultural competence in the delivery of healthcare services: a model of care. *Journal of Transcultural Nursing*. Volume 13:181-184.

Campinha-Bacote, J. (2003). Many faces: addressing diversity in health care. *Online Journal of Issues in Nursing*. [online]. Available from: www.nursingworld.org/MainMenuCategories/ANAMarketplace/ANAPeriodicals/OJIN/TableofContents/Volume82003/No1Jan2003/AddressingDiversityinHealthCare.aspx accessed 15 June 2010.

Campinha-Bacote, J., Kardong-Edgren, S. (2008). Cultural competency of graduating US Bachelor of Science nursing students. *Contemporary Nurse*. Volume 28. Issue 1-2:37-44.

Castle, N.G., Decker, F.H. (2011). Top management leadership style and quality of care in nursing homes. *The Gerontologist*. Volume 51. Number 5:630–642.

Chenoweth, L., Jeon, Y., Merlyn, T., Brodaty, H. (2010). A systematic review of what factors attract and retain nurses in aged and dementia care. *Journal of Clinical Nursing*. Number 19: 156–167.

Christiansen, C.H., Baum, C.M. (ed). (2005). *Occupational Therapy: performance, participation, and well-being*. Thorofare: Slack Incorporated. Total pages:647.

Chung, J.C.C. (2004). Activity participation and well-being of people with dementia in long-term-care settings. *Occupational Therapy Journal of Research: Occupation, Participation and Health*. Volume 24. Number 1: 22-31.

Chung, P.F., Ellis-Hill, C., Coleman, P.G. (2008). Carers perspectives on the activity patterns of people with dementia. *Dementia*. Volume 7. Number 3: 359–381.

Claassen, A. (2012). *Hours of work and overtime*. The South African Labour Guide. [online]. Available from: <http://www.labourguide.co.za/conditions-of-employment/hours-of-work-and-overtime-389> accessed on 19 April 2012.

Clare, L., Marková, I.S., Roth, I., Morris, R.G. (2011). Awareness in Alzheimer's disease and associated dementias: theoretical framework and clinical implications. *Aging & Mental Health*. Volume 15. Number 8: 936–944.

Clarke, A., Hanson, E.J., Ross, H. (2003). Seeing the person behind the patient: enhancing the care of older people using a biographical approach. *Journal of Clinical Nursing*. Number 12:697–706.

Cohen, L., Manion, L., Morrison, K. (2007). *Research methods in education*. New York: Routledge. Total pages:638.

Cohen-Mansfield, J., Jensen, B., Resnick, B., Norris, M. (2011). Knowledge of and attitudes toward nonpharmacological interventions for treatment of behavior symptoms associated with dementia: a comparison of physicians, psychologists, and nurse practitioners. *The Gerontologist*. Advance Access published 9 November 2011. [Downloaded from <http://gerontologist.oxfordjournals.org/> at University of Free State on November 18, 2011].

Cooke, D.D., McNally, L., Mulligan, K.T., Harrison, M.J.G., Newman, S.P. (2001). Psychosocial interventions for caregivers of people with dementia: a systematic review. *Aging & Mental Health*. Volume 5. Number 2:120–135.

Cooper, C.L., Marshall, J. (1976). Occupational sources of stress: a review of the literature relating to coronary heart disease and mental ill health. *Journal of Occupational Psychology*. Volume 49:11-28.

Cornman-Levy, D, Gitlin, L.N., Corcoran, M.A., Schinfeld, S. (2001). The role of physical therapy in helping families provide daily care. *Alzheimer's Care Quarterly*. Volume 2. Number 1: 47–55.

Creswell, J.W. (2007). *Qualitative inquiry and research design: choosing among five approaches*. Thousand Oaks: Sage Publications Inc. Total pages:393.

Creswell, J.W. (2012). *Educational research planning, conducting and evaluating quantitative and qualitative research*. Boston: Pearson. Total Pages:670.

Cutler, C.J., Kane, R.A. (2004). *Towards better quality of life: manual*. Louis J Cutler & Rosalie A Kane. Total pages: 110.

Dahlin, E., Kelly, E., Moen, P. (2006). *Is work the new neighborhood? Social ties in the workplace, family, and neighborhood*. Department of Sociology, University of Minnesota. A Draft:1-28.

Davies, S., Aveyard, B., Norman, I.J., (2006). Person-centred dementia care. In: Redfern, S.J., Ross, F.M. (ed.). *Nursing Older People*. Philadelphia: Elsevier. Total pages:778.

De Vugt, M.E., Stevens, F., Aalten, P., Lousberg, R., Jaspers, N., Winkens, I., Jolles, J., Verhey, F.R.J. (2004). Do caregiver management strategies influence patient behaviour in dementia? *International Journal of Geriatric Psychiatry*. Volume 19:85-92.

Delport, C.S.L., Roestenburg, W.J.H. (2011). Quantitative data-collection methods: questionnaires, checklists, structured observation and structured interview schedules. In: De Vos, A.S., Strydom, H., Fouché, CB. and Delport, CSL (ed.). *Research at Grass Roots*. Pretoria: Van Schaik Publishers. Total pages:547

Dementia Care Australia. (2012). *A positive approach to challenging behaviour*. [online]. Available from: http://www.dementiacareaustralia.com/index.php?option=com_content&task=view&id=358&Itemid=81 accessed on 18 June 2012.

Dementia South Africa. (2009). *Home page*. [online]. Available from: <http://dementiasa.org/> accessed on 24 November 2011.

Douglas, S., James, I., Ballard, C. (2004). Non-pharmacological interventions in dementia. *Advances in Psychiatric Treatment*. Volume 10:171-177.

Du Plessis, J.V., Fouché, M.A., Van Wyk, M.W. (2001). *A practical guide to labour law*. Randburg: LexisNexis Butterworths. Total pages:400.

Du Toit, S. (2005). *Occupational techniques applied in psychiatry*. University of the Free State. Total pages:55.

Du Toit, S. (2009). (Consulting occupational therapist at a Residential Care Home). Personal communication on the need for and effects of training. 13 February, Bloemfontein.

Du Toit, S. (2011). (Consulting occupational therapist at a Residential Care Facility). Personal communication on the results of dementia care mapping. 15 December, Bloemfontein.

Du Toit, S., Surr, C. (2011). Wellbeing and person-centred care of people with dementia cared for in institutional settings in South Africa. *World Federation of Occupational Therapists Bulletin*. Volume 63. May 2011: 48-54.

Ducharme, J.K., Geldmacher, D.S. (2011). Family quality of life in dementia: a qualitative approach to family-identified care priorities. *Quality of Life Research*. Volume 20:1331–1335.

Ebersole, P., Hess, P., Luggen, A.S. (2004). *Towards healthy aging: human needs and nursing response*. (6th ed). St. Louis: Mosby. Total pages:789.

Economic and Social Research Council. (2007). *On well-being in developing countries*. [online]. Available from: <http://www.bath.ac.uk/econ-dev/wellbeing/research/aims.htm> accessed on 4 June 2009.

Edberg, A., Bird, M., Richards, D.A., Woods, R., Keeley, P., Davis-Quarrell, V. (2008). Strain in nursing care of people with dementia: nurses' experience in Australia, Sweden and United Kingdom. *Aging & Mental Health*. Volume 12. Number. 2, March 2008, 236–243.

Eden Alternative. (2009) *10 Principles of the Eden Alternative*. [online]. Available from: <http://www.edenalt.org/our-10-principles> accessed on 23 November 2011.

Eden Alternative. (2010a). *Certified Eden associate training workbook*. Eden Alternative. Total pages: 58.

Eden Alternative. (2010b). *Haleigh's Almanac: Eden Alternative associate training manual*. Eden Alternative. Total pages: 300.

Eden Alternative. (2011). *Eden Alternative associate manual*. Eden Alternative. Total pages: 81.

Eden Alternative. (2012). *Eden Alternative training notes*. Eden Alternative Associate training. Menuah, Free State. Total pages: 8.

Engstrom, M., Skytt, B., Nilsson, A. (2011). Working life and stress symptoms among caregivers in elderly care with formal and no formal competence. *Journal of Nursing Management*. Volume 19:732–741.

Fagan, R.M. (2003). Pioneer Network: changing the culture of cging in America. *Journal of Social Work in Long-Term Care*. Volume 2. Number 1:125-140.

Family Caregiver Alliance National Centre on Caregiving. (2006). *Fact Sheet: dementia, caregiving and controlling frustration*. [online]. Available from: http://www.caregiver.org/caregiver.org/caregiver/jsp/print_friendly.jsp?nodeid=891 accessed on 3 April 2006.

Faragher, E.B., Cooper, C.L., Cartwright, S. (2004). A shortened stress evaluation tool (ASSET). *Stress and Health*. Volume 20: 189–201.

Farran, C.J., Fogg, L.G., McCann, J.J., Etkin, C., Dong, X., Barnes, L.L. (2011). Assessing family caregiver skill in managing behavioral symptoms of Alzheimer's disease. *Aging & Mental Health*. Volume 15. Number 4:510–521.

Fruhauf, C.A., Jarrott, S.E., Lambert-Shute, J.J. (2004). Service-learners at dementia care programs: an intervention for improving contact, comfort, and attitudes. *Gerontology & Geriatrics Education*. Volume 25. Number 1:37-52.

Gillespie, J.Z., Barger, P.B., Yugo, J.E., Conley, C.J., Ritter, L. (2011). The suppression of negative emotions in elder care. *Journal of Managerial Psychology*. Volume 26. Number 7:566 – 583.

Greeff, M. (2011). Information collection: interviewing. In: De Vos, A.S., Strydom, H., Fouché, CB., Delport, CSL (ed.). *Research at Grass Roots*. Pretoria: Van Schaik Publishers. Total pages:547.

Harmer, B.J., Orrell, M. (2008). What is meaningful activity for people with dementia living in care homes? A comparison of the views of older people with dementia, staff and family carers. *Aging & Mental Health*. Volume 12. Number 5:548–558.

Hasselkus, B.R., Murray, B.J. (2007) Everyday occupation, well being, and identity: the experience of caregivers in families with dementia. *American Journal of Occupational Therapy*. Volume 61 number 1:9–20.

Hasson, H., Arnetz, J.E. (2007). Nursing staff competence, work strain, stress and satisfaction in elderly care: a comparison of home-based care and nursing homes. *Journal of Clinical Nursing*. Journal compilation: 1-16.

Hoe, J., Katona, C., Roch, B., Livingston, G. (2005). Use of the QOL-AD for measuring quality of life in people with severe dementia-the LASER-AD study. *Age and Ageing*. (British Geriatrics Society). Volume 34 number 2:130-135.

Holstege, H., Riekse, R. (ed) (2003). *Caring for aging loved ones*. Carol Stream: Tyndale House Publishers, Inc. Total pages: 558.

Hughes, J.C., Baldwin, C. (2006). *Ethical issues in dementia care*. London: Jessica Kingsley Publishers. Total pages: 144.

Hung, L., Chaudhury, H. (2011). Exploring personhood in dining experiences of residents with dementia in long-term care facilities. *Journal of aging studies*. Volume 25:1-12.

Innes, A., Macpherson, S., McCabe, L. (2006). *Promoting person-centred care at the front line*. Joseph Rowntree Foundation. Total pages:81.

Isaksson, U., Graneheim, U.H., Astrom, S., Karlsson, S. (2011). Physically violent behaviour in dementia care: characteristics of residents and management of violent situations. *Aging & Mental Health*. Volume 15. Number 5:573–579.

Ivankova, N.V., Creswell, J.W., Plano Clark, V.L. (2007). Foundations and approaches to mixed methods research, in: Maree, K. (ed.). *First Steps in Research*. South Africa: Van Schaik Publishers. Total pages:334.

Iwama, M.K. (2004). Meaning and inclusion: revisiting culture in occupational therapy. *Australian Occupational Therapy Journal*. Volume 51:1–2.

Jeon, Y., Luscombe, G., Chenoweth, L., Stein-Parbury, J., Brodaty, H., King, M., Haas, M. (2011). Staff outcomes from the caring for aged dementia care resident study (CADRES): a cluster randomised trial. *International Journal of Nursing Studies*. doi:10.1016/j.ijnurstu.2011.10.020.

Kada, S., Nygaard, H.A., Mukesh, B.N., Geitung, J.T. (2009). Staff attitudes towards institutionalised dementia residents. *Journal of Clinical Nursing*. Number 18:2383–2392.

Kai, J., Spencer, J., Wilkes, M., Gill, P. (1999). Learning to value ethnic diversity – what, why and how? *Medical education*. Volume 33:616-623.

Kane, R.A., Lum, T.Y., Cutler, L.J., Degenholtz, H.B., Yu, T. (2007). Resident outcomes in small-house nursing homes: a longitudinal evaluation of the initial Green House program. *Journal of American Geriatrics Society*. Journal compilation:1-8.

Karatepe, O.M., Uludag, O. (2008). Affectivity, conflicts in the work–family interface and hotel employee outcomes. *International Journal of Hospitality Management*. Vol. 27:30–41.

Kellett, U., Moyle, W., McAllister, M., King, C., Gallagher, F. (2010). Life stories and biography: a means of connecting family and staff to people with dementia. *Journal of Clinical Nursing*. Volume 19:1707–1715.

Kitwood, T. (1997). *Dementia reconsidered: the person comes first*. Philadelphia: Open University Press. Total pages:160.

Kitwood, T. (2000). Cultures of care: tradition and change. In: Kitwood, T., Benson, S. (ed.). *The New Culture of Dementia Care*. London: Hawker Publications. Total pages:80.

Kovach, C.R., Noonan, P.E., Schlidt, A.M., & Wells, T. (2005). A model of consequences of need-driven, dementia-compromised behavior. *Journal of Nursing Scholarship*. Volume 37. Number 2:134–140.

Lauria M.M., Clark, E.J., Hermann, J.F. & Stearns, NM. (2001). *Social work in oncology*. American Cancer Society. Total pages:402.

Law, D. (2012). Telecare comes home. *Nursing & Residential Care*. Volume 14. Number 1:40-42.

Law, M., Steinwender, S., Leclair, L. (1998). Occupation, health and well-being. *Canadian Journal of Occupational Therapy*. Volume 65. Number 2:81-91.

Levin, P.F., Hewitt, J.B., Misner, S.T., Reynolds, S. (2003). Assault of long-term care personnel. *Journal Of Gerontological Nursing*. March: 28-35.

Lewis, S. (2003). *Elder care in occupational therapy*. Thorofare: Slack Incorporated. Total pages: 507.

Lum, D. (2000). *Social work practice and people of color: a process-stage approach*. Belmont: Brooks/Cole. Total pages:338.

Luttenberger, K., Donath, C., Uter, W., Graessel, E. (2012). Effects of multimodal nondrug therapy on dementia symptoms and need for care in nursing home residents with degenerative dementia: a randomized-controlled study with 6-month follow-up. *Journal of American Geriatrics Society*. Volume 60:830-840.

Makhotla, F.M. (2012). (Sesotho speaking occupational therapist at National District Hospital). Personal communication regarding the Sesotho culture. 26 April. Bloemfontein.

Maree, K., Pietersen, J. (2007). Surveys and the use of questionnaires, in: Maree, K. (ed.). *First Steps in Research*. Pretoria: Van Schaik Publishers. Total pages:334.

Margallo-lana, M., Swann, A., O'Brien, J., Fairbairn, A., Reichelt, K., Potkins, D., Mynt, P., Ballard, C. (2001). Prevalence and pharmacological management of behavioural and psychological symptoms amongst dementia sufferers living in care environments. *International Journal of Geriatric Psychiatry*. Number 16:39-44.

Maslow, A.H. (1954). *Motivation and personality*. New York: Harper & Row Publishers. Total Pages:334.

Matzo, M.L. & Sherman, D.W. (2004). *Gerontologic palliative care nursing*. Missouri: Mosby. Total pages:560.

Menken, A., Schwartz, S. (1994). Lyrics: *Colours of the Wind*. Burbank: Disney.

Milwain, E. (2009). The brain and person-centred care. *Journal of Dementia Care*. Volume 18 number 1: 23-25.

Mitchell, S.L., Teno J.M., Kiely D.K., Shaffer M.L., Jones R.N., Prigerson H.G., Volicer L., Givens J.L., Hamel M.B. (2009). The clinical course of advanced dementia. *The New England Journal Of Medicine*. Volume 361. Number 16: 1529-38.

Miyamoto, Y., Tachimori, H., Ito, H. (2010). Formal caregiver burden in dementia: impact of behavioral and psychological symptoms of dementia and activities of daily living. *Geriatric Nursing*. Volume 31. Number 4:246-253.

Moyle, W., Murfield, J.E., Griffiths, S.G. (2010) Care staff attitudes and experiences of working with older people with dementia. *Australasian Journal on Ageing*. Volume 2. Number 4:1-5.

Mtose, X. (2011). Black peoples' lived experiences of everyday racism in post-apartheid South Africa. *The Journal of International Social Research*. Volume 4. Number 17:325-338.

Munoz, J.P. (2007). Culturally responsive caring in occupational therapy. *Occupational Therapy International*. Volume 14. Number 4:256–280.

Nakahira, W., Moyle, W., Creedy, D., Hitomi, H. (2008). Attitudes toward dementia-related aggression among staff in Japanese aged care settings. *Journal of Clinical Nursing*. Volume 18: 807–816.

Natan, M.B. (2008). Perceptions of nurses, families, and residents in nursing homes concerning residents' needs. *International Journal of Nursing Practice*. Volume 14:195–199.

Neuman, W.L., Kreuger, L.W. (2003). *Social work research methods: qualitative and quantitative approaches*. Boston: Allyn and Bacon. Total pages: 584.

Olivier, I. (2009). (Professional nurse at a residential care facility). Personal communication regarding education of caregivers and the setup. 16 March, Bloemfontein.

Padgett, D.K. (1998). *Qualitative methods in social work research: challenges and rewards*. Thousand Oaks: Sage Publications. Total pages:178.

Park, M. (2010). Nursing staff stress from caregiving and attitudes toward family members of nursing home residents with dementia in Korea. *Asian Nursing Research*. Volume 4. Number 3:130-140.

Perrin, T., May, H. & Anderson, E. (2008). *Wellbeing in dementia: an occupational approach for therapists and carers*. (2nd ed). Philadelphia: Elsevier. Total pages:166.

Pierce, D. (1998). The issue is: what is the source of occupation's treatment power? *The American Journal of Occupational Therapy*. Volume 52. Number 6:490-491.

Pierce, D. (2001). Occupation by design: dimensions, therapeutic power, and creative process. *American Journal of Occupational Therapy*. Volume 55: 249–259.

Pioneer Network. (2011). *About us*. [online]. Available from: <http://www.pioneernetwork.net/AboutUs/About> accessed on 23 November 2011.

Polit, D.F., Beck, C.T. (2006). *Essentials of nursing research: methods, appraisal, and utilization*. Philadelphia: Lippencott Williams and Wilkins. Total pages: 554.

Power, G.A. (2010). *Dementia beyond drugs: changing the culture of care*. Baltimore: Health Professions Press. Total pages: 265.

Priebe, S. (2004). Institutionalization revisited – with and without walls. *ACTA Psychiatrica Scandinavica*. Volume 110:81-82.

Pulsford, D. (1997). Therapeutic activities for people with dementia — what, why... and why not? *Journal of Advanced Nursing*. Volume 26:704–709.

Raubenheimer, J. (2009). (Biostatistician at the University of the Free State). Personal communication regarding the design of an interview schedule. 11 December. Bloemfontein.

Raubenheimer, J. (2011). (Biostatistician at the University of the Free State). Personal communication regarding the reliability of the interview schedule. 2 November. Bloemfontein.

Raubenheimer, J. (2012). (Biostatistician at the University of the Free State). Personal communication regarding quantitative data. 26 April. Bloemfontein.

Reed, J. (1999). Keeping a distance: the reactions of older people in care homes to confused fellow residents, in: Adams, T., Clarke, C.L. (ed). *Dementia Care: Developing Partnerships in Practice*. London: Baillière Tindall. pp 167: 385.

Rubin, H.J., Rubin, I.S. (1995). *Qualitative interviewing: The Art of Hearing Data*. Thousand Oaks: SAGE Publications. Total pages: 302.

Saldana, J. (2009). *The coding manual for qualitative researchers*. London: Sage. Total pages: 223.

Seeleman, C., Suurmond, J., Stronks, K. (2009). Cultural competence: a conceptual framework for teaching and learning. *Medical Education*. Volume 43: 229–237.

Selbaek, G., Kirkevold, O., Engedal, K. (2007). The prevalence of psychiatric symptoms and behavioural disturbances and the use of psychotropic drugs in Norwegian nursing homes. *International Journal of Geriatric Psychiatry*. Number 22: 843–849.

Shen, B., Dicker, B. (2008). The impacts of shiftwork on employees. *The International Journal of Human Resource Management*. Volume 19. Number 2:392–405.

Sloane, P.D., Hoeffler, B., Mitchell, M., McKenzie, D.A., Barrick, A.L., Rader, Stewart, B.J., Talerico, K.A., Rasin, J.H., Zink, R.C., Koch, G.G. (2004). Effect of person-centered showering and the towel bath on bathing-associated aggression, agitation, and discomfort in nursing home residents with dementia: a randomized, controlled Trial. *Journal of American Geriatrics Society*. Number 52:1795–1804.

South Africa. (2006). *Older Persons Act*. Number 13 of the Act of 2006. Government Gazette 29346(797). November 2. (Regulation Gazette No. 1098: Pretoria: Government Printer.

Strubel, D., Samacoits, P. (2006). Ethical questions surrounding end of life in a long-term care unit. *Supporting and Caring for People with Dementia throughout End of Life*. Number 2:106-115. June.

Strydom, H. (2011a). Ethical aspects of research in the social sciences and human service professions. In: De Vos, A.S., Strydom, H., Fouché, CB., Delport, CSL (ed.). *Research at Grass Roots*. Pretoria: Van Schaik Publishers. Total pages:547.

Strydom, H. (2011b). Information collection: participant observation. In: De Vos, A.S., Strydom, H., Fouché, CB. and Delport, CSL. (ed.). *Research at Grass Roots*. Pretoria: Van Schaik Publishers. Total pages:547.

Strydom, H. (2011c). Sampling in the quantitative paradigm. In: De Vos, A.S., Strydom, H., Fouché, CB. and Delport, CSL. (ed.). *Research at Grass Roots*. Pretoria: Van Schaik Publishers. Total pages:547.

Strydom, H. (2011d). The pilot study in the quantitative paradigm. In: De Vos, A.S., Strydom, H., Fouché, CB., Delport, CSL. (ed.). *Research at Grass Roots*. Pretoria: Van Schaik Publishers. Total pages:547.

Strydom, H., Delpont, C.S.L. (2011). Sampling and pilot study in qualitative research. In: De Vos, A.S., Strydom, H., Fouché, CB. and Delpont, CSL (ed.). *Research at Grass Roots*. Pretoria: Van Schaik Publishers. Total pages:547

Swann, J.I. (2012). From pottery to plays: arts activities in the home. *Nursing & Residential Care*. Volume 14. Number 4:195-198.

Thomas, W.H. (1996). *Life worth living: how someone you love can still enjoy life in a nursing home*. Massachusetts: VanderWyk and Burnham. Total pages: 208.

Tobin, J. (2000). Sharing the care: towards new forms of communication. In: Kitwood, T., Benson, S. (ed.). *The New Culture of Dementia Care*. London: Hawker Publications. Total pages:80.

Townsend, E., Wilcock, A.A. (2004). Occupational justice and client-centred practice: a dialogue in progress. *Canadian Journal of Occupational Therapy*. Volume 71. Number 2:75-87. April.

Trombly, C.A. (2002). Occupation. In: Trombly, C.A., Radomski, M.V. *Occupational therapy for physical dysfunction*. Philadelphia: Lippincott Williams & Wilkins. Total pages:1155.

United Kingdom. (2005). *Mental Capacity Act*. Norwich: Crown Copyright. Total pages:88.

University of Bradford (2011). *Dementia care mapping*. [online]. Available from: <http://www.brad.ac.uk/health/dementia/dcm/> accessed on 23 November 2011.

Van Beek, A.P.A., Gerritsen, D.L. (2010). The relationship between organizational culture of nursing staff and quality of care for residents with dementia: Questionnaire surveys and systematic observations in nursing homes. *International Journal of Nursing Studies*. Volume 47:1274–1282.

Van den Pol-Grevelink, A., Jukema, J.S., Smits, C.H.M. (2012). Person-centred care and job satisfaction of caregivers in nursing homes: a systematic review of the impact of different forms of person-centred care on various dimensions of job satisfaction. *International Journal of Geriatric Psychiatry*. Volume 27: 219–229.

Van der Merwe, T. (2010). Occupational therapy and the quest for human dignity: why human rights matter. *South African Journal of Occupational Therapy*. Volume 40 number 1:17-21.

Verbeek, H., Zwakhalen, S.M.G., Van Rossum, E., Kempen, G.I.J.M, Hamers, J.P.H. (2011). Small-scale, homelike facilities in dementia care: a process evaluation into the experiences of family caregivers and nursing staff. *International Journal of Nursing Studies*. July:1-9.

Volicer, L. (2006). Quality of life in end-of-life dementia. *Supporting and Caring for People with Dementia throughout End of Life*. Volume 2:88-97. June.

Watts G.J.C (2011) Applying skills and knowledge: principles of nursing practice F. *Nursing Standard*. Volume 25. Number 33:35-37.

Wilcock, A.A. (1998). Occupation for health. *British Journal of Occupational Therapy*. Volume 61. Number 8:340-348.

Zeller, A., Dassen, T., Kok, G., Needham, I., Halfens, R.J.G. (2011). Nursing home caregivers' explanations for and coping strategies with residents' aggression: a qualitative study. *Journal of Clinical Nursing*. Number 20:2469–2478.

Zimmerman, S., Williams, C.S., Reed, P.S., Boustani, M., Preisser, J.S., Heck, E., Sloane, P.D. (2005). Attitudes, stress, and satisfaction of staff who care for residents with dementia. *The Gerontologist*. Volume. 45. Special Issue I: 96–105.

7. ADDENDA

ADDENDUM A

Information document: English

**UNIVERSITY OF THE FREE STATE
INFORMATION DOCUMENT**

Quality of life and occupation for persons with dementia: the perception of caregivers

_____ and the relevant participants are being asked to participate in a research study. Participation in this study is completely voluntary. Please read the information below and ask questions about anything that you do not understand before deciding if you want to participate. The researchers listed below will be available to answer your questions.

RESEARCH TEAM

Lead Researcher:

Ms. Corné Kotzé

Occupational Therapist

National District Hospital

Telephone number: (051) 403 9678

24-Hour Telephone number: 072 748 6970

Study Leader

Dr. Sanet du Toit

Senior Lecturer

University of the Free State

Telephone number: (051) 401 2832

Co-study Leader

Dr. Rita van Heerden

Senior Lecturer

University of the Free State

Telephone number: (051) 401 3078

AIM OF THE STUDY

The researcher is an Occupational Therapist undertaking a research study regarding the care that is being provided to residents suffering from dementia. Due to their level of deterioration, these residents are in need of 24-hour care.

Through research, pertinent questions about issues that directly influence the residents' quality of life are investigated in order to contribute to new information for improving quality of care.

In this study, the researcher will investigate the perspectives of the caregivers with regard to the quality of life and occupation of the residents with dementia.

Additional information regarding study goals will be supplied during the execution of the study.

SUBJECTS

Inclusion criteria

Participants (caregivers) will be included if they are currently working with residents with dementia.

Time commitment

The participants who sign the consent form must be willing to commit to a maximum of two hours. These two hours will be through the course of a working day as arranged with management.

PROCEDURES

The participants will be transported by an authorised person from the residential care facility to a local church for one interview only. The driver has indemnity to transport the participants. This session will take no longer than two hours, including travelling time. During this session, the participants will be interviewed individually and then be transported back to the residential care facility. The participants will be transported, one at a time, during the afternoon when most of the residents are asleep, or as personally arranged with the professional nurse in charge.

RISKS AND DISCOMFORTS

There are no known risks or discomfort associated with this study.

BENEFITS

Although the procedures hold no direct benefits for the participants, the whole facility (including residents and members of the multi-disciplinary team) can benefit from improved care to the residents. The residents could benefit due to receiving more accurate and appropriate care and treatment from the multi-disciplinary team.

COMPENSATION, COSTS AND REIMBURSEMENT

Compensation for Participation

There will be no financial compensation for the institution or the participants for partaking in this study.

Costs

There will be no cost involved for the participants or the institution for participating in this study.

WITHDRAWAL FROM OR TERMINATION OF THE STUDY AND CONSEQUENCES

The institution or individual participants are free to withdraw from this study at any time. If the institution or an individual decides to withdraw, please notify the research team immediately. The research team may also end the participation of the institution or individual participants in this study if they do not follow instructions, miss the scheduled visit or feel that their safety and welfare are at risk. If you decide not to participate, or if you withdraw from this study before it is completed, there are no alternative procedures available. The only alternative is not to participate in this study.

CONFIDENTIALITY

Audiovisual material will be recorded during the interview to attempt to capture the non-verbal messages (such as the emotions of the participants) that will be

included in the data. Information (written and audiovisual) will be treated with confidentiality throughout the study. No names will be released or published.

Data Storage

All research data, including the audiovisual recordings, will be maintained in a secure location at the University of the Free State. Only the research team will have access to it.

NEW FINDINGS

If, during the course of this study, significant new information becomes available that may relate to your willingness to continue participation, this information will be provided to you by the research team listed at the top of the form.

IF YOU HAVE QUESTIONS

If you have any comments, concerns, or questions regarding the conduct of this research, please contact the research team listed at the top of this form.

ADDENDUM B

Information document: Afrikaans

UNIVERSITEIT VAN VRYSTAAT
INLIGTINGSDOKUMENT

Kwaliteit van lewe en aktiwiteitsbetrokkenheid vir persone met demensie: die persepsie van versorgers

_____ en die relevante deelnemers word gevra om deel te neem aan 'n navorsingstudie. Deelname aan die studie is vrywillig. Lees asseblief die onderstaande inligting en vra vrae oor enigiets wat u nie verstaan nie voordat u besluit of u wil deelneem aan die studie. Die navorsers wat gelys is sal beskikbaar wees om u vrae te beantwoord.

NAVORSINGSPAN

Hoofnavorser:

Me. Corné Kotzé

Arbeidsterapeut

Nasionaal Distrikshospitaal

Telefoonnommer: (051) 403 9678

24-uur telefoonnommer: 072 748 6970

Studieleier

Dr. Sanet du Toit

Senior Lektrise

Universiteit van die Vrystaat

Telefoonnommer: (051) 401 2832

Medestudieleier

Dr. Rita van Heerden

Senior Lektrise

Universiteit van die Vrystaat

Telefoon nommer: (051) 401 3078

DOEL VAN DIE STUDIE

Die navorser is 'n arbeidsterapeut wat 'n navorsingstudie uitvoer rakende die versorging wat gebied word aan die inwoners wat aan demensie lei. Die vlak van deteriorasie van die inwoners veroorsaak dat hulle 24-uur sorg benodig.

Deur die verloop van die studie sal vroeë ondersoek word wat die inwoners se kwaliteit van lewe direk beïnvloed. Indien hierdie vroeë beantwoord kan word, sal nuwe inligting beskikbaar wees om die kwaliteit van versorging te verbeter.

In die studie sal die navorser die persepsies van die versorgers ondersoek rakende die kwaliteit van lewe en aktiwiteitsbetrokkenheid van die inwoners.

Addisionele inligting rakende die doelwitte van die studie sal gedurende die uitvoering van die studie aan die deelnemers verduidelik word.

DEELNEMERS

Insluitingskriteria

Deelnemers (versorgers) sal ingesluit word in die studie indien hulle tans werk met inwoners met demensie.

Tyd wat vereis sal word

'n Maksimum van twee werksure sal van die deelnemers vereis word, soos gereël met die bestuur van die instansie.

PROSEDURES

Die deelnemers sal vanaf die instansie vervoer word na 'n kerk vir een onderhoud. Die bestuurder het vrywaring om die deelnemers te vervoer. Die sessie sal nie langer as twee ure neem nie (reis ingesluit). Gedurende die sessie sal daar individuele onderhoude met die deelnemers gevoer word, waarna elkeen weer terug geneem sal word na die instansie. Die deelnemers sal individueel vervoer word gedurende die middag wanneer die meeste van die inwoners slaap, of soos wat persoonlik gereël sal word met die professionele verpleegkundige in beheer.

RISIKO'S

Geen risiko's word met die studie geassosieer nie.

VOORDELE

Alhoewel die studie geen direkte voordele vir die deelnemers inhou nie, sal hulle sowel as die res van die multidissiplinêre span bevoordeel word omdat versorging wat aan die inwoners gebied word, moontlik sal verbeter. Die inwoners sal bevoordeel word deurdat hulle moontlik meer akkurate en toepaslike versorging en behandeling sal ontvang vanaf die multidissiplinêre span.

VERGOEDING EN KOSTES VERBONDE

Vergoeding vir deelname

Daar is geen finansiële vergoeding betrokke vir die instansie of die deelnemers van die studie nie.

Kostes

Daar is geen kostes verbonde aan deelname vir die instansie of deelnemers van die studie nie.

BEËINDIGING VAN DIE STUDIE EN DIE NAGEVOLGE

Die instansie of individuele deelnemers is vry om te enige tyd te onttrek. Indien die instansie of individue besluit om te onttrek, moet die navorsingspan onmiddelik ingelig word. Die navorsingspan mag ook besluit om die deelname van die instansie of individuele deelnemers te staak indien instruksies nie gevolg word nie, as die geskeduleerde afspraak nie nagekom word nie, of as die deelnemers negatief beïnvloed word. Indien u besluit om nie deel te neem nie of indien u onttrek voordat die studie voltooi is, is daar geen alternatiewe prosedures beskikbaar nie. Die enigste alternatief is dan om nie aan die studie deel te neem nie.

VERTROULIKHEID

Audiovisuele materiaal sal opgeneem word tydens die onderhoude om nie-verbale boodskappe van die deelnemers as data in te samel. Alle inligting

(geskrewe en audiovisueel) sal met vertroulikheid hanteer word. Geen name sal bekend gemaak of gepubliseer word nie.

Berging van data

Alle data, insluitende die audiovisuele opnames, sal in veilige bewaring gehou word by die Universiteit van die Vrystaat. Slegs die navorsingspan sal toegang hê tot die data.

NUWE BEVINDINGE

Indien belangrike nuwe inligting na vore kom wat u bereidwilligheid tot deelname sal beïnvloed, sal die navorsingspan hierdie inligting aan u bekend maak.

VERDERE NAVRAE

Kontak asseblief die navorsingspan indien u enige opmerkings en/of vrae het rakende die uitvoering van die studie.

ADDENDUM C

Information document: Sesotho

UYNIVESITHI YA FREISTATA
TOKOMANE TSA DINTHLA/TLHAHISO LESEDING

Bophelo bo nang le boleng le mosebetsi ho batho ba nang le lefu la dementia:
Ho tswa leihlong la mohlakomedi.

..... le batho ba kgethilweng ba koptjhwa ho nka karolo patlisisong ena ke ka boithaupi. Bala tokomane ena na mme o nto botsa dipotsomoo o sa utlwisising pele o ka inehela thutong ena. Ba batlisisi ba latelang baka fumaneha bakeng sa ho arabela dipotso.

Sehlopha sa dipatlisiso

Me. Corné Kotzé

Occupational Therapist

National District Hospital

Tsa mohala: (051)403 9678

Tsa mohala wa dihora tse 24: 0727486970

Moetapele wa dithuto

Dr. Sanet du Toit

Morutwa bana

Yunivesithi ya Freistata

Tsa mohala: (051)401 2832

Motlatsi wa dithuto

Dr. Rita van Heerden

Morutwa bana

Yunivesithi ya Freistata

Tsa mohala: (051)401 3078

MAIKEMISETSO A PATLISISO

Mobatlisisi ona ke Occupational Therapist a etsang dipalo tsa pouputsu mabapi le hlokomelo e fuang bakudi ba dementia. Mabapi le bofokodi ba bakudi ba hlokomelo dihora tse 24. Ka tlasa patlisiso, dipotso tse nepanang le boemo ba budulo boo, ho batlisisitswe metsha etla eketsa boleng ba hlokomelo. Dithutong tsena, mmatlisisi o tla etsa dipatliso ho bahlokomedi mabapi le boleng ba bophelo le mosebetsi wa bakudi ba dementia. Tsebo e oketsehile mabapi le ditabatabelo tsa thuto di tla fanwa ha dipatlisiso dintse di tswela pele.

DITHUTO

Pallo

Baithaupi /bahlokomedi ba tla kenyelletswa ha bantse ba sebetsa le baahi ba dementia.

Nako

Baithaupi ba tekenang ditokomane ba ikemisetse ho sebetsa dihora tse pedi di kenyelleditse thuto ya mosebetsi ya letsatsi jwaloka dihlophiso le baetapele.

TSAMAISO

Baithaupi bat la tsamaiswa ho tloha bakeng sa bohlokomedi ho fitla kerekeng. Puisano ha ena ho nka ho feta hora tse pedi, ho kopantse nako ya tsela. Ka nako eo batla hlalubiwa ka bongwe, ka morao ba kgutlisetswe sebakeng sa bohlokomedi. Batla tsamaiswa ka bongwe maintsibuwa ha baahi ba se ba robetse kappa base ba hlophisitswe ke baoki.

DITLAMORAO

Ha ho ditlamorao tse lebelletsweng ho tswa thutong.

MELEMO

Le ha tsamaiso esa tswara melemo ho baithaupi, kaofela (ho kenyelleditswe le ditsibi tse ding) ba ka una molemo ho tswa hlokomelong e ntle ya bakudi. Baahi ba ka una molemo o moholo ho tswa hlokomelong e nepahetseng ya bakudi le hlokomelo ho tswa botsamaising ba booki.

PATALA, DITJEHO LE KGUTLISO YA TJHELETE

Kgutliso ya tjelete

Ha ho ditjhelete tse tse tla kgutliswa ho barutwana ha ban ka karolo ya ho ithuta.

Ditjeho

Ha h tjelete eo moithapi a tla e patala ho kenela thuto ena.

BOITOKOLLO

Moithaupi o lokollohile ho itokolla nako engwe le engwe. Ha motho a nka qeto ya ho itokolla o lokela ho tsibisa bafuputsi ka nako. Bafuputsi ban a le tokelo ya ho fedisa thuto ya baithaupi ha bas a tsamaye ka taelo. Ha o nkile qeto ya ho se nke karolo kapa ho tlohella pele dithuto di fela, ha ho tsamaiso e ngwe, se teng ke hore o tlohelle ho nka karolo ho thuto.

LEKUNUTU

Di sebeiswa tsa kutlo di tla sebediswa ka nako ya puisano ho tsamaisa melaetsa ya maikutlo ya ba nkang karolo, tse tla kenywang dating.

Poloko ya data

Dipatlisiso tsa data tse kenyeleletswang ho rekotwa ho disebediswa tsa kutlo, di tla tshehetswa ho bolokellwa moo UFS. Ke ba batlisisi fela banang le tokelo ya ho etsa jwalo.

THUTO E NTSHA

Ha eba ka nako ya dithuto, thuto e ba molemo ho wena, mme o e kemisetsa ho swela pele o tla e fuwa ke ba batlisisi ba baduweng tokomaneng ena.

HA ONA LE DIPOTSO

Ha ona le dipotso maapi le patlisiso ena, kopana le komiti ya thuto e ngotsweng tokomaneng ena.

ADDENDUM D

Information document: Tswana

UYNIVESITHI YA FREISTATA
DITLANKANA TSA TSHEDIMOSSETSO

Botshelo bo tlhwa tlhwa le tiro (mosomo) ya motho a dementia: motho motihokomedi.

..... le batho ba ithaopileng go tsenela dipatlisiso ka botshelo le tiro ya mofuta wa motho yo boletsweng kwa godimo. Bala senatswna se ka fa tlase monago o botse dipotso moo o sa tlhaloganyeng pele ga o ka kenela dipatlisiso. Baphuputsi ba latelang ba ka fumanega bakeng sa go arabela dipotso.

LEKOKO LA BAPHUPUTSI (SETLHOPHA SA BAPHUPUTSI)

Moetapele wa patlisiso

Me. Corné Kotzé

Occupational Therapist

National District Hospital

Tsa mohala: 051 403 9678

Tsa mohala wa ura tse 24: 0727486970

Mmatlisisi

Dr. Sanet du Toit

Murutwabana

Yunivesithi Ya Freistata

Tsa mohala: 051 401 2832

Motlatsi wa moetapele

Dr. Rita van Heerden

Murutwabana

Yunivesithi Ya Freistata

Tsa mohala: 051 401 3078

MAIKAELELO A GO BALA

Tlhotlhomiso ena ke Occupational Therapist ya dirang palo ya bophuputsi mabapi le tlhokomelo e hiwang balwetsi ba dementia. Mabapi le phokolo balwetsi ba batlhoka tlhokomelo di ura tse 24. Ka tlase ga patlisiso, dipothso, tse nepanang le boemo ba bodulo boo, go batlisisitshwe tse tla hana ka tsebo e ntsha oketsa boleng ba tlhokomelo. Dithutong tsena, mmatlisisi o tla dira dipatlisiso ho batlhokomedi, mabapa le boleng jhwa bophelo mosetsi wa balwetsi ba dementia. Tsebo e okeditshweng mabapi le dintla tsa dithuto di tla fanwa ga dipatlisiso dintse di tswela.

DIRUTWA

Palelo

Baithaopi kgotsa batlhokomedi batla kenyeletswa ga ba ntse ba dira le baagi ba dementia.

Nako

Baithaopi ba tekenang foromo bo ikemisetse go dira di ura tse pedi. Diura tse pedi di kenyeleditse thuto ya tiro ya letsatsi jaaka go rulagantswe (taolo).

TSAMAISO

Baithaopi ba tla tsamaisiwa go tloga lefelong la batlhokomedi go fitlha kwa kerekeng go dira puisano e le nngwe fela, ka nako eo ba tla tlhatlhabiwa ka bonngwemorago ba busediwe lefelong la batlhokomedi. Ba tla tsamaiswa ka nako e le nngwe ka tlhapama ga baagi ba robetse kapa go ya thulagano ya mooki o mo tirong.

DITLAMORAGO

Ga go ditlamorago tse di lebeletsweng go tswa mo thutong e.

MELEMO

Le ha ele mo thuto e esa twsara melemo e tlamaletseng ho moithaupi, botlhe go tsenyeleditswe le ditsibi tse dingwe, ba ka una molemo tlhokomelong e ntle ya balwetsi. Setsa se se ka una molemo e tseneletsing le tlhokomelo ho tswa batsibing ba booki.

PUSELETSO YA BAITHAOPI

Ga go na madi a puseletso a mokgatlo kapa morrtwa ga ba ithaopa ga nka karolo go ithuta.

Maduo

Ga go meduo kapa morokotso a moithaopi go nka karolo ya go ithuta.

Boitokello

Moithaopi o golotsegile go itokolla go ithuta ka nako e ngwe le e nngwe. Ga motho a tsere kgetso ya go itokollo, itsise baphuputsi ka nako, batla fedisa thuto ya baithaopi fa ba sa tsamaye ka taelo.

Ga o dirile kgetho ya go sa nke karolo kapa go lesa go ithuta pele thuto e tswelela ga go tsamaiso e nngwe, se se gona ke gore o lesa go nka karolo ga ithuta.

TSHEPISO

Disebediswa tsa kutlo di tla rekotwa ka nako ya puisano. Go tsamaisa melaetsa jaaka phuduego ya ba nka karolo tse tla kengwang mo dateng.

Poloko ya data (Dintlha)

Dipatlisiso tsa data, tse tsenyeleditsweng go rekotiwa go di diriswa tsa kutlo, di tla tshegetswe mo go bolokegileng mo Yuniversithi Ya Freistata. Ke babatlisisi feela ba nang le tetla ya ga dira jaalo.

THUTO E NTSHA

Ga eba ka nako ya dithuto, thuto e ba mosola mo go wena, o ikemisetsa go tswela pele, e tla nna gona go tswa babatlisisi ba boletsweng mo tokomaneng.

GA DIPOTSO DI LE TENG

Ga o na le dipotso, dikananelo malebana le dipatlisiso kapana le komiti ya patlisiso e ngotswe mo tokomaneng

ADDENDUM E

**Consent form: Residential Care
Homes (English)**

FORM OF CONSENT REGARDING PROSPECTIVE RESEARCH STUDY:

Quality of life and activity involvement for persons with dementia: the perception
of caregivers

_____ Residential Care Facility is requested to participate in the prospective research study.

You were informed about the study by Ms. Corné Kotzé and you can contact her (072 748 6970) if you have any enquiries regarding the research or if a resident or caregiver was injured as result of the study.

You can contact the Secretary of the Ethics Committee of the Faculty of Health Sciences, UFS at (051) 405 2812 if you have any questions regarding the rights of the participants as respondents in the study.

The participation of the institution in this study is voluntary and will not be penalized or forfeit any advantages if participation is refused or discontinued at any stage.

All information will be regarded as confidential. The institution will receive feedback on the results of the study as well as recommendations for further training of the caregivers.

If permission to participation is granted, you will receive a signed copy of this document as well as an information document containing a summary of what the research entails.

Contract:

I, _____, the manager of
_____ Residential Care Facility understand what the

institution's involvement in the study entails. The research study, including the abovementioned information was conveyed verbally as well as in writing

DECLARATION OF UNDERSTANDING

I have read the information document and acknowledge that I have full comprehension of the proposed study.

Signature: Manager

Date

I have explained this study to the Manager of the _____ Residential Care Facility and have sought his/her understanding for informed consent.

**Signature: Corné Kotzé
(Researcher)**

Date

**PERMISSION TO CONDUCT THE STUDY AT _____
RESIDENTIAL CARE FACILITY:**

Please indicate the applicable block:

Approval to conduct the proposed research study at _____ Residential Care Facility is GRANTED	Approval to conduct the proposed research study at _____ Residential Care Facility is NOT GRANTED
---------------------------------------------------------------------------------------------------------	-------------------------------------------------------------------------------------------------------------

_____ Signature: Manager	_____ Date
------------------------------------	----------------------

_____ Signature: Corné Kotzé (Researcher)	_____ Date
---------------------------------------------------------	----------------------

_____ Signature of Witness	_____ Date
_____ Printed name of Witness	

ADDENDUM F

**Consent form: Residential Care
Homes (Afrikaans)**

TOESTEMMINGSVORM RAKENDE VOORNEMENDE NAVORSINGSTUDIE:

Kwaliteit van lewe en aktiwiteitsbetrokkenheid vir persone met demensie: die persepsie van versorgers

_____ word versoek om deel te neem aan 'n voornemende navorsingstudie.

U is ingelig rakende die studie deur me. Corné Kotzé en u kan haar kontak by (072 748 6970) indien u enige navrae het rondom die studie of in 'n geval waar 'n kliënt of versorger benadeel is as gevolg van die studie.

U kan die Sekretariaat van die Etiekkomitee van die Fakulteit Gesondheidswetenskappe, UV skakel by (051) 405 2812 indien u enige navrae het rakende die regte van die deelnemers.

Deelname aan die studie is vrywillig en deelnemers sal nie gepenaliseer word of enige voordele verloor indien hy/sy deelname weier of besluit om nie voort te gaan met deelname nie.

Alle inligting sal vertroulik hanteer word. Die institusie sal terugvoer ontvang rakende die resultate van die studie en aanbevelings sal gemaak word rondom verdere opleiding van die versorgers.

Indien u toestemming gee tot deelname, sal die inligtingsdokument aan u verskaf word wat 'n opsomming bevat van wat die studie behels sowel as 'n getekende kopie van die dokument.

Kontrak:

Ek, _____, die bestuurder van _____
_____ Versorgingseenheid verstaan wat die deelname

van die institusie aan die studie behels. Inligting rakende die studie is mondelings, sowel as in geskrewe vorm aan my oorgedra.

VERKLARING VAN BEGRIP

Ek het die inligtingsdokument geleers en verklaar dat ek ten volle verstaan wat die navorsingstudie behels.

Handtekening: Bestuurder

Datum

Ek verklaar dat ek die studie aan die Bestuurder van _____ Versorgingseenheid verduidelik het en sy/haar begrip vereis het vir ingeligte toestemming.

Handtekening:
Corné Kotzé
(Navorser)

Datum

TOESTEMMING VIR DIE UITVOERING VAN DIE STUDIE BY

VERSORGINGSEENHEID:

Dui asseblief die toepaslike blok aan:

Hiermee gee ek toestemming vir die uitvoering van die studie by <hr/> Versorgingseenheid		Hiermee weier ek toestemming vir die uitvoering van die studie by <hr/> Versorgingseenheid	
---------------------------------------------------------------------------------------------	--	-----------------------------------------------------------------------------------------------	--

<hr/> Handtekening: Bestuurder	<hr/> Datum
---------------------------------------	--------------------

<hr/> Handtekening: Corné Kotzé (Navorsers)	<hr/> Datum
--------------------------------------------------------	--------------------

<hr/> Handtekening van getuie	<hr/> Datum
<hr/> Naam van getuie	

ADDENDUM G
Consent form: Participants
(English)

FORM OF CONSENT REGARDING PROSPECTIVE RESEARCH STUDY:

Quality of life and activity involvement for persons with dementia: the perception of caregivers

_____ is requested to participate in the prospective research study.

You were informed about the study by Ms. Corné Kotzé and you can contact her (072 748 6970) if you have any enquiries regarding the research or if a client or caregiver was injured as a result of the study.

You can contact the Secretary of the Ethics Committee of the Faculty of Health Sciences, UFS at (051) 405 2812 if you have any questions regarding the participants' rights as respondent in the study.

Participation in this study is voluntary and no participant will be penalized or forfeit any advantages if he/she refuses participation or decides to discontinue participation at any stage.

All information will be regarded as confidential.

If permission to participation is granted, you will receive an information document containing a summary of what the research entails as well as a signed copy of this document.

Contract:

I, _____, understand what my involvement in the study entails and grant permission that I may be included to participate in the study. The research study, including the abovementioned information was conveyed to me verbally as well as in writing.

Signature of participant/
legal guardian

Date

Signature of witness

Date

Signature of researcher

Date

ADDENDUM H
Consent form: Participants
(Afrikaans)

TOESTEMMINGSVORM RAKENDE VOORNEMENDE NAVORSINGSTUDIE:

Kwaliteit van lewe en aktiwiteitsbetrokkenheid vir persone met demensie: die persepsie van versorgers

_____ word versoek om deel te neem aan 'n voornemende navorsingstudie.

U is ingelig rakende die studie deur me. Corné Kotzé en u kan haar kontak by (072 748 6970) indien u enige navrae het rondom die studie of in 'n geval waar 'n kliënt of versorger benadeel is as gevolg van die studie.

U kan die Sekretariaat van die Etiekkomitee, Fakulteit Gesondheidswetenskappe, UV skakel by (051) 405 2812 indien u enige navrae het rakende die regte van die deelnemers.

Deelname aan die studie is vrywillig en deelnemers sal nie gepenaliseer word of enige voordele verloor indien hy/sy deelname weier of besluit om nie voort te gaan met deelname nie.

Alle inligting sal as vertroulik hanteer word.

Indien u toestemming gee tot deelname, sal die inligtingsdokument aan u verskaf word wat 'n opsomming bevat van wat die studie behels sowel as 'n getekende kopië van die dokument.

Kontrak:

Ek, _____, verstaan wat my deelname aan die studie behels en verleen toestemming dat ek ingesluit kan word in die studie. Die inligting rakende die studie is mondelings aan my oorgedra asook in geskrewe vorm.

Handtekening van
deelnemer/Voog

Datum

Handtekening van getuie

Datum

Handtekening van navorser

Datum

ADDENDUM I
Consent form: Participants
(Sesotho)

TOKOMANE YA TUMELLANO MABAPI LE PATLISISO

Bophelo bo nang le boleng le tsebedisana ya mokudi wa dementia: Ho tswa ho mohlakomedi.

..... O kupuwa ho nka karolo thutong ena. O ne o tsibiswa ka thuto ke Me. Corné Kotzé mme o ka mo fumana ho (072 748 6970), mabapi le dipotso ka patlisiso kappa ka mokudi/mohlakomedi a utlwile bohloko thutong.

O ka fumana mongodi wa komiti tsa Boitswaro ba Botho wa Medical Faculty mona UFS ha (051 405 2812) ha hona le dipotso mabapi le ditokelo tsa moithaupi thutong.

Karolo patlisisong ke ka boithaupi, mme motho a k eke a kopana le ditlamorao ka ho se nke karolo.

Dintla ka o feela di tla tswarwa ka lekunutu.

Ha moithaupi a loketswe ho nka karolo, o tla fuwa ditokomane tsa dintla hammoho le tokomane e sinuweng.

Kontraka

Nna, _____, ke utlwisisa tsebedisano yaka thutong ena mm eke fana ka tokelo ho nka karolo patlisisong ena. Patlisiso ena, hammoho le dintla tse ka hodimo di fuwa ka molomo le mongolo.

Letswaho la moithaupi/
Mohlokomedi a molawong

Letsatsi

Letswaho la paki

Letsatsi

Letswaho la mmatlisisi

Letsatsi

ADDENDUM J
Consent form: Participants
(Tswana)

TOKOMANE YA TUMELLANO MABAPI LE PATLISISO ENA

Botshelo bo molemo le tsebediso ya molwetsi wa dementia : Ho tswa ho mothlokamedi.

_____ o gopelwa go tseha karolo thutong ena. O ne o tsibisitswe ka thuto ena ke Me. Corné Kotzé mme o ka mo fumana ho (072 748 6970) mabapi le dipotso ka patlisiso kapa ka molwetsi/mohlokamedi a lemaditsweng ke thuto ena.

O ka founela mongodi wa komiti tsa Boitswaro ba Botho wa Medical Faculty, UFS ho (051) 405 2812 ha gona le dipotsho mabapi le ditokelo tsa moithaupi thutong.

Karolo patlisisong ke ka boithaupo, mme mongwe a ke ke a tobana le ditlamorao ka ho se nke karolo.

Dintlha tsohle di tla tswarwa ka lekunutu.

Ha moithaupi a lokellletswe go nka karolo, o tla fuwa ditokomane tsa dintla hammoho le tokomane e sinuweng.

Kontraka

Nna, _____, ke a utlwisisa tshebedisano yame thutong ena mm eke fana ka tokelo ya gore ke nke karolo patlisisong ena.

Patlisiso ena, hammoho le dintla tse fa godimo di fuwa ka molomo le mongolo.

Letswaho la moithaupi/
Mohlokomedi a molawong

Letsatsi

Letswaho la paki

Letsatsi

Letswaho la mmatlisisi

Letsatsi

ADDENDUM K

Probing questions

Every choice the participant makes in Section B,C,D,E,F will be followed by the applicable questions as indicated:

Hoekom sê jy so?/*Why do you say so?* (Clarification)

Gaan aan.../Go on... (Elaboration)

Dis wonderlik! Kan jy my meer daarvan vertel?/*Wonderful! Can you tell me more about that?* (Encouragement)

Ek verstaan heeltemal wat jy sê/*I really understand what you are saying* (Showing understanding)

Wat het toe gebeur?/*What happened then?* (Elaboration)

Herhaal 'n deel van die sin waarop jy wil hê sy moet uitbrei/*Repeat a part of the sentence on which you want her to elaborate* (Repeating)

So wat jy sê is.../*So what you are saying is...* (Paraphrasing)

So jy voel dat.../*So you feel that...* (Reflection)

As haar sinne onduidelik is, vra vir duidelikheid/*Ask for clarification if necessary* (Clarification)

Moenie vra 'hoe weet jy' nie. Vra eerder verdere detail, bv. 'Was jy daar toe dit gebeur het?'/*Do not ask 'how do you know?' Instead ask for more detail, e.g. 'were you there when it happened?* (Experience)

Hoe voel jy oor...?/*How do you feel about?* (Slant)

Kan jy my 'n voorbeeld gee?/*Can you give me an example?* (Evidence)

Ek verstaan nie wat jy nou gesê het nie, kan jy asseblief verder verduidelik?/*I do not understand what you said just now. Can you explain it please?* (Faking puzzlement)

Vertel my meer van.../*Please tell me more about* (Clarification)

ADDENDUM L
Interview Schedule
(Objective A & B)

NOMMER VAN DEELNEMER

--	--

 1-2

AFDELING A

Antwoord asb. die volgende vrae

1. Wat is jou geboortedatum? (dd/mm/jjjj)

___/___/_____

--	--	--	--	--	--	--	--

 3-10

2. Wat is jou ouderdom?

_____ jaar

--	--

 11-12

3. Aan watter kultuurgroep behoort jy?

1	Sesotho
2	Tswana
3	Ander

--

 13

4. Wat is jou geslag?

1	Manlik
2	Vroulik

--

 14

5. In watter woonbuurt bly jy?

--	--

 15-16

6. Hoe ver woon jy van die werk af?

_____ km

--	--

 17-18

7. Met watter vervoermiddel ry jy werk toe?
(meer as 1 opsie kan gemerk word)

1	Taxi
2	Bus
3	Motor
4	Eie vervoer (fiets)
5	Eie vervoer (motor)
6	Te voet
7	Ander (spesifiseer)

	19
	20
	21
	22
	23
	24
	25

8. Hoeveel ure voordat jy in die oggend werk, moet jy opstaan?

_____ ure

26

9. Wat is jou hoogste kwalifikasie?

27-28

10. Is jou maandelikse salaris genoeg om jou en jou afhanklikes mee te versorg?

1	Ja
2	Nee

29

11. Is die inkomstes van almal in die huis genoeg om jou en jou afhanklikes mee te versorg?

1	Ja
2	Nee

30

12. Hoeveel kamers is in die huis waar jy bly?

_____ kamers

31-32

13. Hoeveel mense woon in die huis?

_____ mense

33-34

14. Hoeveel kinders het jy?

_____ kinders

35-36

15. Het jy enige ander afhanklikes?

1	Ja
2	Nee

37

16. Indien ja, hoeveel?

_____ afhanklikes

38-39

spesifiseer:

40-41

17. Watter tipe skofte werk jy?

1	Dag
2	Nag
3	Roteer

42

18. Hoeveel skofte werk jy per week?

_____ skofte

43-44

19. Hoeveel ure werk jy per skof?

_____ ure

45-46

20. Hoe lank werk jy al met persone met demensie?

_____ maande

47-49

AFDELING B

21. Watter aktiwiteit/deel van aktiwiteit sal inwoners aan kan deelneem sonder dat versorgers/personeel alles vir hulle hoef te doen?

1	eet en drink
2	was
3	aantrek
4	skeer
5	hare was
6	hare kam
7	ander

spesifiseer: _____

<input type="text"/>	50	<input type="text"/>	51
<input type="text"/>	52	<input type="text"/>	53
<input type="text"/>	54	<input type="text"/>	55
<input type="text"/>	56	<input type="text"/>	57
<input type="text"/>	58	<input type="text"/>	59
<input type="text"/>	60	<input type="text"/>	61
<input type="text"/>	62	<input type="text"/>	63

22. Hoekom dink jy doen die versorgers tans alles vir die inwoners in die eenheid (was hulle, voer hulle, trek hulle aan)?

- 1 te min tyd
- 2 te veel stres
- 3 versorgers is baie moeg en oorwerk
- 4 versorgers weet nie hoe om take soos eet in kleiner stappe op te deel sodat inwoners sekere stappe op hulle eie kan doen nie
- 5 versorgers is bang om 'n nuwe manier te probeer wanneer hulle met inwoners werk
- 6 die inwoners is oud en swak en kan niks meer vir hulself doen nie
- 7 die versorgers het nie die kans gekry om te oefen hoe om die inwoners te help om take self te doen nie en kan dit nog nie doen nie
- 8 die inwoners behandel die versorgers sleg
- 9 ander spesifiseer _____

- 1 2
- 3 4
- 5 6
- 7 8
- 9 10
- 11 12
- 13 14
- 15 16
- 17 18

23. Hoekom dink jy probeer die versorgers selde verskillende maniere vir dit wat hulle elke dag met die inwoners moet doen?

- | | | | |
|-----------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------|-----------------------------|
| <input type="checkbox"/> 1 | versorgers word nie genoeg betaal nie | <input type="checkbox"/> 19 | <input type="checkbox"/> 20 |
| <input type="checkbox"/> 2 | versorgers is al te veel aan die dood blootgestel en wil nie geheg raak aan die inwoners nie | <input type="checkbox"/> 21 | <input type="checkbox"/> 22 |
| <input type="checkbox"/> 3 | daar is te veel bakleiery met die Susters en die multi-dissiplinêre span | <input type="checkbox"/> 23 | <input type="checkbox"/> 24 |
| <input type="checkbox"/> 4 | die inwoners behandel die personeel sleg | <input type="checkbox"/> 25 | <input type="checkbox"/> 26 |
| <input type="checkbox"/> 5 | daar is van die inwoners waarvan die versorgers nie hou nie | <input type="checkbox"/> 27 | <input type="checkbox"/> 28 |
| <input type="checkbox"/> 6 | versorgers weet nie genoeg van die inwoners se lewe en belangstellings nie | <input type="checkbox"/> 29 | <input type="checkbox"/> 30 |
| <input type="checkbox"/> 7 | versorgers word nie die kans gegun deur die organisasie om kreatief te wees nie. Daar moet slegs gedoen word wat van hulle verwag word. | <input type="checkbox"/> 31 | <input type="checkbox"/> 32 |
| <input type="checkbox"/> 8 | die inwoners moet aanpas by die versorgers, nie die versorgers by die inwoners nie. | <input type="checkbox"/> 33 | <input type="checkbox"/> 34 |
| <input type="checkbox"/> 9 | om vir die inwoners te sorg is 'n werk met min status, dus doen die versorgers so min as wat hulle kan, solank hulle net uit die moeilikheid bly | <input type="checkbox"/> 35 | <input type="checkbox"/> 36 |
| <input type="checkbox"/> 10 | ander spesifiseer: _____

_____ | <input type="checkbox"/> 37 | <input type="checkbox"/> 38 |

24. Wat dink jy is belangrik vir die inwoners?

- | | |
|---|-------------------------------------------------------------------------------------------|
| 1 | om skoon te wees |
| 2 | om genoeg te hê om te eet en te drink |
| 3 | om keuses te maak |
| 4 | om dinge vir hulleself te doen |
| 5 | om deel te neem aan aktiwiteite |
| 6 | om stil te sit |
| 7 | om te rus |
| 8 | om emosioneel kontak te maak met iemand (bv. om drukkies te kry en saam te lag en gesels) |
| 9 | iets anders spesifiseer: |
- _____
- _____
- _____

- | | | | |
|--|----|--|----|
| | 39 | | 40 |
| | 41 | | 42 |
| | 43 | | 44 |
| | 45 | | 46 |
| | 47 | | 48 |
| | 49 | | 50 |
| | 51 | | 52 |
| | 53 | | 54 |
| | 55 | | 56 |

25. Wat dink jy is belangrik vir die bestuur van die organisasie vir die inwoners?

- | | |
|---|-------------------------------------------------------------------------------------------|
| 1 | om skoon te wees |
| 2 | om genoeg te hê om te eet en te drink |
| 3 | om keuses te maak |
| 4 | om dinge vir hulleself te doen |
| 5 | om deel te neem aan aktiwiteite |
| 6 | om stil te sit |
| 7 | om te rus |
| 8 | om emosioneel kontak te maak met iemand (bv. om drukkies te kry en saam te lag en gesels) |
| 9 | iets anders spesifiseer: |
- _____
- _____
- _____

- | | | | |
|--|----|--|----|
| | 57 | | 58 |
| | 59 | | 60 |
| | 61 | | 62 |
| | 63 | | 64 |
| | 65 | | 66 |
| | 67 | | 68 |
| | 69 | | 70 |
| | 71 | | 72 |
| | 73 | | 74 |

26. Wat dink jy is belangrik vir die familie vir die inwoners?

- | | |
|---|-------------------------------------------------------------------------------------------|
| 1 | om skoon te wees |
| 2 | om genoeg te hê om te eet en te drink |
| 3 | om keuses te maak |
| 4 | om dinge vir hulleself te doen |
| 5 | om deel te neem aan aktiwiteite |
| 6 | om stil te sit |
| 7 | om te rus |
| 8 | om emosioneel kontak te maak met iemand (bv. om drukkies te kry en saam te lag en gesels) |
| 9 | iets anders |
- _____
- _____
- _____

- | | | | |
|--|----|--|----|
| | 1 | | 2 |
| | 3 | | 4 |
| | 5 | | 6 |
| | 7 | | 8 |
| | 9 | | 10 |
| | 11 | | 12 |
| | 13 | | 14 |
| | 15 | | 16 |
| | 17 | | 18 |

27. Watter mense kan hulle lewens die meeste geniet?

- | | |
|---|-------------|
| 1 | Kinders |
| 2 | Tieners |
| 3 | Volwassenes |
| 4 | Bejaardes |

- | | | | |
|--|----|--|----|
| | 19 | | 20 |
| | 21 | | 22 |
| | 23 | | 24 |
| | 25 | | 26 |

28. Wie is die meeste verantwoordelik daarvoor dat die inwoners die lewe geniet en self deelneem aan take?

- | | |
|---|---------------------------------|
| 1 | Die suster |
| 2 | Die versorgers |
| 3 | Die arbeidsterapeut |
| 4 | Die naaste familie spesifiseer: |
- _____
- _____
- | | |
|---|--------------------------------------|
| 5 | Die uitgebreide familie spesifiseer: |
|---|--------------------------------------|
- _____
- _____
- | | |
|---|----------------------------------|
| 6 | Die inwoner self |
| 7 | Die vrywilligers |
| 8 | Vriende |
| 9 | Iemand anders spesifiseer: _____ |
- _____

- | | | | |
|--|----|--|----|
| | 27 | | 28 |
| | 29 | | 30 |
| | 31 | | 32 |
| | 33 | | 34 |
| | 35 | | 36 |
| | 37 | | 38 |
| | 39 | | 40 |
| | 41 | | 42 |
| | 43 | | 44 |

AFDELING C

Kies asb. een van die volgende antwoorde.

29. Wat het gebeur toe jy vir Inwoner X probeer help het om self 'n selfsorgaktiwiteit te doen?

- 1 sy het niks probeer doen nie
- 2 sy het self probeer, maar kon dit nie regkry nie
- 3 sy kon net sekere van die stappe self doen, die ander moes ek vir haar doen
- 4 sy het my geslaan
- 5 sy het op my geskree
- 6 iets anders
spesifiseer: _____

45

30. Wat dink jy bepaal hoe die versorgers teenoor die inwoners van ander kulture optree?

- 1 Versorgers sien nie kultuurverskille raak nie en dink almal is soos hulle
- 2 Versorgers sien kultuurverskille raak, maar voel steeds ander moet soos hulle dink
- 3 Versorgers sien kultuurverskille raak, maar weet nie wat om daaraan te doen nie
- 4 Versorgers sien kultuurverskille raak en weet hoe om inwoners wat ander is te hanteer, maar het nog nie geoefen om dit reg te doen nie
- 5 Versorgers weet hoe om inwoners van ander kulture te behandel en doen dit daarvolgens

46

31. Wat dink jy bepaal hoe die inwoners teenoor die versorgers optree?

- 1 Inwoners sien nie kultuurverskille raak nie en dink almal is soos hulle
- 2 Inwoners sien kultuurverskille raak, maar voel steeds ander moet soos hulle dink
- 3 Inwoners sien kultuurverskille raak, maar weet nie wat om daaraan te doen nie
- 4 Inwoners sien kultuurverskille raak en weet hoe om mense wat anders is te hanteer, maar het nog nie geoefen om dit reg te doen nie
- 5 Inwoners weet hoe om mense van ander kulture te behandel en doen dit daarvolgens

47

AFDELING D

Antwoord asb. die volgende vrae

32. As jy met Inwoner X praat, wat noem jy haar?

48

33. Hoekom noem jy haar so?

49

34. As jy met Inwoner Y praat, wat noem jy hom?

35. Hoekom noem jy hom so?

50

AFDELING E

Antwoord asb. die volgende vrae

36. Meeste van die versorgers het al opleiding gekry oor hoe om die inwoners te help om bv. self te eet of aan te trek. Dink jy AL die versorgers doen ELKE dag hierdie dinge?

- | | |
|---|-----|
| 1 | Ja |
| 2 | Nee |

51

37. Indien vraag 53 se antwoord JA is: Gee asb. 'n voorbeeld van hoe een van die versorgers een van die inwoners gehelp het om self 'n taak te doen?

AFDELING F

Kies asb. die belangrikste antwoord by elke vraag

38. Dit is my verantwoordelikheid om:

- | | |
|---|------------------------------------------------------|
| 1 | die inwoners by te staan sodat hulle hulself kan was |
| 2 | die inwoners te was |

52

39. Dit is my verantwoordelikheid om:

- | | |
|---|--------------------------------------------------------------------------------------------------------------------|
| 1 | die inwoner self te laat kies (of opsies te gee) wat hulle aantrekklere te kies wat vir die inwoner aangetrek word |
| 2 | klere te kies wat vir die inwoner aangetrek word |

53

40. Dit is my verantwoordelikheid om te sorg dat inwoners :

- | | |
|---|------------------------------------------------|
| 1 | altyd veilig is en stil sit |
| 2 | gereeld opstaan en rondstap |
| 3 | kan kies wanneer hulle wil opstaan en rondstap |

54

41. Inwoner X het altyd daarvan gehou om stadig te eet voordat sy 'siek' geword het. Dit is my verantwoordelikheid dat sy:

- | | | |
|----------------------------|----------------------------------------------------|-----------------------------|
| <input type="checkbox"/> 1 | kans gegee word om so stadig te eet as wat sy wil? | <input type="checkbox"/> 55 |
| <input type="checkbox"/> 2 | gevoer word sodat sy vinniger kan klaarkry? | |
| <input type="checkbox"/> 3 | gevoer word teen 'n rustiger pas al vat dit langer | |

42. Die suster aan diens vra jou om haar te gaan help in die kantoor nadat jy vir inwoner Y laat tande borsel het. Die suster is redelik haastig. Sal jy:

- | | | |
|----------------------------|------------------------------------------------------------------------------------------------|-----------------------------|
| <input type="checkbox"/> 1 | sy tande rustig borsel en hom kans gee om dit self te doen, maak nie saak hoelank dit vat nie? | <input type="checkbox"/> 56 |
| <input type="checkbox"/> 2 | so vinnig as moontlik sy tande borsel en die suster gaan help? | |

43. Die suster in beheer van die organisasie roep jou na haar kantoor maar jy is besig om Inwoner Y se tande te borsel. Sal jy:

- | | | |
|----------------------------|------------------------------------------------------------------------------------------------|-----------------------------|
| <input type="checkbox"/> 1 | so vinnig as moontlik sy tande borsel en na die kantoor gaan? | <input type="checkbox"/> 57 |
| <input type="checkbox"/> 2 | sy tande rustig borsel en hom kans gee om dit self te doen maak nie saak hoe lank dit vat nie? | |

44. Is die inwoners steeds instaat om self te eet, aan te trek, en dinge te doen waarvan hulle gehou het bv. om hulle eie tee te maak as hulle op die regte manier gehelp word?

- | | | |
|----------------------------|-----|-----------------------------|
| <input type="checkbox"/> 1 | Ja | <input type="checkbox"/> 58 |
| <input type="checkbox"/> 2 | Nee | |

45. Dink jy die inwoners sal dit geniet as hulle iets vir hulleself kan doen bv. om self tee te maak of self suiker in hulle eie tee te gooi?

- | | | |
|----------------------------|-----|-----------------------------|
| <input type="checkbox"/> 1 | Ja | <input type="checkbox"/> 59 |
| <input type="checkbox"/> 2 | Nee | |

46. Dink jy die lewe kan nog lekker wees vir die inwoners?

1	Ja
2	Nee

 60

47. Dink jy die inwoners hou nogsteeds van dieselfde goed as voordat hulle siek geword het?

1	Ja
2	Nee

 61

48. Kan die inwoners steeds trots voel wanneer hy/sy iets reggekry het wat hy/sy gewoonlik nie meer kan doen nie, bv. self tande borsel?

1	Ja
2	Nee

 62

49. Dink jy die inwoners hou steeds daarvan om drukkie te kry en te lag en gesels?

1	Ja
2	Nee

 63

50. Verkies die inwoners almal dieselfde dinge bv. dieselfde tee met melk en dieselfde hoeveelheid suiker soos die kombuis dit stuur?

1	Ja
2	Nee

 64

51. Is die inwoners steeds mense wat liefde en aandag nodig het?

1	Nee
2	Ja

 65

52. Kan jy 'n inwoner wat lag en gesels dieselfde behandel as 'n inwoner wat glad nie praat nie?

1	Ja
2	Nee

 66

53. Is die inwoners almal dieselfde m.a.w. Is almal tevrede met 'n veilige omgewing, kos en toesig?

- | | |
|---|-----|
| 1 | Ja |
| 2 | Nee |

67

54. Wat is die belangrikste vir die inwoners?

- | | |
|---|-------------------------------------------------------------------------------------------------------------------------------------------|
| 1 | Medisyne en fisiese versorging |
| 2 | Medisyne, fisiese versorging en emosionele versorging en dat hulle kan kies wat hulle wil hê bv. Hoeveel suiker hulle in hulle tee wil hê |

68

55. Wat is die belangrikste vir die inwoners se familie?

- | | |
|---|-------------------------------------------------------------------------------------------------------------------------------------------|
| 1 | Medisyne en fisiese versorging |
| 2 | Medisyne, fisiese versorging en emosionele versorging en dat hulle kan kies wat hulle wil hê bv. Hoeveel suiker hulle in hulle tee wil hê |

69

56. Wat is die belangrikste vir die organisasie se bestuur?

- | | |
|---|-------------------------------------------------------------------------------------------------------------------------------------------|
| 1 | Medisyne, fisiese versorging en emosionele versorging en dat hulle kan kies wat hulle wil hê bv. Hoeveel suiker hulle in hulle tee wil hê |
| 2 | Medisyne en fisiese versorging |

70

57. Dink jy dit is nodig om te weet hoe 'n inwoner se persoonlikheid was voor hy/sy 'siek' geword het bv. het sy maklik gehuil of was hy 'n baie kwaai man?

- | | |
|---|-----|
| 1 | Ja |
| 2 | Nee |

71

58. Dink jy dit is nodig om te weet watter werk die inwoners gedoen het toe hulle jonger was?

- | | |
|---|-----|
| 1 | Ja |
| 2 | Nee |

72

59. Dink jy dit is nodig om te weet van watter kos die inwoners gehou het en nie gehou het nie voordat hulle 'siek' geword het?

- | | |
|---|-----|
| 1 | Ja |
| 2 | Nee |

<input type="checkbox"/>	73
--------------------------	----

60. Inwoner Z dink sy is op 'n trein en dat sy jou daar raakgeloop het. Sal jy:

- | | |
|---|-------------------------------------------------------------------------------|
| 1 | maak asof jy ook op die trein is? |
| 2 | vir haar sê presies waar julle regtig is en haar aandag aftrek van die trein? |
| 3 | vir haar sê dat julle nie op die trein is nie? |

<input type="checkbox"/>	74
--------------------------	----

61. Dink jy die inwoners sal die lewe meer geniet as hulle besig bly met dinge waarvan hulle altyd gehou het, bv. om kuns aktiwiteite te doen?

- | | |
|---|-----|
| 1 | Ja |
| 2 | Nee |

<input type="checkbox"/>	75
--------------------------	----

62. Dink jy die inwoners sal die lewe meer geniet as take self kan doen bv. om self hulle gesigte te was?

- | | |
|---|-----|
| 1 | Ja |
| 2 | Nee |

<input type="checkbox"/>	76
--------------------------	----

ADDENDUM M

Case Study

CASE STUDY

In an attempt to provide an overview of the practical aspects of QoL through person-centred care, a case study is interpreted through the framework provided by the Person-Environment-Occupation-Performance (PEOP) model. This model was chosen due to its emphasis on the daily occupations of an individual that are restricted due to personal factors (pathology and disability) and environmental factors (the physical environment or societal factors) (Christiansen & Baum 2005:254).

The case study incorporates Kitwood's psychological needs of people living with dementia (cited by Brooker & Surr: 2005: 27-32). Kitwood put a lot of emphasis on the psychological needs of people with dementia to provide person-centred care and optimal QoL. These psychological needs refer to comfort, identity, attachment, inclusion, occupation and love, all factors that are negatively impacted by the environment in the RCH (cf. Table A; p283). The case study is based on the experience of the researcher while working at Greenacres RCH and aims to illustrate the positive effect of person-centred care as opposed to the traditional model. Please note that the name of the resident has been changed due to ethical considerations.

CASE STUDY

Diana is 72 years of age. She is the seventh member of her family to be diagnosed with Dementia. As a trained nurse she spent most of her working years, caring for the elderly, in a local hospital in Zambia. Diana loves children and has six of her own. According to background information, Diana enjoyed listening to classical music and doing needlework. Pre-morbidly, Diana was very caring and had strong Christian beliefs. She was kind and gentle towards others. Currently she is living in a Greenacres RCH.

CASE STUDY APPLIED TO PEOP MODEL

The abovementioned case study will now be applied to the PEOP model

a) Personal Factors: The Intrinsic Enablers of Performance

Personal factors include neuro-behavioural, physiological, cognitive, psychological and emotional, as well as spiritual factors.

Although Diana still reacts to all sensory input, it is not always in an appropriate manner. It is thus evident that Diana does not always interpret sensory stimuli in a correct way. When her long-term memory is triggered, she almost always reacts to sensory stimuli in a way that is meaningful to her, e.g. touching the material in the multi-sensory room between her thumb and forefinger and responding to the visual stimuli on the sister's desk.

Diana normally presents with catatonic behaviour, poor coordination, slow movements and praxis problems, but in spite of this, she dances to the rhythm of her favourite classical music when she is guided in the multi-sensory room.

Despite the fact that Diana has aged considerably, she is still relatively active in comparison to some of the other residents. Although she mostly roams the corridors, she can occasionally be very passive. In order to stimulate her to be more active, it often helps when she is escorted for a walk outside of the SCU.

Due to the fact that Diana suffers from dementia, her brain has been severely affected. Diana's short-term memory is more severely impaired than her long-term memory, which is evident in the way she sometimes automatically acts appropriately towards certain stimuli, e.g. straightening 'her patients' beds or rearranging the files on the sister's desk. The beds as well as the desk in the SCU trigger her long-term memory from when she was working in

the hospital in Zambia many years ago. Although she does not react to spoken language and seldom says any words of her own, she can be guided by the use of touch to perform certain tasks like washing her hands.

Diana was a very caring, loving mother and grandmother to her six children and grandchildren. This only describes one of her emotions and personality traits. These factors seem to appear in her occupational habits even after she acquired the illness. Activities of daily living are often used in therapy sessions with sensory stimulation to facilitate Diana's awareness of herself and others. During these sessions she is likely to tell the students to eat their food and she washes their hands instead of her own.

Diana's spirituality is intrinsic to her nature. Although she seldom speaks, she can be prompted to hum the melody to a hymn when the song is initiated by a therapist. She also bows her head in prayer before eating.

b) Environmental Factors: The Context of Performance

The environmental factors include the built, natural and cultural environments as well as societal factors, social interaction and social and economic systems.

Previously residents have been seated on chairs in a communal area in front of the television for most of the day, including meal times. Recently some changes have been made due to the OT programme regarding the seating arrangements at meal times. The large living room has been divided into a dining room and a living room. Since these changes have been made, Diana spontaneously sits at the dining room table at meal times. She also serves 'her family' by carrying their plates from the trolley to the table.

In the winter time, Diana easily catches a cold and has to stay inside, but during the summer, she goes to the multi-sensory garden with the other residents. When she is made aware of stimuli, she becomes more aware of

herself and surroundings. After a session in the garden, she is usually more directed and independent in activities of daily living like eating. She also makes more eye contact and shows positive emotions.

When Diana was young, apartheid was still a reality. Nowadays, all of the caregivers in the SCU are black and from different cultures and sometimes they give instructions to Diana, something that she is not used to and she does not always want to comply with these instructions.

As a form of respect, these caregivers sometimes call her 'Ouma', a term used to address an old woman, but when Diana is not addressed by her first name, she does not respond at all.

Residents with dementia are often stigmatised. Recently, an OT student attempted to involve Diana's sister, Maggie, in therapy in order to determine Diana's response to a family member during activity. At first, Maggie was very enthusiastic about the therapy, but as soon as she spoke to a doctor, who told her that her sister's condition remains irreversible, she declined the offer from the student and decided that she did not want to partake in any OT with her sister.

During the day, in the living room, Diana does not make eye contact at all, but when she is greeted by a person who bends down on his/her knees to make eye contact with Diana, she looks the person in the eyes with an excited facial expression.

In the SCU, physical resources for therapy sessions are limited. Previously, Diana loved to use a particular kind of lavender soap, but in the SCU she has to use the less expensive soap that all of the other residents use. This could possibly influence Diana's occupational performance negatively, seeing that she is usually more aware of herself, gives more emotional responses and takes part in more steps of the activity when the lavender soap is used during an OT session, although soap is not the only variable.

From the case study integrated with the PEO model, it is evident that occupation can be restored to a certain degree with the application of person-centred care. Environmental Factors can be changed in order to compensate for declining Personal Factors e.g. after the Built Environment had changed, Diana's occupational behaviour changed to being more directed and purposeful. The result: enhanced well-being and QoL.

CASE STUDY EXPLAINED ACCORDING TO KITWOOD'S PSYCHOLOGICAL NEEDS OF PEOPLE LIVING WITH DEMENTIA (CITED BY BROOKER & SURR: 2005:27-32):

Table A: Kitwood's psychological needs of people living with dementia (taken directly from Brooker & Surr 2005: 27-32):

THE NEED FOR COMFORT	
Undermined by Malignant Social Psychology	Met through Positive Person Work
INTIMIDATION: Making a participant frightened or fearful by using spoken threats or physical power.	WARMTH: The demonstration of affection, care and concern for another.
WITHHOLDING: Refusing to give asked for attention, or to meet an evident need for contact.	HOLDING: Providing safety, security and comfort.
OUTPACING: Providing information and presenting choices at a rate too fast for a participant to understand.	RELAXED PACE: Recognising the importance of helping to create a relaxed atmosphere.
IDENTITY	
INFANTALISATION: Treating a participant in a patronising way as if they were a small child.	RESPECT: Treating a participant as a valued member of society and recognising their experience and age.
LABELLING: Using a label as the main way to describe or relate to a participant.	ACCEPTANCE: Entering into a relationship based on an attitude of acceptance or positive regard for the other.
DISPARAGEMENT: Telling a participant that they are incompetent, useless, worthless, and incapable.	CELEBRATION: Recognising, supporting, and taking delight in the skills and achievements of a participant.

ATTACHMENT	
ACCUSATION: Blaming a participant for things that they have done, or have not been able to do.	ACKNOWLEDGEMENT: Recognising, accepting and supporting the participant as a unique person and valuing them as an individual.
TREACHERY: Using trickery or deception to distract or manipulate a participant in order to make them do or not do something.	GENUINENESS: Being honest and open with the participant in a way that is sensitive to their needs and feelings.
INVALIDATION: Failing to acknowledge the reality of a participant in a particular situation.	VALIDATION: Recognising and supporting the reality of the participant. Sensitivity to feeling and emotion to take priority.
INCLUSION	
STIGMATISATION: Treating participants as if they were diseased objects, aliens or outcasts.	RECOGNITION: Meeting a participant in his or her own uniqueness, bringing an open and unprejudiced attitude.
IGNORING: Carrying on (in conversation or action) in the presence of participant as if they were not there.	INCLUDING: Enabling and encouraging a participant to be and feel included, physically and psychologically.
BANISHMENT: Sending a participant away, or excluding them; physically or psychologically.	BELONGING: Providing a sense of acceptance in a particular setting regardless of abilities and disabilities.
MOCKERY: Making fun of a participant; teasing, humiliating them and making jokes at their expense.	FUN: Accessing a free, creative way of being and using and responding to the use of fun and humour.

Throughout the course of her life, Diana was a very kind and loving person to everyone with whom she came into contact. When the caregivers treat her with warmth (i.e. putting their hand on her shoulder when talking to her), she immediately makes eye contact and smiles and she is more willing to comply during bath times, but when she is forced to stand up to go to the bathroom, she usually starts screaming and biting on her teeth.

Some days, when Diana appears to be more confused than others, she shows the need to be close to one of the caregivers. When the caregiver touches her and holds her, speaking to her quietly and calmly, she becomes relaxed and returns the caregiver's hug.

When giving instructions to Diana, the caregivers need to be very specific and use one or two word sentences, as opposed to speaking fast and in full sentences which she does not respond to at all.

One day, a month after Diana was admitted to the RCH, her daughter came to visit and found Diana with a caregiver who was speaking to her like she would speak to a toddler. Diana's daughter was very upset and told the caregiver that she was confusing her mother even more and had no respect for her at all.

When Diana does not want to cooperate with any of the other caregivers, they call on the help of Maria, a caregiver working at the RCH who has a genuinely deep and accepting relationship with Diana. Diana always responds well to Maria and shows great appreciation for everything that Maria does for her. At present, this appears to be the most significant relationship that Diana has with anyone in her life.

Diana loves OT sessions with the students when she is encouraged to take part and recognition is given to her efforts and achievements. One day a caregiver, who appeared to be under a lot of stress, asked Diana to brush her own teeth like she does every day. On this particular day, Diana accidentally squeezed the toothpaste onto the wall. The caregiver showed her anger and Diana refused to take part in any activities for two weeks.

Diana always put a lot of emphasis on being truthful and honest to others. She usually responds to instructions when they are to the point, truthful and communicated to her in a gentle manner.

Some days when Diana is more lucid, she attempts to leave the SCU by banging on the door. She tends to get very upset when she cannot open the door. Maria usually calms her down by validating her feelings of longing to go home, and confirms that the SCU is her home now and that (she) Maria is there to take care of her.

Although Diana serves the other residents very slowly at meal times, Maria gives her the time and space to do so to show respect for Diana's uniqueness and personhood.

Diana's family members have come to love Maria for caring for their mother in such a loving way. They do not attempt anymore to speak to Maria as if Diana is not present. Maria wants Diana to always feel included.

During OT sessions, Diana responds most friendly to the students who make her feel accepted and as if she belongs despite her shortcomings. She usually likes the therapy sessions that are fun and laughs with the students at the top of her voice.

Above, Kitwood's psychological needs of people living with dementia were integrated with the case study of Diana, to explain the power and effects of meeting the psychological needs of the person with dementia in a person-centred manner, leading to optimal QoL.