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The Lived Experience of Male and Female Caregivers of People with Dementia: a Qualitative Study.

by

Farah Deba Khokhar-Cottrell.

For the qualification for Professional Doctorate in Health Psychology.

City University London, School of Social Sciences, Department of Psychology.

February 2017.

Funding and Ethical Approval.

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Declaration

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City, University of London
Northampton Square
London
EC1V 0HB
United Kingdom

T +44 (0)20 7040 5060

THE FOLLOWING PARTS OF THIS THESIS HAVE BEEN REDACTED FOR DATA PROTECTION REASONS:

p. 197-244, Case Study

SECTION A.

Preface.

On commencement of Stage 2 of the Health Psychology Doctorate programme in October 2006 at City University, I was working full-time for a Japanese pharmaceutical company in West London. I was employed as a Clinical Associate Manager in the department of clinical operations in the therapeutic areas of Parkinson's, Alzheimer's and Vascular Dementia Disease. Whilst undertaking this role I was responsible for overseeing several therapeutic clinical studies, including a phase III open-label, double-blind, randomised controlled drug trial in vascular dementia and moderate to severe Alzheimer's patients. In this project, I managed and led several stakeholders, who all formed part of a consultancy partnership, where I was the Sponsor and where the Clinical Research Organisation (CRO) was the client. I was responsible for managing the consultancy programme, for establishing a 'Process Consultation Model' (Schein, 1987) with external vendors (clinical laboratory and ECG vendors), with internal departments and was involved in managing multimillion pound project budgets on behalf of the Sponsor. It was whilst working on this project that I undertook therapeutic training in the disease area of dementia, and as a result my interest in the field of dementia developed. At my place of work I was given the opportunity to use my health psychology skills in the design and creation of an intra- and inter-reliability coaching and training programme for clinical raters based on the Clinician's Interview-Based Impression of Severity with Caregiver (CIBIS-Plus) scale, together with the opportunity to design an expectation and satisfaction questionnaire for dementia carers working in close collaboration with a fellow clinical neuropsychologist.

During the seventh year of the doctorate programme I found new employment with a West Yorkshire University. As a clinical project manager I am currently managing a targeted ultrasound clinical study in patients with rheumatoid arthritis. This has provided me with a unique opportunity to work in a multidisciplinary team, ranging from academic professors based in hospitals around the world, ultra-sonographers, research nurses, clinicians, the finance department, the research and development department, the ethic committee and two major stakeholders (a research organisation and a funder for the project).

Due to their diverse nature, these work placements have enriched my skills and my competencies as a health psychologist and have assisted me with my continued development in becoming a clinical professional. Close collaboration with clinical health professionals in the National Health Service (NHS), such as with other clinical staff, has contributed towards my academic, generic and clinical skills development. The knowledge I have gained has provided me with the confidence and discipline to work both in a clinical practice and within the remit of an NHS setting. The set of practice skills that I have gained as an applied health psychologist have been paramount towards shaping my learning and development, and I have been successful in being able to transfer my skills and apply them outside work in a non-clinical setting.

The work presented in this portfolio demonstrates the skills and attributes that have been developed over the eight-year period, especially in terms of my training as a trainee health

psychologist, and the current transition of my skills and competencies, which are important towards being an applied health psychologist.

The portfolio is divided into two parts; the first is my research thesis and the second includes a series of case studies and a systematic review which demonstrate my competencies and skills in other areas related to the health psychology doctorate programme.

The aims and objectives of the research thesis are to look at the lived experiences encountered by both male and female caregivers whilst caring for a person with dementia at home. The lived experiences of the carers are examined in relation to the caregiver's daily management care and adjustment, of having to live with someone with dementia, and the effect these lived experiences has on the carers' quality of life (QoL).

The original aim of this research thesis was to look at the 'experiences of satisfaction' encountered by both male and female carers whilst caring for a person with dementia at home. Therefore, all the original documentation relevant to this research thesis from the time of submission to approval was granted by the City University Ethics Committee contain the word 'satisfaction' in the text. In addition, the materials presented to the participants, for example the list of questions, and the participant information sheet and the consent forms for the interviews with the carers all contain the word 'satisfaction' in the text. However, during the research process the decision was made to broaden the research focus to the 'lived

experience of carers' and this change is reflected in the research thesis. The results of this research provide a meaningful insight into the lived experience of a carer with regard to their daily management and care of a person with dementia. In addition, it highlights how these experiences affect the QoL and well-being of carers. The findings of this research thesis provide insights that may be useful to health professionals who are considering interventions, educational programmes, training and support services for carers.

The second part of this portfolio begins with the first case-study which comprises of an eight-week healthy eating consultancy programme that was delivered to 11-12 years at a semi-professional football club in North Middlesex (Sponsor). The aims and objectives of the consultancy were to target children aged 11-12 years, together with their parents/guardians, by making them aware of what the children should or should not be eating, and to identify whether there was a difference in the 11-12-year-olds' physical performance by the eighth week. Not only did I deliver this intervention for the healthy eating programme to the client but I also provided psychological advice to the 11-12-year-old boys, their parents/guardians, the Sponsor and the club caterer on healthy eating choices and options. This case-study also formed the basis for the optional case study 1. Optional case study 1 consisted of communicating the processes and the outcomes of the eight-week healthy eating intervention/consultancy to the semi-professional football club in North Middlesex (Sponsor).

The second consultancy case study included the delivering of a physical activity and healthy eating programme to nurses and clinical professionals of a North London Primary Care Trust (PCT). The third consultancy/intervention case-study encompassed delivering and implementing the Creating Health Active London Kids (CHALK) programme for healthy eating and physical activity behavioural change for parents and children. This intervention was run by the London Teaching Public Health Network and formed the basis for the Second Optional Case Study 2. This second optional case study was a practice log, which is not included as part of this portfolio, but described a three-hour physical activity training session delivered to General Practitioners (GPs) and Practice Nurses who formed part of the front-line staff in a primary care setting. The training was part of the Department of Health's Half Day Post-Obesity Conference Training on Physical Activity Promotion & Healthy Eating and was delivered to the North London PCT. The aims and objective of this training were to increase knowledge and awareness of the benefits and recommendations for physical activity and to introduce the general practice physical activity questionnaire.

These case studies demonstrate my capabilities in implementing the core fundamentals of the consultancy process and in applying the theoretical models of health psychology, both in theory and practice.

The fourth case study consists of my teaching training competencies, which were carried out with a variety of clients at my place of work. These range from the training of principal investigators at an investigator meeting to conducting communication skills training to lay-

people in North London PCT. My teaching and training experience has also included delivering a lecture on gender, culture, and health to MSc students at City University. The whole experience of teaching and training has been extremely valuable, especially in my understanding of different learning and delivery styles to students, and in my continuous professional development as an applied health psychologist.

The fifth case study on generic and professional skills describes and reflects my professional practice over the seven-year period. It reflects on my transition from a trainee health psychologist and my journey towards becoming an applied health psychologist. This case study provides a detailed account of how I have enhanced my skills professionally, and how through theory and practice I have applied myself towards becoming a confident health psychologist, especially in the areas of teaching, training, and consultancy.

The sixth case study is a systematic review that aims to look at the psychological and health benefits of motivational interviewing (MI) as an intervention, and the influence that MI has on patients' everyday management of diabetes (both Type 1 and Type 2). The systematic review found that even though MI was seen to be a desirable form of intervention for clinicians or practitioners in a clinical health setting, in practice, MI was not effective when used on its own as an intervention according to many outcome measures for a given disease or illness, nor was it successful when combined with another adjunct therapy. Consequently, MI has not been implemented or adopted in practice universally. Only when the fidelity of MI was tested prior to the start of an intervention or during the intervention was MI seen to

have any significant effect. With the rapid rate at which diabetes mellitus (Type 2 non-insulin dependent) is affecting the younger patient population, it is inevitable that the findings of this systematic review need to be considered regarding the value of MI being included in interventions, and more longitudinal studies need to be conducted on MI. The applicability of MI as an intervention when combined with other adjunct therapies needs to be re-evaluated and the introduction of too many outcome measures in an intervention seems to over complicate and interfere with measuring the effectiveness of MI.

Over the eight year, as a trainee health psychologist I have become more confident in myself. The knowledge and skills I have gained have consolidated both my learning and understanding of health psychology and enhanced my practice skills as a health psychologist. I have become more open, and reflective in myself and in my practice. I have adopted new ways of working which are essential to becoming a more proficient health psychologist. This self-assurance as a health psychologist has provided me with the drive to seek out new opportunities, both inside work (generic and consultancy) and outside work (health interventions and health promotion). The experience of working and communicating in a multidisciplinary team of professionals has also been advantageous in my development as an applied health psychologist. The experience I have gained over the eight years as a trainee health psychologist has been extremely valuable and the possibility of soon working as a chartered health psychologist is extremely rewarding and a great privilege.

References.

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SECTION B.

Research Competence Unit 2.

Thesis Title.

The lived experience of male and female caregivers of people with dementia: a qualitative study.

Abstract.

Background: Burden, satisfaction, depression, anxiety, social support, coping strategies and the disease state of dementia patients all influence carers' quality of life (QoL) and well-being. Qualitative research looking at carers' lived experiences and the effect that this has on their well-being is limited. **Aim/Objectives:** To explore carers' lived experiences in relation to their daily management care and adjustment of having to care for a person with dementia, and to examine the differences or similarities of carers' lived experiences in relation to the care provided to the recipients and the effect that this has on carers' QoL and well-being. **Design:** Interpretative phenomenological analysis (IPA). **Methods:** Semi-structured interviews were conducted with fourteen carers (seven males and seven females) and the audio-taped raw data was transcribed. Key constructs and initial meanings in relation to the everyday lived experiences were identified. **Results:** Carers' accounts clustered around five master themes: 'just normal', providing best and safe care, managing to cope, sharing and supporting others, and cherished moments. **Conclusions:** Health professionals and governmental agencies need to consider carers in clinical interventions, psychological and educational programmes. Local communities should adopt a positive image of carers, dementia patients, and health professionals, and have a greater understanding of carers' criteria for the standard of care and factors affecting carers' life circumstances in relation to QoL and well-being.

Keywords: Carers, Caregivers, Dementia, Well-being, Lived, Interpretative Phenomenological Analysis (IPA) and Qualitative.

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Chapter 1.

Introduction.

1.1. Background to Dementia.

Dementia is a condition that has been around since the early Roman and Egyptian times (Bowie & Yakiriti, 2004) describing a disorder that affects both the neurological and psychiatric aspects of the human mind, and covers a broad spectrum of diseases and conditions, including Alzheimer's disease (Earlstein, 2016). Researchers over time have tried to provide a definition of dementia (Bowie & Yakiriti, 2004) and according to Roth (1955), dementia is an acquired global impairment of the intellectual memory and memory itself. The standard definition for dementia is provided by the American Psychiatric Association (1994) of Diagnostic and Statistical Manual of Mental disorders (DSMIV) and the World Health Organization (WHO, 1992) as a condition which is chronic in nature causing a gradual deterioration and causing several multifaceted disruptions within the brain functionality. These include problems with memory, reasoning, coordination, understanding, calculation, ability to learn, and verbal and executive decision making. These interrelated symptoms cause a slow and progressive decline in the mental ability of an individual who has dementia and interferes with a person's normal functionality regarding their daily living (Earlstien, 2016). Although these symptoms are typical of dementia, not all of these symptoms indicate the presence of dementia as everyone gets forgetful as they get older. In order for the presence of dementia to be verified diagnostically, five core mental functions need to be affected in an individual, such as memory, ability to focus and be aware, communication and language, reasoning and judgement, and visual perception (Earlstien, 2016).

The first signs and symptoms of dementia include damage to the memory, whereby a person becomes forgetful (Graham & Warner, 2009, which is seen in early onset and affects the short-term memory of an individual instead of their long-term memory initially. Intellect is also seen to worsen in early stages of dementia and affects a person's character, such as variations in mood and a decline in social skills with a person becoming withdrawn; this is also associated with depression, anxiety, and irritability and worsening of behaviour (Kumar & Clark, 1990). In addition, there are language problems with finding words (Graham & Warner, 2009). In the middle stages everyday functioning and the ability to live independently is affected, and there are marked changes in behaviour, problems associated with reasoning, understanding and mental frustration (Graham & Warner, 2009). Memory problems arise, including forgetfulness, sense of direction and understanding, and individuals may wander out of their house and become lost. There are problems with understanding and executive function problems, such as carrying out daily chores, household tasks, getting dressed and managing personal hygiene (Graham & Warner, 2009). Paranoia and delusions are accompanied by problems in audio hearing and visual disturbances, such as illusions accompanied by physical dependence and aggression (Kumar & Clark, 1990). In the very late stages there are significant memory problems and a person becomes completely dependent upon others for their mental and physical care (Graham & Warner, 2009). In this stage, there may be problems in communicating, there is limited or no recognition of family and friends, there is a lack of understanding or reasoning, and assistance is required with eating. There may also be problems in swallowing, incontinence, and mobility, and a person may be chair or bed bound (Graham & Warner, 2009).

1.2. Dementia and Diagnosis.

Dementia is very common amongst the elderly and it is projected that over 750,000 people in the UK have dementia (Graham & Warner, 2009). The prevalence of dementia is increasing with the aging population, and one in six people aged eighty years or above will have some type of dementia (Graham & Warner, 2009). Around two-thirds of people with dementia live at home, while around one third of people with dementia live in care homes (Graham & Warner, 2009). Individuals diagnosed with dementia are expected to live seven to ten years after diagnosis (Ganguli, Dodge, Shen, Pandav, & DeKosky 2005; Larson, Shadlen, Wang, McCormick, Bowen, & Teri, 2004; Xie, Brayne, & Matthews, 2008.), although some individuals have been reported to live for twenty years following their diagnosis (Graham & Warner, 2009). From the time of diagnosis onwards the disease gets progressively worse and the individuals need to be cared for by a friend, family member or an independent carer because they cannot care for themselves or live alone (Graham & Warner, 2009).

In the UK, only one in two people receive a diagnosis of dementia and it takes two years from the start of symptoms to seeing a doctor and obtaining a correct diagnosis (Graham & Warner, 2009). It is usually a family member, spouse or a friend who discovers that there is something is not the same about the person they love or care for, and that there are changes occurring in the person with regards their memory and language, and that there is a decline in their ability to perform both mental and physical tasks. The clinical diagnosis of dementia is a long and arduous route, where brain scans, such as magnetic resonance imaging (MRI), computed tomography (CT) and positron emission tomography (PET), are used to detect changes in the brain pathology, and memory and

cognitive tests indicate the type of dementia an individual has (Graham & Warner, 2009). One cognitive test for mental ability is the mini-mental state examination (MMSE), a 30-point questionnaire looking at memory damage; scores greater than or equal to 27 points (out of 30) indicate normal reasoning, while a score below this indicates severe (≤9 points), moderate (10–18 points) or mild (19–24 points) damage to intellect (Mungas, 1991). In addition, a person's medical history and current medications are reviewed, along with biological markers, such as the levels of abnormal proteins in the brain associated with Alzheimer's disease (Graham & Warner, 2009).

Early diagnosis of dementia is paramount, and research indicates that there is no suitable cost saving method for the early diagnosis of dementia (Alzheimer's Society, 2010). In the UK only 60 people out of the expected 122 people over the age of 80 with dementia per 1,000 people have been formally diagnosed with dementia (Alzheimer's Society, 2010; National Institute for Health & Clinical Excellence (NICE) & Social Care Institute for Excellence (SCIE), 2007; National Audit Office, 2007).The inability of clinical professionals and memory clinics to separate the symptoms from disease for diagnosis, plus inadequate dementia training, a lack of suitable dementia diagnostic tools and no life-changing therapy available for patients with dementia, has created a huge burden on society and carers (Alzheimer's Society, 2010; National Institute for Health & Clinical Excellence (NICE) & Social Care Institute for Excellence (SCIE), 2007; National Audit Office, 2007).

1.3. Types of Dementia.

Typically, all types of dementias are labelled under the general heading of dementia; however, medical research indicates that the type of dementia is dependent on the area in

the brain affected or damaged, the physical changes manifested in terms of depreciation, disintegration and signs of deterioration shown in an individual (Earlstein, 2016). One commonality found amongst all the different dementias is problems associated with the cerebral cortex, which is the part of the brain which controls memory, perception, thoughts and consciousness (Earlstein, 2016). Dementia is classified as either primary dementia, were the dementia is not the cause of another disease but is itself the cause of the symptoms, and secondary dementia, where the cause is another illness, disease, injury or trauma (Graham & Warner, 2009).

Dementia is also defined as being reversible and irreversible (Bowie & Yakiriti, 2004), where reversible dementia is temporary and the result of other causes, such as injury, brain disease, medication and alcohol, a lack of oxygen to the brain, physical trauma or injury. This type of dementia is responsive to treatment, has slow initial progression and some of the symptoms of dementia can be reversed (Graham & Warner, 2009). Irreversible dementia is progressive, incurable and causes long-lasting damage to the brain (Graham & Warner, 2009). Irreversible dementias include Alzheimer's disease, which accounts for 60-80% of all cases of dementia (Alzheimer's Association & Dementia, 2012), followed by cerebrovascular disease (vascular dementia), Parkinson's disease, Huntington's disease, acquired immunodeficiency syndrome (AIDS), Korsakoff's syndrome, Creutzfeldt-Jakob disease (CJD), multiple sclerosis, and motor neurone disease. Mixed cases of dementia have been reported, such as Alzheimer's disease and dementia with Lewy bodies, and this combination accounts for 15-20% of all cases (National Institute for Health & Clinical Excellence (NICE), & Social Care Institute for Excellence (SCIE), 2007). In young-onset dementia, frontotemporal dementia is the most common disease, followed by Alzheimer's disease. The remaining 10% of cases are

due to reversible causes of dementia and are less associated with brain worsening diseases (Bowie & Yakiriti, 2004).

1.3.1. Alzheimer's Disease.

Alzheimer's disease is the most common form of progressive dementia which worsens over time, and is associated with memory loss which is often mistaken as a normal sign of aging (Earlstein, 2016). As the disease progresses there are some changes in that a person becomes confused and has problems with language (Graham & Warner, 2009); however, there are very few marked changes in relation to an individual's behaviour and their ability to do perform tasks. Apathy and depression are also seen in in the early phases (Alzheimer's Association & Dementia, 2012). In the middle stages forgetfulness is quite marked and a person suffering from the disease will require more assistance in their daily management and care (Alzheimer's Society, 2010). Sleep problems, delusions, aggression, inappropriate behaviour and mood changes also occur during this stage (Earlstein, 2009). In the later stages symptoms include damage to decision making, bewilderment and confusion, behaviour changes, challenges with language, swallowing and walking (Alzheimer's Association & Dementia. 2012). During this phase an individual faces many challenges in all areas of their abilities regarding their physical mobility and cognitive faculties, and thus are totally dependent on care provided by a carer (Alzheimer's Society, 2010).

1.3.2. Vascular dementia.

Vascular dementia is also known as multi-infarct dementia or vascular cognitive impairment, and is the second most common cause of dementia after Alzheimer's disease (Earlstein, 2016). People suffering from vascular dementia are found to have experienced many silent infarctions or a series of mini-strokes (Alzheimer's Association & Dementia,

2012), which often leads to the brain being deprived of sufficient blood flow and oxygen, resulting in the death of brain cells (Earlstein, 2016) and causing cognitive impairment, difficulties in memory, thinking and reasoning (Earlstein, 2016). Usually, an individual remains stable for a period of time until they encounter a gradual decline in their capabilities, such as their ability to judge or make plans, and their executive reasoning is more likely to be the initial symptom in comparison to memory loss which is often associated with the early symptoms of Alzheimer's disease (Alzheimer's Association & Dementia, 2012). Depending on which part of the brain is damaged, other symptoms may include motor function difficulties, hallucinations, behavioural and emotional changes (Earlstein, 2016).

1.3.3. Dementia with Lewy Bodies.

Dementia with Lewy bodies shares some common symptoms with Parkinson's disease and others with Alzheimer's disease (Earlstein, 2016). The signs and symptoms seen in dementia with Lewy bodies are associated with cognitive difficulties regarding memory, organisation, planning and awareness. Other presentations include depression, visual hallucinations (Earlstein, 2016), sleep disturbances and motor problems, such as slow movement, stooping posture, muscle rigidity and problems with balance, as associated with Parkinson's disease (Earlstein, 2016).

1.3.4. Frontotemporal Lobar Degeneration.

Frontotemporal lobar degeneration dementia is the culmination of a group of disorders affecting the frontal and temporal lobes of the brain. Individuals suffering from this condition display changes in their personality, behaviour and language (Earlstein, 2016). There are three categories of this form of dementia: behavioural variant front temporal lobar degeneration, primary progressive aphasia, Pick's disease and progressive

supranuclear palsy (Alzheimer's Association & Dementia, 2012). Frontotemporal lobar degeneration affects people of a younger age and despite its similarity to Alzheimer's disease, other problematic areas, such as movement, indifference and ecstasy are more marked (Earlstein, 2016). In later stages, it is similar to Alzheimer's disease and individuals require nursing care (Alzheimer's Society, 2010; Alzheimer's Research Trust, 2010).

1.3.5. Creutzfeldt-Jakob Disease.

CJD dementia is progressive and associated with memory impairment and hallucinations, while coordination and a person's behaviour are also affected by the disease (Alzheimer's Association & Dementia, 2012). In addition, paranoia, depression, obsessive-compulsive symptoms and physical problems related to coordination and balance may be evident (Earlstien, 2016).

1.3.6. Parkinson Disease Dementia.

Parkinson disease dementia is similar to Lewy bodies' disease, Alzheimer's disease (Alzheimer's Association & Dementia, 2012) and human immunodeficiency virus (HIV) (WHO, 1992). In this type of dementia motor changes occur first and cognitive decline occurs later, which is related to memory loss, problems with concentration and judgment, visual problems, muffled speech, irritability and depression (Earlstien, 2016).

In most cases, drugs and medication are used to treat all these types of dementia, and may also be supported by psychological interventions and therapeutic interventions. Where individuals are unable to manage to care for themselves or are unable to live alone, the services of a caregiver are required to provide support and help (Earlstein, 2016).

1.4. Dementia Projection.

Dementia is prevalent both across Europe and worldwide. It was estimated in 2015 that 46.9 million people worldwide are living with dementia, and that this figure would double every 20 years (Earlstein, 2016). In total, 7.7 million new cases of dementia are reported every year and the total number of people diagnosed with dementia is predicted to reach 65.7 million in 2030 and 115.4 million in 2050 (WHO, 2013).

One in every 90 people in the UK has dementia, and it is estimated that approximately 820,000 people have dementia (Graham & Warner, 2009; Alzheimer's Society, 2010; Alzheimer's Research Trust, 2010) and that this will rise to 1.7 million by 2025 (Graham & Warner, 2009; Alzheimer's Society, 2010; Alzheimer's Research Trust, 2010; Knapp, Prince, Albanese, Banerjee, Dhanasiri, Fernandez, Ferri, McCrone, & Stewart, 2007). In the UK, it was reported that 683,597 people were affected by dementia in 2005 and that this would increase to 940,110 by 2021 and 1,735,087 by 2050. In the US, 5.4 million people have Alzheimer's disease, with approximately 200,000 diagnosed when younger than the age of 65 years (Alzheimer's Association & Dementia, 2012).

1.5. Dementia, Age and Gender.

The incidence of developing dementia increases with age (Graham & Warner, 2009). Studies carried out over a ten-year period looking at the incidence of dementia and age found that the incidence was 0.8% in those aged 65 to 69 years and 28.5% in those aged 90 years and older (Fratiglioni, Launer, Andersen, Breteler, Copeland, Dartiques, Lobo, Martinez-Lage, Soininen, & Hofman, 2000). Dementia in older people is known as late-onset dementia, whilst in the young it is known as young-onset dementia (Alzheimer's

Society, 2010) and can even occur in the thirties (Graham & Warner, 2009). Research considering gender differences have found that dementia is more common amongst women than in comparison to men (Ruitenberg, Ott, A van Swieten, Hofman, & Breteler, 2001). Women are also at a higher risk of developing Alzheimer's disease, whilst men are at a higher risk of developing vascular dementia (Gao, Hendrick, Hall et al., 1998). Ruitenberg et al. (2001) found no gender differences in the incidence of dementia in a higher age group; however, the incidence of Alzheimer's disease was higher for women at the age of 90 than for men. As people are living longer the burden on those who provide care for people with dementia is increasing (Wattis & Curran, 2004).

1.6. Dementia and the Effect on the Economy.

Dementia is a condition that requires the care of a person with dementia, either at home or in a residential care setting and is one of the costliest health conditions in society today (Gustavsson & Svensson, 2011). In the UK, approximately £23 billion is spent each year on dementia in comparison to other diseases such as cancer, heart disease and stroke (Alzheimer's Society, 2010). Caring for a person with dementia has an enormous impact and it is estimated that around £27,647 per year (Alzheimer's Society, 2010) is spent on dementia care. The new Care Act of 2014 (Department of Health, Gov.UK, 2014) in England has made the funding for those caring for a person with dementia much clearer and fairer. Funding payments are based on a need's assessments of the carer and the needs of a person with dementia.

Caring for a person with dementia is both emotionally and physically draining, and carers face huge challenges and stresses, especially regarding their family life, their own quality of life (QoL) and well-being. Drentea (2007) found caregiving to be a huge responsibility

taken on by carers who deliver care to family members and friends with physical, psychological and development needs, yet is without any payment or reward. Such care is mostly provided by family members, neighbours, friends and these carers do not fall into the same category as paid care workers in the community.

1.7. Government Initiatives for Dementia Patients and Carers.

In March 2015, much media attention was focused on dementia (Department of Health, Gov.UK, 2015) and the UK government devised a programme to improve the early diagnosis and quality of care for dementia patients. This initiative was designed to increase awareness, communication and support for dementia patients and carers by providing friendly communities across cities and towns in the UK. This initiative also assists in the early diagnosis and treatment of dementia patients by supporting people with dementia, empowering local General Practitioners (GP's) and local clinic practices by allowing them access to the Dementia Directed Enhanced Service (DES), and instigated a GP reward scheme. Every general hospital in England is aiming to become supportive and dementia-friendly (Department of Health, Gov.UK, 2015) and 'dementia champions' have been employed. Funding for hospitals was increased by around £54 million to assist with quality care of dementia patients, which was accompanied by the appointment of senior clinical leads for dementia care. In addition, £50 million was provided for care homes for people with dementia in order to improve the quality of care, treatment and support available for people with dementia (Alzheimer's Disease International, 2012; Gov.UK, 2015). Further training is recommended for health and care workers in how to handle dementia patients, and dementia tool kits have been implemented to enable rigorous diagnosis, monitoring and assessment of dementia (Alzheimer's Disease International, 2012). A further £400 million was injected into the economy to help fund

breaks for carers and to provide better support for carers, in particularly for carers who are looking after a person with dementia. This initiative is the first programme in the UK with the aim of supporting carers by easing their burden and providing assistance with regards to their daily needs, wants and well-being of carers.

1.8. Carers.

1.8.1. Gender of Carers and the Delivery of Care.

Research around caregiving has increased its focus on gender in order to describe the diversity of care observed between male and female carers (Bedard, Kuzik, Chambers, Molloy, Dubois, & Lever, 2005). In Western countries, women tend to provide more care and are usually older and live alone (Bedard et al., 2005) without any surrounding support or assistance. Women live longer and are expected to provide more care according to the traditions of nature and nurture, and because women tend to develop a nurturing role they are less like to consult support services (Hooyman & Gonyea, 1995) in comparison to men. Navaie-Waliser, Spriggs and Feldman (2002) found that women caregivers aged 65 years provide most of the care for a person with dementia with very little support from formal carers and were more likely to report being stressed. As per society's expectations, women provide more hours of personal care, household work and social support in comparison to men (Collins & Jones 1997; Neal, Ingersoll-Dayton, & Starrels, 1997; Statistics Canada, 1996). Women provide more individual care for a person with dementia and are more likely to experience greater relational deprivation, loneliness (Beeson, 2003) and a loss of self (Skaff & Pearlin, 1992).

Despite the focus on women, the gender difference between men and women providing care for a person with dementia is changing (Baker & Roberson, 2008), and the number

of male caregivers is increasing (Pöysti, Laakkonen, Strandberg, Savikko, Sakari, Eloniemi-Sulkava, Tilvis, & Pitkala, 2012). Cahill (2000) found that men caring for their partner or spouse with dementia are aged 65 years and older, and couples have been married for a long time when husbands begin caring for their wives. Men are found to be very hands on and practical in regards to delivery of care and its management, and no gender differences have been found regarding the type of care delivered to the recipient. However, the way the care is administered is different between men and women; if men are struggling to cope in providing care to a person with dementia then they are less likely to seek any assistance in terms of support (Cahill, 2000).

Most carers providing care for a person with dementia are family members, usually spouses and older children (adult) who receive very little formal help (Cox, 2013; Wider & Covinsky, 2011). In comparison to child carers and spouse carers, it has been found that dementia has an adverse effect on a spouse's well-being and mental state because they have little respite from their caring duties. Carers reported feeling burdened and stressed, which affected their desire to continue in their role as a carer (Cox, 2013). The risk of developing dementia is greater in married couples where one partner is caring for their partner or spouse with dementia, and caring partners or spouses are six times more likely to develop dementia, with the incidence of dementia greater amongst husbands who are caring for their wives (Norton, Smith, Østbye, Tschanz, Corcoran, Schwartz, Piercy, Rabins, Steffens, Skoog, Breitner, & Welsh-Bohmer, 2010). Between spouses in a caring situation, caring wives have been found to have poorer communication combined with higher levels of depression than caring husbands (Cox, 2013; Norton et al., 2010).

Earlier research into family dynamics and gender found that amongst sons and daughters who were caring for their parents, immediate daughters and daughters-in-law were more likely to take on a primary role as a carer in combination with childcare, household tasks and their career (Horowitz, 1985). Globermann (1996) found that a daughter-in- law, because of her relationship with her husband, is more likely to be the carer for her parents-in-law without any other formal support, as they want to please their husband's expectations rather than the family member for whom they are caring for, and vice versa for sons-in-law because of their relationship with their wives. Immediate sons tend to only step into the care of an elderly person with dementia if a female carer is not available, but when their wives are available then they seek additional support from them whilst caring for their parents. Sons have been found to be less involved with the care delivered to their family member because of a lack of emotional attachment and are also less likely to be stressed whilst providing care (Horowitz, 1985); a situation reflected in the experiences of sons-in-law (Globermann, 1996). Male carers are more likely to organise and make decisions regarding a care facility (Montegomery & Kamo, 1989), whereas women are more likely to manage and deliver care to a person with dementia on a day to day basis.

Drentea (2007) found that the level of care provided was not different between the genders and was split into three levels: instrumental support, comprising of daily chores; emotional support, comprising of psychological needs and wants, and informational support, which is associated with the carer adapting his/her situation to accommodate the disease condition of a person with dementia. Miller and Cafasso (1992) reported no differences between male and female caregivers when managing the general care of a

dementia patient regarding money related matters or when a dementia patient was unable to carry out any normal operational tasks.

Colin and Jones (1997) noted no gender differences amongst men and women carers when faced with the challenging behaviours of a person with dementia. Women carers reported that the demands made by a person with dementia were more problematic in comparison to male carers and a wife's stress and self-esteem levels were significantly lower than their husbands. Women carers in comparison to men are better geared towards a caring role but are more likely to get frustrated by the demands placed on them by a person with dementia. Research studies in the Nigerian community have found that females and older caregivers are more satisfied in providing care in comparison to males and younger caregivers. However, neither age nor gender are a predictor or indicator of the gratification experienced by carers when it comes to caring (Uwakwe & Azikiwe, 2006).

1.8.2. Caregiver Burden and Gender.

The caregiver burden can be defined in terms of the stresses and strains that a caregiver experiences as result of the care recipient's status. It is a position that a caregiver finds themselves in as a result of the caring tasks and challenges that they face which cause distress to the caregiver (Zarit, Reever, & Bach-Peterson, 1980). The caregiver burden is also defined as the strain or stress experienced by a carer who cares for a person with chronic ill health, disabled, or an elderly family member (Stucki & Mulvey, 2000). It is a multidimensional response to physical, psychological, emotional, social, and financial stressors which are related to the experience of caregiving (Zarit et al., 1980; Parks & Novielli, 2000). Carer's can find that there is minimal support and no time to relax or rest,

which affects carers' health and causes then to suffer from burn-out and depression (Vickery, Strickland, Fitten, et al., 2007).

Women suffer more from this burden than men, despite their similar caregiving situations (Bedard et al., 2005; Gallicchio, Siddiqi, Langenberg, & Baumgarten, 2002; Muller & Cafasso, 1992), as men are more reluctant to report this burden than women (Lutzky & Knight, 1994; Verbrugge, 1985). While men present more of a 'macho' image and have conventional ideas about masculinity, they are less likely to admit to feeling burdened and more likely to air positive aspects of caring in comparison to women, who are seen to be less 'macho' and have less conventional beliefs about masculinity (Baker, Robertson, & Connell, 2010). Women reported a greater burden when performing daily household tasks and personal care for a person with dementia in comparison to men (Miller & Cafasso, 1992). Pöysti et al. (2012) found that male carers in comparison to women who had low levels of education, had low levels of burden, generally accompanied by low levels of depressive symptoms when caring for a wife who was severely demented or suffering from a range of illnesses associated with dementia, and it has been suggested that male carers accept the simplicity of life more readily because of their low educational status. In contrast, carers who experienced high levels of burden and had a high educational status do not accept the simplicity of life more readily.

Bedard et al. (2005) looking at burden and care-recipients who had been diagnosed with Alzheimer's disease behaviour in a sample of 557 primary caregivers from local memory clinics, found that gender and burden were closely related. Despite carers similar circumstances, when providing care women reported a greater burden in their role as

carers than men. It was suggested that these results do not reflect how women cope when managing the care for a person with dementia but instead reflect the level of stress experienced by women when caring for men (Bedard et al., 2005). This explanation is one reason for why women are seen to react differently to men when caring for a person with dementia (Robinson, Adkisson, & Weinrich, 2001). Problem behaviours were seen to be an important factor in determinants of burden in line with emotional and repetitive behaviours. Younger caregivers gravitated more towards personal burden instead of problem behaviours, and this did not reflect the way that care was managed by the carer. Daughter carers in families reported more personal burden then spousal caregivers, and general family caregiving showed no difference in burden due to inherent biases and a limited study design. Bedard et al. (2005) support the use of a regression model and the conceptual difference between a carer's role and personal burden and found support for behaviours that displayed a physical threat or were difficult to manage that could result in additional concern for women caregivers. The research showed that caregiving could be operationalised by burden but failed to look at the pre-morbid relationship between men and women, especially in relation to the burden. The research also failed to look at the positive aspects of caregiving, the identification of different problem behaviours, and their desired treatments. The paper called for the barriers faced by women when seeking support services to recognised and eliminated via appropriate support interventions and underlying factors, such as anxiety and alcohol abuse should not be underestimated in relation to burden, especially in men who reported a reduced burden in comparison to women (Croog, Sudilovsky, Burleson, & Baume, 2002).

Ethnicity studies looking at burden and support have found that amongst African American and White dementia carers living in rural areas of Alabama, women carers in

both ethnic groups in comparison to male carers are more likely to report having received high levels of informal social support (Kaufman, Kosberg, Leeper, & Tang, 2010). No differences were reported between African American and White dementia male and female caregivers in terms of ethnicity or culture, and no differences were found between ethnicities or male and female carers in relation to burden. It was suggested that male caregivers could have experienced the same levels of burden and depression as those found amongst female carers. Social support was found to be split into two levels; one focused on accessibility of a carer to other people in terms of being able to converse and socialise with them, while the second focused on when a carer meets other people the positive respect that is displayed towards the carer. The emotions and self-confidence that other people promote in carers assists carers in recognising that the care they provide to the recipient with dementia is the best possible care. Further research is recommended for the identification of aspects that influence life contentment of rural dwelling caregivers and more psychological interventions in the local community are suggested (Kaufman et al., 2010).

1.8.3. Carers' Coping.

Many studies have looked at coping styles within general caregiving (Upton & Reed, 2006) and the type of social support available to carers, while other research has looked at the experiences of carers caring for a person with dementia and found that carers are bound by duty or because it was expected of them through nurture or nature and out of love for a person with dementia. However, for the carers this experience was often projected as being very lonely and isolated, with very little or no support, accompanied by feelings of burden, stress and a range of emotions which can have major ramifications on their health and well-being.

A study in the Netherlands looking at the coping element in caring for a person with dementia found that two out of three dementia patients lived at home and were cared for by informal carers, with no governmental plans in place for these dementia patients to move into residential care (Kraijo, Brouwer, Leeuw, Schrijvers, & Exel, 2011). Fifty-three carers were recruited and it was found that five distinct profiles could be identified for carers caring for a person with dementia: carers who coped well with their care providing situation; carers who required help but still wanted to be in control of their care providing situation; carers who found it very challenging to provide care and received assistance from their family and friends; carers who found caring for a person with dementia difficult and received no help from their family and friends; and carers who could not cope in providing care. It was found that carers experienced an arena of mixed feelings, including helplessness, anger, opposition, and unhappiness when caring for a person with dementia. A carer's QoL became affected when the dementia patient's behaviour and personality was affected by their dementia. In general, the experience of providing care was seen to be a very satisfying experience for the carer; however, when changes occurred to the dementia patient's character and behaviour, then this experience became demanding and stressful for their carer, and raised the issue of losing control and not knowing what was going to happen next in a given situation, thereby affecting a carer's wellbeing. The profiles identified in the study not only provide important information on the caring situation of a carer and their needs, but indicate what challenges they face and the stressors and perseverance of carers over time. Longitudinal studies investigating relevant interventions to suit the needs and wants of carers were suggested (Kraijo et al., 2011).

Research into gender has found that men are seen to associate the concept of caring as being quite feminised and are less likely to seek external support or assistance (Baker et al., 2010). Men and women use different coping skills (Parks & Pilisuk, 1991), as women caregivers use more cognitive strategies in comparison to men, who use more avoidance strategies in order to cope (Devries, Hamilton, Lovett, Gallagher-Thomson, 1997). Women carers are expected from birth to take on a nurturing role in caring for a person with dementia and to provide care well into their old age (Pöysti et al., 2012). In contrast, male carers take on a more defending role for their family and in comparison, to women, men carers suffer more from mental health issues and are less likely to engage in problem-focused coping strategies (Hooker & Manoogian-O'Dell, 2000).

Sequeira (2013) looked at the challenges associated with coping strategies, the sources of gratification, and levels of burden portrayed by informal Portuguese carers of older people who were dependent because of their physical or mental impediment. Of the 184 carers over the age of 40 years, 101 cared for people with a physical impairment and 83 for people with dementia; 87% were women with low levels of education, most were married (78.8%) and were spouses or daughters. It was found that carers of older dementia patients had lower levels of fulfilment and greater burden, and there was a strong relationship between the challenges faced and burden, and between the effectiveness of coping strategies and gratification. Carers looking after older people with dementia were more likely to have increased amounts of burden, high levels of difficulties, and reduced levels of fulfilment. More health interventions were recommended to look at the reduced level of carer susceptibility and challenges facing carers were recommended to be reviewed in line with the burden, with greater carer gratification to be promoted in terms of care.

Younger carers who are caring for a person with dementia with dementia often find it challenging to adapt to the changes affecting someone with dementia in terms of the disease and the difficulties that this causes with regards to their care management and the changes in a carer's situation (Roach, Keady, Bee, & Hope, 2008). The way younger carers cope can have a negative psychological impact on both the caregiver and the person with dementia. Simpson and Lockeridge (2012) used interpretive phenomenological analysis (IPA) to look at the coping strategies employed by six young carers caring for a person with dementia and four major themes from the analysis emerged: denial as a coping strategy; stigma in the young following the onset of dementia; struggling to maintain control of events; and carers adaptation to losses. The study found that younger carers employed a range of emotional and problem coping strategies which had a negative impact on both the carers and the person with dementia. There was a call for increased social awareness of younger carers and the promotion of educational support programmes based on younger carers needs and wants (Simpson & Lockeridge, 2012).

Recent studies looking at carers' individual skills, self-efficacy and coping styles (Harmell, Chattillion, Roepke, & Mausbach, 2011) have found that these factors play an important role in the health of the caregiver, especially regarding their health state and are future indicators of diseases such as depression. Individual skills and a belief in their own ability are associated with a greater use of positive coping strategies, which ultimately has a beneficial effect on the health status of both carers and on the person with dementia (Harmell et al., 2011; Lloyd, Patterson, & Muers, 2016).

1.8.4. Carers' Positive and Negative Experiences and Gratification.

Carers' experiences are affected by several stressors and positive influences that affect not only the carer but also the way they manage the care of the person with dementia and cope with the daily difficulties or stresses they face (André & Elmsťahl, 2005). Being, motivated, driven and accountable as a caregiver is central to carers' experiences and a feeling of gratification as a carer (Grant & Nolan, 1993). A carer's desire and capability can be combined with the enjoyment and importance they feel in their role as a caregiver (Nolan & Grant, 1992).

Providing care for someone with dementia and feeling fulfilment and satisfaction can be divided into three main areas: the personal dynamics between a carer and the person being cared for; the personal or intrapsychic focus of a carer; and the need to stimulate a positive effect and to avoid a negative effect on the person being looked after (André & Elmståhl, 2005). Andrè and Elmståhl (2005) looked at different aspects of caring provided by a carer who lived at home whilst caring for a person with dementia who reported experiences of both reward and fulfilment. Of the 153 dementia patients and family carers that participated in the study, a high percentage of carers perceived a reasonable amount of burden and a high level of gratification at the same time. It also found that carers could experience more than one kind of gratification at the same time in a caregiving situation. In the family caregiver situation, total burden and subjective health were found to have no influence on the degree of gratification. A better understanding was suggested for future studies by looking at ways in which burden could be reduced, whilst increasing carers' sensation of satisfaction (André & Elmståhl, 2005).

Lundh (1999) found that factors such as stress and fulfilment could occur at the same time and were related to different aspects of the caregiving situation. Kinney and Stephens (1989) found that positive aspects of caregiving could decrease the amount of stress and improve the caregiver outcome. Positive experiences of carers' gratification have been extensively reviewed (Lawton, 1997; Roff, Burgio, Gitlin, Nichols, Chaplin, & Harding, 2004). African-American caregivers reported higher scores regarding positive aspects of caregiving in comparison to Caucasians (Cox, 2013), while Roff et al. (2004) reported that African-Americans' belief and faith in religion, their low social economic status and their levels of anxiety were less likely to affect them when faced with the challenging behaviour of a person with dementia. All these factors had a positive effect on the carers' experiences and no differences were reported between the two ethnic groups in relation to managing care and depression, their educational status and levels of support received or not received by the carers. Sterrit and Porkony (1998) found that African-American communities were more likely to rank their belief in God first and then rank their family as second as a form of support. Other studies have reported positive experiences concerning management and care when accompanied by worth, love, appreciation and personal fulfilment (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991).

Negative and positive aspects of caring have been reported to cover a vast arena of emotions, especially those associated with negative experiences of caring, such as loneliness, regret, depression and vulnerability (Beeson, 2003; Rodriguez, Deleo, Girtler, Vitali, Grossi & Nobili, 2003). Bohim, Barrosob and Davis (2011) looked at the individualities of the spousal caregivers in relation to positive and negative experiences whilst caring for a person with Alzheimer's disease and found that there were three groups

of caregivers: positive, negative and an ambivalent group. The negative group of carers focused more on their needs rather than on their spousal needs and reported no positive experiences of caregiving but tended to review their experience more in negative terms in relation to their past and present experiences, together with a large caregiving burden. The ambivalent group of carers reported that the relationship they had with their spouse no longer existed but still reported gratification when caring for a person with dementia. This group reported a mixture of challenges facing them as carers and could not overcome the fact that their spouse could no longer engage in a relationship with them. The positive group of carers reported that the relationship they had with their spouse from their past and present experiences was a loving one. This group fully understood that their spouse could no longer engage in the relationships that they had before in the past but instead had an understanding that their current life circumstances had changed because the person they care for has Alzheimer's disease and accepted the situation as it now is. This group tended to focus more on the present rather than the past, experienced less burden and were more fulfilled. It was suggested that a better understanding and tolerance was required for individuals with dementia, and spousal caregivers should be directed more towards positive experiences of caregiving through compassion (Bohim et al., 2011).

Hodge and Sun (2012) found a close link between spirituality amongst Latino family carers and the positive aspects of caregiving when caring for a person with Alzheimer's disease. Other cultural caregiving studies have reported that amongst Indian family caregivers 21.6% of carers reported that they could identify with at least one positive aspects of caregiving, i.e. a feeling of gratification. Of the 68 caregivers, 44.1% were children who reported being gratified with caring, while the 43.6% who were spouses reported being gratified by caring for a person with dementia (Jathanna & Latha, 2011).

Other research looking at the positive aspects of caregiving in dementia has found that there are several underlying indicators that play an essential role in assisting the optimistic carer's experience. These indicators include emotional compensation, personal development, capability, skill, increased faith, and spiritual development, and all have a positive effect on the care being provided. The intimacy between a carer and the person being cared for, the benefits of the relationship, satisfaction experienced regarding reciprocity, fulfilment and the sense of duty experienced by a carer, all have a positive effect on the experiences of a carer (Lloyd et al., 2016).

1.9. Quality of Life.

1.9.1. Definition of Quality of Life.

Researchers over the years have attempted to provide a concrete definition for the term QoL, but despite these attempts there is still not a clear definition (Forward, 2003). One definition provided by Dalkey and Rourke (1973, in Ferrans and Powers, 1985) is an individual's perception of well-being and their pleasure or displeasure with life, or their contentment or discontentment with life, while other researchers have looked at the experiences of well-being and satisfaction in line with happiness, self-confidence, and healthiness (Forward, 2003) which also tend to interlink with QoL (Felce & Perry, 1995; Lim, Yuen, & Low, 1999; Ranzijn & Luszcz, 2000). In contrast, research has suggested that a QoL measure complicates matters in the assessment of an individual (Forward, 2003; Felce & Perry, 1995) and does not consider an individual's life circumstances (Forward, 2003). Alternatively, it has been argued that QoL needs to consider contentment in terms of a person's intentions and wants via their capabilities, lifestyle and experiences (Emerson, 1985) and the effect this has on them in their social environment (Massam, 2002).

1.9.2. Health and Quality of Life of Carers.

QoL is found not to be linked to a carer's age or their mental health (Banerjee, Smith, Lamping, Harwood, Foley, Smith, & Knapp, 2006). Thomas, Hafiz-Thomas, Delagnes, Bonduelle and Clément (2005) conducted a study looking at 100 patients with an average age of 80.2 years who were diagnosed with dementia and living at home with their caregivers, who had an average age of 65.7 years, with regards to both the carers' and patient's needs. A QoL measure was used comprising of a 20-item questionnaire related to four domains: behavioural capacities to face difficulties, generated by the patient; relationship with the environment; psychological perception of the situation; and perception of a possible distress. In addition to this, the Alzheimer Disease Related Quality of Life (ADRQL) scale was employed to assess the patients' medical and therapeutic data, together with Cornell's depression scale and the Katz independence index scale. It was found that patients' QoL was linked to their carers' QoL, and when the patient's dementia worsened in terms of their cognition then this had a tremendous effect on their daily management and manifested other challenges, such as behavioural disorders in the patient and depression in the carer. These factors were seen to influence the health of carers, and the vulnerability of the situation affected both the carers' mental and clinical well-being and the possible prospect of suffering from long periods of depression in the future. Women caregivers were found to have the worst QoL and were found to be more depressed than men (Thomas et al., 2005).

The relationship between the carer and the recipient has a fundamental role in carers' QoL and well-being. The two-factor model by Lawton et al. (1991) has influenced research on caregiving over a number of years and conceptualises the idea that care recipient

behaviour is a possible stressor and a caregiver's well-being is a possible consequence of this stressor (Wilson-Genderson, Pruchno, & Cartwright, 2009). This two-factor model is based on previous research carried out by Lazarus (1966) on the stress model and the two-factor model of psychological well-being (Bradburn, 1969; Diener & Emmons, 1984). Lawton et al. (1991) used the two-factor model of caregiving for appraisal and psychological wellbeing to study 285 groups of spouses, and 244 adult caregivers were interviewed regarding their caregiving behaviours, their assessment of caregiving, and general psychological wellbeing. In the groups of spouses, caregiving satisfaction was not related to features of the objective stressors but instead found to have a positive influence on the carers' health and well-being. In adult child carers, greater levels of caregiving behaviour were related to greater levels of caregiving satisfaction and burden. In both spouses and adult child caregivers burden was linked to depression; however, caregiving satisfaction did not have any bearing on positive influences in adult child carers. There was no support for positive and negative factors of caregiving influencing similar aspects of psychological well-being.

Although studies have looked at carers' experiences of stressors through positive aspects of caring, Kinney and Stephens (1989) argue that QoL needs to consider the domain of contentment in terms of a person's aims and wants, their capability, abilities and lifestyle (Emerson, 1985).

1.9.3. Support and Wellbeing of Carers.

Research confirms that women receive less informal and formal support in comparison to men (Goode, Haley, Roth, & Ford, 1998). A cross-sectional study of 134 caregivers in Hong Kong caring for patients with dementia found that informal social support was

associated with the wellbeing of caregivers with dementia. In addition, the informal social support and care provided by husbands/wives and children of the carers was seen to have a significant effect on increasing the life satisfaction of carers and reducing depressive effects. Some different types of informal social support, whether provided by family or friends, in terms of instrumental support, such as helping with the daily care management of the person with dementia, with their chores, advice on health or financial support, had different effects on the well-being of carers but overall was closely linked to their psychological well-being when caring for and managing for a person with dementia (Lau, Koo, Cheung, Pan, & Wong, 2009).

Factors associated with the carers' role, the dynamics between a carer and the recipient, the type of support received by a carer, and the social and cultural influences all effect caregiving. African-Americans who have been caring for a person with dementia over a long period of time are more likely to experience more depressive symptoms in comparison to Caucasians who have also been caring for a person with dementia for the same length of time. Caucasian's are also found to remain more stable in terms of their emotions and well-being in comparison to African-Americans (Cox, 2013). African-Americans, Hispanics, and American–Chinese carers face significant amounts of stigma when caring for a person with dementia and these groups and are less likely to seek help in terms of advice and medical interventions (Cox, 2013; Vickery et al., 2007). Self-efficacy, the ability to cope with emotions and feelings, the type of relationships, and the way carers respond to stress, all influence carers. It has been suggested that factors affecting carers' health and wellbeing need to be addressed and appropriate interventions based on carers' requirement and predicament need to be considered in communities (Cox, 2013).

Research looking at problem behaviours and vulnerability factors associated with the wellbeing of their spousal caregivers has found that amongst wife carers and younger husband carers (64 years and under), the volume of patient problem behaviours is negatively associated with scores of wellbeing but not among older husband carers (Croog et al., 2002). The correlational analysis found that patient problems had more of an impact on younger women carers (aged 64 years and under), whereas, multiple regression analysis found that the patient problem measure of emotional liability was the single predictor of impaired well-being for all five sub-dimensions (anxiety, depressive symptoms, positive wellbeing, vitality and general health) of the caregiver wellbeing measure. Destructive behaviours was found to be a significant factor, especially in age-related destructive behaviours, which when combined with patient destructive behaviour resulted in high levels of depression, anxiety and low levels of wellbeing amongst younger caregivers. Husband carers had higher anxiety scores in comparison to women carers and these scores indicated the impact patient problem behaviours had on the wellbeing of caregivers. Susceptibility, stress and patient behaviour problems were related to the age of both male and female carers. However, this study failed to look at the basics of well-being and called for a better understanding of the relationship between patient behaviour problems and caregivers' emotional and physical health.

For communities and societies, the well-being of patients affected by dementia is very important and is highly dependent on the social relationships, support and social environment. The social relationship is a factor affecting other facets of life, such as the physical health and psychological wellbeing of a dementia patient. Increasing a patient's wellbeing, reducing susceptibility amongst individuals with dementia, and providing more assistance towards supporting relationships and social inclusion will undoubtedly

influence the well-being of dementia patients, their carers, and society (Austin, Skevington, & O'Neill, 2016).

1.10. Summary and Conclusions.

Dementia is a disease which is increasing in frequency due to the aging population and results in additional cost implications to the economy. Accompanied by this rise is the increasing number of people caring for someone with dementia and the increasing effect that this has on carers' health and wellbeing.

Caring for someone with dementia is a dynamic relationship between the carer and the recipient, which can be both rewarding and stressful, and affects carers in several ways, such as making them feel emotionally, physically and mentally drained (Alzheimer's Association & Dementia, 2012). These strains and stresses have a marked effect on carers' mental health, QoL and well-being. The experience of a caregiver may be influenced by a range of factors associated with the behaviour of the person with dementia, a carer's coping style, and access to social support. These influencing factors are also linked to a carer's belief systems regarding their ability, individual skill, reciprocity, reward and fulfilment experienced between a carer and care recipient, which has a fundamental effect on the carer's role, their life circumstances and future health. While there is, some research looking at the personal lived experiences of those who care for people with dementia (Kindell, Sage, Wilkinson, & Keady, 2014) it is limited.

In line with the above literature review and the recent government initiative, the aim of this research is to consider the personal lived experiences of male and female carers who

are looking after a person with dementia at home. This research will not only provide a useful insight into carers' everyday life circumstances, but also provide a meaningful insight into how carers' personal lived experiences are influenced by factors linked to coping strategies, the support received, gratification experienced, and the challenges associated with managing the care of a person with dementia.

The findings of this research thesis will also provide insights that may be useful to health professionals, such as practitioners, nurses and GPs, who are considering interventions, educational programmes, training and support services for carers in the community together with those professionals who are seeking a better understanding of carers' monotony in relation to their personal lived experiences.

Chapter 2.

2.1. Methodology.

2.1.1. Aim of the Study.

The aim of this research thesis is to look at the lived experiences encountered by both male and female carers whilst caring for a person with dementia at home. The lived experiences are examined in relation to the carers' daily care management and their role as a carer.

2.1.2. Study Design.

In-depth, semi-structured interviews were carried out with groups of carers and each carer was asked a series of nine open-ended questions which allowed them to describe his or her lived experiences. Raw data was collected in the form of recorded audio-taped interviews during face-to-face and telephone interviews. An in-depth qualitative research design was used employing IPA to highlight the initial meanings, themes, and categories in the transcribed interviews. IPA was utilised in the analysis of the raw data to draw out the key constructs and meanings in relation to the carers' everyday lived experiences.

2.1.3. Rationale for the use of Interpretative Phenomenological Analysis.

The qualitative research method that was most suited to evaluate the lived experiences of carers was IPA. Whilst this is a relatively new research method it has been extensively used in the areas of health, clinical and social psychology by researchers and especially in the field of health psychology (Smith, Jarman, & Osborn, 1999). IPA is based on phenomenology, which is the philosophical study of the structures of experiences and consciousness. It owes its origin to the early work carried out by Edmund Husserl in the

1930s, who developed a scientific rationale for consciousness (Husserl, 1999). IPA combines the principles of hermeneutics, which is the theory of interpretation, and combined with the symbolic interactive approach. Through the experiences encountered by an individual, meanings are constructed by individuals in their social and personal world (Denzin, 1997). A great deal of focus and importance is given to situations and events that people align themselves to (Smith & Osborn, 2003). This inter-subjective understanding (Standing, 2009) enables an insider's perspective (Conrad, 1987) to be appreciated. Where a person's account tells us something about their innermost feelings and thoughts, these are expressed through their personal lived experiences of the subject matter that is being investigated (Willig, 2001). IPA provides a personal account of the individual instead of an impartial account of their personal experience (Flowers, Hart, & Marriott, 1999). It is because of this individual approach that IPA creates a theoretical pledge at an idiographic (particular) level and establishes a close link between what people say, what they are thinking, and what emphasis they place on their emotional state of mind and their physical existence (Pringle, Drummond, McLafferty, & Hendry, 2011). This creativity of IPA enables the participant to tell the researcher about their lived experiences in their own words through either an interview, a record or a diary (Willig, 2001). IPA also recognises that people struggle to express their innermost feelings and emotions in a situation or given event and may choose not to say anything but instead leave it up to the researcher to interpret their mental and emotional state (Smith & Osborn, 2007).

IPA recognises that the research being conducted by the researcher needs to be conducted in such a way that it results in a dynamic process in terms of its outcome. Consequently, a researcher during the research process will realise that they need to go beyond a simple

spirit-less effort in order to get close to an individual's personal world during the interview phase. However, a researcher must also understand and recognise that he or she will never have direct or complete access to an individual's own personal experiences or their inner world (Smith, Flowers, & Osborn, 1997). IPA acknowledges that a researcher's own understanding of an individual's own personal world can be influenced by the researcher's own personal thinking and experiences, and thus may bias the research process and analysis phase. IPA accepts this is a challenge during the research and the analysis phase, but also understands that this is an integral part of the research process (Smith et al., 1999; Smith, 1996), and therefore the researcher is given the opportunity to reflect and analyse the data. The core principals of IPA have been questioned in the literature as to whether IPA can truly explain or describe an individual's personal experience and their inner world (Willig, 2001). These criticisms of IPA are challenged by contrary supporting research, which suggests that IPA studies go beyond simply describing themes and instead develop robust models and methods which provide an in-depth explanation of an individual's personal account which is fundamental to IPA research (Benner & Ketefian, 2008). With the emphasis of IPA on an individual's personal experiences (Smith, 2004) combined with its hermeneutic (interpretation) belief (Palmer, 1969), and a researcher's attention to detail during the research and analysis process, it is therefore a strong contender as a method of analysis for this research.

2.1.4. Other Qualitative Methodologies.

IPA versus Grounded Theory.

IPA shares some common features in relation to grounded theory, especially regarding the focus on the individual or on a group of participants, the systematic working through the text, and shared analytical terminology (Smith, 1996). Where IPA differs from

grounded theory is that the latter as a research methodology is more interested in conducting qualitative research that is well-matched with the social cognitive model (Smith,1996), whereas IPA is more geared towards gaining an understanding of an individual's opinion of a phenomenon or event. Therefore, grounded theory is designed to study basic social processes (Smith, 1996; Willig, 2001) in the environments in which they take place (Glaser & Strauss, 1967). In addition, grounded theory is more focused on answering research questions which provide a description of an individual's account (Brocki & Wearden 2006) alongside the sequential collection of data (Benner & Ketefian, 2008). Because the core elements of the individual account or story in grounded theory is shared amongst with other participants' detailed accounts, grounded theory as a method of research lacks attention to the key features of a participant's account or story (Benner & Ketefian, 2008). In contrast, IPA highlights the importance of language, and qualitative analysis differs in its insights and the status it gives to thought and reason (Smith et al., 1999; Smith, 1996). Therefore, as a method IPA is less focused on the story told or an individual's account and more focused on the key elements of meaning behind their story or account, the phenomenon and experience (Benner & Ketefian, 2008). Because of this heavy dependence on language to describe a participant's personal experience (Benner & Ketefian, 2008), IPA has been subject to much criticism. One suggestion is that as people tend to describe events or situations differently when talking, IPA may be evaluating how people describe their personal innermost experiences by language through talking rather than the actual experience itself (Willig, 2001).

IPA versus Discourse Analysis.

Discourse analysis and IPA are similar in that they are both concerned with looking at the importance of language when relating a person's experience but where these two methods differ is in regards to an individual's behaviour, reason and thought (Smith et al., 1999). Discourse analysis is more sceptical of mapping verbal reports on underlying cognitions and is more focused on the interactive tasks that are performed via a verbal statement, viewing these verbal reports as part of the functional analysis (Smith et al., 1999; Smith, 1996). Verbal responses in discourse analysis are translated in terms of behaviour, which decreases the risk of explicit behaviour and any underlying reasoning or thought (Benner & Ketefian, 2008). In contrast, IPA forms a more direct and also an indirect link with people's verbal responses, their emotions, their reasons and thoughts (Benner & Ketefian, 2008). Therefore, IPA mediates between the two qualitative methods of discourse analysis and grounded theory, and because it is ne, it allows room for flexibility, creativity and further exploration on the part of the researcher who uses it (Smith, 1996). It is therefore used extensively by clinical and health researchers when trying to determine the meaning of verbal responses, the physicality of symptoms and the mental states of individuals (Benner & Ketefian, 2008).

Limitations of IPA.

IPA as a qualitative method of research is subject to pragmatic and theoretical limitations and has been critiqued because of its emphasis on language. This is seen to be problematic because so much importance is placed on the reasons and construction behind the development of this language, instead of focusing on the way language occurs practically (Willig, 2001). Language is used by the participant to communicate to the researcher how

they feel, think about and experience a given event or situation and is a means by which a researcher can capture an experience through the dynamic process of phenomenological analysis (Willig, 2001). It is a method in terms of applicability is questioned because the meanings and experiences of an event are evaluated through the individual's point of view by the researcher who uses his/her own experience to conduct the phenomenological process. The reliability of a participant's account in terms of the phenomenological analysis is questioned more in the finer details (words/contexts) of the way language is expressed in terms of the participant's experience and the way it is shared amongst the group is questioned (Willig, 2001). Lemon and Taylor (1997) carried out a study with IPA looking at the experiences of participants with head injuries who had been confined to a drug regime in a hospital setting. IPA in this study was concluded not to be a suitable method of analysis mainly because of the nature of the head injury and drug intervention, but also because each participant's circumstances and experiences were different.

Another limitation of IPA is that it works with a very small and similar group of participants who are chosen to generate shared themes. However, the small samples sizes employed by IPA display a logical and an in-depth process in the generation of themes (Benner & Ketefian, 2008). IPA differs from methods such as grounded theory, which use much bigger sample groups (Barbour, 2007), and this uniqueness in the use of small samples creates a limitation to IPA as it can produce a narrow set of less powerful results. In addition, it is more challenging to develop further research in the given subject area because of less conclusive outcomes, a number of false positives may be generated because of the small sample size, where the evidence for true effects is lacking.

However, despite this limitation IPA studies have been carried out with a larger number of participants ranging from one to fifteen (Smith & Osborn, 2007) or even forty-two participants, although current thinking as that IPA studies should still be conducted using smaller sample groups (Smith & Osborn, 2007). In support of this small sample viewpoint, there are several challenges encountered by a researcher when faced with a large sample size. In particular, a researcher might become over-burdened by the large amount of qualitative data during the analysis process and produce a less suitable and less powerful analysis (Smith & Osborn, 2007). Because of the time is taken to undertake the analysis and the in-depth nature of the analysis a manageable sample size enables generalities to be avoided. Smith, Flowers and Larkin (2009) advocates that research should provide an in-depth and clear account related to the current literature, which a reader can review and appraise the transfer or sharing of information from participant groups (Pringle et al., 2011). In this way, the transfer and sharing of information is a challenge because the accounts of participants are from a unique and similar group of individuals, with shared themes making it difficult to relate to other fields of research, such as health, disease and other groups of participants (Pringle et al., 2011). These limitations identified can only be recognised if they are thoroughly explained by the researcher (Pringle et al., 2011), together with a detailed, monotonous in-depth case by case analysis of each participant's transcript (Smith & Osborn, 2007). The purpose of this research is to say something in-depth about the viewpoints and perceptions of the identified group, i.e. carers, and not to create generalisations (Smith et al., 1999; Smith, 1996). Therefore, the thematic process of IPA research can be described as conducting a detailed approach in comparison to an approach laden with a set of rules (Smith, Harre, & Van Langenhove, 1995).

During the phenomenological research stage participants provide descriptive accounts filled with verbal language and descriptive images, which are further used in the analysis process by the researcher to derive the true reflections of the participants' words and meanings (Pringle et al., 2011). IPA, therefore, engages in pinpointing or emphasising a theme in a given sentence during the analysis process (Brocki & Wearden, 2006; Pringle et al., 2011) and provides a basis for other qualitative research methodologies (Braun & Clarke, 2006). In comparison, other qualitative research methods lack the same focus on themes and meanings within sentences because of their over-focus on the theoretical background (Braun & Clarke, 2006; Pringle et al., 2011).

One further criticism faced by IPA is in its different methods of data collection, as IPA research studies can use descriptive spoken accounts, diaries, e-mails, detailed accounts from participant interviews and focus groups. The information gained via these different methods of data collection is not always adequately detailed, and prompts researchers to mention the pros and cons of the method undertaken during the research process (Brocki & Wearden, 2006). IPA is seen to provide more originality and independence in comparison to other qualitative methodologies (Willig, 2001; Pringle et al., 2011), and this needs to be recognised and considered, especially when points of views of the group selected are challenging to research or are not within the realms or the same perceptual field of healthcare professionals (Biggerstaff & Thompson, 2008; Pringle et al., 2011).

The credibility and validity of IPA as a qualitative research method have been questioned, especially when a researcher's personal knowledge and experiences could possibly influence communication with the participants in relation to their experiences and

detailed accounts (Benner & Ketefian, 2008). In defence of IPA, it is argued that IPA studies need to go beyond the simple and ordinary method of analysis, and instead need to be auditable, open and in-depth, particularly regarding its pledge and thoroughness (Smith et al., 2009). During the data collection phase more than one method needs to be utilised, such as the use of diaries, interviews, and focus groups. The use of mixed methods, where more than one type of method is used to study a phenomenon, yields powerful results (Casey & Murphy, 2009; Pringle et al., 2011).

Studies of Carers using IPA.

IPA has been used in research studies examining people dealing with a variety of issues related to both illness and health (Smith, 2004) and many studies have looked at dementia and the wellbeing of caregivers. Quinn, Clare, Pearce and Van Dijkuizen (2008) investigated the issues affecting caregivers during the early stages of dementia, and 34 spouses of individuals who had been diagnosed with early stage dementia were interviewed using IPA. Four themes emerged relating to the challenges concerned with the understanding and meaning of dementia by caregivers, the challenges and difficulties faced by caregivers in their life adjustments and changes in their relationship and ways of coping, and communication and it was concluded that better and more effective knowledge of dementia in the early stages was required by family members (Quinn et al., 2008). Mullin, Froggatt and Simpson (2011) also looked at the experiences of 10 spouses with dementia and their long-term care via IPA and found four themes related to identity: till death us do part; making sense of change; relationship with the care provided: visiting as surveillance; and the relationship with the future: hope versus despair. The results of their study showed contradictory feelings for the spouses, with positive emotions being

expressed with despondency. It was suggested that future research needed to focused on providing a better understanding of spouses' and patients' experiences during long-term care by improving dementia care, through care homes and implementing a more of a relationship-centred care approach (Mullin et al., 2011) which focuses on relationships and promoting the positive effects of well-being (Nolan, Davies, Brown, Keady & Nolan, 2004).

Other studies have looked at the experiences of couples where one partner had received a diagnosis of either Alzheimer's disease or vascular dementia, with an emphasis on psychological responses to loss and the shared experiences/assessments that couples make about an early-stage diagnosis of dementia. The study developed a family system perspective and used IPA to look at participants' experiences of having received an early diagnosis of dementia which was compared amongst the couples. Ten themes emerged: not quite the same person, tell me what is wrong and everything's changed, we must go from there, which were linked through the overarching theme of making sense and adjusting to the loss. This study found that couples went through a process of exchange, whereby they rationalised, tried to understand what it was like, and tried to make sense of early-stage dementia through facing challenges and self-adjustment, both as individuals and as a spouse. The couples tended to gravitate more towards loss, moving on to adjusting to living with dementia (Robinson, Clare & Evans, 2005; Benner & Ketefian, 2008).

From the above studies, it can be seen that IPA can be used to explore the lived experiences and opinions of participants or a group of people in relation to their life

circumstances, well-being, and their health in connection with a person diagnosed with dementia. The aim of this research is to explore the personal lived experiences of carers; therefore, a symbolic interactive perspective (Willig, 2001) has been taken in order to explore the subjective meanings that both men and women carers endorse to an event or situation. Especially attention is given to how this interaction is shaped by their past experiences and social history of having to care for someone with dementia and is reflected through their own personal lived accounts which were interpreted by the researcher during the research process.

2.2. Recruitment Methods.

A total of twenty community support groups, consisting of recognised charities such as the Alzheimer's Society, Dementia Society, United Carers in Central London, and Crossroads in Berkshire, were contacted by the researcher. Social network websites, including Facebook, in the geographical area of Berkshire and London, were also employed to assist in the recruitment of potential carers. Out of the 20 establishments contacted, only two support groups and one charity responded. A posting was placed on one of the recognised charity web page outlining the aims and objectives of the study, including the researcher's City University of London e-mail address, the participant information sheet, and the researcher's mobile phone number (please see Appendix A for a copy of the posting placed on the charity website).

Direct community contact with caregivers was made by a representative employed by United Carers in Central London and a community liaison representative working with Crossroads (Berkshire). Carers that showed a keen interest in the study had their details forwarded by the representative of the support group to the researcher by e-mail. The

representative of the support group also contacted each carer separately, informing them about the study and requested each carer to make direct contact, either by telephone or e-mail, with the researcher. In the later stages of recruitment word of mouth was used by carers to recommend friends or associates that were caring for spouses, partners or individuals with dementia.

2.3. Qualitative Procedure.

2.3.1. Gaining Informed Consent.

Carers that expressed an interest in the study were briefed on the research study by a local representative or person employed by the support group, and provided with the researcher's contact details, including as e-mail address and mobile phone number. The carers then contacted the researcher by e-mail or by telephone. If carers had not already been provided with a participant information sheet and a consent form, then these were sent by the researcher, either by post or e-mail. The carers were requested by the researcher to take ample time to read the consent form and once they agreed to take part in the study the carer was requested to sign and date the consent form and return it to the researcher via a pre-paid envelope. If a carer had not returned the consent form at the start of the face-to-face interviews both the carer and researcher signed and dated two copies of the consent form prior to commencement of the interview; one copy was provided to the carer for their safe-keeping and the second was kept by the researcher. If the interviews were to be conducted by telephone, then carers were requested to return the signed consent form to the researcher by post or e-mail prior to the interview session. If a carer failed to return the consent form prior to the telephone interview, then consent was taken over the telephone and carers were instructed by the researcher to post their consent

following completion of the telephone interview. The setting and type of location of the interview were dependent on the request of the carers taking part in the study.

2.4. Participants.

In order for the carers to be enrolled in the study they needed to satisfy the following inclusion criteria: provide their informed consent, be a male or female caregiver, be aged 18 years and over, and needed to be caring for an individual diagnosed with dementia on a long-term basis at home. Carers needed to have a confirmation from a medical professional that the person that they were caring for had been clinically diagnosed with dementia. Carers excluded from the study were those that had cared for someone for less than one year, a person with dementia who had been hospitalised, were clinic in-patients or in residential homes, a person with dementia undergoing surgery, caregivers caring for dementia spouses and partners of individuals with other associated conditions, such Parkinson's diseases etc. Finally, carers were excluded if a clinical diagnosis of dementia by a medical professional had not been made.

The intention of this research study was to recruit a total of ten males and ten females over a six-month period. However, only fourteen carers volunteered and agreed to take part in the study and of these fourteen, seven were male caregivers and seven were female caregivers. The carers taking part in this study had diverse academic and working backgrounds, ranging from a GP, to teachers, a plumber, community nurse, retired engineer and office workers. All the carers were geographically spread out across the UK, with four carers living in the Berkshire area, one in Middlesex, two in South London, three in Hertfordshire, one in Manchester, one in West London, one in Kent and one in North London. The ages and ethnicities of the recruited carers are shown in Tables 1 and 2.

Table 1: Ages of carers.

Ages of Carers	Number of Carers*		
	1	2	3
20-30 years	×		
30- 40 years	×		
40-50 years			×
50-60 years			×
60-70 years		×	
70- 80 years	×		
80- 90 years			×
90- 100 years			

Key: ×= Shows the number of carers in this age group.

*= total number of carers 14.

Table 2: Ethnicity of carers.

Ethnicity of Carers	Number of Carers*
Caucasian	11
African-Caribbean	1
British Indian	1
British Pakistani	1

Key: *= a total number of carers 14.

Of the fourteen carers, nine were spouses and five were family members. Of the five family carers, one had given up work to look after the person with dementia and four were looking after family members while still in employment. Of the nine spousal carers, one was caring for their spouse while still working, seven were retired, and one was working part-being cared for, six had been diagnosed with dementia, two with dementia of the frontal lobe, four with Alzheimer's disease, one with vascular dementia and Lewy body, and one with senile dementia.

2.5. Materials.

The materials used in this study comprised of an interview schedule consisting of nine open-ended questions. The interviews were audiotaped using a tape recorder and a ninety-

minute audio cassette tape. Other materials included a mobile phone, ballpoint pen and paper. The consent forms (please see Appendix B for the participant information sheet and consent form) used in this research study were provided to the carer by the support group representative or posted by the researcher to each care giver for their information. A pre-paid envelope was provided to the carers addressed to the researcher in order for them to return their completed consent form.

2.6. Questionnaires.

The interview schedule consisted of an opening question (Q1), followed by seven specific questions relating to the research area under discussion (Q2-Q8) and a closing question (Q9) which were all reviewed by the university supervisor (please see Appendix C for the list of questions used by the researcher).

2.7. Data Collection.

2.7.1. Conducting the Semi-Structured Interviews.

The interview was set-up with each carer individually and separately, and took place in an appropriate setting and at a time specified by the carer. The face-to-face interviews were conducted in the carer's home at a time convenient for the carer. Telephone interviews were also conducted at a suitable time and at the convenience of the carer. Each carer in the study was involved in a single interview session which lasted between approximately one hour to one hour and a half. The procedure outlined below was conducted with each carer separately, meaning that fourteen interviews in total were conducted.

At the start of the interview, the carer was asked by the researcher whether they would prefer to use a pseudonym rather than their own name during the interview session. This enabled the carer's identity to be protected and any disclosing information about a carer made during the interview process to be disguised as the use of a pseudonym ensured confidentiality and anonymity.

It was made clear to the carer at the start of the interview that his/her participation in the study was completely voluntary, and if at any time during the interview he/she did not feel comfortable then they had the right to withdraw from the study. It was also emphasised that if he/she felt did not want to answer a question they did not have to and that they could stop the interview at any time and request a break. The carer was informed by the researcher that with their permission the interview would be tape-recorded and participants were informed that the taped interviews would be transcribed by the researcher, and on completion of the stud, the tape recordings would be kept in a confidential and secure place within the researcher's home and would be archived for a period of ten years, whereupon they would be destroyed. This provided the carers with the opportunity to discuss the study and to raise any further questions regarding the issues surrounding confidentiality and anonymity. The researcher reassured the participants that the researcher was a Doctorate trainee health psychologist at a university in London and that no one outside the research study would have access to the participants' transcripts except the researcher. The transcribed interviews would only be used in the analysis and the university would review these transcripts in the final thesis. Prior to starting the interview the researcher asked the carers to talk into the tape recorder by simply saying hello or by stating their chosen name so that the tape recording could be tested for its audibility and clarity.

The interview itself was informal and semi-structured, and commenced with a general open question, such as tell me a bit about yourself. During the interview the researcher probed further issues of interest that were raised during the interview by the carer. Topics that were relevant and important to the carer in relation to caring were further explored, whilst still concentrating on the research question being asked. The validity of semi-structured interviews and what they reveal during the interview process in terms of a participant's representation of his/her world have been questioned by some researchers (Osborn & Smith, 1998; Smith et al., 1999). Smith et al. (1999) explained that semi-structured interviews provide a pathway to a participant's underlying internal world and internal reality (Smith et al., 1999).

Good practice in phenomenological interviewing is considered to occur when there is very little intrusion or interference by a researcher during the interview stage and an interviewee can share their experience via their personal detailed account with a researcher (Smith et al., 1995). During the interview process, the researcher used minimal intervention and acknowledged the carers' responses through non-verbal communication via head nods, smiles and body language. Sounds and confirmation were used to encourage the carers to continue, as well as general questions such as *"Is there anything else you would like to add?"* At all times eye contact was maintained with the carers during the interview process, which provided confidence to the carer that the researcher was interested and listening to their detailed account. In addition, it provided encouragement to the carers to continue talking or a way to communicate to the researcher that they might need a break.

All fourteen carers' interview accounts were diverse, yet related to the research area being discussed. The interviews with the female carers tended to be shorter in duration and on average lasted 32 minutes, which was because they tended to be clearer and more concise in their responses, were less likely to transgress away from the subject area, and were less willing to discuss anything additional about themselves. The longest female carer interview lasted fifty-three minutes. The interviews with the male carers were relatively longer, with an average time of 42 minutes, which was because the men tended to talk more in relation to the person with dementia and were more likely to transgress away from the subject area and talk more about themselves. The longest interview for a male carer was sixty-six minutes and the shortest was seventeen minutes.

At the end of the interview, the researcher thanked the carers for agreeing to take part in the research study and emphasised to the participants that their time and assistance was greatly appreciated. The researcher also asked both the male and female carers if they had any questions that they would like to address to the researcher. The researcher also informed each carer that the audio tape recording would be stopped at the end of the interview and the time for each interview would be noted. During the face-to-face interviews, the researcher in front of the carer broke the seals of the audiocassette to provide re-assurance to the carer that the tape recording would not be used for any other purpose other than transcribing. Where the interviews were conducted over the telephone, the same method was applied and the carer was informed that the seals of the audiocassette were being broken by the researcher. The carers during both the face-to-face interviews and the telephone interviews were given the opportunity to receive a copy of their interview transcript and a summary of the research thesis if he or she wished at

the end of the write-up period. All fourteen participants requested a copy of their interview transcript and also a copy of the thesis summary on completion of the study.

2.8. Analysis.

During the analysis process a researcher engages in an explanatory relationship with the text, whereby the researcher works systematically through the text word by word, and line by line. Firstly, the researcher reads the text and then re-reads it again and again to generate a variety of non-specific notes that reflect the researcher's initial encounter, thoughts and observations in relation to the text (Willig, 2001). These notes are documented in the left-hand margin of the text and after this stage is completed the researcher tries to identify themes and categories. These themes and categories are gradually incorporated to capture the meanings in the represented text and thus encapsulate the essence of what it means to the individual (Willig, 2001). IPA starts with individual cases, which may then be integrated across other individual cases to obtain master themes (superordinate themes) that reveal more information about the phenomenon (Smith,1996; Willig, 2001). The verbatim transcripts of each participant in this research were analysed separately and in accordance with the IPA guidelines recommended by Smith et al. (1999). A summary of the analysis stages carried for each carer's account is provided below.

Stage 1.

During this stage of the analysis each carer's transcribed verbatim text was re-read again and again. This allowed the researcher to become familiar with the account provided by the carer and the researcher engaged in the interpretative process by making notes in the right-hand margin of any interesting and significant issues raised by the carer in the

transcript. The researcher at this stage also provided a detailed account of his/her initial encounter of the transcript.

Stage 2.

In the next step of the analysis the researcher conducted a systematic reading of the transcript of the carer's accounts. Working line by line the researcher in the left-hand margin noted down a catalogue of emerging themes and categories represented in the transcript.

Stage 3.

In this stage of the analysis an organisational structure was introduced. The researcher listed the emergent themes identified in stage two and moved back and forth in the transcript to create connections between them. Several themes identified by the researcher were formed into natural clusters which shared common meaning, and concepts were grouped together whilst others needed further exploration and integration with a cluster.

Stage 4.

In this stage of the analysis a summary table was created so that a clear systematic overview of the themes could be provided. The clusters were established together with keywords along with the textual citation and location of the relevant quotation. This allowed the researcher to capture a participant's experience of the subject matter under discussion. At the discretion of the researcher, themes and clusters that did not occur

across the shared experiences of the carers accounts or were not relevant to the research area were disregarded during the analysis process.

Stage 5.

In this stage a carer's clusters and subordinate themes were derived from the carer's transcript. This process was then repeated for each of the carers so that shared clusters and subordinate themes were created.

Stage 6.

A summary table consisting of each carer's clusters and subordinate themes was created. All the themes emerging for each carer's transcripts were then cross-examined as a whole together in order to ascertain themes and meanings that were commonly shared amongst the carers. A list of the shared subordinate themes and clusters were grouped together and aligned to generate master themes (superordinate themes) that reflected their meaning. The analysis revealed four common superordinate themes for both male and female participants.

At the end of the analysis process, each male and female carer's transcribed verbatim texts were positioned in a folder and placed in a locked cupboard, with the key stored in a safe place its location only known to the researcher.

2.9. Ethical Considerations.

The ethical considerations relating to the study design, logistics and practicalities of conducting the research were considered and evaluated by the researcher. Recruitment of potential carers was carried out with the assistance of recognised societies and support groups. Due to confidentiality and the nature of caring for a vulnerable person with dementia, some of the support groups, clinics or charitable organisations did not want the researcher to contact the carers directly. In this research no hospital inpatients were recruited to take part nor were other patients seen from local GP practices or other health clinical setting. For this reason, the research thesis was not submitted to any other local regional ethics committees or the research and development departments of hospitals, and ethical approval was only requested and approved by City University (please see Appendix D for City University Ethics Approval e-mail).

During the interview process, there were issues raised between the carer and the researcher that were of a personal in nature and were emotionally distressing to the carer. When the carer appeared distressed or expressed verbally they felt upset during an interview then the researcher stopped the interview and the recording. The carer was then provided with ample time to regain his/her composure and when they were ready to restart the interview again their re-consent was taken verbally again. There were other instances during the interviews where the person affected with dementia walked in on the interview session and started to engage in the interview by conversing with both the carer and the researcher. Again, the researcher stopped the interview with the carer and permitted the carer to take control of the situation by the carer taking the person with dementia out of the interview room. Upon the carer's return consent was re-taken verbally by the

researcher and researcher requested confirmation from the carer that they were happy for the interview to continue and they were reminded of their right to withdraw from the study at any time.

After the interviews, had been completed guidance was sought by the researcher from her supervisor because some of the carers who had been interviewed during the research process started to contact the researcher by telephone or by e-mail to discuss issues related to dementia and caregiving. The researcher responded to the carers by clearly informing them that she would only contact them in the professional context of the research and not in the realms of a confidante. Other sources of additional support and recommendations were provided to the carers by the researcher, such as contact details of support groups or recognised charities and the names of research journals.

Chapter 3.

3.1. Results.

3.1.1. Chapter Outline.

The examination of the fourteen carers' interview transcripts during the analysis phase generated a series of illuminating representations of all the carers' accounts regarding their lived experiences whilst caring for a person with dementia on a long-term basis at home. A variety of subordinate and superordinate themes emerged during the analysis stage and the priority was given to those themes that were most relevant to the research question.

The results section provides both an interpretative account and meaningful insight into the various topics that arose during the analysis phase. For this reason, all the carers' lived experiences are presented as descriptive paragraphs, and no references are made to the literature nor any theoretical accounts provided in this section. The shared superordinate themes which were identified as being common to all carers during the analysis process are presented together under the main heading followed by quotes from individual carers. Each subordinate and superordinate theme is presented in terms of their relevance, and quotes are presented using open speech marks and italicised text, with each quote referenced by page and line number. As not all the carers used a pseudonym during their interview, the gender of the carers is noted by M for male and F for female. The seven female and seven male carers are individually identified by the numbers one to seven for females and eight to fourteen for male participants.

The five common superordinate themes that were identified amongst the fourteen carers' accounts in terms of their lived experiences are as follows:

1- Just normal.

2- Providing best and safe care.

3- Managing to cope.

4- Sharing and supporting others.

5- Cherished moments.

Please see Appendix E for a summary of the commonly shared superordinate themes for women and Appendix F for a summary of the commonly shared superordinate themes for men.

3.2. Analysis of Transcripts.

3.2.1. Superordinate Theme 1 - Just Normal.

The first superordinate theme 'just normal' encapsulates the carers' lived experience regarding their daily lives in relation to their management care of the person with dementia. It demonstrates the ways that carers instil normality for themselves, both inside their homes, in their surroundings and socially outside.

The carers provide both descriptive and illuminating accounts to describe their lived experiences, and two of the carers through their separate accounts describe the overwhelming sense of fulfilment they experience when they see the person with

dementia engaging and sharing in activities or tasks related to everyday, normal operational tasks. These tasks consist of cooking together, engaging in pleasurable times together, such enjoying each other's company, relaxing on the sofa watching TV or doing a crossword puzzle together, which the carers find both pleasurable and rewarding.

> *"We both enjoy watching these together. We often have become much sleepier in the evenings. Often she goes to sleep in the front room and I have a job to wake her up. Sometimes I persuade her to come up to be and it's the middle of the night. I usually make her a cup of tea" and get her back to bed."* (Participant 11, M, page 5, lines 185-189)

There were other situations which the carers experienced which were both pleasurable and rewarding, such as enjoying a meal together.

> *"When we are able to enjoy things like the meal we had at the café. That was a week ago on Monday and was very enjoyable. We've got two roast meals to go to this week. We go to the Civil Service Retirement Fellowship because people who were in the civil service can go to the fellowship and that's a monthly meeting."* (Participant 11, M, page 6, lines 200-204)

This can be interpreted as having a pleasing effect on both the carer and the person with dementia. In addition, the carers recognised that they still could maintain a degree of normality in their everyday lives.

Some carers described the happiness they experienced when the saw the person they cared for carrying out ordinary tasks on their own without any help, and this promoted carers to both motivate and encourage the person with dementia to carry on with the task.

> *"I know she does she has lot more confidence now back I know she does than before. She's doing more things during the day than she was not doing before and also she's quite good in the whole day and things like that I just tend to get and do with things like that. You know she's quite active in the kitchen, I tend to encourage to do much of that if she possibly can. It goes wrong at times but there's nothing wrong with that."* (Participant 14, M, page 2, lines 54-59)

Other carers experienced a personal sense of fulfilment and contentment when they saw the person they cared for in a less volatile state and being able to carry out every day simple tasks without much interference or assistance.

> *"No, not really, I am just pleased when I can be when she is normal really can be really her old self…where she is more responsive and yes that's when I would be more excited…when I can see things she can do things for herself and is no so demented."* (Participant 14, M, page 4, lines 115-116, 117-118 and 120)

It could be interpreted that the carers' experienced a sense of relief, hope and normality within themselves again. Living and experiencing these emotions together with the person with dementia in a given situation had a profound effect on the carers' own personality health, QoL and well-being, especially when the person they cared for could deteriorate mentally at any given moment or time because of their dementia symptoms, and in some way this experience empowered the carers to provide the care.

The analysis of the above carer quotes revealed more commonalities amongst the carers regarding their descriptive accounts and lived experiences. In particular, the intimacy that was experienced by the carer and the person they cared for with dementia through the daily engagement in everyday conversations or the niceties experienced through pleasurable times spent together or the sharing of activities, tasks and household chores.

> *"And erm I am pottering around the house with and doing things or cooking with him. We do go out and about…So, we went out to dinner last night. So, I take him to restaurants and things but I have to teach him. So, you know if I go out with friends and I get the carer just to* come in and sit with him, which works well." (Participant 1, F, page 2, lines 68-69 and 70-73)

Other experiences included going out to social events with friends, family and the person they cared for with dementia.

> *"Then in the afternoon he gradually gets more active. We try and get him outside for at least a part of the afternoon, walking somewhere, doing something, going somewhere, and seeing something to give him a bit of excitement. Usually, he will interact with various local people."* (Participant 4, F, page 3, lines: 105-108)

> *"So, we will walk there, it's about a mile away, and we will sit and he will actually sit and watch a film. Sometimes he'll comment on it afterwards. He's much more restless doing anything else. Plays are not as good usually, he can only last about an hour and a half in a play, but he will sit right through a film. The darkness and the big screen help him to focus in on it and that's really good. Then we'll walk back or have supper in a little pizza place and then come home."* (Participant 4, F, page 4, lines 125-130)

The carers described how they spent time together with the person they cared for with dementia by experiencing each other's company and by engaging in typical tasks which other normal people might take for granted. For example, taking a walk into town, or enjoying a play or seeing a film at the cinema. It was these every day, typical, real life moments that could be interpreted as being both peaceful and enjoyable for the carer and which made their daily life existence more manageable. It was also this lived experience that allowed both the carer and the person with dementia for a brief period to have some free time away from the reality of dementia faced by the person the carer cared for.

> *"It's also nice to see him eating well because he never really was interested in food. It was terrible to feed him because he was just one of those people who ate to live, he didn't live to eat. He didn't really particularly enjoy food; he just ate it because it was fuel and was to keep your body and soul together, but now that's completely changed; he loves food and he loves dessert. I never knew him eat a dessert ever before, so that's nice to see him eating food because he was always frustrating with food before. So, that's nice to see him enjoying tucking in, whereas he would've been indifferent to that before."* (Participant 7, F, page 7, lines 231-238).

For some carers, seeing the person they cared for with dementia taking pleasure in, or experiencing new feelings towards something mechanical, like eating, which in the past they might not have given much thought or taken for granted, experienced a tremendous sense of pleasure and excitement.

Other carers described a sense of relief and the comfort they experienced mentally when they saw the person they cared for with dementia in a more stable state of mind and their behaviour being less challenging. This experience made the carer feel less emotionally

upset, stressful and sad, which could be interpreted by the fact that the carer did not feel a sense of hopeless or burdened about the state of affairs affecting their lives.

> *"I suppose it makes me happy when I have a visit with him, and I use this word in inverted commas, but when he seems 'normal'. ...I might have a visit where he seems just like a regular person to how he was and you can have a more normal conversation. That makes a visit so much easier and if you were to measure my stress levels at that point it would be much lower and I would feel happy. I'd had a good visit and he was OK."* (Participant 2, F, page 5, lines 175-176 and 177-179)

> *"So, I suppose the answer would be when he's not demonstrating extreme distress and is able to have a semblance of a normal conversation. That would make me happy."* (Participant 2, F, page 5, lines: 183-185)

Through their own individual accounts the carers described the sense of pleasure, relief and happiness they felt when the saw they the person they cared with dementia being more normal or in touch with reality in themselves and also in their surroundings, which undoubtedly had a beneficial effect on the carer's mental QoL and well-being.

> *"He's much more in touch with reality, which is good."* (Participant 4, F, page 5, lines 184-185)

All the carers felt a sense of confidence that they were not only capable of looking after the person with dementia under the circumstances but still could maintain a degree of normality, which was very rewarding to all the carers. More importantly, the carers acknowledged that the person with dementia who they cared for was still normal despite having dementia and did not need to be ostracised because of their condition. The carers

recognised that they could still share and experience normal moments of intimacy, be less stressed and over-burdened, and live together as normal people in the real world.

3.2.2. Superordinate Theme 2 - Providing Best and Safe Care.

The second superordinate theme explored the lived experiences of carers when providing a safe and protective environment within both the spousal and family home. The carers described similarity in their accounts when ensuring that the environment that they were providing at home was not only personally safe for the person with dementia but also safe in relation to their physical surrounding. Within this home environment the person with dementia was protected from any possible danger that they might encounter, like falling down the stairs or things that could potentially harm them, like sharp utensils in the kitchen. The carers felt comfortable knowing that the person with dementia was being taken care of by someone that loved them and wanted to protect their safety. There was also a sense of mutual acknowledgement experienced amongst the carers that they felt they were the sole care providers for the person with dementia and were the only ones that could provide the best standard of care.

> *"The satisfaction, really, is the overall picture, the fact that she's still her… As far as I can tell, she's fairly happy. She's warm and comfortable."* (Participant 9, M, page 12, lines 439-440)

> *"But what makes me happy is when I know she's feeling those feelings of security, safety and of feeling loved. And she gives me that feedback and I know that's a good place." (*Participant 8, M, page 6, lines 229-230)

Some carers also experienced a sense of personal gratification knowing that the care that was being provided by them to the person with dementia was by someone that they trusted

and not by an unknown stranger. These experiences of security and trust dominated the carers' detailed accounts. Knowing that the person with dementia trusted them with all their life gave the carers a great sense of confidence that they still were part of the recipient's life and that they were someone that the person with dementia still recognised. This could be interpreted by the fact that the carers felt that the person being cared for with dementia still had some understanding or past knowledge that the carer was either their husband or wife, a family member or a friend that they could trust.

> *"I think the biggest thing I feel is that he puts all of his trust in me and that really comes across. I know it might seem strange…Come on, we're going to go in the car now,' and I put his coat on or whatever. He's just so trusting that I will look after him and that's the biggest thing for me normally...We're going to go and do this or we're going to go and do that and he just looks at me like to say okay I trust you."* (Participant, 1, F, page 6, lines 224-225, 226-227 and 229-231).

In addition, the positive response that the person with dementia fed back via verbal comments or through simple gestures provided the carers with a sense of fulfilment and happiness that the person with dementia, despite their symptoms, still felt loved, protected and felt secure in their company.

> *"So, yes, he generally reacts positively to me being there because he trusts me, but when he's in his bad moments he's not able to mask it for my benefit."* (Participant 2, F, page 7, lines 246-248)

The carers went to enormous lengths to ensure that a high standard of care for the person with dementia was not only maintained at home but was also adhered to by others, such

as social services. One carer through his personal account described the sense of achievement and satisfaction he experienced when he ensured that whilst social services or other care providers visited both the carer's and the person with dementia's home that they adhered to the same standards of care that had been implemented by the carer in his/her home. Some carers also made mental notes to ensure that the care being provided and delivered by social services met their *requirements* and checklist for care. This authoritarian behaviour from the carer could almost be interpreted that the carer did not want the person who had dementia to be taken advantage of because of their disease, and that the care being provided by social services was both safe and was non-negligible in nature.

> *"So, I had to pay attention then. So, I have set up a system that allows the carers to come in and do what they do, give me a certain amount of freedom, but not necessarily peace of mind because I'm always worried that she is vulnerable and she is not getting 24-hour care unless I'm there."* (Participant 8, M, page 2, lines 47-50)

> *"Also, I feel quite defensive of her needs, in the case of what social services offer, which in terms of her vulnerability on a daily basis. What is acceptable to them is not acceptable to me in this case."* (Participant 8, M, page 2, lines 60-62)

This protective behaviour in safeguarding the welfare and rights of the person with dementia was also shared by two other carers. It can be interpreted that the carers felt that it was their prerogative to ensure and monitor the care being administered by social services, especially in situations when social services were entrusted to provide the sole care for the person with dementia in times of short and long-term respite time for the carers.

> *"You're very protective as well. You don't want people to take advantage of her, …then when you entrust someone else to deal with your loved one, that's also a scary thing."* (Participant 5, F, page 6: lines 220 and 225-226)

Other carers went out of their way to make sure that when social services visited them that they did not fail to recognise that the person with dementia was still a normal person who needed to be respected, and who could still talk and interact with others around them. In this way, the carers eliminated any feelings of anxiety or anguish they might have otherwise experienced in this situation.

> *"A bit proud of him that he did that, protective. I wanted to show the carers how to speak to him, how to include him. It was like I was still showing he was still capable of answering questions and remembering some things and for them to respect that."* (Participant 2, F, page 6, lines 225-227)

Despite the unexpected challenges, stresses or uncertainties that the carers faced regarding their lived experiences, they spent a colossal amount of time and energy ensuring that the care the person with dementia received was to the best standard and meticulously executed in every possible aspect of their daily lives. This was especially evident when it came to providing the best personal care for the person with dementia, where carers felt privileged that they were able to provide this intimate care without any assistance or support from others. Two of the carers provided both descriptive and inspiring accounts of how they coped and managed to provide the best personal care to the best of their ability to the person with dementia.

> *"I feel some satisfaction that I've been able to keep my promise to her and cope. ...I make sure it all happens and that's good. It's part of life."* (Participant 9, M, page 14, lines 519, 526 and 527)

> *"I'm happy that I can do the best I can for her, but I always want to try and do things as well as I can. I, obviously, want to try and help my wife as much as possible with things."* (Participant 11, M, page 5, lines 166-168)

Through their experiences the carers described how they felt that it was their sole responsibility and burden to manage the care of the person with dementia. The main factors underlying this care was that the carers firstly felt obligated to provide the care because the person they cared for with dementia was either their partner or spouse, secondly, the carers felt that they could not entrust this responsibility to someone else as they did not feel that other people or strangers would be able to provide the same level of care as they could provide, and thirdly, they felt they truly knew what was best for the person with dementia because they knew them personally, they loved them, and they needed to provide the care because it was their duty do so.

> *"Oh yeah, no I feel perfectly happy with that no objections doing at all it's within my capability yes so I should 'a do it myself and then have somebody else to try and do it. I think it's oh well my duty to it does as well that right, it's my duty and I will do it if I can."* (Participant 14, M, page 5, lines 152-159)

> *"I would like to have given a more satisfying. I do the best I can for Marion, she's my wife and she brought up the family and everything. She's always done her best to try and help other people and to do her best for the family*." (Participant 11, M, page 10, lines 351-353)

Some carers felt a great sense of fulfilment when providing the best possible care to the person with dementia through the engagement of personal touch and physical care. In

some ways, this intimate experience of personal care brought both the carer and the person with dementia closer together, which was both a rewarding and pleasing experience for the carer and the person with dementia. This could also be interpreted by the fact that when providing this personal care, the carer felt that they were doing something worthwhile and pleasant for the person they cared for with dementia, and sub-consciously they also realised that the person they were caring for would do the same for them because they were family. This lived experience was most gratifying and cherished by the carers.

> *"I like to dress her, I like giving her a bath, and I like helping her in the shower when she's at home. … But when she does want to I like to wash her hair for her and give her a rub down with a body buffer thing and put the cream on. I like doing that for her. I get a sense of satisfaction out of it and feel that we're both pleased with the outcome."* (Participant 3, F, page 4, lines 146-147 & 149-152)

Some carers felt that providing the best and safest care was providing the best standard of care. Other carers described their acceptance of their role as a carer and how they achieved and maintained the best standards of care from both a QoL and well-being perspective.

> *"I try to make the best that I can out of any situation that's put in front of you. As I say, we have a really happy and still a social life, which is really nice."* (Participant 1, F, page 7, lines 260-261)

> *"Yes, I am, yes I said it before, it makes me feel that I am doing the best that I can to ensure that he's contented that he is full-filled as he can be and happy."* (Participant 6, page 4, lines 108-109)

> *"My primary purpose now is to be his carer and to give him the best possible quality of life. So, in doing that I think, OK, this is my major job and I will do it as well as I can."* (Participant 4, F, page 7, lines 258-260)

The carers also described the contentment and gratification they experienced when seeing the person, they cared for with dementia reciprocate gratitude towards them by visual appreciation through a simple gesture or smile, by non-verbal acknowledgement, or by simply saying 'thank you'. This sense of recognition afforded to the carer provided the carer with a further sense of personal self-worth and confidence that all their efforts in terms of providing care for the person with dementia were not in vain but very much appreciated by the person they cared for and they could provide the best care.

> *"Then there is the most intimate joy where she will say, 'I really love you,' and she is expressing that I am really important to her and that she has taken me in and the figure in her life that she leans on, that she relies on, that she feels safe with.*" (Participant 8, M, page 8, lines 311-313)

> *"She'll often say, 'Where would I be without you?' and I say, 'You'd manage,' but I know she wouldn't. So, I just say to her, 'Where would I be without you?'"* (Participant 3, F, page 5, lines 156-158).

> *"He does sometimes say, 'I don't know what I'd do without you, you help me such a lot,' ...He tells us how wonderful you are and how marvellous you are,' he just doesn't tell me that often. I take that as a backhanded compliment; that he talks to other people and tells them how wonderful I am."* (Participant 7, F, page 8, lines 269-272 and 274)

All the carers recognised that by being in control and providing the best and safest care to the best of their ability was gratifying.

3.2.3. Superordinate Theme 3 - Managing to Cope.

The third superordinate theme described the carers' lived experiences concerning how each of them managed and coped with everyday life challenges, such as stressors and strains, and still managed to provide a good standard of care for the person with dementia. As the carers described their lived experiences of coping and management of care similarities began to emerge between the detailed carers' accounts. All of the carers provided thought provoking insights into how they personally managed the care of the person with dementia all by themselves. This ability to cope and manage provided the carers with an inner strength to cope, both on a mental and physical level, and also gave them a sense of fulfilment and empowerment that they could provide the care needed.

> *"Well, there is general satisfaction with being able to cope, quite honestly. It's quite satisfying that I have been able to cope."* (Participant 9, M, page 12, lines 426-427)

> *"The fact that I can keep him at home and I can still cope, that makes me happy because I really do not want him to go into a home."* (Participant 1, page 4, lines 132-133)

> *The fact that we can still go out; we're not housebound. That's the most important thing to me because I'd hate it if we were housebound all the time. And the fact I can still cope with things now."* (Participant 1, F, page 5, lines 157-159)

A range of emotions and feelings were experienced by the carers, especially in times of adversity where the behaviour or mental state of the person they cared for with dementia was unpredictable or difficult to manage. Knowing that they were the only primary carers and they could not rely on anyone else to provide this care motivated the carers to cope and manage in providing the best care, especially during challenging times. Two of the

carers provided illuminating accounts of how they managed to cope and 'muddle their way through' everyday physical challenges, such as household chores or tasks. These carers' experiences of coping were made easier when the symptoms of the person with dementia were less demanding, and the carers expressed feeling emotionally less stressed, anxious and more relaxed when coping and managing the care of the person with dementia.

> *"Of course, yes, because it just makes it that little bit easier that day. Otherwise, if you don't have those moments and every single day is a struggle, morning and night, which is particularly when I care for her, ... So, when every day is a struggle, that she's being difficult, it's very hard to find pleasure in those moments.*" (Participant 5, F, page 6, lines 202-204 and 208-209)

> *"Well, at those moments I feel a bit easy and quite happy. It's like a moment of, I don't want to say stress-relief, but it's not as stressful because she's being easy-going. In turn, it makes me feel, for that day."* (Participant 6, F, page 7, lines 232-234)

Being less stressful and anxious gave the carers a new-found confidence that they could cope and manage the care for the person with dementia in a more relaxed way without feeling overwhelmed or burdened by the care. This lived experience had a pleasing effect on the carer's psychological state, health and wellbeing.

One carer emphasised that her ability to cope and manage was influenced by her husband's light physical state, which played an important part in her being less stressed or anxious when managing his physical and personal care on her own:

> *"I'm lucky being that he's not a very large man. If he was over six foot or something, there's just no way I'd be able to cope on my own. But I do manage to cope and that's the most important thing for me, really, is that I can look after him, care for him."* (Participant 1, F, page 7, 241-245)

The sense of fulfilment felt by some of the carers from this lived experience of coping inevitably encouraged two of the carers to continue with providing the best care to the person with dementia. This experience gave the carers a great sense of self-assurance that they could not only cope with managing the care of the person with dementia, but that they were able to cope and manage with their own emotions and feelings and provide a good QoL for both of them. These positive experiences gave the carers the confidence and drive to continue to cope and provide care.

> *"No, I feel some sort of satisfaction and fulfilment that I, personally, have been able to cope with dealing with things as they've shot up. Even every now and then somebody turns up with a laugh with so that's good. I can't say I feel any particular happiness in any of the stuff, just a feeling of satisfaction and fulfilment. It's not a happy thing to be doing."* (Participant 9, M, page 12, lines 430-431 and 434-436)

> *"The niceties are that I can cope because I know in our support group some of the people find difficulties because their partner is difficult to deal with and things like that. I don't have any of that. I am so lucky. That's the main thing that drives me on, really, the fact that, OK, he's ill and he's got this terrible illness, but we'll go on happy and contented in our self."* (Participant 1, F, page 5, lines 182-186)

In contrast, one carer provided an interesting account of how presenting a positive image both mentally and physically in being able to cope and manage portrayed a false impression to others, especially to her close family and friends and external support

groups that she did not need any help from them at all, when in fact she needed all the help she could get from them.

> *"My default position is, as I said before, I tend to make jokes about things. That hasn't always worked to my advantage because it sometimes gives the wrong impression to people. It gives the impression that I'm coping brilliantly and that I don't need any help because I'm managing because I'm a coper. And I am, but, of course, sometimes it's a bit of a smokescreen."* (Participant 7, F, page 6, lines 324-330)

This false image portrayed by the carer could be interpreted by the fact that as a carer you are so used to presenting an image to other people that you can cope that you simply forget to ask for help or you do not have the confidence to ask others around you because it is expected that a carer will provide care. It could also be interpreted that carers might feel embarrassed or are ashamed to say to other people that they are not coping and need help. Carers also felt that family members or friends might not understand the challenges they are facing and might not want to share the carer's burden. In contrast, it could be interpreted that family and friends do not know when to ask, that they are not intuitive enough concerning a carer's situation, that if they were asked they would not be able to cope, and do not want to be seen as patronising.

3.2.4. Superordinate Theme 4 - Sharing and Supporting Others.

The fourth superordinate theme described the lived experiences of the carers, especially when they came across other people in their lives and could share their experiences with them, including strangers, family and friends or support groups. This sharing and exchange of information played a fundamental part in the carers' lives and provided the carers with a sense of importance and fulfilment. The introduction of someone new into

a carers life was exciting, and represented a time when the carer felt alive again, when they could have an intelligent conversation with someone and escape from their plight or suffering by talking to this new person. A new person coming into their life would in some way give them the attention that had been missing from their lives for a very long time and they would listen to them, which carers felt in some way raised the profile of dementia. The carers had an enormous amount of satisfaction in that they were able to share their lived experiences with their families, friends and support groups and be supported by them.

A total of six carers expressed how they could through their lived experiences develop a sense of contentment and happiness, especially when they were able to engage in conversations with other people, share with them their experiences and challenges of care knowing that they were complete strangers.

> *"I feel very passionate about sharing information because it gives me a chance, and you said you're recording it and might send me a transcript, it's easy to talk freely from being honest, particularly when you're explaining it to someone who's interested, they've got some experience and understanding, and you know that they're listening and understanding a lot of what I'm saying. It's very satisfying to take part in that sense."* (Participant 8, M, page 14, lines 540-546)

> *"Yes, it's you know it's good to talk about the problems and issues around the illness. We do have people coming – social workers, carers and other people – coming and talking. Useful to talk about the problems with other people."* (Participant 10, M, page 4, lines 121-123)

> *"Yes. It's nice to be able to speak to somebody about it. I suppose my boss is the one who gets most of the story because I was working with her when my mum started exhibiting her strange behaviour. ..She sometimes helps me to see the funny side of what's happening, so I can laugh about it with her. It*

> *sorts of takes the pain away sometimes, I suppose."* (Participant 3, F, page 7, lines 253-255 and 257-259)

By having someone new, such as a stranger, to talk to gave the carers a great sense of relief and excitement as this was someone who would listen to them and would not pass criticism or feedback on their way of life. This new stranger would be able to empathise with them, would understand the effect of caring for a person with dementia had on a carer's QoL, health and well-being, and would be interested in dementia from a medical or professional point of view. More importantly, the carers' acknowledged that a new stranger was someone not connected to them in any way and for a moment of time give them their attention; in some ways giving them a sense of self-worth about themselves.

> *"People are becoming much better and people are becoming much more tolerant of others and that's what all about because then I can get people to be positive about dementia and the effects of the illness has, but the person is still a human being. You just have to recognise the fact that they can't do the things they used to do."* (Participant 1, F, page 5 lines 149-152)
>
> *"Still, a person and still have valuable lives."* (Participant 1, F, page 5, lines 153).

The above descriptive detailed account of the carer revealed the importance of sharing, and exchanging knowledge and information about the condition of dementia with other people and getting other people to recognise that the person with dementia was still a human being just like any other person.

Other carer's emphasised, how caring for a person with dementia resulted in them receiving a tremendous amount of support from other voluntary support groups. They also found other people in the support group sympathetic towards their plight which made the carers feel less lonely, isolated or helpless about their lived predicament as a carer.

> *"Having these support groups to go to and as a member of a church, we get support from other members of the church. Everybody has been sympathetic and helpful and I could always go across the road to get a carer, they said, if I wanted to."* (Participant 11, M, page 5, lines 168-171)

> *"I feel very happy that there are these organisations – the carers in Hertfordshire and we came across – all these organisations that do a wonderful job in supporting people who have a relative with dementia. I feel very pleased that there are these voluntary bodies."* (Participant 11, M, page 5, lines 174-177)

This exchange and sharing of information with other people or support groups made the carers realise that not only could they raise awareness amongst other people, but they could also assist in fundraising activities and support other carers in the local community. More importantly, they could make others aware of the type of support they required as a carer in their local community.

The carers acknowledged that without this sharing and assistance from others they would have found it very hard to cope and with the everyday life demands and challenges placed on them by the person with dementia. This assistance not only helped the carers to cope better in their lives, but they felt more relaxed and flexible when managing the care of the person with dementia. Knowing that they could rely on their close family and friends for support was shown by the fact that it gave the carers a sense of gratification. There was a

general acceptance amongst the carers that they were not alone, that they could share their burden with other people such as family and friends, and especially those with similar lived experiences. This could also be interpreted by the carers feeling less burdened and having a sense of assurance that they could rely on family and friends whom they trusted.

> *"Family, on the whole, are very supportive and friends are very supportive. I think that's nice, that we both have friends of the church and people that we enjoy seeing."* (Participant 11, M, page 7, lines 257-259)

Other carers found that the support they received from new friends who shared similar situations and experiences was more beneficial in comparison to the support and companionship offered by older friends, who tended to disappear and did not want to know. The carers recognised that these new-found friends and their friendship would last longer because of the commonalities shared and experienced regarding the care they provided to the person with dementia and because of their role as a carer.

> *"You find out who your friends are, though, because, although we had a very large circle of friends, that's now become quite a small circle of friends. And also family some of our family can't cope with it, especially his son...But, all in all, we get good support from family and friends."* (Participant 1, F, page 3, lines 74-78)

> *"Apart from the fact we're carers, our paths wouldn't have crossed, but because you're kind of thrown together because of dementia, I have made some really good supportive friends and we all support each other, so that's been a positive because that wouldn't have happened."* (Participant 7, F, page 7, lines 195-200)

This lived experience for some carers brought families closer together and had a beneficial effect on the carers' lives, especially with regard to their QoL and wellbeing.

> *"I just think it's essential to carry on doing those things that we've always enjoyed as a family for as long as we can, really, because it's a very isolating illness. Friends drift away, so the family are very, very important. As a family, I suppose it has brought us closer together and that's a nice thing as well. That's one of the nice things about it."* (Participant 7, F, page 7, lines 253-257)

3.2.5. Superordinate Theme Five - Cherished Moments.

The fifth theme explored the lived experiences that the carers encountered together during both memorable and pleasurable situations. These cherished moments related to the intimate moments experienced in a given situation, through expression, affection and appreciation which made the lived experience for the carer both rewarding and enjoyable.

The carers, via their shared lived experiences, provided both descriptive detailed accounts through the illustration of emotion. The carers shared a sense of magic, sentiment and emotional highs when they saw the person with dementia regress into a reminiscent of their old self or when they engaged in entertaining or pleasing moments. This sense of gratification experienced by the carers could be interpreted as being both cherished and unforgettable memories for the carers:

> *"It's just there are some moments when he communicates well with you and, obviously, you see a little bit of his old self back."* (Participant 10, M, page 3, lines, 79-80)

> *"Yes, he reacts to you and sometimes I'll put on some old Asian songs for him, which he enjoyed in the past, and he likes to watch those and sometimes we'll sit there and watch things together on what's on and he sometimes will react and interact with them as well."* (Participant 10, M, page 3, lines 89-92)

> *"When I see glimpses of my old grandmother every now and then, that makes me smile."* (Participant 5, F, page 5, line 173)

Twelve of the carers shared enlightening accounts of experiencing happiness when the person they cared for with dementia showed a smile on their face, demonstrated affection towards them by a simple gesture, or allowed the carer to touch or a hug them. This gave the carers a great sense of gratification and the acknowledgement that the person they cared for still appreciated them, and as a carer they could still experience normal, pleasurable and affectionate moments together with the person they cared for.

> *"…hold her hand and it goes back to the old days where there was a lot more of the normal affection between us. I suppose that's the thing that makes me happiest."* (Participant 12, M, page 5, lines 165-167)

> *"Oh wonderful, wonderful we still sleep together or when she goes to bed before me or if she's awake she obviously sees me and is happy and cuddles me. And holds me and those are things that make the whole thing worthwhile. Those are the things that are most satisfying."* (Participant 12, M, page 3, lines 81-84)

> *"Most joyful? It's lovely when she looks at me and smiles at me that very satisfying it's like guess it the knowledge she's still in there somewhere yes."* (Participant 13, M, page 3, lines 87-88).

One carer described how the cherished moments he shared with the person with dementia were made extra special when the person he cared for said: *"I love you"*. The feelings of pleasure that the carer experienced in this living moment was unforgettable and this

special experience was magical to the carer alone and no one else, which could be interpreted as the carer experiencing an emotional high.

> "*Anything that makes me happy? she often struggles to get it out I love you something like that or smile at me and that's the most satisfying there's nothing to beat that."* (Participant 13, M, page 3, lines 73, 75 and 77)

Another carer described the pleasure and happiness she felt when she saw the person she cared for with dementia appreciate all the care she had given him, and despite his incoherent memory he still could remember who she was and what she meant to him.

> *"Or, 'Where's Glenny?' because he calls me Glenny, and I say, 'I'm Glenny.' So, he doesn't always know who I am. Sometimes he does, but not always. How it makes me feel? I feel loved when he recognises me and smiles because that's nice."* (Participant 4, F, page 7, lines 239-242)

Some of the carers provided enriching accounts of when the person they cared for with dementia was in a more pleasant state of mind, which could be interpreted in being the most special, relaxing and pleasing cherished moments for their carer.

> *"Yes, I mean just to be able to have periods when he reasonable to say and communicatively is quite rewarding in that respect…we cherish the moment."* (Participant 10, M, page 3, lines 71-73)
>
> *"It's just about if you have a visit where he seems relaxed and happy, it makes me happy."* (Participant 2, F, page 6 lines 193-194)
>
> *"Well, it's when I can describe when he is in the good state really…cutting up some vegetables which we sometimes do to make soup or he be it running*

> *three miles on a running …Him listening, or enjoying a television program you know engaging with it really and laughing that kind of thing... brings out his previous personality really."* (Participant 6, F, page 3, lines 98-104)

Some of the carers expressed that when experiencing such moving moments at the same time they also experienced emotional sadness, knowing that the lived experience that was being shared at this present time by the two of them was only momentary and short-lived.

> *"It's a bittersweet moment because obviously for that moment I feel I've got my old grandma back, but you know that it's temporary. I guess the hard part is accepting she's fully gone now. It's very fleeting moments. I feel like I'm happy for that briefest second or two and then you know the rest of it is back to her normalness."* (Participant 5, F, page 5, lines 185-189)

> *"I just enjoy the moment at the time it's happening. I enjoy those moments while I can really."* (Participant 7, F, page 7, lines 242-244)

> *"It's lovely, it's really nice because it is a lot of work and it is hard, so when you get a nice moment, it's your reward and it makes your spirits lifted.*" (Participant 2, F, page 7, lines 251-252)

This could be interpreted by the carers' acceptance that even though the moment experienced was short-lived it would be remembered forever and not be taken for granted. The only way that the carers could make this experience poignant was to ensure that it was the most joyful and pleasing moment not only for themselves but also for the person they cared with dementia.

Some of the carers described a real sense of happiness when they saw the person they cared for with dementia enjoying, engaging and experiencing real living, and appreciating

their surroundings gave the carers a real sense of fulfilment that this moment was both enchanting and unforgettable, and they together could still be part of the real world.

> *"Once she was just outside in the garden wandering and she was just smelling a rose all by herself! That was a special moment to see that."* (Participant 8, M, page 8, lines 287-288)

> *"She always liked dancing and she will get up and have danced around and want me to get and have a dance with her and these things are very satisfying."* (Participant 13, M, page 3, lines 102-104)

> *"We just sat in the sunshine and had a bit of conversation here and there, not that she chats much. It was just sitting in companion fuelled silence. That was a really nice moment."* (Participant 3, F, page 3, lines 99-102)

Sharing this lived experience and enjoying this special moment with the person with dementia had a beneficial effect on the carers' psychological state of mind, their QoL and their well-being.

> *"…And I bought her an ice cream and she was conducting the music with the ice cream and then offering me some and then pointing around saying, 'Look, look!' So, that was a happy moment, to see her happy again and to know that you have an influence on her happiness is rewarding and, yes, I'm happy too."* (Participant 8, M, page 7, lines 240-247)

> *"'She'll start laughing when everyone else is laughing on the telly. She hasn't got a clue what's on it, but she's following the rhythm, the intonation, the sense of what's going on and she's still in touch with that. In her head, she is still part of the world."* (Participant 8, M, page 8, lines 300-303)

3.3. Gender Differences.

The analysis stage of this research did not reveal any gender differences amongst the carers in their management and care of the person with dementia or even when a carer made life changes to take on the role as that of a primary carer. In addition, there were no real significant gender differences found within the five shared superordinate themes and instead more similarities were identified amongst the carers.

One female carer noted that both men and women carers carried out the similar level of care for the person with dementia.

> *"I don't know if gender comes into it anymore, because I, occasionally, go to a carers' group and there are men there who are looking after their wives or their mothers and they're doing more or less exactly the same sorts of things as I'm doing for her."* (Participant 3, F, page 8, lines 242-244)

Whilst another female carer found that in the family caring dynamic situation she took more on as the role of a physical carer regarding physical and personal hygiene care, whilst her brother took on the role more of a supportive carer towards the person with dementia in terms of organising care for him and managing administrative tasks. She did find that male friends tended to disappear from their lives but there was not enough supporting evidence to determine whether this was gender orientated or influenced by culture. However, overall there were no substantial gender differences found regarding the type of care being provided by the carers.

> *"One thing I've noticed is how well my brother has done. My perception is that often females tend to do more caring roles in a situation than men, but my brother is really wonderful and he does loads to support my father and he does it really well, so, I think that's great. The other thing that springs to mind is something you often here because a lot of the friends have vanished who would or should be providing care, helping at least, they say, 'I don't like to see him like that.' That's the kind of excuse people give themselves to not have to help their friend. When I say 'friends', I'm talking about his male friends. I don't know if this is a male/female thing."* (Participant, 2, F, page 8, lines 285-292)

This view was also supported by another male carer, who in a similar family dynamic situation noted no gender differences in the amount of care being delivered or administrated. Whilst the whole family assisted with the care of the person with dementia, the more personal hygiene care was performed by carers visiting the house and not the male carer.

> "*The whole family looks after him. The carers, obviously, help obviously personal hygiene and so on, it's very useful to have them coming in three times a day. Other times it's really the family who deal with him and will look after him at various times."* (Participant 10, M, page 3, lines 101-104)

Chapter 4.

4.1. Discussion.

In this final chapter the results presented in the previous chapter are discussed in relation to the literature on caregiving, carers' burden, coping, support, gender, and carers' QoL and well-being. The findings are discussed in line with the descriptive personal accounts of each carer's lived experience and in relation to the research question being asked. The lived experiences of the carers will be explored regarding the carers' daily care management, their adjusted role as a carer, whether the lived experiences of the carers are similar or dissimilar, and the effect on carers' QoL and well-being. The practicality of this research will be viewed in relation to the findings and its limitations will be detailed. Opportunities for future research and the implications of this research on future healthcare practice will be discussed.

4.2. Appraisal of the Research.

Previous literature found that there were number of studies looking at carers' satisfaction (Lawton et al., 1991), burden and anxiety associated with caring (Bedard et al., 2005; Cox, 2013; Zarit et al.,1980), the various copying styles implemented by carers (Hooker & Manoogian-O'Dell, 2000; Parks & Pilisuk, 1991; Upton et al., 2006), the type of support or lack of formal support received by carers (Kraijo et al., 2011; Navaie-Waliser et al., 2002), the positive and negative experiences of married spouses in caregiving (Bohim et al., 2011), family caregivers (André & Elmsťahl, 2005), and carers' well-being and QoL (Felce & Perry, 1995). More recent studies have looked at the positive aspects of caring and health outcomes in carers (Harmell et al., 2011; Lloyd et al., 2016). In addition, some research has been carried out looking at the lived experience of carers who

care for a person with dementia (Kindell et al., 2014). There are a small number of IPA studies that have looked at the areas of illness, health, the wellbeing of carers, the positive influences associated with caring, the opinions of participants in relation to their life circumstances, and shared experiences of couples when a spouse is diagnosed with early-onset dementia (Mullin et al., 2011; Smith, 2004; Quinn et al., 2008; Robinson et al., 2005).

Research in caregiving has primarily reviewed gender differences in the caregiving burden amongst men and women (Bedard, Chambers, Molloy, Lever, & Stones, 1999; Miller, Townsend, Carpenter, Montgomery, Stull, & Young, 2001; Miller & Catasso, 1992; Gallicchio et al., 2002). This has mainly been because of the nature and nurture debate as per society's expectations, whereby women are seen to be the primary providers of personal care (Baker & Roberson, 2008; Navaie-Waliser et al., 2002). Women have been reported to provide more hours of personal care, household work and social support in comparison to men (Collins & Jones 1997; Neal et al., 1997; Statistics Canada, 1996).

Nearly all the gender studies reviewed in literature have looked at the lived experience of caring amongst male and female carers and found no difference in general caregiving. Recently, there has been a gradual increase and dominance of male caregivers in our society, but again no differences have been found amongst the genders in the level of general care being provided although a difference has been found in the uniqueness of care and division of support received (Pöysti et al., 2012; Drentea, 2007). There are also differences found in the way that carers attend to the psychological needs and wants of

the recipient and the way that a carer adapts their lifestyle to accommodate a person with dementia (Collins & Jones, 1997; Drentea, 2007; Miller & Cafasso, 1992).

Differences are found in the coping strategies adopted between men and women. Women employ more cognitive coping strategies in comparison to men, who use more avoidance coping strategies. Male carers are reported to take on a more defending role towards their family and are less likely to be focused on more problem coping strategies (Baker et al., 2010; Parks & Pilisuk, 1991; DeVries et al., 1997; Hooker & Manoogian-O'Dell, 2000). Male carers are also more likely to be seen to organise and make decisions concerning care services or the care management of the person with dementia, and provide this care well for many years when caring for a spouse diagnosed with dementia (Cahill, 2000; Montegomery & Kamo 1989). This is also evident among a family caring environment, where both daughters and daughter s-in-law undertake more of the personal care (Globermann, 1996). Other differences are that women are less likely to seek formal support in comparison to men (Hooyman & Gonyea, 1995), and women carers are found to suffer more from stress and burden despite their similar situations to men (Bedard et al., 2005; Gallicchio et al., 2002; Muller & Cafasso, 1992; Navaie-Waliser et al., 2002). Men, like women carers, have a hands-on approach in relation to the type of care being delivered; however, the only difference is in the way that care is provided and men are less likely to seek any assistance in terms of support (Cahill, 2000).

In summary, all the studies mentioned provide a vast amount of information and support for the design of the research question and the research itself. However, despite the access and availability to literature, the simple fact remains that caring for someone with dementia is a special and dynamic relationship which solely exists between a carer and

the recipient. In addition, there are a variety of underlying factors which determine a caregiving situation. The person providing the care through their lived experience encounters a range of both rewarding and challenging situations that can affect both the carer's mental and physical health. These challenges include emotional strains and stresses, while the rewards include feelings associated with fulfilment, happiness and contentment; these factors coexist (André & Elmsťahl, 2005) in a carer's life and play a fundamental role on their QoL and well-being. Research has indicated a close link between these lived experiences on a carer's well-being and QoL; however, a carer's QoL needs to focus more on a person's intentions and wants, their capabilities, lifestyle and experiences (Emerson, 1985) combined with the influence that this has on them in their social environment (Massam, 2002).

In this research, no differences were found amongst the carers and instead more commonalities were noted with regards to each carer's shared lived experience. Therefore, this research has revealed that the lived experiences of carers consists of five superordinate themes: just normal, providing the best and safe care, managing to cope, sharing and supporting others, and cherished moments.

4.3. Discussion of the Themes.

4.3.1. Just Normal.

The theme of normality played a significant role in the shared lived experience amongst the carers' detailed accounts. Its predominance and maintenance were captured in the functioning of the carers' everyday life circumstances in relation to their management and care of the person with dementia. The carers emphasised how they engaged in everyday events and operational tasks in order maintain normality, not only at home but

also outside in their social environment. The feeling of normality had a pleasing effect on the carers and gave them a sense of empowerment and fulfilment in themselves to carry on providing the care. In doing so they too experienced normality within themselves and felt encouraged that the person with dementia was still part of the real outside world. The overall personal sense of gratification that the carers felt had a favourable effect on their QoL, health and well-being.

The carers in this research reported several rewarding and pleasurable experiences together with the person with dementia, for example via engagement in daily conversations, enjoying a meal together, involvement in social events with their family or friends, or spending time watching TV. More importantly, through their lived experiences the carers encountered an arena of emotions, consisting of relief, hope, and peace of mind when they saw the person with dementia in a less volatile state. In addition, the carers experienced a sense of happiness, contentment and motivation when the person with dementia was seen to be normal. This favourable lived experience meant that the carers felt less emotionally stressed, burdened or overwhelmed. While studies have demonstrated that the carer who is caring for a patient with dementia can experience an overall sense of gratification, they can at the same time feel distressed, especially when the personality or the behaviour of the person with dementia is worsened by their dementia symptoms. This worsening of a person's symptom undoubtedly has a profound effect on carers' well-being (Kraijo et al., 2011). This finding is supported by studies where carers are seen to encounter several challenges in their caring tasks which can cause distress to them (Zarit et al., 1980). Other studies have indicated that spouse carers are more likely to suffer adverse effects because of the very little respite they receive from their caring duties, which affects their wellbeing and mental state (Cox, 2013) and which

can result in burnout and depression (Vickery et al., 2007). Despite carers' similar circumstances, women suffer more from stress and burden in their role as carers which causes them to react differently when providing care (Bedard et al., 2005; Robinson et al., 2001).

However, in this research the carers felt confident that they were not only capable of providing a normal environment for the person with dementia but could live and do things as normal people too in the real world. It was this typical real life lived experiences that made the carers' daily existence more manageable. In these normal moments, the carers could share intimacy with the person with dementia, be less stressed, and live together as two normal people, which had a beneficial effect on the carers' QoL and their wellbeing.

4.3.2. Providing Best and Safe Care.

The carers in this research emphasised how they had accommodated their lifestyle to make sure that the person that they cared for with dementia was made to feel safe and protected, both in their home environment or outside their setting. The carers ensured that the care being provided by others, especially social services, met the carers' criteria in terms of the best standard of care. This form of controlling and defensive behaviour by the carers was implemented throughout the carers' daily life existence and diminished any feelings of uncertainties or anxieties that the carers would have otherwise experienced concerning the external care being delivered by social services. The carers spoke of their desire for the person with dementia to be recognised as a normal person, and to be subjected to less discrimination due to their dementia by other people, social services or by society. Ethnicity studies have found that certain groups, such as African-Americans, Hispanics and American–Chinese, encounter a lot of stigma regarding caring and are less

likely to seek help concerning advice and medical interventions (Cox, 2013; Vickery et al., 2007).

In this research, the carers felt that as they were the sole providers of care, they were the only ones who truly understood the needs and wants of the person who had dementia, and they were the only ones who had the right to provide this care. Therefore, the carers experienced a great sense of personal gratification knowing that the care that was being provided to the recipient was by someone that loved them and that they could trust. The carers found this lived experience to be both rewarding and positive. This finding is supported by other research which has noted the importance of being in control of the care and loss of control by not knowing what the future may bring having a tremendous effect on a carer's wellbeing (Kraijo et al., 2011). In addition, it is important for future research to obtain a better understanding of the needs and wants of carers with regards to their life circumstances and to focus on the conditions of care instilled by a carer at home and in line with the requirements of the person who has dementia (Kraijo et al., 2011). Ironically, the only other available requirements for care are those that are provided to the carer in how to care for a person at home and how to establish a safe environment. This information does not consider a carer's view in terms of the standard of care, nor does it take into account the requirements of the person who has dementia (Alzheimer's Society, 2010).

It was found that carers experienced a sense of fulfilment, contentment and happiness knowing that the person they cared for with dementia still recognised them or appreciated them. This lived experience was verified by the person with dementia through the

intimacy of personal touch, a physical hug or via the gratitude displayed by the recipient through a simple gesture, smile or by the words ‘I love you’ or ‘thank you’. This lived experience was both rewarding and pleasurable for the carers who felt they still played an important part in the life of the person who had dementia. This lived experience motivated the carers to respond positively towards the person with dementia. Being motivated, driven and responsible as a caregiver is central to the carers’ experiences and feelings of gratification as a carer (Grant & Nolan, 1993), and desire and capability are combined with the enjoyment and importance they feel in their role as a caregiver (Nolan & Grant, 1992). This finding is further strengthened by research findings that the finest care originates from satisfaction, which is derived from three main considerations, the personal dynamics between a caregiver and the person being cared for, the personal or intrapsychic focus of the caregiver, and the need to stimulate a positive response and to avoid a negative influence on the person being looked after (André & Elmsťahl, 2005).

It was also found in this research that the carers felt a sense of responsibility, burden and obligation to provide the best possible care to the person with dementia. This was mainly because the person they cared for with dementia was their spouse, that they could not share this responsibility with others who they did not trust, and they were the only ones who understood what the person with dementia needed in terms of care. This obligation towards to the person with dementia is a significant incentive and has a gratifying effect on the carer in their role as a carer (Grant & Nolan, 1993). This obligated intimacy between a carer and the person being cared for due to the love the carer has for the person with dementia, the benefits of the relationship encountered, the experience of gratification and reciprocity shared, the fulfilment and sense of duty experienced by the carer, the

simplicity of nature and nurture, all have a positive effect on the experiences of carers and because it is simply expected of a carer (Grant & Nolan, 1993; Lloyd et al., 2016).

4.3.3. Managing to Cope.

Despite facing everyday life challenges and stressors, more commonalities were found amongst the carers in their ability to cope when managing the care of a person with dementia. This inner strength to cope both mentally and physically with the demands placed on the carers by the person who has dementia motivated the carers to continue in providing care. Self-efficacy played an important role in the carers' ability to cope in terms of their emotions, feelings, relationship and the way they responded to stress (Cox et al., 2013). Carers' skills, beliefs, ability and willingness to provide care is not only governed by their capacity to find gratification and meaning in their role as a carer, but is also associated with positive coping strategies which have beneficial effects on the health of both carers and the person with dementia (Nolan et al., 1992; Harmell et al., 2011; Lloyd et al., 2016).

Carers were found to be more relaxed, less anxious and in a positive state of mind when the person with dementia who they cared for was in a more agreeable and pleasing state of mind. This gave the carers a sense of confidence and encouraged them to employ a range of coping strategies when managing the care of the person with dementia. This is supported by other studies which have found that the positive aspects of caregiving can have beneficial effects on the carer by reducing stress and anxiety. This was found to be particularly significant amongst certain ethnic groups who managed to cope more positively with the problematic behaviours of the person with dementia (Kinney & Stephens, 1989; Roff, 2004; Jathanna & Latha, 2011). These positive coping strategies

due to several factors, such as their religious faith, spiritual development, low economic status, and emotional and personal development, which assisted in the carers' personal fulfilment and enthusiasm (Kinney & Stephens, 1989; Jathanna & Latha, 2011; Sterrit & Porkony, 1998). Studies have found no gender differences in terms of caring when faced with the challenging behaviours of a person with dementia (Colin et al., 1997) or the ability of a carer to provide care when facing problematic behaviours for the person who has dementia (Bedard et al., 2005).

In this research, it was found that younger carers found it more difficult to cope with the challenges of dementia and their living situation, and these carers employed a mixture of emotive and problematic coping strategies which tended to have a negative impact on the carer (Roach et al., 2008). There were three young carers in this research; one carer was in her late twenties and caring for her grandmother in a family caregiving situation, one carer was in her mid-fifties and caring for her husband, and one carer was in her mid-thirties and caring for her father. All these carers reported negative experiences of caring, particularly when the person with dementia displayed problematic behaviours or was in an unstable state of mind. There were underlying factors which affected these younger carers' ability to cope and were associated with the carer having to adapt not only their working and personal lives, but also their caring status in relation to the caring situation and thus they reported being less content with the living situation and what life had dealt them. From this finding, it is evident that the problematic behaviours of a person with dementia are correlated to the age and gender of the carer and their well-being, for example anxiety, depressive symptoms, positive wellbeing vitality and general health (Croog et al., 2002). Stresses, strains and negative lived experiences of caring, including loneliness and regrets, are combined with depression, enjoyment and fulfilment, and all

co-exist in a caring situation. These factors provide an invaluable insight into the needs of carers, together with their vulnerabilities which affect different aspects of the caregiving predicament (André & Elmståhl, 2005; Beeson, 2003; Rodriguez et al., 2003; Lundh, 1999).

The research found that portraying a positive image to others alienated one female carer from seeking additional support or assistance from others. This could be misconstrued by the fact in some countries it tends to be women who provide most of the care, because it is viewed by certain societies that women are better suited to a caring role. However, other research has indicated that women generally tend to develop a nurturing role and are less likely to consult support services (Bedard et al., 2005; Colin & Jones, 1997; Hooyman & Gonyea, 1995). Women are also less likely to receive informal and formal support compared to men (Bedard et al., 2005; Goode et al., 1998) and because of society's expectations, women provide more hours of personal care, household work and social support than men (Collins & Jones 1997; Neal et al., 1997; Statistics Canada, 1996). Despite the changing role of women in society, studies carried out in America, India and China by the 10/66 Dementia Research Group (a group of researchers carrying out collaborative research in developing and developed countries into Alzheimer's and dementia) and across several countries in Europe looking at 280 spouse carers have found that in all settings most carers are women (Prince, 2000; Alzhiermers Disease International, 2009). Even though women perform more of the daily household chores and personal care there were no differences between men and women when managing the general care of a patient with dementia, particularly when the patient was unable to carry out operational tasks (Miller & Cafasso, 1992). However, the findings of these studies are

not comparable to the findings of this research where more similarities were found amongst carers' abilities to cope and manage.

4.3.4. Sharing and Supporting Others.

It was found in this research that the carers felt a real sense of self-worth about themselves, particularly when they could share their lived experiences with other people, and especially with someone new, such as a stranger, family, friends and external support groups. This sharing and exchange of information played an important part in a carer's life and had a beneficial effect on their health, QoL and well-being. The carers discovered that they could share and discuss personal things about their life as a carer, their needs and wants, and raise awareness for dementia with others and also be involved with a support group for the purposes of fund raising. It was reported that the that the assistance the carers received from their family, friends or support groups made it possible and easier for the carers to cope with the everyday life challenges, strains and stresses. More importantly, it was found that the carers felt a sense fulfilment that they could share their burden with other people they trusted. Previous research has found that different types of informal social support, whether provided by a family member or friend, in terms of instrumental support, such as daily chores, advice on health or finance, and informal social support, all influence the psychological well-being of carers (Lau et al., 2009). Ethnicity studies also support these findings, as African-Americans and White dementia caregivers demonstrated that there were two levels of social support, one being the accessibility of other people to talk and socialise with, and the second being where other people demonstrate positive respect and self-confidence in a carer, which were predictors of gratification for the caregivers (Kaufman et al., 2010).

This research found that the support and assistance received from new friends who shared a similar lived experience as a carer were more beneficial and the friendship tended to be long-lasting in comparison to older friends who simply vanished from the carers' lives. This could be explained by the fact that older friends found it hard to cope with the changing circumstances of the carer, simply did not know how they could provide assistance, or simply did want to share the burden and responsibility of the carer. It was also found that the lived experience of caring for someone else brought one carer's family closer together. It is well documented that carers who receive minimal support and have no time to relax or rest are more likely to suffer from burn-out or depression (Vickery et al., 2007). These research findings suggest that sharing and supporting others has a gratifying effect on a carer's health, QoL and wellbeing.

4.3.5. Cherished Moments.

The cherished moment's theme was a major finding and a commonality amongst the carers. The time carers and the person with dementia spent together were found to be the most memorable, pleasurable and unforgettable. These special moments were seen through the lived experiences of the carers in times of intimacy, the appreciation the person with dementia displayed towards their carer, the engagement of the person with dementia in their external surroundings, and in the times when the person with dementia regressed into their own previous self. It was found that these moments were extra special, fulfilling, and gratifying for the carer and gave them a sense elation. It was also found that the carers experienced a real sense of pleasure on seeing the person with dementia appreciating their surroundings, being part of the real world, and displaying recognition of their carer's identity. In these pleasurable moments, the carers felt less stressed and more relaxed. All the carers also reported sadness in knowing that even though these cherished moments were short-lived, although they were important to both the carer and

the person with dementia and would be implanted in the carer's memory for a very long time.

4.3.6. Gender Differences.

This research did not reveal any gender differences amongst the carers when managing the care of the person with dementia. One carer felt that both men and women carers carried out the same and a similar level of care to a person with dementia, whilst another carer reported that within the family caring situation, as a female she found herself taking on more of the role of a physical and personal carer, and a male carer took on the role of a supportive carer towards the person with dementia. This view was echoed by another carer who reported that both genders assisted in the care of the person with dementia; however, even though the whole family assisted in the care, more of the personal care and hygiene was taken on by external carers visiting the house and not by male carers.

4.4. Carer's Stress, Burden, Gratification, Quality of Life and Well-Being.

Previous studies have focused on the burden, stress, anxiety, satisfaction, positive and negative experiences of caregiving, social support, the family caregiving situation, and carers coping strategies, and it is only recently that researchers have concentrated on the influence that positive aspects have on the carers' well-being and QoL. The findings of this research raise some very interesting points of discussion about the carers' lived experiences, but more importantly questions arise concerning how these various factors are interlinked with the carers' lived experiences of caring and the effect that these have on carers' QoL.

The carers' lived experiences in this research thesis included stress, burden, fulfilment, happiness and gratification within the caregiving situation, and these affect the psychological and physical health and wellbeing of the carer. This is particularly prevalent when the health or condition of the person being cared for worsened, resulting in the behaviour of the person with dementia becoming more problematic and causing the carer to becoming stressed, burdened and less content with their caregiving situation. It is well documented that when the condition of dementia worsens, then the relationship between the carer and the person with dementia also deteriorates. These experiences result in carers suffering from a diverse range of psychological and emotional responses, ranging from feelings of regret, guilt and becoming overprotective (Grafstrom, Fratiglioni, & Winblad, 1994). Other studies have found that the experience of carers' gratification is derived from several life circumstances, such as carers' pleasure from seeing the person with dementia happy, the delivery of intimate care through tactile touch, carers' beliefs and reward system, recognition and reciprocity provided by the person with dementia towards their carer, appreciation and support from family and friends, and the carer feeling bound by duty (Kindell et al., 2014; Lloyd et al., 2016).

Even though the lived experience of a carer can be seen to be gratifying, it cannot be ignored that caring for a person with dementia can be a challenging and problematic experience (Lundh, 1991). This is consistent in family caregiving situations, where carer's satisfaction is seen to coexist at the same time as stress and burden (André & Elmståhl, 2005). The worsening of a person's health in terms of their dementia, cognition, challenging behaviour and QoL, is inter-linked to the QoL of the carer, both on a physical and mental level. This can be seen to lead to future depression, which particularly affects female carers (Thomas et al., 2005). When the person with dementia improves mentally

then their behaviour also becomes less challenging, resulting in their carer becoming less stressed, less anxious and happier in their own mental state and well-being. There is undoubtedly an inter-relationship between the person who has dementia, their temperament and their caregiver's fulfilment combined with burden, which seems to increase over time. Initially the caregiver burden is seen to be mainly related to the carer's general health and the problematic behaviours of the person with dementia. However, as the disease state worsens the carer's satisfaction becomes increasingly related to the patient's state of mind, with an increased dependency on the carer (Holst & Edberg, 2011).

4.5. Limitations of the Research.

In relation to other research studies, this research has several limitations. It was planned to recruit a total of twenty carers; however, only fourteen carers agreed to take part in this research study. The carers involved in this research were a homogeneous group and the small sample size raises questions about this study's generality. However, through the application of IPA and its investigative approach, the lived experience of the carers generated a series of meaningful accounts (Benner & Ketefian, 2008).

As the research thesis relied heavily on semi-structured interviews, this meant that the conveyance of language was emphasised via the spoken accounts of carers' lived experiences. Even though every attempt was made by the researcher to ensure that the lived experiences of each carer projected was unbiased and in their own words, the researcher also realised that it was impossible for the researcher to have complete and direct access, which could result in the findings of the research being open to interpretation. The researcher also acknowledges that other researchers carrying out

identical research may identify different subordinate and superordinate themes, and thus look at different aspects of the carers' interview accounts (Smith et al., 1997).

The credibility and validity of the spoken language of the carers' accounts are the only method of collection used in this research. For future studies, other data collection methods together with semi-structured interviews could be considered in order to validate the robustness of the research questions. This could be assessed via focus groups or detailed interviews and other data collection methods, such as e-mails (Murray, 2004).

The type of research questions asked during the interviews was very specific to the research question concerning carers' lived experience and tended to produce an overlap in some of the answers provided by the carers. The researcher in retrospect identified that prior to the research questions being addressed to carers it would have been advantageous to pilot the questionnaires to a similar homogenous group of carers to assess the validity of the questions being asked. Attention needs to be paid to the wording and format of questionnaires (Trigg, Skevington, & Jones, 2007). In addition, during the interview process the researcher noted that some of the carers were confused by some of the terminology used to describe their lived experiences in the questions, and did not comprehend or fully understand why their lived experience was being looked at because of the challenges, burden and stress associated with caring for a person with dementia. It would have been advantageous during the consent stage to have provided some additional information explaining the research question, why the research was being undertaken and why particular terminology was used in the questions.

Due to the lack of interest expressed by some support groups, mainly because of financial concerns and organisational constraints, this meant that the carers were recruited mainly from localised geographical areas, such as Central London, Hertfordshire and Berkshire. There was also a general reluctance by carers to come forward because the research area was related to dementia and their lived experience, resulting in a minimal number of participants. This meant that the findings from this current research are more led by the shared experiences encountered by carers in relation to their caregiving and their lived experiences. There was very little attention paid to the social, cultural, ethnicity and age criteria of the carers (participants), which may have had a significant effect on the findings (Yardley, 2000).

4.6. Future Research.

The findings of this research suggest that further qualitative studies in the area of dementia and the lived experiences of carers regarding their life circumstances need to be undertaken. In future studies, it would be interesting to look at a larger sample of carers and to compare the findings with this research to determine whether the shared accounts are consistent among a larger number of participants. It would also be advantageous to invest in longitudinal studies looking at the different factors that are associated with the life circumstances of a carer in relation to their lived experiences and to follow-up whether these lived experiences are short-lived or consistent over time. The carers in this research reported that the assistance of health care services and support provided by governmental agencies varied in terms of the consistency of care provided in one area compared to another. It may be worthwhile for future studies to include a more diverse population of carers from different areas in the UK and to look at whether the formal

support received for care or care in general in their local community has an impact on carers' QoL and well-being.

The carers in this research had a diverse academic and working professional background, with most the carers aged over sixty, Caucasian, not in employment and looking after their spouses with dementia. For comparative purpose, it would be advantageous to conduct future studies of the lived experiences of younger carers from diverse ethnic and cultural backgrounds, who are either in employment or not working to ascertain whether any of these factors are influence the carers' life circumstances.

The findings of this research further highlight the need for future studies to consider the lived experiences of carers regarding their needs and wants, their ability to cope and manage, the challenges they face in terms of the stresses and strains, the personal adjustment carers make in relation to their life circumstances, and the relationship between burden, stress, and fulfilment on carers' QoL and well-being. In addition, future studies need to evaluate the short-lived gratifying moments that carers share with the person with dementia, the confidence and motivation of carers, their obligation, their focus of control, and their determination to instil normality, which all influence a carer's life circumstances and effect their psychological and physical health, QoL and wellbeing. These research findings are in line with research which has suggested that QoL needs to consider the dimension of gratification in relation to carers' desires, capability and lifestyle (Emerson, 1985, in Forwards, 2003).

4.7. Implications for Clinical Practice.

From this research, it is evident that carers play a pertinent role in the welfare and care of the person with dementia. Future learning workshops need to involve carers in educational interventions (Cox, 2013) at both an advisory and consultative level. In partnership with the current government initiative for Dementia Champions, there is also a need for Carer Champions to work together with existing support groups, government bodies and clinical professionals. The involvement of carers needs to be considered in the development and creation of governmental programmes and future health strategies in the local community, such as within local GP surgeries and carers' support groups.

These future educational interventions need to consider appropriate coaching and training on the lived experiences of carers for health professionals, so that carers can be supported and assisted by these professionals. There is also a need for health professionals, social health services and general hospitals to dedicate time towards understanding carers' lived experiences, to recognise carers' ability and skill in being able to provide the best and safe care at home, to consider providing motivational and positive strategies for carers, and to assist in the design of supportive materials which are tailor-made for the needs and wants of not only existing carers but also new carers.

Health professionals and researchers need to further consider additional research and development into psychological programmes that evaluate the effect carers' lived experiences has on their mental and physical state, especially on their health and QoL. Regular medical or clinical checks need to be considered and be provided by health professionals to assess and ensure that the carers who provide the care for the person with

dementia are in a favourable mental and physical state of health and are able to continue providing care. Therefore, a standard and consistent respite programme needs to be offered to carers so that do not become overburdened and overwhelmed by their role as a carer. In combination with this, there is a need for additional governmental funding to consider a 24-hour telephone service, which could provide regular contact and support to carers so that they do not feel isolated but can be listened to about their challenging lived experiences of caring and be supported.

In this research, some of the carers expressed their frustration and anger towards their local health authorities due to the lack of support, assistance and the care they offer towards them as a carer and the person with dementia. In addition, some carers complained about the dictatorial and hierarchical working practices of their local health authority and found them to be unapproachable and unfriendly. Most carers' mentioned that different regional areas in the UK provided varying amounts of care and support, and some reported that when their local social services visited them then this was usually short in duration, consisting in some cases of two hours during which social services would go through a manual checklist telling the carer what needs to be done to their home, instead of taking time to listen to the needs and wants of the carer and working with them to achieve a constructive outcome.

The carers also called for more admiral nurses to be trained and provided in local areas. Admiral nurses are registered nurses who specialise in supporting families and carers living with dementia by providing complete and patient centred support services. In 2012 there were 100 Admiral nurses employed in England and Wales working in the

community, primary care settings and care homes (Bunn, Goodman, Pinkney, Drenan et al., 2016). One of the carers in this research commented that there were not enough Admiral nurses to cover the number of people who had been diagnosed with dementia and the number of carers who were providing their care. Even though this apparent finding is unrelated to the research question and not within the domain of this research thesis to be explored further, these findings have clinical implications for future learning, development, initiatives and interventions in the field of dementia and carers' QoL.

4.8. Conclusions.

The findings of this research do not provide conclusive results because of the limited sample of participants who took part. However, in line with existing research, it does indicate that the lived experiences encountered by carers have a fundamental bearing on carers' health, QoL and well-being. These lived experiences are seen to coexist with factors associated with burden, stresses and strains, which are evident when caring for a person with dementia; however, they are also inter-linked with short-lived moments of fulfilment, gratification and happiness experienced by carers during the less challenging times of care. From the literature discussed and the findings of this research it can be deduced that the lived experiences of gratification, burden and stress are not isolated phenomena but instead are interactive in the experience of caregiving. The well-being of the person with dementia is also not an isolated phenomenon as it affects the life circumstances of the carer regarding their QoL and well-being. Other factors, such as a carer's ability, coping strategies, the amount of support received, and adjustments a carer makes in their role and lifestyle to accommodate the care management of a person with dementia, all have an impact on carers, their current everyday life circumstances, and their future. Even though several qualitative and quantitative studies have been conducted

which consider dementia and caregiving, there are very few studies that have examined lived experiences of these life circumstances and the effect that they have on carers. The findings of this research provide an illuminating insight into the lived experiences of carers, particularly in relation to the various factors affecting their life circumstances. However, no concrete conclusions can be drawn from the findings of this research regarding lived experiences and the effect of gender.

This research thesis provides a useful insight into the lived experiences of carers, and is beneficial to various clinical and health professionals when looking at diverse educational programmes, training sessions and future health interventions.

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Appendices.

Appendix A.

A copy of the posting placed on the charity website.

Charity Talk Forum.

You as a Carer are being invited to take part in a research study. This study will look at the different experiences of satisfaction encountered by both men and women carers whilst caring for a loved with Dementia on a long-term basis at home.

The study will look at the different experiences of satisfaction faced by you as a male or female carer. Your positive experiences will be looked in relation to your daily management, care and adjustment of having to care for your loved one with dementia; but to also explore whether your experiences are similar or dissimilar in your everyday lives and what effect this has on your quality of life. This study will hopefully provide a better understanding of the positive aspects of caring when caring for your loved one.

If you do decide to take part, your involvement in the study will be completely voluntary. You the carer will be contacted by the researcher by telephone or by post or via your caregiver support group. As the carer, you will be interviewed by the researcher. The interviews will last for approximately an hour and an hour and a half and the questions will be based on caring for your loved one.

Throughout this study, confidentiality will be maintained and any information collected during this study about you will be completely anonymized. The researcher will ask you if you will like a copy of your interview transcript and you will be given a summary of the study.

Thank you for taking the time out to read this information and if you have any questions about the study or would like to take part please do not hesitate to contact me.

Kind regards
Farah

E-Mail Address: [redacted]

Appendix B.

Information Sheet and Consent Form.

Participant Information Sheet.

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CITY UNIVERSITY LONDON

CAREGIVER INFORMATION SHEET.

Prospective CAREGIVER: Please read this information sheet very carefully and ask as many questions as you like before you decide whether or not you want to participate in this research study. You are free to ask as many questions as you like at any time, before, during or after your participation in this research.

TITLE The Experiences of Satisfaction Encountered by both Men and Women Caregivers Whilst Caring for a loved one with Long-term Dementia

1. INTRODUCTION.

You the Caregiver are being asked to participate in a research study. Before you decide to take part, it is important that you understand why the research is being done and what it will involve. Please take your time to read the following information sheet very carefully. If there is anything that is not clear, or if you have any questions and would like more information, please ask and I will try my best to answer them. Please take enough time as you need to decide as to whether you would like to take part.

2. PURPOSE OF THIS RESEARCH STUDY.

The purpose of this research study is to compare the different experiences of satisfaction encountered by both men and women caregivers whilst caring for a loved with Dementia on a long-term basis at home. The different experiences of satisfaction confronted by both male and female caregivers will be examined in relation to satisfaction in terms of their daily management, care and adjustment of having to care for someone with dementia; but to also explore whether the experiences encountered by both male and female caregivers are similar or dissimilar in terms of satisfaction experienced in their everyday lives and the effect this has on their quality of life.

The research study will be carried out with caregivers through the contact with various support groups, charities, private clinics and local community groups. The research study will be conducted within the UK and will involve the participation of twenty caregivers in total. The research study will last a year, with a six months' recruitment period involving a single interview session lasting for an approximately an hour or hour and a half.

3. WHY HAVE I BEEN ASKED TO TAKE PART?

The reason why you have been asked to take part in this research study is because you are either a male or female caregiver aged eighteen years and over, providing care for a loved one who has been clinically diagnosed with dementia by the medical profession on a long-term basis at home and able to read and understand this information sheet.

4. YOUR INVOLVEMENT IN THE STUDY.

As a caregiver, it is up to you to decide whether you would like to part in the research study or whether you do not wish to part in this study. If you do decide to take part in this research study, you will be given this information sheet to carefully read and be given plenty of time to think about the research study, to discuss with your family and friends and to decide. If you do decide to take part in the study you will be asked to sign a consent which will confirm your involvement in the study and this form is attached to the back of this information sheet. One copy of the consent form will be kept for the researcher's record and a second copy will be given for you to keep.

5. VOLUNTARY PARTICIPATION AND WITHDRAWAL.

As a caregiver, if you do decide to take part in the study, your participation and contribution to the study will be voluntary and you still will be free to withdraw at any time and without giving a reason. A decision to withdraw at any time or a decision not to take part will not put a risk or loss of benefits to which you may otherwise be entitled.

You may leave the study early. This could happen if:

- The researcher and you feel that it is not in your best interest for you to remain in the study.
- The researcher decides to stop the study for any reason.
- Or other personal circumstances that prevent you from taking part in the study.

6. TAKING PART IN THE RESEARCH STUDY.

As a caregiver, if you do decide to take part in the study, you will be contacted by the researcher by telephone or by the post or via your caregiver support group. You will be involved in being interviewed by the researcher. The interviews will take place in an

appropriate setting and will last for approximately an hour and an hour and a half. The interview will be very informal and loosely structured. At the start of the interview, the researcher will ask you whether you would prefer to use a pseudonym a fictitious name rather than your real name, in order to maintain anonymity. With your permission, the interview will be tape-recorded. The questions in the interview will look at your positive experiences of caregiving in terms of satisfaction, in terms of your daily management, care and adjustment of having to care for someone with dementia. The interviews that are tape recorded will be transcribed by the interviewer and on completion of the study the tape recordings will be destroyed.

7. POSSIBLE RISKS OR DISCOMFORT.

The questions that you may be asked during the interview about you as a caregiver may be personal and may cause some distress. You do not have to answer any question that you feel uncomfortable with or do not want to.

8. POSSIBLE BENEFITS.

As a caregiver, you will not receive any direct benefit by taking part in this study. However, the information gained in this research study will provide a better understanding and insight as to whether the experiences encountered by both male and female caregivers are similar or dissimilar in terms of satisfaction experienced in their everyday lives and in the effect this has on their quality of life.

9. WHO WILL PAY FOR THE STUDY.

As your participation in the research study is voluntary you as the caregiver will not be paid for taking part in this research study. All costs relating to reasonable travel, parking and any other expenses will be incurred by you.

10. CONFIDENTIALITY.

Confidentiality will be maintained throughout this research study and is the uttermost importance to this research. If you consent to take part in this study, you will be required to sign an informed consent form and your participation in this study; will involve you being interviewed by the researcher. In order to protect your identity, your name will be replaced by a pseudonym. All the information collected during the interviews relating to your details will be anonymized. Any identifying information like your name, details or other personal information will not be used or disclosed to anyone outside, to any third party or appear on any transcripts, thesis, publications or on any written paper.

However, there might be certain circumstances in which it may be necessary to breach this confidentiality and disclose information to a third party. This includes situations when someone provides information during the study that raises serious concern about:

- Intention to harm themselves or other people

- Risk to the health, welfare or safety of any children or vulnerable adults

- Disclosure of a criminal offence

The researcher will be obliged to share this evidence with her supervisor, who may advise that further action is taken.

Also, the anonymized interview information may be looked at by City University, London.

11. RESULTS OF THE STUDY.

The results of this study will be submitted to City University, London in the form of a thesis and may contribute to any possible future publication. You will not be identified in any publication or thesis. The researcher will offer you the caregiver the opportunity of having a copy of your transcript sent to you and a copy of research study summary. The interview transcripts and audio tape recordings will be kept in a sealed box, in a locked cabinet in the researcher's home and on completion of the study this data will be destroyed.

12. WHO WILL REVIEW THE STUDY?

The research study has been reviewed and approved by the Research and Ethics Committee of the Department of Psychology of City University London (project approval number PSYETH (UPTD) 12/13 69).

Comments, concerns or Observations Procedure:

If you have any comments, concerns or observations about the conduct of the study or your experiences as a participant, please contact the Secretary to the Committee Mrs. Carmai Pestell, quoting the above project approval number:

Telephone: [redacted]

Email: [redacted]

Postal Address:

Mrs xxxxxxxxxxxxx

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

Any new information that comes to light during the course of the research study will also be provided to this authority and yourself.

14. COMPLAINTS

If you would like to complain about any aspect of the study, City University London has established a complaints procedure via the Secretary to the University's Senate Research Ethics Committee. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is:.....……

You could also write to the Secretary at:

Anna Ramberg

Secretary to Senate Research Ethics Committee

Research Office, E214

City University London

Northampton Square

London

EC1V 0HB

Email: Anna.Ramberg.1@city.ac.uk

15. CONTACT FOR FURTHER INFORMATION.

If you have any questions about this research study or require any additional information, please contact Farah Khokhar-Cottrell (DPsych Health Psychology Doctorate student) and Clare Eldred Supervisor at City University, London on following telephone number xxxxxxx or alternatively on the following e-mail address xxxxxxxxxxxxx

Do not sign this form before you have had a chance to ask questions and have received answers to your questions.

If you agree to participate in this study, you will receive a signed and dated copy of this consent form.

Thank you for taking the time to read this information sheet.

Consent Form.

CITY UNIVERSITY LONDON

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CAREGIVER CONSENT FORM.

TITLE: **The Experiences of Satisfaction Encountered by both Men and Women Caregivers Whilst Caring for a loved one with Long-term Dementia.**

NAME OF PARTICIPANT……

NAME OF RESEARCHER……

Please initial or tick if you agree or leave blank if you do not agree.

For the Caregiver.

Please initial box

1.	I agree to take part in the above City University London research project. I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records.	☐
2.	I understand this will involve • be interviewed by the researcher • allow the interview to be videotaped/audiotaped	☐

3.	This information will be held and processed for the following purpose(s): I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation.	☐
4.	I understand that I will be given a transcript of data concerning me for my approval before it is included in the write-up of the research.	☐
5.	I understand that my participation is voluntary, that I can choose not to participate in part or all the project, and that I can withdraw at any stage of the project without being penalized or disadvantaged in any way.	☐
6.	I agree to City University London recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998.	☐
7.	I agree to demographic data being collected during the study.	☐

8.	I consent to take part in the above study.	☐

Name of Participant. Signature. Date.

_____ _____ _____

Name of Researcher. Signature. Date.

_____ _____ _____

When completed, 1 copy for the participant; 1 copy for researcher file.

Appendix C.

List of Questions used during the Interviews for Carers.

Interview.

Start of Interview

Informed Consent and consent to audio tape the interview.

Introduction

Please say, if you feel uncomfortable about discussing any of the issues raised during the course of the interview. Please feel free to stop or withdraw at any time without your rights be affected. Please feel, free to use a pseudonym in place of your real name. The interview will last approximately to an hour to an hour and a half.

Interview questions

1) Tell me a bit about yourself?
2) Tell me a bit about your loved one's condition (name the Dementia) and how it occurred?
3) Describe to me what every day is like for you?
4) Is there anything challenging that you find when caring for your loved one?
5) Is there anything that makes you happy when managing your loved one and describe to me how this affects you?
6) What sort of situations do you find pleasing? Which are joyful? And what about you? Can you describe how this makes you feel?

7) How do you think your loved one reacts to you when seeing you take pleasure in their care and describe to me how you react them?

8) As a Man or Woman caring for a loved one with Dementia how contented do you feel and how fulfilled do you see your loved one to be?

9) Has this conversation made a difference to you?

Appendix D

City University E-mail.

From: [redacted]
To: [redacted]
CC: [redacted]
Subject: PSYETH(UPTD) 12/13 69
Date: Mon, 16 Sep 2013 08:12:32 +0000
Dear Farah

The Psychology Department Research & Ethics Committee has approved your application for ethical approval for the study 'The experiences of satisfaction encountered by both men and women caregivers whilst caring for a loved one with long-term Dementia at home.' Reference: PSYETH(UPTD) 12/13 69.

The unique reference number 'PSYETH(UPTD) 12/13 69.' should be included on the top of all information and consent forms, and in all future correspondence about your ethical approval for ease of reference.

Please also include the following text:

"Comments, concerns or observations procedure:

This project has been approved by the Research and Ethics Committee of the Department of Psychology of City University London (project approval number PSYETH(UPTD) 12/13 69).

If you have any comments, concerns or observations about the conduct of the study or your experiences as a participant, please contact the Secretary to the Committee Mrs. Carmai Pestell, quoting the above project approval number:

Telephone: +44 (0)20 7040 8529.

Email: [redacted]

Postal Address:

Mrs. Carmai Pestell

[redacted]

[redacted]"

Please do not hesitate to contact me should you have any questions.

Best wishes,

Carmai

_____

Carmai Pestell

Assistant Registrar (Arts and Social Sciences)

Student and Academic Services

City University London

t: [redacted]

w: www.city.ac.uk/arts-social-sciences

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Appendix E.

List of Commonly Shared Superordinate Themes Amongst Women.

Table 1. Summary of Stage 5 Quotes for Lived Experiences of Women Carers.

STAGE 5: INTERGRATION OF CASES							
PARTICIPANTS	**1**	**2**	**3**	**4**	**5**	**6**	**7**
MASTER THEME 1: Just Normal.							
SUBORDIANATE THEME: Normality	**1-Normality (Theme2, Theme 9)**	**1-Normality (theme 7)**		**2- (Normality (Theme 6)**		**1-Normality (Theme 4)**	**6- Normality (Theme 11)**
	Doing things And erm I am pottering around the house with and doing things or cooking with him. So, we went out to dinner last night. So, I take him to restaurants and things but I have to teach him. So, you know if I go out with friends and I get the carer just to come in and sit with him, which works	Normal I suppose it makes me happy when I have a visit with him, and I use this word in inverted commas, but when he seems 'normal'. I might have a visit where he seems just like a regular person to how he was and you can have a more normal conversation. That makes a visit so much easier and if you were to measure my		**going somewhere, seeing something** Then in the afternoons he gradually gets more active. We try and get him outside for at least a part of the afternoon, walking somewhere, doing something, going somewhere, seeing something to give him a bit of excitement. Usually, he will interact with various local people **Page 3 Lines:105-108**		**Normality** Yes, you know the fact that he still has his sense of humour at times and he is very pleased at times, he asks for things and he dances about and yes obviously, these are the things. Yes, and obviously, those things play a big part and yes build his personality and yeah helps you feel that you are doing the right thing and there's an answer at the door. Yes, and that you still enjoy certain activities together and you know yes enjoy you can still enjoy each other even though different and yes, it's still good. **Page 3 Lines 78-84**	**NICE** He might not remember exactly who they are, but if people make eye contact with him and know his name, he just presumes that he knows them, so will carry on a conversation with them. So, that's nice, that he can still do that. He might say, 'I know that face and I know that voice, but I can't remember who it is. Can you remind me?' That's quite nice, that he's still with it enough to be able to do that and he's still got the social skills and the communication skills to be able to do that. **Page: 10 Lines 345-351**

	well. **Page 2 Lines 68-69 & 70-73**	stress levels at that point it would be much lower and I would feel happy. I'd had a good visit and he was OK **Page: 5 Lines: 175-176 & 177-179**					
	<u>Normal Life</u> So, I don't feel stressed about things. If I need to do something then I'll get a carer to come and sit with him and they're happy to come and sit with him, because he's not violent or aggressive, like some people can be with this illness. So, all those things mean we can carry on, in inverted commas, a 'normal' life as much as possible. **Page 5 Lines 186-190**	**<u>'not demonstrating extreme distress'</u>** So, I suppose the answer would be when he's not demonstrating extreme distress and is able to have a semblance of a normal conversation. That would make me happy. **Page: 5 Lines: 183-185**		**<u>really seems to be absorbed</u>** Then, in the evenings we'll either go out to eat or I'll cook something here or, quite often, about once a week we go to the cinema, and that's the one place where he really seems to be absorbed by what is going on. **Page 4 Lines 119-121**			**<u>Niceties of Life</u>** It's also nice to see him eating well because he never really was interested in food. It was terrible to feed him, because he was just one of those people who ate to live, he didn't live to eat. He didn't really particularly enjoy food; he just ate it because it was fuel and was to keep your body and soul together. But now that's completely changed; he loves food and he loves dessert. I never knew him eat a dessert ever before, so that's nice to see him eating food because he was always frustrating with food before. So, that's nice to see him enjoying tucking in, whereas he would've been indifferent to that before **Page 7: Lines: 231-238**
				<u>Normality</u> So, we will walk there, it's about a mile away, and we			

				will sit and he will sit and watch a film. Sometimes he'll comment on it afterwards. He's much more restless doing anything else. Plays are not as good, usually, he can only last about an hour and a half in a play, but he will sit right through a film. The darkness and the big screen help him to focus in on it and that's good. Then we'll walk back or have supper in a little pizza place and then come home. **Page 4 Lines 125-130**			
				<u>Which is great</u> Then we'll have supper of some kind and I usually try and give him a nice meal then. Then, to settle him down, if we're not going out, I try and sit with him in front of the television. And we sit there and we have a little bit of chocolate, which is a great treat, we both love chocolate, and quieten down. Then, usually after			

				the news, we will go to bed, and most nights he sleeps very well. He goes off to sleep rapidly once he lies down. **Page 4: Lines 140-145**			
				Touch of reality He's much more in touch with reality, which is good. **Page: 5 Lines 184-185**			
MASTER THEME 2: Support and Sharing with Others.							
SUBORDIANATE THEME: 2: Raising awareness	**2: Raising awareness (Theme 7 & theme 13)**		**4: Sharing with Others (theme 10)**				
	Positive Aspect is the people And the other positive aspect is the people I have met because of my fundraising activities. We have a charity dinner dance last week and raised £5,500 towards dementia and specifically for admiral nurses because that is the thing that gives me		**Sharing with Others** Yes. It's nice to be able to speak to somebody about it. I suppose my boss is the one who gets most of the story because I was working with her when my mum started exhibiting her strange behaviour. She sometimes helps me to see the funny side of what's happening, so I can laugh about it with her. It sort of takes the				

	a real buzz, that is hopeful that one day we can all get more admiral nurses throughout the country. Lines **Page 4 138-148**		pain away sometimes, I suppose. **Page 7 lines 253-255 & 257-259**				
	Person still a human being People are becoming much better and people are becoming much more tolerant of others and that's what all about because then I can get people to be positive about dementia and the effects of the illness has, but the person is still a human being. You just have to recognise the fact that they can't do the things they used to do, but they are still a person and still have valuable lives. **Page 5 lines 149-153**						

	<u>Sharing with Others</u> I suppose you don't talk about things to other people. I'm just not that sort of person, so if I've got an issue then I'll try and deal with it, I won't talk about it with anybody else. So, just the fact that the information can be passed to other people or be used in the research that you're doing to help make life better for people who are going to be diagnosed in the future, and the way people are treated. I mean if this goes some little way towards that and improving it then I feel as though I've done my bit, really. That's about it**. Page 7: Lines 265-271.**						

SUBORDIANATE THEME: Supported	**3-Supported (Theme 3)**						**2- Support (Theme 7 & Theme 10)**
	<u>Good Support</u> You find out who your friends are, though, because, although we had a very large circle of friends, that's now become quite a small circle of friends. And, family – some of our family can't cope with it, especially his son. But, all in all, we get good support from family and friends. **Page 3 lines 74-78**						**Family Support** I just think it's essential to carry on doing those things that we've always enjoyed as a family for as long as we can, really, because it's a very isolating illness. Friends drift away, so family are very, very important. As a family, I suppose it has brought us closer together and that's a nice thing as well. That's one of the nice things about it. Page **7: Lines: Lines 253-257**
							Friends Support Apart from the fact we're carers, our paths wouldn't have crossed. but because you're kind of thrown together because of the dementia, I have made some really good supportive friends and we all support each other. So, that's been a positive because that wouldn't have happened: **Page 6 Lines 195-200**

MASTER THEME 3: Managing to Cope.							
SUBORDIANATE THEME: Coping	**4: Coping (theme 5)**				**3-Unchallenging situations (Theme 6)**	**2- Coping (theme 5)**	**4-Coping (Theme 14)**
	I can still cope The fact that I can keep him at home and I can still cope, that makes me happy because I really do not want him to go into a home **Page 4 lines 132-133**				**Easier** Of course, yes, because it just makes it that little bit easier that day. Otherwise, if you don't have those moments and every single day is a struggle, morning and night, which is particularly when I care for her when every day is a struggle, that she's being difficult, it's very hard to find pleasure in those moments. Page: page 6: Lines 202-204 & 208-209	**Lack of distraction** You know I think it's good, you know to go through the day without him being distracted or particularly anxious. I would say you know that is a good thing as you know we are both are affected really, it's very distressing you know you feel and you become very distressed yourself and sometimes his language- this was affected very early on. Page 3: **Lines 87-89**	**Coping by making jokes** My default position is, as I said before, I tend to make jokes about things. That hasn't always worked to my advantage because it sometimes gives the wrong impression to people. It gives the impression that I'm coping brilliantly and that I don't need any help because I'm managing because I'm a coper. And I am, but, of course, sometimes it's a bit of a smokescreen. **Page 6: Lines 324-330**
	Cope with things The fact that we can still go out; we're not housebound. That's the most important thing to me because I'd hate it if we were housebound all the time. And the fact I can still cope with things at				**Stress-relief** Well, at those moments I feel a bit easy and quite happy. It's like a moment of, I don't want to say stress-relief, but it's not as stressful because she's being easy-going. In turn, it makes me feel, for that particular day, **Page 7: Lines: Lines 232-234**		

	the moment. **Page 5 lines 157-159**						
	<u>Manage to cope</u> I'm lucky being that he's not a very large man. If he was over six foot or something, there's just no way I'd be able to cope on my own. But I do manage to cope and that's the most important thing for me, really, is that I can look after him, care for him **Page 7 241-245**						
	<u>The niceties</u> The niceties is that I can cope because I know in our support group some of the people find difficulties because their partner is difficult to deal with and things like that. I don't have any of that. I am so						

	lucky. That's the main thing that drives me on, really, the fact that, OK, he's ill and he's got this terrible illness, but we'll go on happy and contented in our self. **Page 5 Lines 182-186**						
MASTR THEME: 4 Providing best and Safe Care.							
SUBORDIANATE THEME: Protected	**6-Protected (theme11)**	**Safe & Protected (Theme 9, Theme 11 & theme 13)**	**Subordinate theme: Contentment** **2-Satisfaction when managing care** (Theme 5)	**4- Best Quality of Care**	**2-Protective (Theme 7)**	**4-Contentment (Theme 7)**	**1- The Best (theme 13 and Theme 15,)**
	'Sense of Trust': I think the biggest thing I feel is that he puts all of his trust in me and that really comes across. I know it might seem strange. 'Come on, we're going to go in the car now,' and I put his coat on or whatever,	'**Fight for help'** But I know I'm doing everything I can to fight for the help he needs. Difficult. Don't get old. You've got to make sure you're wealthy so that you can pay for a carer to live with you. That's what I've	**Taking care of her** …my mum is half Scottish, but she'd never been there. I wanted her to see a part of Scotland before she dies. She knew this. So, I persuaded her to come with me and we drove up. She was OK with the journey. But when we were there it was really nice, helping her in the bath. This is what we do when we go away on holiday, helping her in the bath and getting her	**Best possible quality in life.** My primary purpose now is to be his carer and to give him the best possible quality of life. So, in doing that I think, OK, this is my major job and I will do it as well as I can' **Page 7 Lines 258-260**	**Old people vulnerable** . You're very protective as well. You don't want people to take advantage of her, then, when you entrust someone else to deal with your loved one, that's also a scary thing. **Page 6: lines 220 & 225-226**	**Doing the best** Yes, I am, yes I said it before, it makes me feel that I am doing the best that I can to ensure that he's contented that he is full-filled as he can be and happy. **Page 4: Lines 108-109**	**Day-to day now'** So, I'm not complaining that we never did anything nice, we did. We had lots of lovely times together as a family. But all of the things that we put on hold until we retired haven't been able to materialise and I feel sad about that, but it's happened and I can't waste energy for too long about it. I just think from day-to-day now and try to make the best of every day for him and for me. **Page 9: Lines 304-308**

	he's just so trusting that I will look after him. And that's the biggest thing for me normally. , 'We're going to go and do this,' or, 'We're going to go and do that,' and he just looks at me like to say 'okay I trust you. **Page: 6 Lines 224-235, 226-227 & 229-231**	learnt. **Page 6: lines 198-200**	out and drying her off and putting body lotion on her because she doesn't do that herself when she's on her own. Her skin gets all dry so I'm slapping on the cream. She just sits there and closes her eyes as though she's really enjoying the feeling, the sensations of being touched, and I quite enjoy doing that part for her. And then taking her food to the bedroom and getting her dressed, picking up her clothes for her. I enjoy that **Page 4: Lines 113-122**				
	Make the best I can I try to make the best that I can out of any situation that's put in-front of you. As I say, we have a really happy and still a social life, which is really nice. **Page: 7 Lines 260-261**	**Respect'** A bit proud of him that he did that, protective. I wanted to show the carers how to speak to him, how to include him. It was like I was still showing he was still capable of answering questions and remembering some things and for them to respect that.	**Sense of satisfaction** I like to dress her, I like giving her a bath, and I like helping her in the shower when she's at home. But when she does want to I like to wash her hair for her and give her a rub down with a body buffer thing and put the cream on. I like doing that for her. I get a sense of satisfaction out of it and feel that we're both pleased with the outcome. **Page 4: lines 146-147 & 149-152**	**make things run as happily and as smoothly** We live on a very simple level together. There is no real intellectual engagement anymore, and I miss that. But it's like having a child – you keep things simple, straightforwa			**Best of my ability** One of the things that keeps me going is that I'm quite hard on myself. I don't do failure. I don't give up easily. I don't do things unless I know I'm going to be good at it. I know I didn't choose to do this, but having had it thrust upon me I work hard to do it to the best of my ability **Page 9: Lines 332-335**

		Page 6 Lines 225-227		rd and try and make things run as happily and as smoothly as you can**.** **Page 8: Lines 275-278**			
							6- Normality (theme 6
		<u>'Trust me'</u> So, yes, he generally reacts positively to me being there because he trusts me, but when he's in his bad moments he's not able to mask it for my benefit. **<u>Page 7 lines 246-248</u>**					**<u>Sees the joke</u>** So, I actually think that deep down he doesn't, he does appreciate it really, but he never says that he appreciates it. I think he's just got to the point where that's what he expects really. That's what his mother would've done and that's my duty to do. But I put him straight and say, 'That's made me even more determined that you're going to go to go out to the centre, I'm not your mother.' He kind of sees the joke in that. **Page 7 Lines 263-268**
			SUBORDIANATE THEME: : Contentment 3-Recognition (Theme 7)				**5-Recognition (Theme 12)**
SUBORDIANATE THEME: Recognition			**<u>Appreciation</u>** She'll often say, 'Where would I be without you?' and I say, 'You'd manage,' but I know she wouldn't. So, I just say to her, 'Where would I be without you?' **Page 5 156-158**				**Compliment** He does sometimes say, 'I don't know what I'd do without you, you help me such a lot,' so I suppose, deep down, he is grateful, but he doesn't say that very often. I think he tells other people how marvellous I am, because Karen, who looks after him at the day centre, will often say, 'He tells us how wonderful you are and how marvellous you are,' he just doesn't tell me that often. I take that as a backhanded compliment; that he talks to other people and tells them how wonderful I am. **Page 8: Lines 269-274**

			Enormously grateful She likes my company and, if I haven't seen her for a few days – I see her most days, actually, it's just Tuesdays and Wednesdays that I don't see her – I phone her every day and she always thanks me for phoning her. I just feel that she's enormously grateful for what I do for her. I don't know how that makes me feel, **really. Page 5 Lines 163-167**				**Something complimentary** I just say, 'Thank you, that's very nice of you to say so,' if he says something complimentary. I let him know that I appreciate it when he says something nice and I am grateful. Or I make a joke of it as that's my default position, that I make jokes of things and try and keep the atmosphere as light as I can, to be honest. **Page 8: Lines 277-280**
MASTER THEME 5: Cherished Moments.							
SUBORDIANATE THEME: Pleasurable moments	**5- Pleasurable moments (Theme 6)**	**Pleasurable moments (Theme 8, theme 10, theme 12 & theme 14)**	**1-Cherished Moments (Theme 3 & Theme 4)**	**1-Cherished Moments (Theme 4, theme 8 & Theme 10 & Theme 11)**	**1- Cherished moments (Theme 5 & Theme 4)**	**3- Pleasing moments (Theme 6)**	**3- Cherished Moments (Theme 6 & 9)**
	A Smile And, if I got and I come back in and he gives me a big smile. So, that means a lot to me. So, if that goes I don't what I would do really. Lines **Page 4: 133-137**	**relaxed and Happy'** Probably just those ones I've described really. It's just about if you have a visit where he seems relaxed and happy, it makes me happy. **Page 6 lines 193-194**	**nice moment.** We just sat in the sunshine and had a bit of conversation here and there, not that she chats much. It was just sitting in companion filled silence. That was a really nice moment. **Page 3 Lines 99-102**	**He smiled at me** One evening we went out to dinner for our 26th wedding anniversary last summer and we were sitting there at the table, candle on the table, looking very nice, and he smiled at me and said, 'And do you know my wife?' That was really quite hilarious.	**Glimpses** When I see glimpses of my old grandmother every now and then, that makes me smile. Page 5: **173**	**Good state** Well, it's when I can describe when he is in good state really …. cutting up some vegetables which we sometimes do to make soup or he be it running three miles on a running curb……. Him listening or enjoying a television program you know engaging with it really and laughing that kind of thing. You know anything that shows him appreciating things and brings out his previous personality really. **Page 3 lines 98-104**	**Nicest times** He still has a good sense of humour, he still sometimes has quite lucid conversations for a short time. The problem is that then, five minutes later he will start the same conversation up again. But he still is able to be quite witty. He still can see a joke, he can still participate in that. And he does enjoy it when we go out together in the car and have a little bit of a country drive, have a cup of tea somewhere. Those, I think, are the nicest times. **Page 5: Lines 182-187**

				Page 2: Lines 51-53			
		‘He able to contribute’ So, that was gleaming, because he demonstrated that he was still able to participate, which I thought was important for the carers to see because sometimes I think people just don’t include him in the conversation. So, they will say to me, ‘What does your dad like?’ and he’s standing next to me, and I think, ‘Ask him, don’t ask me.’ That happens a lot and it’s very frustrating. So, that was good and it made me happy that he was able to contribute**.** **Page 6: Lines 218-223**	**feelings of touch.** I feel better when she puts her arms round me. Page 5 **Lines173-**	**Most of the time** Most of the time he is very loving, he will do what I ask, we’ll do things together and I think love and kindness is the hallmark of our relationship and that’s wonderful. Just occasionally he looks at me with suspicion, gets a bit paranoid and difficult and says, ‘No, I won’t do that, I can do what I want, there’s nothing wrong with me.’ And that’s very hard to cope with. The best thing to do is to just back off and say, ‘OK,’ change the subject and then come back later, if it’s something that needs doing **Page 5: Lines 170-176**	**Cherished moments** Once there was a time when the radio was broken and she was listening to it and the tuning wasn’t right; when I got to the right station for her, her face broke out into a massive smile. So, that made me happy that she was very deliriously happy for that moment. **Page 5: Lines 177-180**	**Reacts in a good way** He reacts in a good way; I don’t whether he can comprehend that with pleasure or care. I don’t know I would imagine that he just feels that he looks at his wife and we are having a good time together probably. I don’t know. I wish I could, god knows what he is thinking but the fact he has a smile on his face I suppose is good enough for me really and that he can see his friends. **Page 4 Lines 115-119**	**Glimpses of old David** I shouldn’t say there are all that many, but sometimes there are glimpses of the old David when we have a joke and a laugh. **Page 6: Lines 203-204**

		‘Pleasant Experiences’ There was one pleasant experience the other day whereby his regular social services carer came in and, at the same time, a new potential private carer was there at the same time. The four of us were there and, on the one hand, I thought this would be slightly overwhelming for him, but on the other hand it seemed to up his game in terms of how he presented himself. He really struggles with his language fluency now, bless him, but it’s almost like he knew that he was with two strangers and a family member and he engaged with the conversation and got a couple of sentences out, which I was surprised that	**Relaxed moments** When I’m really relaxed I quite enjoy looking after her, but only when I’m relaxed. The only time I’m really relaxed is when we are on holiday. We go away together every Christmas, and that’s still going ahead, we’re going away this year, but I fear this might be the last time. But this summer I decided I was going to go to Scotland and my mum is half Scottish, but she’d never been there. **Page 3: Lines 109-113**	**I am always very happy** Well, I’m always very happy when he smiles at me and says, ‘I love you,’ and, ‘You’re wonderful, you do things so beautifully,’ and he often says that to me and it makes me very happy that he’s happy and content, and we get along well. I’m also happy when he’s engaged with something, like the cinema. You can see him sitting there and watching and that’s good because a lot of the time he’s sort of detached. And I’m happy when he’s with people and enjoying them. We’ve been very lucky in Spain, we’ve met some very nice people and they had us round. We sat round the table with them and Adam can be very funny still and make people laugh, and he had a wonderful evening, a whale of a time, and we were all laughing	**Bittersweet moments** It’s a bittersweet moment because obviously for that moment I feel I’ve got my old grandma back, but you know that it’s temporary. I guess the hard part is accepting she’s fully gone now. It’s very fleeting moments. I feel like I’m happy for that briefest second or two and then you know the rest of it is back to her normalness. **Page 5: Lines 185-189**		**Appreciating his grandchildren** But it’s nice to see that he’s appreciating his grandchildren. We’ll often comment on that. My girls jokingly say, ‘Well, I never remember dad doing that when we were little,’ or, ‘I never remember dad being that sympathetic when we fell over or anything like that.’ But now he’s, ‘Are they alright?’ **Page 6: Lines 213-216**

		he did **Page 6: lines 207-214**		away and he was being quite uproarious. That's nice. **Page 6: lines 191-200**			
		'Really nice' It's lovely, it's really nice because it is a lot of work and it is hard, so when you get a nice moment, it's your reward and it makes your spirits lifted. **Page 7: Lines 251-252**	**Relaxing mode** Because I feel as though I'm always rushing all the time. So, being on holiday and being in relaxed mode means I can just take my time and do things with her at a leisurely pace. **Page4: Lines 131-133**	**I'm happy** So, I'm happy when he's happy and I'm happy when people are nice to him and he responds. That's a lot of the time. There are many days when we have good times. **Page: 6 lines 201-202**	**Fleeting moments** I find things which are pleasing when she does what you ask her to with little resistance. Like if you give her good food she eats it without complaining; when you see the glimpses that she understands or knows stuff and when she appreciates what you do for her. Again, these are very fleeting moments. **Page 6 Lines 197-200**		**Enjoying the moment'** I just enjoy the moment at the time it's happening. I enjoy those moments while I can really, **Page 7: Lines 242-244**
		'Positive things' Yes, positively. He likes me being there and he says some nice things. He says positive things when he's in a good way. You get some praise, you get some thanks sometimes. Well, not really thanks, but you get things like, 'I don't know	**'Nice Stroll'** And then going off for a stroll somewhere, arm in arm, because she can't walk unaided. She's got a walking stick and she has that in one hand and then she's clinging onto me with her other arm, and just having a nice stroll in pleasant surroundings. I enjoy that	**Appreciation of the surrounding** So, when he's appreciative, that's smashing. Or sometimes we'll go for a walk and we'll go somewhere and he'll really like it, like Kew Gardens or something like that. If he's happy there, that's great. **Page 6: Lines 214-217**			

		what I'd do without you, you're my angel,' things like that, which is really nice to hear. **Page 7: Lines 242-245**	aspect. That's really nice. **Page 4: Lines 122-126**				
			Hug Sometimes she'll give me a hug, but she's not really a touchy-feely person. Usually, it's me who gives her a hug and sometimes she'll just stand there and let me hug her, sometimes she'll put her arms round me. **Page 5 Lines 169-171**	**The way he reacts** I think the way he reacts to me is with great love and affection and gratitude, most of the time. Occasionally, he's not sure who I am, but he's still quite a warm person and will say, 'Oh, thank you so much, bless you.' He's a delightful man. So, that's mostly how he reacts to me. Sometimes, he reacts to me, if I come with his four tablets in the morning, he might look at me very suspiciously and say, 'What are these? I've never had these before.' And I'll say, 'Sweetheart, you have them every day.' But mostly he doesn't. Page 7 Lines 230-236			
				I feel loved Or, 'Where's Glenny?' because he calls me			

				Glenny, and I say, 'I'm Glenny.' So, he doesn't always know who I am. Sometimes he does, but not always. How it makes me feel? I feel loved when he recognises me and smiles because that's nice,' **Page 7. Lines 239-242**			

Appendix F.

List of Commonly Shared Superordinate Themes Amongst Men.

Table 2. Summary of Stage 5 Quotes for Lived Experiences of Men Carers.

STAGE 5: INTERGRATION OF CASES							
PARTICIPANTS	**8**	**9**	**10**	**11**	**12**	**13**	**14**
MASTER THEME 1: Providing best and Safe Care.							
SUBORDIANATE THEMES: Safe and protected.	**1-Safety and Protection (theme 4, 17)**	**2-Safe and Protected (theme 8 and Theme 11)**		**SUBORDIANATE THEMES: Best Care** **1-Best care (Theme 4 & Theme 9)**			**SUBORDIANATE THEMES: My Duty**
	'Not getting the care unless I am there' 'So, I had to pay attention then. So, I have set up a system that allows the carers to come in and do what they do, give me a certain amount of freedom, but not necessarily peace of mind because I'm always worried that she is vulnerable and she is not getting 24-hour care unless I'm there. Like	**Warm and Comfortable'** The satisfaction, really, is the overall picture, the fact that she's still here... As far as I can tell, she's fairly happy. She's warm and comfortable. **Page 12: Lines 439-440**		**the best I can for her** I'm happy that I can do the best I can for her, but I always want to try and do things as well as I can. I, obviously, want to try and help my wife as much as possible with things **Page 5: Lines 166-168**			**My duty** Oh yeah, no I feel perfectly happy with that no objections doing at all it's within my capability yes so I should 'a do it myself and then have somebody else to try and do it. I think it's oh well my duty to it does as well that right, it my duty and I will do it as long as I can, **Page 5 lines 152-159**

	when I am in the hospital, that was an issue with social services; they did offer emergency respite for me and between my fiancé and the carers we would manage. **Page2 Lines 47-52**						
	'Defensive of her needs' 'Also, I feel quite defensive of her needs, in the case of what social services offer, which in terms of her vulnerability daily. What is acceptable to them is not acceptable to me in this case' **Page 2 Lines 60-62**	'Looked after' I feel some satisfaction that I've been able to keep my promise to her and cope……. I make sure it all happens and that's good. It's part of life. **Page 14: Lines 519-526-527**		**Best to try and help** I would like to have given a more satisfying. I do the best I can for Marion, she's my wife and she brought up the family and everything. She's always done her best to try and help other people and to do her best for the family. **Page 10: Lines 351-353**			**Muddle my way** And I don't whether what going to happen, I do know what's expected my older brother's wife she has got to go into a home and he's going through what I expect that's what I will go through in the next number of years. So, I am aware of that and I know that she will be worse to care for and I do know that I will muddle my way through and that's the job of a carer and I have heard the stories and I know what's going to happen. Well, I will cross that bridge when I come to it. Not Much I can do about it can I **Page 4: Lines 141-147**
	'Feels secure' In an emergency, it is always the right thing to do, but I've tried to leave as much personal care so that my mum has a separate relationship with me that is about her being with someone			**do their part** As she's always done so much for other people, her kind help with things at the church, making sure everything runs smoothly. Now, as I said, she must sit back and let other people do their part**. Page 10: Lines 365=367**			

	she loves and somebody she always feels secure around and does things for her. So, we're trying to separate the relationships and caste offs. **Page 3 Lines 88-90**						
	'is safe and comfortable and protected' But care ends up being knowing the person and, possibly without them even knowing, making sure their life is safe and comfortable and protected. A lot of that is background stuff, but you are not, necessarily, in contact with the person, but you're still caring. You become responsible and you carry that and you fight their battles for them and protect them from other people that might take advantage in the world **Page 3 Lines 110-114**						

	<u>'security, safety and of feeling loved'</u> But what makes me happy is when I know she's feeling those feelings of security, safety and of feeling loved. And she gives me that feedback and I know that's a good place. **Page Lines 6: Lines 229-230**						
	<u>'Protected'</u> My mum is happy in her own little world if she's protected. And we've all got to protect our own little world and be happy in ourselves, and with friends and family to do that with, and with artists to share it with on a higher level socially, conditions and all that Prime Minister Thatcher, she went doolally, so none of us are immune. It doesn't make the experience of living less important.						

	Page 9 Lines 353-357						
	So, it's not like a normal relationship; it's like a relationship through a window or glass. It's a bit like you can put your hand up to it, like an incubator, and you can do what's needed to make the person inside feel comfortable. That might be my relationship with her, because I can't I think Val has got a more mutually projected bond or meeting place, but psychologically, in a situation like this and with mainly it's natural to project what you would like to see back onto the person and, if they give you the right triggers and responses, then you feel that. It's not that you share that.						

	Page 10 lines: Lines 393-399						
SUBORDINATE THEME APPRECIATION	**4-Appreciation of Care (Theme 13 & 19, 21) I best care**					**SUBORDINATE THEME RECOGNITION** **3-Recognition (Theme 5)**	
	'**Real person'** It's pleasing when my mum, maybe she's in pain or discomfort for some reason, and when that's relieved and you can see the real person in there appreciates it. It's pleasing to see that when she does have a genuine human appreciation of having been cared for. Page 8: **Lines 295-298**					**Recognition by carer** I am not sure she realizes even who I am and when she comes through that period and every thing alright she will often shed a little tear and she realises what been happening and regrets all. These are the sort of things that the medical field know about. **Page 3: Lines 91-95**	
	I love you Then there is the more intimate joy where she will say, 'I really love you,' and she is expressing that I am important to her and that she has taken me in and the figure in her life that she leans on, that she relies on, that she feels						

	safe with. Page : **Lines 311-313**						
	'**Affection or appreciation'** Again, there are times when she does. I'll make a nice soup for her, put it in front of her, the normal care, she'll be drinking it and it's the same soup, but she's in the mood for sharing affection or appreciation. And its current to her. And there is no rhyme or reason to it. So, I don't overvalue the good times, because then I get drawn into what's going on in her head and it's irrelevant to her needs. As long as she's being fed and looked after, that's the first thing. Page 14: **Lines 527-532**						

MASTER THEME 2: Support and Sharing with others.							
SUBORDIANATE THEMES Sharing with others	**5- Sharing with others (Theme 5)**		**3-Sharing with Others (Theme 9)**				
	Sharing with others I feel very passionate about sharing information because it gives me a chance, and you said you're recording it and might send me a transcript, it's easy to talk freely from being honest, particularly when you're explaining it to someone who's interested, they've got some experience and understanding, and you know that they're listening and understanding a lot of what I'm saying. It's very satisfying to take part in that sense. Page 14 lines: **Lines 540-546**		**Good to talk** Yes, it's you know its good to talk about the problems and issues around the illness. We do have people coming – social workers, carers and other people – coming and talking. Useful to talk about the problems with other people. **Page 4: Lines 121-123**				

SUBORDIANATE THEME: Supported				**Support (Theme 5)**			
				<u>Support groups</u> Having these support groups to go to and as a member of a church, we get support from other members of the church. Everybody has been sympathetic and helpful and I could always go across the road to get a carer, they said, if I wanted to. **Page 5: Lines 168-171**			
				<u>Voluntary bodies</u> I feel very happy that there are these organisations – the carers in Hertfordshire and **we came across** – all these organisations that do a wonderful job in supporting people who have a relative with dementia. I feel very pleased that there are these voluntary bodies. **Page 5: Lines 174-177**			
				<u>Family & friends</u> Family, on the whole, are very supportive and friends are very supportive. I think that's nice, that we both have friends at the church and people that we enjoy seeing. **Page 7: Lines 257-259**			

MASTER THEME 3: Managing to Cope.							
SUBORDIANATE THEME: Coping		**1-Coping (Theme 7)**					
		<u>Satisfaction in being able to cope</u> 'Well, there is general satisfaction with being able to cope, quite honestly. It's quite satisfying that I have been able to cope. **Page 12 Lines 426-427**					
		<u>'Satisfaction and Fulfilment'</u> No, I feel some sort of satisfaction and fulfilment that I, personally, have been able to cope with dealing with things as they've shot up……. Every now and then somebody turns up with a laugh with so that's good. I can't say I feel any happiness in any of the stuff, just a feeling of satisfaction and fulfilment. It's not a happy thing to be doing. **Page 12: Lines 430-431 & 434-436**					

MASTER THEME: 4 Just Normal.							
SUBORDIANATE THEME: Normality.				**<u>3-Enjoyable moments (Theme 6, Theme 8 and Theme 7)</u>**			1- Normality (Theme 3, Theme 5, Theme 7)
				<u>Things we both enjoy</u> We both enjoy watching these together. We often have become much sleepier in the evenings. Often, she goes to sleep in the front room and I have a job to wake her up. Sometimes I persuade her to come up to be and it's the middle of the night. I usually make her a cup of tea and get her back to bed. **Page 5 Lines 185-189**			**<u>'Encouragement'</u>** I know she does she has lot more confidence now back I know she does than before. She's doing more things during the day then she was not doing before and also, she's quite good in the whole day and things like that I just tend to get and do with things like that. You know she's quite active in the kitchen I tend to encourage to do much of that if she possibly can. It goes wrong at times but there's nothing wrong with that. **Page 2: Lines 54-59**
				<u>Enjoy things</u> When we are able to enjoy things like the meal we had at the **[0:25:41.4]** café. That was a week ago, on Monday and was very enjoyable. We've got two roast meals to go to this week. We go to the Civil Service Retirement Fellowship because people who were in the civil service can go to the fellowship and that's a monthly meeting. **Page 6: Lines 200-204**			J**<u>ust Normal;</u>** I don't know really when she's resting when she's clean mentally, I don't mean in that way. When she's up, when she's feeling reasonably okay, I know whether she's feeling happy or whether she's just feeling normal and happy. I don't see her any more happy it's just normal its things like that. **Page 3: Lines 82-85**

				<u>Social events</u> It's very nice if we both can enjoy these events. We enjoy going to the church each week and we have coffee mornings and things like that. We have, every Friday, a coffee morning we can go to and the other meetings – the Wednesday church group is once a week and we have a monthly meeting with the Civil Service Retirement Fellowship. So, all of these things break the week up and are nice social things. **Page 7: Lines 232-237**			**<u>Feeling better and doing things</u>** Oh yes, yes when she's normal like that she's acts how can I say she wants to be more involved which is a good thing to a point she says and questions and when she does not want to do anything its hard work. Yeah, it is not probably a very happy and probably yeah you get to enjoy things when she is probably okay and when she does enjoy and is feeling better and she tries to do things for herself. **Page 3 Lines 87-91**
				<u>Voluntary work</u> It's something to look forward to when we have these kinds of activities and events to go to. Even with Age Concern, I get satisfaction in trying to make sure that everything runs smoothly with the **running,** that people are going to turn up and that there are two people on duty. I've always had a busy life. When I was at work I did voluntary work then as well as doing my own work that I was paid for. I've			**<u>Not so demented'</u>** No, not really, I am just pleased when I can be when she is normal really can be really her old self. No, I don't think there is anything else that makes me pleased. I think when you have days when her condition is worse, you have days where she is more responsive and yes that's when I would be more excited No I don't think there are things that are pleasing or exciting like that, its only when I can see things she can do things for herself and is no so demented. **Page 4: Lines 115-120**

				always enjoyed doing the voluntary work. **Page 6: Lines 212-217**			
							'Feel a lot better' I feel a lot better because what can I say I can be myself again more when she is off doing her own thing but I can't do everything and well then I can't be me. **Page 3 Lines 104-105.**
MASTER THEME 5: Cherished Moments.							
SUBORDIANATE THEME: Cherished moments	**3- 'Pleasing moments' (Theme 12, theme 20)**		**1-Cherished moments (theme 3, theme 5 & Theme 8)**		**1-Fleeting moments (Theme 5 & 7)**	**1-Pleasing Moments (Theme 5)**	**2- Cherished moments (Theme 6**
	Friends I have mentioned a few. The odd occasion, going out and, maybe, for a drive on a sunny day and she's looking and pointing at trees and clouds and saying that's peaceful. I find it pleasing when her friends came round once and they sat there and had a cup of tea. Obviously, she didn't know who they were anymore, but it was pleasing to see that they had access and could see she		**We Cherish the Moment'** Yes, I mean just to be able to have periods when he reasonable to say and communicative is quite rewarding in that respect. We cherish the moment. **Page 3: Lines 71-73**		**Happiest** hold her hand and it goes back to the old days where there was a lot more of the normal affection between us. I suppose that's the thing that makes me happiest. **Page 5: Lines 165-167**	**Makes me happy** Anything that makes me happy? she often struggles to get it out I love you something like that or smile at me and that's the most satisfying there's nothing to beat that. **Page 3: lines 73, 75-77**	**Cherished Moment** Her kissing by me, keeping me warm and running in and out of the house like that, on an adventure with her friends, they take her out to go to the shops, doing things, going shopping things like that I don't know when buying things like that. I think she thinks that I restrict her from buying things; I don't restrict her from buying things like that do I. And she knows she makes up her own mind what she wants without me look over her shoulder basically. **Page 3: Lines 93-98**

	was looked after. **Page 8 Lines 281-285**						
	Happy moments' And I bought her an ice cream and she was conducting the music with the ice cream and then offering me some and then pointing around saying, 'Look, look!' So, that was a happy moment, to see her happy again and to know that you have an influence on her happiness is rewarding and, yes, I'm happy too. **Page 7 Lines 240-247**		**'Happy and Contented'** If she's happy and contented then that's obviously very pleasing for the whole family, generally. **Page 3: Lines 73-77**		**Moments are fleeting** Well, just, as I say, the odd occasion that she's drifting off to sleep and she's pleased to have me. That makes me happier, but these moments are fleeting. Quite frankly, nothing makes me joyful at all now, but I can accept it. I'm very much a stoic in my now age of life**. Page 6: Lines 194-195**	**Whole things worthwhile** Oh wonderful, wonderful we still sleep together or when she goes to bed before me or if she's awake she obviously sees me and is happy and cuddles me. And holds me and those are things that make the whole thing worthwhile. Those are the things that are most satisfying. **Page 3: Lines 81-84**	
	Special Moments Once she was just outside in the garden wandering and she was just smelling a rose all by herself! That was a special moment **Page 8: Lines 287-288**		**Enjoyed in the past** Yes, he reacts to you and sometimes I'll put on some old Asian songs for him, which he enjoyed in the past, and he likes to watch those and sometimes we'll sit there and watch things together on what's on and he sometimes will react and interact			**Most Joyful** Most joyful? It's lovely when she looks at me and smiles at me that very satisfying it's like guess it the knowledge she's still in there somewhere yes **Page 3: Lines 87-88**	

			with them as well. **Page 3: Lines 89-92**				
	‘**Part of this world’** , ‘Hmm, oh,’ or she’ll start laughing when everyone else is laughing on the telly. She hasn’t got a clue what’s on it, but she’s following the rhythm, the intonation, the sense of what’s going on and she’s still in touch with that. In her head, she is still part of the world. **Page 8: Lines 300-303**		**Old Self** It’s just there are some moments when he communicates well with you and, obviously, you see a little bit of his old self back. **Page 3: Lines79-80**			**Very satisfying** She always liked dancing and she will get up and have dance around and want me to get and have dance with her and these things are very satisfying. **Page 3: Lines 102-104**	
	Music With music – a friend of mine has a violin and he came and stayed for a bit and he played some music with her. She used to enjoy music in her youth, she played the piano. So, then she picks up on music and starts either conducting it or singing along with it and feeling it. **Page 8: Lines 304-307**		**Normal self** Yes, you can see that he’s happy. He talks and he’s at times and he’s not in any distress. He interacts with people around him and he will have a joke sometimes with people around him. **Page 4 Lines 113-115**				

	<u>Special moments</u> There are very few moments when she's tucked up in bed and I'm saying goodnight, and she's like a little child you put to bed – that special moment when you kiss them goodnight and turn the light off. We're both happy – I'm happy to say goodnight and she's happy that she's safe in bed. She's got a context of safety that I've created. So, her dementia does not worry her in that sense**. Page 14: <u>Lines 532-537</u>**						

Core Unit: 4 Teaching and Training Competence MSc Lecture for Students.

Case Study

Students: Second Year MSc Health Psychology.

Module: Lifespan, Gender and Culture.

Topic: An Aging Population.

Unit 4.1 Plan and design training programmes that enable students to learn about psychological knowledge, skills, and practices.

In the early stages of the teaching and training competency the 'Process consultation Model' (Schein, 1987) was used, and in this stage the needs assessment and the learning objectives of the teaching course were established. Communicative e-mails and telephone calls were made between both the course modulator (contact client) and the trainee health psychologist. The aim of these discussions was to firstly understand the needs and wants of the contact client, secondly to identify the MSc students learning objectives and outcomes and thirdly to clarify the role of the trainee health psychologist.

The trainee health psychologist also drew on her MSc experiences and made sure during the systematic review that she selected information not only in-line with the course 's requirements but also abreast with the latest political/ economic developments regarding

health and the aging population (Please see Appendix 1 in the practice log book). This part of the research process that the trainee health psychologist found both challenging and time-consuming. However, the learning experience was extremely helpful in planning the lecture materials (Please see appendices 2 in the practice log book and Appendix A for needs assessment. For appendices 3 and 4 in the practice log book).

In the didactic presentations and the group-work exercise the trainee health psychologist tried to cover all the different ways individuals approach learning (pragmatists, reflectors, theorists and activists) (Honey & Mumford, 2000) and considered three different psychological models as follows:

- The Stages of Change model (Prochaska & Diclemente, 1983)
- The Health Belief Model (Becker & Rosenstock, 1984)
- The Self-Efficacy Model (Bandura, 1986)

For more information please see Appendix 5 in the practice log book.

Twenty students attended the teaching session, of which all were full-time students, apart from two who studied and worked both part-time. One of the students who had special and educational needs (visually disabled) failed to attend the teaching session.

The trainee health psychologist at the start of the teaching session found it beneficial to ask the students a series questions regarding their MSc course status and carried out an informal needs assessment on the MSc students. The information gained from such an assessment helped the trainee health psychologist to gain more of an insight into the

student's knowledge, their learning objectives and allowed the trainee health psychologist to adapt and pitch the teaching session accordingly (Please see Appendix 6 in the practice log book). This had not been planned by the trainee health psychologist but was helpful on the day because of the information obtained.

These questions were designed to encourage the students to think and reflect more openly on the subject area and to take more control of their learning and development. This type of teaching style is in line with the learner-centred model (Exley & Dennick, 2004) where the teacher acts as a facilitator of learning by appreciating both the knowledge and experience that the students bring to the classroom and works with them in harmony to take more control and responsibility. In this type of teaching style, the teacher acts more of a chaperon and collaborator of learning, by focusing on the needs, interests and learning styles of the student rather than someone who promotes 'rigid learning tasks' (Exley & Dennick, 2004).

It was imperative that the lecture was planned, organised and designed with precision and according to all the learning styles. It was also important that the information being delivered not only increased the student's knowledge base but was qualified and thought provoking to allow students to think and evaluate topics more critically.

During the planning phase, the trainee health psychologist was very conscious of the timing and time being spent (Please see Appendix 7 in the practice log book) on each component of the training (Please see Appendix 8 in the practice log book). She was also very aware that in her delivery she needed to be audible, clear and comprehensible.

During the group exercise, all the instructions were provided to the students verbally, in order not to discriminate against someone with a visual disability. (Please see Appendix 9 in the practice log book and Appendix B for student group exercises). The group exercises were designed to encourage the students to communicate, engage, learn, and share and exchanging information and ideas.

Due to the limited participation from the audience, the teaching style during the didactic presentations was adapted by the trainee health psychologist more in line with the 'Teacher-Centred Model' (Exley & Dennick, 2004). When implementing such a teaching style, the teacher uses her/his expertise in the students learning. In such a situation, the teacher not only acts as a transmitter of knowledge but also a conveyer of information, when interacting, bonding and organising students that take on a more of a receptive role to learning (Exley & Dennick, 2004).

A variety of interactive approaches were used in the classroom style setting (e.g. audience participation via open-ended questions, use of flip chart paper, group work, feedback via student discussions, didactic presentations via positive reinforcement and questions) to accommodate the different learning styles of the students.

The students were split into 4 groups of 5 and were provided with a piece of paper with written information. They were then asked in their groups to discuss the information and present their findings back to the class. During the group-work, the trainee health psychologist made sure that there was enough time for the students to ask questions, reflect on their learning and development. For a summary of the type of materials and the

different kinds of media used during the communication training (please see Appendix 10 in the practice log book).

Unit 4.2 Deliver such training programmes.

Lessons learnt.

The only teaching opportunity the trainee health psychologist had previously had was when delivering training in her place of work. Having been approached by a senior lecturer at the University and on agreeing to deliver the teaching, the trainee health psychologist had some questions and concerns (Please see Appendix 11 in the practice log book). These concerns regarded the group size, dynamics and the students' knowledge on the subject area. During her preparation, she realized that she had over-compensated for the student with a visual disability and therefore had included less visual aid in the materials and this was feedback by the students in the evaluation forms.

As the students sat next to someone they already knew or felt comfortable with. The trainee health psychologist used an ice-breaker by getting the students to answer some questions at the start. At the time this seemed a good idea to get the students more actively involved. However, on the contrary, this was perceived by some students as being too direct, intimidating and thus inhibited their participation (Exley & Dennick, 2004). On reflection, it might have been more useful for the students to be given a few minutes to settle down and then get them to discuss amongst themselves in pairs. This would have reduced the student's anxiety and would have optimized their self-confidence (Exley & Dennick,2004). Due to the lack of participation, the trainee health psychologist led

discussions with students more willing to take part. In hind-sight, this was not a good tactic because some students became more distant and more reluctant to take part.

During the group-work, the trainee walked around and visually observed the communication amongst the students. She learnt to listen carefully to the student's discussions and where necessary interacted and managed to re-engage the students back into group discussions. She also provided the students with reassurance and support via ideas when they got stuck with their own line of thoughts. In this way, it was helpful to view the different types of non-verbal behaviour students displayed, the type of questions they asked and the information that sparked their interest for longer periods of time.

Training methods and materials.

One of the challenges the trainee health psychologist faced was that even though she had planned the session on the day based on the 'Learner Centred Model' during the teaching she had to change it to more of a 'Teacher Centred Model' (Exley & Dennick, 2004). On further, reflection she realized that this later style of teaching had not been beneficial to all the students. To remedy the predicament, she tried to get the students involved again by asking more questions or getting them to discuss their feelings or thoughts around topics.

Most the students were pragmatists and enjoyed the group work activities. Some students were reflectors in wanting to stand back, listen and not wanting to be in the limelight or have the tight timelines. There were some students that were theorist's that wanted to have real credible facts and figures and one student was an activist who enjoyed the lime-

light and wanted to problem-solve all the questions that were raised in the lecture (Honey & Mumford, 2000).

On further reflection, the trainee health psychologist realized that she needed to be aware of all learning styles and flexible in her teaching approach. Therefore, in future, preparation of the teaching materials she needed to make sure that she catered for all the students and not just one student with a visual disability.

On reflection, the trainee health psychologist used a tool called the circle of influence (Stephen, 2006) in which she realised there were some elements of the session, she could not influence as follows:

- The student with a visual disability not turning up.
- The fluctuating temperature in the room.
- The trainee health psychologists first time in teaching the MSc students.

However, there were other elements that she could improve and for future learning, these were her teaching style; her listening and understanding skills; and the content of her teaching materials.

On the day, the students commented on the coldness of the room. In response, the trainee health psychologist tried to turn up the temperate in the room via the air conditioning unit but this proved to be unsuccessful. Being flexible and time aware the health psychologist brought the breaks forward, added in two extra breaks to allow the students to get a hot

drink and spoke to the university regarding the temperature in the room. In hindsight, this was something that she should have checked in advance but due to the limited availability of the room prior to the teaching session, this was not possible.

Unit 4.3 Plan and implement assessment procedures for such training programmes.

The trainee health psychologist throughout the teaching, constantly monitored, referred back to the students via positive reinforcement, complemented the students on their effort and ideas and thus encouraged the students to elaborate further without being too critical. At the end, she again assessed how they felt regarding there learning objectives and evaluated if these had been achieved. The learning objectives of the students were met and this was evident by the student's overall scores for the learning outcomes, which were changed from zero at the start of the session to three at the end of the teaching session**.**

For Unit 4.4 Evaluate such training programmes.

The session was assessed via an evaluation form. The aim/objective of this form was assessed the trainee health psychologist, teaching and delivery style; the content and presentation of the materials: whether session had met all the students learning outcomes, what the students had enjoyed and where the training could be further improved (Please see Appendix 12 in the practice log book and Appendix C for tables showing evaluation results for teaching session).

Conclusion.

The trainee health psychologist realised that even though she had enormously enjoyed delivering the teaching session she further discovered that she had thoroughly enjoyed the group work more and this was something she would like to further develop. The whole experience had been extremely useful to the trainee health psychologist in her continuous professional development. For future learning' (Please see Appendix 13 in the practice log book). At the end, the students were provided with a list of references for future research (Please see Appendix 14 in the practice log book and Appendix D for reflection and future learning).

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Appendix A Needs Assessment.

Unit 4.1 Plan and design training programmes that enable students to learn about psychological knowledge, skills, and practices.

Need assessment of the audience.

Teaching and Training module.

Health Psychology plays a significant role in society by looking at the various health issues and behaviours effecting individuals/group of people within a given society and within a Health-care setting. It explains how such health behaviours can change over time and identifies the different types of health issues that can accompany these behaviours. The MSc health psychology course at City University, London has both a strong theoretical and pragmatic framework. The MSc students at City University will be able to gain a better understanding of how the various theories of Health Psychology work and how they can be critically evaluated and applied in the real world.

This course module is based on lifespan, gender and culture, there will be a group exercise in this lecture, to enable students to think and reflect more on the unique set of health issues effecting an aging population, what challenges this brings to both the carer and the effects this has on society, culture and gender. Also, the students will be asked to identify ways in which the management of the old people within the community can be improved in line with Health Psychology interventions.

This lecture will enable students to think more critically and evaluate the benefits and disadvantages of an aging population in terms of living longer, gender and culture. The students will be provided with a theoretical framework of an aging population and the various health psychology models used to promote behaviour change in an aging population via health promotion and governmental campaigns. Health Psychology models such as The Health Belief Model (Becker & Rosenstock, 1984), Stages of Change Model (The Transtheoretical model) Diclemente, Prochaska, Fairhurst, Velicer, Velasquez and Rossi (1991); Prochaska and DiClementine (1984); Prochaska, DiClemente, and Norcross (1992), and self-efficacy and barrier (Bandura, 1997; Pender, 1996) will be examined in relation to various research studies carried out.

During the lecture and the group exercise, different teaching styles will be applied such as presentation, discussion and group exercise. A learner-approach instead of a teacher-led approach will be applied to encourage collaborative learning skills amongst the students (Exley & Dennick, 2004). As most students have different learning needs and one student in the group of 20 has diverse and special educational needs. The lecture and the group exercise will try to include these principles of learning.

From, the theoretical presentation and the group exercise of this lecture, the students will hopefully gain a better insight plus understanding into some of the issues (both positive and negative) that effects the elderly population, the cultural diversity and gender. The students will hopefully be able to identify what part health psychology models and health psychologists can play within healthcare community setting. This teaching session will hopefully increase their knowledge base and provide them with the tools to think and

evaluate critically matters effecting an aging population and the contribution health psychology must play.

Aims and Objectives.

- To provide the MSc students with a better understanding of how the various theories of Health Psychology work and how they can be critically evaluated and applied in the real world

- To increase the student's knowledge on the unique set of health issues effecting an ever longer living aging population, the challenges this brings to both the carer, the effects this has on effects this has on society, culture and gender.

- To enable the students to think and evaluate critically matters effecting an aging population and the how health psychology should play a role in this behaviour change.

- To familiarise students with an understanding of the different types of health interventions that are being implemented in the society via health promotion and governmental campaigns for the elderly to encourage behaviour change.

Learning Outcomes.

- On successful completion of this lecture students will be able to:

- Be able to identify the benefits and disadvantages of an aging population in terms of living longer, gender and culture.

- Be able to understand the current and diverse issues effecting an aging population, gender and culture.

- Knowledge of the various methods and approaches applied within society or a health-care setting in helping an elderly population in implementing changes in behaviour.

- Awareness of the different types of health interventions that are being implemented in the society via health promotion and governmental campaigns for the elderly to encourage behaviour change.

- Evaluate the theories of health psychology and reflect the contribution a health psychologist can make in society.

Appendix B Student Group Exercises.

TEACHING AND TRAINING GROUP EXERCISES

Age and Culture Group Exercise-1

'Caring has been said to give meaning to people lives and to determine what matters' (Heidegger, 1975)

1-Instructions: In your group please choose one person to read the following paragraph out aloud to rest of the group.

Paragraph

'In the Chinese family structure the oldest son remains with his parents and he and his family provide the care required for the elderly parents. The sons are selected from an early age and usually delegate the caring responsibilities for their aged parents to their wives (Wolf, 1968). The sons whose families provide the care usually stand the most chance of inheriting property upon their parent's death (Chow, 1983). In such a kinship ties the elderly parents share the house-hold with their children and provide care to the grandchildren' (Finch & Mason, 1991)

2-Then in your group discuss the **positive aspects** of the Chinese family culture in relation to care of the elderly, the effects this has on the elderly person's quality of life, on the individuals that provide the care and type of care the elderly receive, the effects this has on gender and the society at large, and what part you as Health Psychologists can play within this community setting.

3- At the end of your discussion, please select one person in your group to feedback your findings to the rest of the class.

Age and Culture Group Exercise-2

'Caring has been said to give meaning to people lives and to determine what matters'

(Heidegger, 1975)

1-Instructions: In your group please choose one person to read the following paragraph out aloud to rest of the group.

Paragraph

'In the Chinese family structure the oldest son remains with his parents and he and his family provide the care required for the elderly parents. The sons are selected from an early age and usually delegate the caring responsibilities for their aged parents to their wives (Wolf,1968). The sons whose families provide the care usually stand the most chance of inheriting property upon their parent's death

(Chow, 1983). In such a kinship ties the elderly parents share the house-hold with their children and provide care to the grandchildren' (Finch & Mason, 1991)

2-Then in your group discuss the **negative aspects** of the Chinese family culture in relation to care of the elderly, the effects this has on the elderly person's quality of life, on the individuals that provide the care and type of care the elderly receive, the effects this has on gender and the society at large, and what part you as Health Psychologists can play within this community setting.

3- At the end of your discussion, please select one person in your group to feedback your findings to the rest of the class.

Reference

Heidegger, M. (1975). *The Basic Problem of Phenomenology*. In A. Hofstadter Translation. Bloomington: University Press Indiana Inc.

Age and Culture Group Exercise-3

1-Instructions: In your group please choose one person to read the following paragraph out aloud to rest of the group.

Paragraph

In the Western Caucasian family structure, the Children leave home at a younger age. The expectation in western families is that the married partners will care for one another. Usually, the first choice of the caregiver is generally the spouse and it is he or her who is often the person living in the household. In western Caucasian families, the personal identity of the individuals feature more than kinship ties of the families (Finch, 1989)

2-Then in your group discuss the **positive aspects** of the Caucasian family culture in relation to care of the elderly, the effects this has on the elderly person's quality of life, on the individuals that provide the care and type of care the elderly receive, the effects this has on gender and the society at large, and what part you as Health Psychologists can play within this community setting.

3- At the end of your discussion, please select one person in your group to feedback your findings to the rest of the class.

Age and Culture Group Exercise-4

1-Instructions: In your group please choose one person to read the following paragraph out aloud to rest of the group.

Paragraph

In the Western Caucasian family structure, the Children leave home at a younger age. The expectation in western families is that the married partners will care for one another. Usually, the first choice of the caregiver is generally the spouse and it is he or her who is often the person living in the household. In western Caucasian families, the personal identity of the individuals feature more than kinship ties of the families (Finch, 1989)

2- Then in your group discuss the **negative aspects** of the Caucasian family culture in relation to care of the elderly, the effects this has on the elderly person's quality of life, on the individuals that provide the care and type of care the elderly receive, the effects this has on gender and the society at large and what part you as Health Psychologists can play within this community setting.

3- At the end of your discussion, please select one person in your group to feedback your findings to the rest of the class.

Appendix C Tables 1 and 2 Showing the Evaluation Results for the Teaching Session.

For Unit 4.4 Evaluate such training programmes.

The teaching session was evaluated by twenty students and the results are concluded from the student's evaluation forms. The trainee health psychologist was graded by the students as 1 being Excellent and 5 being Poor.

Table 1: Shows the Assessment Criteria Grading for the Trainee Health Psychologist for the MSc Teaching Session.

Trainee Health Psychologist Grading.	**1 Excellent**	**2**	**3**	**4**	**5 Poor**	**No Score**
Assessment Criteria.						
Clarity of Structure.		7	9	2		2
Appropriateness of content and quality of arguments.			10	4		6
Verbal Communication.		9	9			2
Use of handouts.		7	8	3		2
Interaction with audience and response.		7	11			2

Summary of key findings in table 1 are discussed below as follows:

Clarity of structure.

- 7 students graded the trainee as 2.
- 9 students graded the trainee as 3.
- 2 students graded the trainee as 4.
- 2 students did not grade the trainee.

Appropriateness of content and quality of arguments.

- 10 students graded the trainee as 3.
- 4 students graded the trainee as 4.
- 6 students did not grade the trainee.

For verbal communication.

- 9 students graded the trainee as 2.
- 9 students graded the trainee as 3.
- 2 students did not grade the trainee.

Use of hand-outs.

- 7 students graded the trainee as 2.
- 8 students graded the trainee as 3.
- 3 of the students graded the trainee as 4.
- 2 students did not grade the trainee.

For interaction with the audience and response.

- 7 students graded the trainee as 2.
- 11 students graded the trainee as 3.
- 2 students did not grade the trainee.

Table 2: Shows the Students Suggestions In Regards To Their Likes, Dislikes and How the MSc Teaching Session could have been improved.

Categories	Group work	Group Interaction	Hand Outs & References	Visual aids	No Comments
Likes	11	4	3	0	2
Dislikes	5	3	0	2	10
Improvement	0	0	0	10	

Summary of key findings in table 2 are discussed below as follows:

Likes.

-11 students out the 20 suggested that they liked the group work.

-4 students out of 20 suggested that they liked the group interaction.

-3 students out of 20 suggested that they liked the use of hand-outs and references.

-2 students out of 20 did not provide any comments.

Dislikes.

-5 students out the 20 suggested that they disliked the group work.

-3 students out of 20 suggested that they disliked the group interaction.

-None of the students suggested that they disliked the use of hand-outs and references.

-2 students out of 20 suggested that they disliked the visual aids.

-10 students out of 20 did not provide any comments.

Improvement.

-10 students out of 20 suggested that the visual aids needed to be improved.

--10 students out of 20 did not provide any comments.

Overall the teaching session was positively evaluated and some suggestions were made by the students for future improvement and learning.

Appendix D Reflection and Future Learning.

Reflection and Future Learnings For The Trainee Health Psychologist.

During the preparatory and delivery stage, the didactic presentations were very wordy and in future, the slides need to more audience-friendly with less text on them with more points for discussions and reminders.

Another lesson learnt was that instead of instructing the students to get into groups of 5 and instructing students from the back of the class to come forward and vice versa. She should have allocated numbers to the students from 1 to 5 and asked the student representing these numbers to join the group with the same numbers. In retrospect, this would have been less stressful to the students.

On further reflection, the trainee health psychologist realized she had enhanced her existing organisational, planning and delivering skills but also strengthened her listening and understanding skills. She learnt about the various learning styles in practice and how as a facilitator of teaching she could improve her teaching style.

Core Unit 4 Teaching and Training for Volunteers and Professionals.

Case Study:

Trainees: Volunteers and Health Professionals

Training: Communication Skills.

Background and Context.

The Trainee Health Psychologist was involved in delivering a three hours training session on communication skills on the 12th of February 2010 to a group of community volunteers from various cultural backgrounds. The training was organised by the North London National Health Service (NHS) and Primary Care Trust (PCT) and for reasons of confidentiality, the NHS PCT will be referred as the North London NHS PCT throughout this document. The training session was part of a Healthy Communities Collaborative initiative. The aim of this initiative was to increase the number of people seeking medical advice for cancer symptoms; to facilitate the earlier diagnosis and treatment of breast, bowel and lung cancers; and to improve the targeted projections by reducing the number of early cancer deaths in North London by 2010.

The training was delivered at a North London NHS Hospital and was designed to increase the volunteer's knowledge and understanding of communication skills and to enhance the volunteer's confidence when approaching the public.

Outlined below is a synopsis of how the trainee health psychologist designed, planned, delivered the training session and the experience she gained.

Unit 4.1 Plan and design training programmes that enable students to learn about psychological knowledge, skills, and practices.

The need, assessments and the learning objectives of the training session, in the preparatory phase, was established via the Process Consultation Model (Schein, 1987) (Please see Appendix 1 in the practice log book). As this partnership developed between the Project Manager (Contact Client) and the trainee health psychologist, the relationship continued along the lines of the Process Consultation Model (Schein, 1987).

The aims/objectives of the above discussions were as follows:

- To have a better understanding of the project outline (Please see Appendix 2 in the practice log book).

- To provide a clearer picture of the needs, wants and expectations of all the parties involved (Please see Appendix 3 in the practice log book).

- To provide clarification in regards to the training and learning outcomes for the volunteer trainees (Please see Appendices 4, 5 and 6 in the practice log book).

The trainee health psychologist drew on her own previous experiences, as a trainer/trainee both within and outside her work-place and implemented this within the creation of the training materials.

A systematic approach was adopted by the trainee health psychologist when preparing the materials. This was because the information presented by the various literature search engines covered only specific aspects of communication (Please see Appendix 7 in the practice log book). On further reflection, the trainee health psychologist realised that she needed to consider other diverse areas of communication such as client '*Sympathy and Empathy'* (Moss, 2008) and *'cultural sensitivity'* (Moss, 2008).

In the didactic and practical exercises, the trainee health psychologist covered all the learning styles (pragmatists, reflectors, theorists and activists) (Honey & Mumford, 2000) and considered the 'Stages of Change Model' (Prochaska & Diclemente, 1983). The stages of change model was used to assess the volunteer's readiness to carry out a behaviour change when approaching the public and the challenges they might encounter when coming face to face with the public as part of their change process. This methodology allowed the trainee health psychologist to be more reflective and creative when designing the training materials.

Twelve trainee volunteers attended the training session, of which eight were from a lay background and four of them were from health background (Nurse, Pharmacist, Health Trainer and Breech Family Worker). For some of the trainee volunteers, English was their

second language because of their cultural background. There was no trainee volunteer that had special, educational needs and wants.

The trainee volunteers signed an attendance sheet at the start of the training session and on completion of the training session were provided with training certificates (Please see Appendix 8 in the practice log book). The trainee volunteers at both the start and end of the training session were asked to complete an informal needs assessment form based on their confidence levels in terms of their communication skills (Please see Appendix 9 in the practice log book and Appendix A for training pre-evaluation form). At the start of the training, all the trainee volunteers were immediately engaged in group work and a feedback session (Appendix 10 in the practice log book). The open-ended questions in this session were designed to act as an ice-breaker and encourage the trainee volunteers to communicate, think and reflect more openly. The trainee health psychologist felt that it was important for the trainee volunteers to be more in control of their training and development process. In the group discussions, some trainee volunteers were more vocal then others and this new-found knowledge helped the trainee health psychologist to pitch and adapt the training session to the various intellects and learning styles. In the session, the trainee health psychologist acted as a facilitator of learning by both appreciating the knowledge and experience that the trainee volunteers brought to the session but also worked in harmony with the trainee volunteers to take more control and responsibility. This type of teaching style is in line with the learner-centred model (Exley & Dennick, 2004) where the trainer acts as a helper and a team player in the students learning, rather than someone who promotes regimental tasks (Exley & Dennick, 2004) for the student.

It was vital that the planned training session was organised and designed with attention to detail. Therefore, the trainee health psychologist ensured that the materials being presented were not only informative but also enhanced the trainee's confidence level. Therefore, all components of communication training session and materials were thoroughly scrutinized by the trainee health psychologist.

The trainee health psychologist was conscious of the amount of time being spent on each item such as the didactic presentations, group work/feedback sessions, (Appendix 11 in the practice log book), questions, the evaluations forms (Please see Appendix 12 in the practice log book) and aware that the language needed to be simple, clear, accurate and comprehensible in the training documents for the trainee volunteers. The reason for this was because she did not want to unfairly discriminate against those whose first language was not English and made sure that all the instructions were given verbally (Please see Appendices 13 & 14, both in the practice log book) during the training session. From previous experiences, the trainee health psychologist made sure that the slides were not over burden with too much text or visual aids. In addition, to this trainee health psychologist sought further advice from her supervisor, the contact client, other health professionals (Please see Appendix 15 in the practice log book) and an external consultant. Even though this part of the process was challenging and time consuming, it allowed the trainee health psychologist to develop the role-plays exercises with a real-life emphasis (Please see Appendices 16 & 17, both in the practice log book) and focus on relevant ideas/ suggestions (Please see Appendix 18 in the practice log book) within the exercises.

There was a large amount of participation by the audience during both the didactic and the group exercise. The trainee health psychologist was delighted to see the trainee volunteers take control of their own learning and developmental process throughout the training day. The trainee health psychologist also found that with some of the trainee volunteer groups she had to use a *'Teacher-Centred Model'* (Exley & Dennick, 2004), where she took more control and responsibility, of the information being conveyed, however, as the trainee volunteers gained a better understanding, of the information they soon shifted the burden of responsibility from the trainee health psychologist onto themselves.

The setup of the room was in a horse shoe style. A variety of interactive approaches were used (e.g. audience participation via questions, the use of flip chart paper, practical exercises, group discussions, didactic presentations via positive reinforcement and researching questions) to accommodate all the trainee volunteers needs.

The group's exercises varied as follows:

- Exercise one consisted of 5 small groups of 2 trainee volunteers.
- Exercise two consisted of one big group of 12 trainee volunteers.
- Exercise three, four and five consisted of 4 small groups of 3 trainee volunteers.

(For more information on how the group work was structured, designed and for reflection please see Appendix 19 in the practice log book and Appendix B for structure, design and reflection on group exercises).

During the didactic presentation and the group-work exercises, the trainee health psychologist ensured that there was enough time for the trainee volunteer's questions and to reflect on what they had learnt during each component of the session. Further suggestions and relevant references were introduced by the trainee health psychologist for the benefit of the trainee volunteers learning (For a summary on the type of materials and the kinds of media used during the communication training, please see Appendix 20 in the practice log book).

Unit 4.2 Deliver such training programmes.

Lessons learnt.

A chartered health psychologist approached the trainee health psychologist regarding the training programme on communication skills and via e-mail introduced the contact client to the trainee health psychologist. On agreeing to deliver the training session on communication skills, the trainee health psychologist had some concerns (please see Appendix 21 in the practice log book) regarding the dynamics of the group (volunteers) in terms of their experience and her unfamiliarity with the subject matter. Upon reflection, the trainee health psychologist realised that she had not paid careful attention to her delivery style as a presenter in previous training sessions and to improve her training skills she attended a training course at her workplace (Please see Appendix 22 in the practice log book).

Not many challenges faced the trainee health psychologist on the day. However, there were certain elements of the training session that were outside her control as follows:

- The half-an- hour delay in getting the training session started. To catch-up, the time lost the trainee health psychologist agreed with everyone in the training session to skip the five minute afternoon tea break and finish on time.

- The contact client interrupting the training session by briefing each volunteer trainees on their volunteer roles. To manage the time the trainee health psychologist requested only one rotation within the group exercise 5.

Unit 4.3 Plan and implement assessment procedures for such training programmes.

The ice-breakers used in the training, on reflection might have been perceived by some learning styles as being too direct and intimidating (Exeley & Dennick, 2004) and could have alienated some trainee volunteers. Whilst for others trainee volunteers this proved to be advantageous and led them to dominate the group discussions. overall, this was an excellent way to get the trainee volunteers to demonstrate their communication skills.

During the group work, the trainee health psychologist listened to the sounds of the discussions and where necessary she intervened, led and managed to re-engage the discussions on the right track. She also provided help, reassurance, and support via ideas when the trainee volunteers got stuck with their own line of thoughts. As the training was delivered in the sprit of a ‘Learner Centred Model’ the trainee health psychologist at times avoided being the expert and worked with the trainee volunteers by listening more to them rather than telling them what to do (Race & Smith, 1996). The trainee health psychologist enjoyed the group work tremendously and found it extremely satisfactory.

Amongst the trainee volunteer, most of them were ‘pragmatists’ and enjoyed the group work. Whereas some trainee volunteers were ‘reflectors’ wanting to stand back, listen and not be in the lime-light. On reflection, the trainee health psychologist realised that she should have engaged these individuals more into the discussions. There was one ‘theorist’ who wanted further explanations regarding facts and figures and one of the trainee volunteers was an ‘activist’ who enjoyed the lime-light and wanted to lead the group discussions (Honey & Mumford, 2000). On the day, a range of accelerated learning techniques was used and the method of ‘learning by doing’ was found to be more effective rather than the trainees ‘just listening’ (Race & Smith, 1996). On further reflection, the trainee health psychologist decided she needed to be more flexible in her approach when trying to engage with the silent trainee volunteers in the group discussions.

The trainee volunteer’s confidence levels in terms of their communication skills were assessed. The trainee health psychologist anonymously completed an informal needs assessment form based on the trainee volunteer’s confidence levels in terms of their communication skills, at both the start and end of the training session. Most of the trainee volunteers reported that their confidence had improved at the end of the training session.

In addition, to researching open-questions, constant monitoring, referrals, positive reinforcements and complements were directed at the trainee volunteers regarding their effort and ideas. Where necessary the trainee health psychologist guided the trainee volunteers to elaborate further without being too critical towards them. In the group exercises the trainee's health psychologist continuously observed the exchange and interactions, she walked around listened, to the trainee volunteer discussions and where necessary provided support and guidance via by answering questions, providing ideas and

suggestions, motivating and leading them to think, learn and develop. At the end of the training session, the trainee health psychologist again asked about their learning objectives and assessed the outcomes via an evaluation form and the information obtained indicated that definite learning had taken place.

Unit 4.4 Evaluate such training programmes.

The training was evaluated individually by the trainee volunteers and this is shown by the results from the evaluation forms (1=Poor and 6=Excellent). Overall the teaching session was positively evaluated and some suggestions were made by the trainee volunteers on the form for improvement for future learning. (Please see Appendix, 23, in the practice log book for further reflection).

Conclusion.

The trainee health psychologist realized that she had thoroughly enjoyed delivering the training session and this was the kind of health behavior change training that she would like to focus on in the future as part of her continuous professional development.

In general, the training session achieved all the learning outcomes in terms of increasing the trainee volunteer's confidence, awareness of good and bad communication; making them aware of matters of sensitivity and applying these communication skills within a community based setting. The trainee volunteers were also provided with training pack to take away with them (Please see Appendix 24 in the practice log book and Appendix C for communication training best practices).

However, there were other elements of the training session that the trainee health psychologist could improve which are part of the trainee health psychologists future learning, in regards to her training and her delivery style (Please see Appendix 25 in the practice log book and Appendix D for the reflection on the video recorded by the trainee's supervisor).

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Appendix A Training Pre-Evaluation Form.

PRE-COMMUNICATION TRAINING EVALUATION FORM.

North London Hospital.

Training: Communication Skills.

Date: 12th February 2010.

Trainer: Farah Deba Khokhar (Trainee Health Psychologist).

Room: A Block, First Floor, Room A.

Pre-Evaluation of Communication Skills.

Grading 1=Poor 2= Fair 3= Satisfactory 4=Good 5=Very Good 6= Excellent

1 2 3 4 5 6

……

Post Evaluation of Communication Skills.

Grading 1=Poor 2= Fair 3= Satisfactory 4=Good 5=Very Good 6= Excellent

1 2 3 4 5 6

…….

Appendix B Structure, Design and Reflection on Group Exercises.

Unit 4.1 Plan and design training programmes that enable students to learn about psychological knowledge, skills, and practices.

Structure, Design and Reflection on the Group Exercises.

All the group exercises were structured and designed so that they would be interactive for all the learning styles of the trainee volunteers taking part. The trainee volunteers in the group exercise were split as follows:

- Exercise one consisted of 5 small groups of 2 trainee volunteers.
- Exercise two consisted of one big group of 12 trainee volunteers.
- Exercise three, four and five consisted of 4 small groups of 3 trainee volunteers.

The trainee volunteers in all the group exercise 1-5 were given instructions verbally.

In the first exercise, the trainee volunteers were requested to find out something about the other person in terms of their name, occupation, a favourite film and something unusual about each other and then requested to swap the role.

In the second exercise, all the trainees were asked to stand up, the first person standing was presented with a card containing a paragraph of words by the trainee health psychologist and asked to read the card to them self silently. Upon reading the card the first trainee volunteer then whispered the information to the next person and so on until

it reached the last person standing up and the last person was then being requested by the trainee health psychologist to feedback the information to the rest of the group. The information relayed back to the class was ‘It Is a Big Time’.

In the third exercise, the trainee volunteers were requested to carry out a series of grading for good and bad communicators on a Likert scale of 1-10 (1= Very Effective and 10=Least Effective).

In the fourth exercise, the trainee volunteer groups were provided with information regarding a role play involving the trainee volunteer, a member of the public and an observer. These roles were then rotated by each member of the group every 5 minutes so that each member of the group got to play each role

For exercise 5 the same scenario was repeated as for exercise 4 with the addition of interruptions. The trainee health psychologist, the primary client and the trainee’s health psychologist supervisor all engaged in interrupting the group via the use of noisy toys. The trainee health psychologist then asked the volunteers to engage in group discussions and present their findings back to the rest of the trainees in the class. This part of the training was planned to encourage the trainees to communicate, learn by engaging in unfamiliar group dynamics and to learn from each other by sharing and exchanging information and ideas.

The feedback received back from the trainee volunteers for the group exercises was extremely positive. However, during the feedback session, there were some valuable

points raised regarding the group exercises and on reflection, these are future lessons learnt for the trainee health psychologist. These are as follows:

- Exercise 1: Some of the trainee volunteers found that they were not able to rotate the roles as the time of 5 minutes was too short and suggested that the time is increased to 10 minutes.

- Exercise 5: Some of the trainee volunteers from a health professional background found that the interruptions in terms of the noisy toys were not challenging enough and suggested that real life examples should have been used e.g. 'Please can you help? As I have lost my child.' For future training, such examples need to be considered for the group exercises.

  In addition, during exercise 5 the trainee health psychologist realised that in the written instructions it suggested that the roles of the trainee volunteer, the observer and the member of the public be rotated again after every 5 minutes so that each member of the group got to play the role. However, on reflection during the training session, the trainee health psychologist realised that the rotation only needed to be carried out once and not three times as per the instruction and therefore this was implemented on the day.

Appendix C Communication Training Best Practices.

TRAINING PACK.

North London NHS Primary Care Trust (PCT).

Increasing Early Presentation of Cancer Symptoms.

Healthy Communities Collaborative (HCC).

North London Hospital.



Training: Communication Skills.

Date: 12th February 2010.

Trainer: Farah Deba Khokhar (Trainee Health Psychologist).

Key Tip on Best Practices:

1. Greet people, say hello and smile.

2. Stay focused on the event, don't leave the stall unattended.

3. Answer your phone later or in private.

4. Talk with the public first, then your fellow volunteers.

5. Have something to eat or drink when not talking to the public.

6. If you don't know an answer to a question, just say so, and ask a colleague or direct the person to a cancer information phone line or website.

7. If you're busy, acknowledge people and see if someone else can speak to them.

8. Remember everyone comes from a different experience and knowledge.

9. Keep calm and carry on!

References for Reading:

Bradley, T., & Satish, S. (2009). *Unified Communication for Dummies* (3rd ed). Indiana: Wiley Publishing Inc.

Thompson, N. (2002). *People Skills* (2 nd ed).Basingstoke: Palgrave Macmillan.

Bernard, M. (2009). *Communication Skills for Health and Social Care.* London: Sage Publications Inc.

North London Primary Care Trust (PCT).

Increasing Early Presentation of Cancer Symptoms.

Appendix D Video Recording Observation and Reflection.

Observations and Reflection on the 10 minutes Communication Skills Training Recording.

The training was video recorded by the trainee health psychologist's supervisor and a total seven clips were chosen by the trainee health psychologist which represented the main elements of the training, which are as follows:

- Introduction by the trainee health psychologist.
- The aims and objectives of the training.
- Use of various methods of delivery, in terms of the didactic slides presentation, and visual aids. The trainee health psychologist dealings with the trainee volunteers whilst answering questions or engaging in the group discussion, the use of flip chart paper and interaction by the trainee health psychologist with the trainee volunteers during the practical exercises.
- A summary at the end of the training session.

On reviewing the pre-recording and during her observation the trainee health

psychologist realised that in the training session she was visibly seen to be hiding behind the lectern and used this as a comforter during the training session. In addition, to this, the trainee health psychologist realised that in her hands she held both a tissue and a pen

in her left hand and thus both items could visibly be seen to be comforters for the trainee health psychologist.

For future learning, this is something that the health psychologist needs to avoid doing and concentrate on a focal point, within the training room to combat her anxieties. During the training, the trainee health psychologist realised that she also used her arms and hands allot to introduce or demonstrate her ideas or explain them further. In addition to this, the trainee health psychologist was seen to be using a lot of body language in terms of her posture, eye contact, facial expressions and in on one instance she was seen to embrace a trainee volunteer to demonstrate a friendly gesture during the group discussions. For future learning the trainee health psychologist needs to be aware of all the trainee volunteers needs, wants and all the learning styles as this delivery style could have been seen to be too intimidating for some trainees and alienated them from engaging further in the training session. The trainee health psychologist also learnt that in the training session she tended to concentrate more towards the left side of the room and was visibly seen to approach the trainees, answer questions, prompt and stimulate discussions. For future learning, the trainee health psychologist must make sure that when she is addressing the audience that she swipes all sides of the room and makes sure that she does not make anyone feel uncomfortable or approach their personal space. In addition, the trainee health psychologist realised that the flip chart stand was placed too close to one of the trainees on the right side of the room and on two occasions one of the trainees had to turn his head to see the flip chart paper. For all future learning, the trainee health psychologist must make sure that prior to the training session all training materials need to be better placed in the room.

On further reflection, the trainee health psychologist realised that she had thoroughly enjoyed planning, preparing and delivering the training session and this was the type training that she would like to focus in the future.

Core Unit: 5.3: Communicate the Processes and Outcomes of Psychological Interventions and Consultancies.

Case Study: An 8-Week Healthy Eating Programme in young Children aged 11-12 years at North Middlesex Borough Semi-Professional Football Club.

SETTING: North Middlesex Borough Semi-Professional Football Club.

MAIN TARGET GROUP: Children aged 11-12 years and Parents/Guardians of these Children.

PRIMARY CLIENT: North Middlesex Borough Semi-Professional Football Club

(for reasons of confidentiality the Football Club will be referred as the North Middlesex Borough Football Club through-out the document).

CONTACT CLIENT: The Youth Team Manager.

INTERMEDIATE CLIENTS: Caterer and Under 12's Manager.

CONSULTANT: Trainee Health Psychologist (Trainee Health Psychologist).

Background and Context.

On the 3rd of October 2006, the consultant was introduced to the contact client and was requested by the contact client to provide a healthy eating programme lasting for a period of 8 week's (commencing in March 2007 and ending in June 2007) with children aged between 11 and 12 years, who were already involved in a physical activity at their club.

The primary objective of the intervention was to determine if there were any behavioural changes in the eating habits of the participants, who were already involved in a physical activity over a period of 8 weeks.

The second objective of the intervention was to determine whether there was a difference in the physical performance of the 11 to 12 year olds further to the eight-week healthy eating programme.

It was agreed by both parties that the trainee health psychologist would also provide to both the parents/guardians and the children, training on the healthy eating programme, knowledge base workshops on the importance of healthy eating/physical activity and advice/support to the club caterer regarding healthy eating options. In addition, the trainee health psychologist would attend the football training sessions and football matches (Please see Appendix 1 in the practice log book and Appendix A for a summary of the eight-week training sessions).

The pre and post questionnaires for the intervention were modelled by the trainee health psychologist on two psychological theories, the first one known as the stages of change model (also known as the theoretical model) Diclemente, Prochaska, Fairhurst, Velicer, Velasquez and Rossi, J. S. (1991); Prochaska and DiClementine (1984); DiClemente and Norcross (1992) and the second model was on the theory of planned behaviour (Ajzen, 1985) (Please see Appendix 2 in the practice log book for more information regarding the theoretical Models of Psychology).

The aim of using both models in the questionnaires was to look at how the participants weighed up the costs and benefits of engaging in a particular behaviour change. This included their attitudes and personal beliefs of whether behaviour change was a good or a bad thing, the social influences' the pressures that affected their daily life and a look at their personal ability in being able to implement a successful behaviour change in terms of healthy eating.

Upon completion of the healthy eating intervention, it was agreed by both parties that the evaluation and communication of the results would be feedback solely to the contact client. For more information regarding the above, please review the case-study for Optional Unit 3: Consultancy Competency.

5.3a Prepare information for dissemination.

Prior to the commencement of the healthy eating intervention both the trainee health psychologist and the contact client had taken an active role in planning, designing and establishing the aims/objectives of the consultancy/intervention. However, throughout

the whole consultancy/intervention process, the primary client maintained a very central role and always retained ‘ownership’ of the ‘problem and solution’ (Schein, 1999).

Due to this ‘ownership’ on completion of the healthy eating intervention, the trainee health psychologist was not permitted to have direct contact or access to the parents/ guardians contact details. This resulted in the trainee health psychologist having to guide both the (Under 12’s Manager) and the contact client. This also transpired into the trainee health psychologist being very dependent on the above parties during the collection process (Please see Appendix 3 in the practice log book for the pre-and post 24-hour recall questionnaires; Appendix 4 in the practice log book for the one to three days eight, week diaries and Appendix 5 in the practice log book for the pre-and post questionnaires for Stages of Change and Theory of Planned Behaviour). Even though this exercise was very enjoyable, it was also very challenging and caused several delays in the collection timelines. Thus, resulting in incomplete sets of the diaries and questionnaires being collected from the parents/guardians.

The materials that were collected by the intermediate client were as follows:

- Seven pre-and four posts, 24-hour recall questionnaires. The data in these questionnaires described the different types of foods that were consumed over the last 24-hours by the participants.

- Nine pre-and five posts, Pre-Stages of Change Questionnaires. The data in these questionnaires described the scores for each stage of change question.

- Nine pre-and five posts, Theory of Planned Behaviour Questionnaires. The data in these questionnaires described the scores for each Theory of Planned Behaviour question.

- Nine three day, eight week diaries. The data in these diaries described different types of foods groups that were consumed over three days for a period of eight weeks

Upon receiving the documents back from the intermediate client, the trainee health psychologist took a systematic approach in anonymising the data by allocating a participant number to each participant from one to nine, to ensure confidentiality. The trainee health psychologist then started the arduous process of deciphering the information in the diaries, the pre/post questionnaires and entering the information into the excel spreadsheet (which were designed by the trainee health psychologist). During this preparatory stage **(**Please see Appendix 6 in the practice log book for information on non-parametric statistics**)** the trainee health psychologist considered the type of the data being collected and considered whether the data could be examined using statistical analysis. The trainee health psychologist measured the use of non-parametric statistics, to compare the pre-and post intervention questionnaire means on the measures used. The reason for using non-parametric statistics was based on the supposition that non-parametric statistics as method do not assume on the type of data being collected, they thus work on the principal of ranking the data and therefore are statistically less powerful (Field, 2000). Both, the Mann-Whitney and the Wilcoxon tests were considered for analysis of the data. The Mann-Whitney because it tests the 'differences between means where there are two conditions and where different subjects are used in each condition' (Field, 2000) and the Wilcoxon test, because it tests where 'two sets of scores to compare,

but these scores come from the same subjects' (Field, 2000) (Please see Appendix 7 in the practice log book for more information regarding the Mann-Whitney and Wilcoxon test). Because of further reflection by the trainee health psychologist regarding the data sets the trainee health psychologist decided not use non-parametric statistics in analysing the data collected from the healthy intervention. The reason for this was because firstly there was a small number of participants (nine) taking part in the intervention, secondly the lack of statistical power and thirdly the lack of significance possibly being achieved because of the non-parametric method used. Instead, the trainee health psychologist decided to use descriptive statistics. In addition, to the above conclusion during a separate meeting between the trainee health psychologist and the contact client, the contact client requested the trainee health psychologist to present the results and outcomes of the healthy eating intervention in a simplified format during the feedback session. Therefore, the trainee health psychologist agreed to use descriptive statistics to analyse the means data. On completion of the data analysis, the trainee health psychologist summarized the results within a power point presentation and compiled a summary report for the primary client (Please see Appendix 8 in the practice log book for the Report).

5.3b Present information to individuals, groups, and organisations on the processes and outcomes of psychological interventions, consultancies.

The results of the healthy eating intervention were presented back to the contact client at a separate meeting (Please see Appendix 9 in the practice log book for the Power Point Presentation). The reasons why the results were solely presented to the contact client was because this was an initial request made by the primary client at the start of the

consultancy/intervention and, also because of the small number of participants taking part in the intervention.

Questionnaires.

Pre-and post 24-Hour Recall Questionnaires.

The pre-and post questionnaires for the 24-hour recall for the parents/guardians were reviewed by the trainee health psychologist but were not analysed. The reason for this was because firstly, the trainee health psychologist only wanted to get an in-sight into the parents eating behaviour's and secondly, the intervention was aimed at the behavioural change patterns of the 11 and 12 year olds over a period of eight weeks. Out of the nine participants, only four participants completed both the pre-and post questionnaires for the 24-hour recall. The pre-and post questionnaires showed a minor behaviour change in the four subjects in that one 11 to 12-year-old substituted fruits for snack and water instead of orange juice. Of the three participants that completed the pre-and post questionnaires, all indicated that they felt healthy. (Please see Appendix 10 in the practice log book for the excel spread sheet and summary of results).

Psychological interventions.

Stages of Change.

The pre-and post questionnaires for the stages of change were completed by five participants out of nine. The summary of results showed that there was a slight increase in the pre-contemplation stage. No difference was shown in the mean scores for the contemplation stage. A positive result was shown in the last two phases of the stages of change model. Where in the preparation stage there was a readiness in the

participants to change their healthy eating behaviours in relation to their environment, during the action/maintenance stage the participants recognized that they needed to make a behaviour change in terms of their healthy eating behaviours and thus exercised every possible effort in maintaining this behaviour change pattern within their daily lifestyle (Please see Appendix 11 in the practice log book and Appendix B for the excel spread sheet and summary of results).

Theory of Planned Behaviour.

The pre-and post questionnaires for the theory of planned behaviour contained both closed measures of theory of planned behaviour and open-ended question. Out of the nine participants, only five subjects completed both sets of the pre-and post questionnaires. The participants over the eight-week period reported no changes in their mean scores on perceived control, beliefs, intentions, barriers and attitudes, and were less likely to make a behaviour change in terms of their healthy eating lifestyle. Whereas, the participants reported higher mean scores on subjective norm and self-efficacy, and were more likely to make a behaviour change in terms of their healthy eating lifestyle (Please see Appendix 12 in the practice log book and Appendix C for the excel spread sheet and summary of results).

Eight Week-Three Day Diaries.

Out of the nine participants, only six participants returned the completed diaries and of these six participants, one participant had completed the diaries incompletely (Therefore, the data for this diary was not evaluated). In the three days eight-week diary, one football is equivalent to one healthy option taken by the participant. Therefore, the number of

footballs tallied for each participant relates to the number of healthy foods consumed by each participant and vice versa. The results in the diaries indicated that there was no difference in the mean scores of the footballs between weeks one to four and at week six there was a marginal decline in the number of footballs. At weeks seven to eight, there was an increase in the number of footballs. However, the mean scores at weeks seven and eight were not a true reflection of an average score because of the missing data for participant four at weeks seven and eight. (Please see Appendix 13 in the practice log book and Appendix D for the excel spread sheet and summary of results). In addition, to the above five out six participants answered the health-related questions at the back of the diary. The results are as follows: five answered that they enjoyed completing the diary, four participants answered that their health had improved over the eight weeks, four answered that they did not feel less healthy after eight weeks and five answered that they would continue with the healthy eating programme after it had concluded.

The second objective of the consultancy/intervention was to determine whether there was a difference in the physical performance of the 11 to 12 year olds further to the eight-week healthy eating programme. This was shown both by the contact client evaluation **(**Please see Appendix 14 in the practice log book for the Table of Results for the Physical Performance of the 11 to 12 year olds) and over the one to eight weeks training sessions where an improvement was seen in the concentration, physical stamina, and energy levels in mostly the eleven to twelve year olds except for one 11 to 12-year-old. In addition to these, there were behavioural changes seen in club caterer who towards the end of the consultancy/intervention started to provide a series of healthy eating options at the football club.

There were other outside influences that affected the children's eating behaviours which were not evaluated in this programme and these were outside the consultant's control (e.g. peer pressure, family and friends eating behaviours' and advertising). However, they are documented in the literature and thus are seen to influence the type of healthier choices that are made by the individuals.

In general, the intervention showed a behavioural change in some of the 11 to 12 year olds, that took part in the intervention and this was supported by one to eight weeks' three-day diaries where the 11 to 12 year olds started to drink more water, eat more yogurts, fruits, vegetables, choose healthier alternatives such as reduced sugary drinks and reduced fat crisps. Healthier options were also identified, by the pre-post questionnaires that showed an improvement in the behavioural change scores in terms of their healthy eating patterns and by their stamina and endurance during the football training and matches.

During the whole consultancy/intervention process the trainee health psychologist reflected on her own experience in carrying out the intervention at North Middlesex Football Club and thus provided feedback to contact client at the end of the presentation in the section titled challenges/ lesson learnt, please see as follows:

- It would have been beneficial for the consultancy/intervention to have run longer than 8 weeks preferably around 12 weeks, to measure a longer period of behaviour change amongst the 11 to 12 year olds.

- During the data collection phase, the trainee health psychologist had very little autonomy in running of the consultancy/intervention and how the data was collected and collated by the under 12's manager from the parents/guardians at the end of the intervention. The main reason for this was because she was not allowed to have any direct contact with the parents/guardians and nor was she allowed any involvement in the collection process, which resulted in delay and collection errors.

- Extra training sessions were required for some of the 11 to 12 year olds in regards of diary/questionnaire completion. In some cases, the diaries and the

  Pre/post questionnaires had not been fully completed and in some circumstances, there was evidence in the raw data that the 11 to 12 year olds did not fully comprehend the questions. This also implicated as a future learning for trainee health psychologist, in that the designed questionnaires needed to go through a more vigorous process of means testing to ensure that the interventions primary/secondary objectives met the interventions end-points.

5.3c Evaluate the impact of disseminated information.

The information feedback to the contact client was received well and was also a lesson learnt exercise. The contact client felt that that the consultancy/ intervention, despite the small number of participants taking part, challenged the 11 to 12 year olds and at the same time enhanced their knowledge base about healthy eating and physical activity. The contact client felt that the consultancy/intervention, as per their original request needed to be both simple and enjoyable, and felt that that the trainee health psychologist had

delivered all the above. Overall the contact client felt that the intervention went well, in that the 11 to 12 year olds involved themselves in the completing the three days, one to eight week diaries and the pre-and post questionnaires. Throughout the training sessions, the contact client observed the 11 to 12 year olds, learning about high energy foods, maintaining a healthy balanced diet and the future benefits physical activity had on the participant's physical form. During the eight-week programme, the improvements within the participants were evident and the summary of the results showed a behavioural change in the 11 to 12 year olds according to the contact client. The contact client mentioned that he would like to see the intervention carried out in the future with an older age group and thus would recommend it to other clubs. The contact client also added that the club caterer was offering healthier options in the club house and fresh fruit was on sale during the match days.

The contact client commented that he appreciated the challenges faced by the trainee health psychologist and that very little autonomy was provided to her during the intervention. However, he felt that this was justified at the time because of the limited funds that they had available for the healthy eating intervention. In other words, the contact client said that they wanted to maintain a tight control in terms of the responsibility and also because it was their first time in running such a programme at the club, he mentioned that they did know what to expect. However, for future consultancy work they would make some amendments based on the trainee health psychologist's feedback regarding the delivery and organization of the healthy eating programme. The contact client also commented that the comments he had received back from the parents/guardian were positive and they felt that the trainee health psychologist was both friendly and professional. The trainee health psychologist at the end of the meeting

provided the contact client with a summary sheet for the parents/guardians (Please see Appendix 15 in the practice log book for the Summary sheet). The contact client promised the trainee health psychologist that he would send the summary sheet to all the parents/guardians. The contact client felt that the results of the data presented to him were both interesting and simple to understand. He thanked the trainee health psychologist for not using complicated statistical measures to explain the data and liked the use of graphs in the report. Two copies of the report were given to the contact client, the first one for the client and the second copy for the primary client, and a summary sheet for the parents/guardians.

Conclusion.

Upon completion of the consultancy/intervention the trainee health psychologist realised that even though she had thoroughly enjoyed the consultancy there were areas as a trainee health psychologist she needed to improve, especially her anxiety regarding the use of parametric and non-parametric statistics and therefore for the future learning the trainee health psychologist needed to source out a relevant course in statistics. In addition, to this when designing an intervention, the trainee health psychologist needed to be more aware of all the interventions objectives/endpoints from the beginning, middle and the end, and therefore needed to take this into account when designing relevant questionnaires for the participants to complete. From having carried out this intervention and having presented the results back to the contact client. The trainee health psychologist felt that not only was she more confident in designing and implementing a consultancy programme of this kind within the local community. However, she was also more sure of herself, when it came to presenting various psychological theoretical models of behaviour change used within health psychology practice. The trainee health psychologist felt that this was the type of

behaviour change intervention, that she would like to focus on in the future as part of her continuous professional training and development as a trainee health psychologist.

References

Ajzen, I. (1985). From intentions to actions: A theory of planned behaviour. In Kuhl & J. Beckman (Ed.). *Action Control: From Cognition to behaviour* (pp.11-39). New York: Springer Verlag.

Diclemente, C., C., Prochaska, J., O., Fairhurst, S., K., Velicer, W., F., Velasquez, M., M., & Rossi, J. S. (1991). The process of smoking cessation: An analysis of pre-contemplation, contemplation, and preparation stages of change. *Journal of Consulting and Clinical Psychology, 59*, 295-304.

Field, A. (2000). *Discovering Statistics Using SPSS For Windows. Advanced Techniques for the Beginner*. London: Sage Publications.

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Prochaska, J., O., DiClemente, C., C., & Norcross, I. C. (1992). In search of how people changes: Applications to addictive behaviours. *American Psychologist, 47,*1102-1114.

Schein, E. H. (1999). *Process Consultation Revisited. Building the Helping Relationship.* Reading, MA: Addison-Wesley.

Appendix A Summary of the 8 Week Healthy Eating Consultancy.

5.3a Prepare information for dissemination.

INTERVENTION

Title: An 8-Week Healthy Eating Programme in young Children aged between 11-12 years at North Middlesex Borough Football Club

SETTING: North Middlesex Borough Football Club.

MAIN TARGET GROUP: Children aged 11-12 years and Parents/Guardians of these Children.

PRIMARY CLIENT: North Middlesex Borough Football Club.

CONTACT CLIENT: The Youth Team Manager.

INTERMEDIATE CLIENTS: Under 12's Manager.

CONSULTANT: The Trainee Health Psychologist.

AIMS/OBJECTIVES OF THE CONSULTANCY:

- To provide a healthy eating programme lasting a period of 8 weeks to children aged between 11- 12 years, who are already involved in a physical activity.

- To determine whether there is a difference in the physical performance of the child further to the 8-week healthy eating programme.
- To provide advice and support to parents/guardians of these children.
- To provide healthy eating advice and support to the club caterer.

Summary of Week 1 Training Session.

Date: 31st March 2007.

Time: 10.30am-12.15pm.

SETTING: North Middlesex Borough Football Club.

Parties Present: The Youth Team Manager, Under 12's Manager and the Trainee Health Psychologist.

Training Session.

Prior to the training session commencing general discussions took place between the trainee health psychologist and the intermediate client. The intermediate client mentioned that usually within 15 minutes into the training session and 60 minutes into a football game the boys became physically exhausted and he was hoping that this could be improved because of the healthy eating programme.

Initially, 17 boys attended the first training session. The coaching session was led by the intermediate client with the contact client observing and taking notes in the training.

Water was provided at the start, during and after the training session. On the recommendation of the trainee health psychologist bananas were provided 20 minutes prior to the start and 15 minutes after the training session. The trainees were allowed a 2 to 3-minute break to have a sip of water for purposes of rehydration.

The boys were put through a series of vigorous football training as per the physical exercises and measures recommended by the Football association consisting of five different exercises:

- Speed.
- Running.
- Accuracy shooting the ball.
- Heading the ball.
- Dribbling the ball.

In which both the concentration levels and the boys' physical endurance were observed by primarily the contact client and the trainee health psychologist. The main function of the trainee health psychologist during this session was to make sure the boys were kept rehydrated and during the session, the trainee health psychologist provided both advice and support to the players and parents/guardians on the healthy eating programme.

During this session, the parents/guardians of the players taking part in the 8-week programme returned both the 24-hour recall and pre-stages of change and pre-theory of planned behaviour questionnaires. In addition, the trainee health psychologist noticed that eight boys out 14 were exhausted 30 minutes into the training session.

Summary of Week 2 Training Session.

Date: 07th April 2007.

Time: 10.30am-12.15pm.

SETTING: North Middlesex Borough Football Club.

Parties Present: The Youth Team Manager, Under 12's Manager and the Trainee Health Psychologist.

Training Session.

14 boys attended the second training session of which two boys dropped out of the healthy eating programme leaving a total of 12. The coaching session again was led by the intermediate client with the contact client observing and taking notes in the training.

Water was provided at the start, during and after the training session. On the recommendation of the trainee health psychologist bananas were provided 20 minutes

prior to the start and 15 minutes after the training session. The trainees were allowed a 2 to 3-minute break to have a sip of water for purposes of re-hydration.

As per the previous training session, the boys were put through a series of vigorous physical exercises and measures recommended by the Football Association. In which both the concentration levels and the boy's physical endurance were observed by primarily the contact client and the trainee health psychologist.

The trainee health psychologist during this session made sure that the boys were kept

rehydrated, the trainee health psychologist provided advice and support, to both the players and parents/guardians on the healthy eating intervention. Plus, the trainee health psychologist also readvised six parents/guardians on how to complete the 3-days diary and provided retraining to the parents/guardians of the essential food groups.

The trainee health psychologist noticed that in comparison to the first training session the boy' s performance this week was better in terms of their motivation. 5 of the boy's out 12 seemed to have improved and overall, the concentration of the players seemed to have improved.

Summary of Week 3 Training Session.

Date: 14th April 2007.

Time: 10.30am-12.15pm.

SETTING: North Middlesex Borough Football Club.

Parties Present: The Youth Team Manager, Under 12's Manager and the Trainee Health Psychologist.

Training Session

12 boys attended the third training session. The coaching session again was led by the intermediate client with the contact client observing and taking notes in the training.

Water was provided at the start, during and after the training session. On the recommendation of the trainee health psychologist bananas were again provided 20 minutes prior to the start and 15 minutes after the training session. The trainees were allowed a 2 to 3-minute break to have a sip of water for purposes of rehydration.

As per the previous training session, the boys were put through a series of vigorous physical exercises and measures recommended by the Football Association. In which both the concentration levels and the boy's physical endurance was observed by primarily the contact client and the trainee health psychologist.

The trainee health psychologist during this session made sure that the boys were kept rehydrated; she provided both advice and support to the players and parents/guardians on the healthy eating programme. Plus, also during this training session, she checked the 3 day diaries of the 12 players taking part and found that even though some of the boys

were still having crisps for snacks, five of the boys instead of having school lunches were taking lunches from home containing ham or chicken sandwiches, 1 or 2 portions of fruit such as apples, banana's, a yogurt for dessert and fresh orange juice instead of a fizzy drink.

As per discussions between the intermediate client and trainee health psychologist, both the parties noticed that in comparison to the second training session the boy' s performance this week was better in terms of their motivation. 5 of the boy's out 12 seemed to have improved enormously but the whole the boy's concentration, stamina, and energy had also improved. In addition to this, the boys in comparison to the first training session seemed to be less distracted and more disciplined in following instructions from the intermediate client and their football technique had improved but this could have been a result of practice effects.

Summary of Week 4-Training Session.

Date: 21st April 2007.

Time: 10.30am-12.15pm.

SETTING: North Middlesex Borough Football Club.

Parties Present: The Youth Team Manager, Under 12's Manager and the Trainee Health Psychologist.

Training Session.

As 3 boys dropped out of the healthy eating intervention only nine boys attended the fourth training session. The coaching session again was led by the intermediate client with the contact client observing and taking notes in the training.

Water was provided at the start, during and after the training session. On the recommendation of the trainee health psychologist bananas were again provided 20 minutes prior to the start and 15 minutes after the training session. The trainees were allowed a 2 to 3-minute break to have a sip of water for purposes of rehydration.

As per the previous training session, the boys were put through a series of vigorous physical exercises and measures recommended by the Football Association. In which both the concentration levels and the boy's physical endurance was observed by primarily the contact client and the trainee health psychologist.

The trainee health psychologist again during this session made sure that the boys were kept rehydrated; she provided both advice and support, to the players and parents/guardians on the healthy eating programme. Plus, also during this training session, she checked the 3 day diaries of the 9 players taking part and found that one of the boys were still having crisps, chips and ice-cream for dinner. However, the 8 other boys were having more fruits and vegetables in their daily diet.

As per discussions between the intermediate client and trainee health psychologist, both parties noticed that in comparison to the third in this training session eight of the boy's performance this week were better in regards to their concentration during the physical exercises and they seemed to be running faster, passing better, had more stamina and energy.

Summary of Week 5-Training Session.

Date: 28th April 2007.

Time: 10.30am-12.15pm.

SETTING: North Middlesex Borough Football Club.

Parties Present: The Youth Team Manager, Under 12's Manager and the Trainee Health Psychologist.

Training Session.

9 boys attended the fifth training session. The coaching session again was led by the intermediate client with the contact client observing and taking notes in the training.

Water was provided at the start, during and after the training session. On the recommendation of the trainee health psychologist bananas were again provided 20

minutes prior to the start and 15 minutes after the training session. The trainees were allowed a 2 to 3-minute break to have a sip of water for purposes of rehydration.

As per the previous training session, the boys were put through a series of vigorous physical exercises and measures recommended by the Football Association. In which both the concentration levels and the boy's physical endurance was observed by primarily the contact client and the trainee health psychologist.

The trainee health psychologist during this session made sure that the boys were kept rehydrated; she provided both advice and support to the players and parents/guardians on the healthy eating programme. Plus, also during this training session, she checked the 3 day diaries of the 9 players taking part and found that out of the nine boys taking part, 8 of the boys had made some changes in their food choices.

As per discussions between the intermediate client and trainee health psychologist, both parties noticed in comparison to the fourth training session, 8 of the boy's performance this week was better in terms of their concentration and during the physical exercises they seemed to be running faster, passing better, had more stamina and were less tired.

Summary of Week 6 Training Session.

Date: 05th May 2007.

Time: 10.30am-12.15pm.

SETTING: North Middlesex Borough Football Club.

Parties Present: The Youth Team Manager, Under 12's Manager and the Trainee Health Psychologist.

Training Session.

9 boys attended the fifth training session. The coaching session again was led by the intermediate client with the contact client observing and taking notes in the training.

Water was provided at the start, during and after the training session. On the recommendation of the trainee health psychologist bananas were again provided 20 minutes prior to the start and 15 minutes after the training session. The trainees were allowed a 2 to 3-minute break to have a sip of water for purposes of rehydration.

As per the previous training session, the boys were put through a series of vigorous physical exercises and measures recommended by the Football Association. In which both the concentration levels and the boy's physical endurance was observed by primarily the contact client and the trainee health psychologist.

The trainee health psychologist during this session made sure that the boys were kept rehydrated; she provided both advice and support to the players and parents/guardians on the healthy eating programme. Plus, also during this training session, she checked the 3 day diaries of the 9 players taking part and found that there had been some change in

the boys eating food choices e.g., fruit yogurts and vegetables such as carrots. During the review of the diaries, 3 of the boys commented that it had been had for them to be healthy at school because in their schools most of the school dinners contained, pizza, chips and pies. The tuck shop machine contained crisps and fizzy drinks, and they tended to be subjected to a degree of peer pressure.

As per discussions between the intermediate client and trainee health psychologist, both parties noticed in comparison to the fifth training session 8 of the boy's performance this week was better in terms of their concentration, stamina and energy.

Summary of Week 7-Training Session.

Date: 12th May 2007.

Time: 10.30am-12.15pm.

SETTING: North Middlesex Borough Football Club.

Parties Present: The Youth Team Manager, Under 12's Manager and the Trainee Health Psychologist.

Training Session.

9 boys attended the seventh training session. The coaching session again was led by the intermediate client with the contact client observing and taking notes in the training.

Water was provided at the start, during and after the training session. On the recommendation of the trainee health psychologist bananas were again provided 20 minutes prior to the start and 15 minutes after the training session. The trainees were allowed a 2 to 3-minute break to have a sip of water for purposes of rehydration.

As per the previous training session, the boys were put through a series of vigorous physical exercises and measures recommended by the Football Association. In which both the concentration levels and the boy's physical endurance was observed by primarily the contact client and the trainee health psychologist.

The trainee health psychologist during this session made sure that the boys were kept rehydrated; she provided both advice and support, to the players and parents/guardians on the healthy eating programme. Plus, also during this training session, she checked the 3 day diaries of the nine players taking part and found that there had been some change in the boys eating food choices apart from one boy who had made a small change.

As per discussions between the intermediate client and trainee health psychologist, both parties noticed in comparison to the sixth training session 8 of the boy' s performance had improved in terms of their concentration, stamina and energy. In addition, where football technique had improved over the weeks, there was evidence of practice bias.

Summary of Week 8 Training Session.

Date: 23rd June 2007.

Time: 10.30am-12.15pm.

SETTING: North Middlesex Borough Football Club.

Parties Present: The Youth Team Manager, Under 12's Manager and the Trainee Health Psychologist.

Additional Note: Please note, that due to major refurbishment work at the North Middlesex Football Club the training sessions were cancelled for a period of four weeks. In addition, due to personal changes of circumstances the trainee health psychologist was not able to attend another week. In total, the consultancy programme stopped for a period of five weeks and thus, the final training session for week 8 was held on the 23rd of June 2009.

Training Session.

9 boys attended the final training session. The coaching session again was led by the intermediate client with the contact client observing and taking notes in the training.

Water was provided at the start, during and after the training session. On the recommendation of the trainee health psychologist bananas were again provided 20

minutes prior to the start and 15 minutes after the training session. The trainees were allowed a 2 to 3-minute break to have a sip of water for purposes of rehydration.

As per the previous training session, the boys were put through a series of vigorous physical exercises and measures recommended by the Football Association. In which both the concentration levels and the boy's physical endurance was observed by primarily the contact client and the trainee health psychologist.

The trainee health psychologist during this session made sure that the boys were kept rehydrated; she provided advice and support to both the players and parents/guardians on healthy eating. Plus, also during this training session, she checked the 3 day diaries of the 9 players taking part and found that there had been some change in the boys eating food choices apart from one boy who had made a small change

As per discussions between the intermediate client and trainee health psychologist, both parties noticed that in comparison to the seventh session, 8 of the boy' s performance had definitely improved over the eight-week programme. The boy's concentration levels, stamina, and energy had improved tremendously and according to the intermediate client the boys had not been complaining of exhaustion and the boys were enjoying the training sessions more. In addition, to this 4 of the boys had improved enormously in terms of their endurance, skills and looked healthier. The evidence of practice bias and delay of five weeks could have affected the results in the consultancy. At this final session and at the work shop certificates were given by the trainee health psychologist to the 9 boys who completed the 8-week healthy eating programme.

Appendix B Summary of The Stages of Change Questionnaires.

Summary of Results for the Stages of Change Questionnaires.

The pre-and post questionnaires, for the stages of change, were completed by five subjects out of nine. The summary of results showed that there was a slight increase in the **pre-contemplation stage** with a mean score of four at pre-eight weeks and a mean score of five at post eight weeks. This result indicated that the participants were still taking their time to decide as to whether they wanted to engage in changing their healthy eating behaviours and were trying to justify their decision as to whether they had a problem.

No difference was shown in the mean scores at the **contemplation stage** for both pre-and post eight weeks. This results indicated that the participants were still not committed to making a change in their healthy eating behaviours but were still deciding what direction they needed to go in terms of changing their behaviour.

A positive result was shown in the last two phases of the model. Where in the **preparation stage** there was a readiness in the participants to change their healthy eating behaviours in relation to their friends and social environment (the mean score at pre-eight weeks was three and post eight weeks was four).

During the **action/maintenance stage,** the participants recognized that they needed to make a behaviour change in terms of their healthy eating behaviours (the mean score at pre-eight weeks was three and post eight weeks was four) and thus exercised every

possible effort in trying to maintain a continuous behaviour change plan according to their lifestyle.

Appendix C Summary of Theory of Planned Behaviour Questionnaires.

Summary of Results for the Theory of Planned Behaviour Questionnaires.

The pre-and post questionnaires for the theory of planned behaviour contained closed measures of theory of planed Behaviour and open-ended question. Out of the nine subjects, only five subjects completed both sets of the pre-and post questionnaires. Of the five subjects, the mean scores are as follows:

Q 1 Perceived Control Belief: mean scores at pre-and post showed no difference in how easy or difficult the eleven to twelve year found it in performing a particular healthy eating behaviour

Q2: Subjective Norm: the mean scores at pre-equalled five and post equalled six. This showed a small increase in the eleven to twelve year olds behaviour when considering to performing a healthy eating behaviour in relation to other family and friend's beliefs

Q3: Intention: the mean scores at pre-and post-showed no difference in the eleven to twelve year olds, readiness to perform a behaviour in terms of healthy eating.

Q4: Barriers: the mean scores at pre-and post-showed no difference in the eleven to twelve year olds healthy eating behaviours in relation any internal/external barriers they faced.

Q5: Barriers: the mean scores at pre-and post-showed no difference in the eleven to twelve year olds healthy eating behaviours in relation any internal/external barriers they faced.

Q6: Self Efficacy: the mean scores at pre-equalled four and post equalled six. This showed a significant increase in the eleven to twelve year olds confidence in terms of carrying an out a healthy eating behaviour change.

Q7: Perceived Control Belief: mean scores at post showed a slight decrease in how comfortable or challenging the eleven to twelve-year-old found it in performing a healthy eating behaviour change.

Q8: Attitudes: the mean scores at pre-and post showed no difference in the eleven to twelve year olds feelings, thoughts and belief towards performing a change in their healthy eating habits

Q9: Attitudes: the mean scores at pre-and post-showed no difference in the eleven to twelve year olds feelings, thoughts and belief towards performing a change in their healthy eating habits.

The participants over the eight-week period reported no change in their mean scores for perceived control, beliefs, intentions, barriers and attitudes, and were less likely to make a behaviour change in terms of their healthy eating lifestyle. Whereas, the participants reported higher mean scores on subjective norm and self-efficacy, and thus were more likely to make a behaviour change in terms of their healthy eating lifestyle.

Appendix D Summary of the 8 Week Diaries.

Summary of Results for the Three Day Eight Week Diaries.

Out of the nine participants, only six participants returned the completed diaries and of these six participants, one participant had completed the diaries incompletely (Therefore, the data for this diary was not evaluated). The results indicated that there were no differences shown in the mean scores of the footballs between weeks one to four and at week six there was a marginal decline in the number of footballs. For weeks seven and eight there was an increase in the mean scores of footballs, however, the mean scores for these weeks were not a true reflection of an average score because of the missing data for participant four at these weeks**.** In addition, five out of six participants said they enjoyed completing the diary, four indicated that they had improved their health over the eight weeks, four did not feel less healthy after eight weeks and five highlighted that they would continue with the healthy eating programme after it had concluded.

Core Unit: 5.1: Implement Interventions to Change Health-Related Behaviour.

Case Study: Intervention: Creating Health for Active London Kids (CHALK).

Sponsor: London Public Health Teaching Network.

Client: Healthy Weight for London's Kids: 4 to 7 Year Olds at the House of Hispanic American Health (CASAHA) in North London.

CHALK Trainer: Trainee Health Psychologist.

5.1a Assess the suitability of clients for health-related behaviour intervention.

The trainee health psychologist has been involved in both designing and delivering an 8-week healthy eating behavioural change intervention in children aged between 11 and 12 years, who were already involved in physical activity (football).

For the Creating Health for Active London Kids (CHALK) intervention, the trainee HP was approached by a fellow trainee Health Psychologist at City University and was introduced to a Child Obesity Project Coordinator at North London Primary Care Trust (PCT). For reasons of confidentiality, the National Health Service (NHS) PCT in North London will be referred to as the North London NHS PCT. All other personnel working within the North London NHS PCT, the London Public Health Teaching Network

(LPHTN) and the House of Hispanic American Health (CASAHA) in North London will remain anonymous. The CHALK programme, was divided into three components, the first part involved the trainee health psychologist being briefed on the organizational structure of both the LPHTN (Sponsors of the CHALK Programme) and the North London NHS PCT (who were contracted on behalf of LPHTN to recruit the potential centres and organize training venues for the CHALK trainers). Prior to agreeing to take part, the trainee health psychologist signed a work contract between herself and the North London NHS PCT (Please see Appendix 1 in the practice log book for the contract).

The second part of the programme involved the trainee health psychologist being briefed on the aims and objectives of the CHALK intervention, being educated on the health conditions associated with obesity and trained on trainer skills as a CHALK trainer (Please see Appendix 2 in the practice log book for the training materials). The third and final part of the programme involved the trainee health psychologist delivering the CHALK intervention to a 4 to 7 Year olds at CASHA in North London.

Before, the trainee health psychologist describes how she delivered the intervention at CASAHA. She will first explain, how the main target group (4 to 7 year olds and their parents/guardians) suitability was assessed and selected for the CHALK intervention.

Research has shown that more than seventy percent of obese children will become obese in later life and that eighty-five percent of adolescent children will become obese in adult life (UK, Association of Obesity, 2008) For these adolescents and young adults there is an increased risk of poor socio-economic outcomes and premature death in adult life (UK,

Association for Obesity, 2008). Thirty three percent of boys aged between the ages from 2 to 15 years are obese and overweight, whereas thirty-five point and one percent of girls aged 2-15 years are obese or overweight (UK, Association for Obesity, 2008). A study, in line with a cross-government strategy for promoting healthy weight in children across England (Healthy Weight Healthy Lives, 2008), was commissioned in 2005/2006, in North London NHS PCT. Children aged between 4 to 5 years' olds (in reception) and 10 to 11 years' olds (in Year 6) had their height and weight measured at school. Of the eighty-four percent, children measured thirteen-point eight percent children were overweight compared to thirteen-point three percent obese. In year 6, seventy seven percent of children measured thirteen-point three percent were overweight compared to twenty-seven point and one percent (London Teaching Health Network, 2009). The main cause of the problem was identified as being lifestyle, which included social, environmental and commercial factors (London Teaching Health Network, 2009).

For, more discussion on the different types influences affecting children's eating and physical behaviours, please see Appendix 3 in the practice log book for the literature search carried out by the trainee health psychologist.

In addition, to the above literature search, the suitability of the target age group of the 4 to 7 year olds was assessed by this current study involving four pilot Boroughs within North London, North West, South West and West London. One hundred and twenty-four children aged between 4 to 7 year olds, were registered for the CHALK intervention, by their parents/guardians.

5.1b Identify and negotiate the behaviour change goals of the clients.

The CHALK intervention took place at CASAHA in North London over a period of 5 weeks, on each Saturday. Each session with the parents/guardian and children lasted three and half-hours. The trainee health psychologist with two other trainers, a general practitioner, nutritionist and a physical trainer, took part in the intervention and the trainee health psychologist agreed to work in the capacity of a trainee health psychologist alongside the physical trainer. The general practitioner, nutritionist worked with the adults because of their limited capability of speaking English fluently. Prior to the intervention taking place, a series of interactive exercises were designed by CASAHA for the five Saturday sessions, in which the trainee health psychologist was not involved in (Please see Appendix 4 in the practice log book and Appendix A for the exercises designed by CASAHA).

The aims/objectives of the CHALK Trainer (trainee health psychologist), with the children, were as follows:

- Raise the issue of healthy weight.
- Increase their knowledge and understanding of good and bad foods.
- Encourage physical activities fun-times.
- Set reasonable learning objectives.
- Maintain sustained achievable outcomes in their life-style following the sessions.

The trainee health psychologist tried to make the five Saturday sessions both informative and enjoyable (Please see Appendix 5 in the practice log book for the CHALK training manual). During this period, the trainee health psychologist reflected on her previous expertise and knowledge of delivering an intervention with healthy eating and physical activity. She discussed with the 4 to 7 year olds why it was important to maintain a healthy weight, eat the correct food portion sizes, increased their knowledge about food nutrition and the importance of taking part in physical activity. She asked them researching questions, about what they liked to eat or did not like to eat, both at home and school. She assessed each child ‘s understanding as to what they had learnt during the session, encouraged them to ask questions and set them learning objectives for the future (e.g. getting them to count how many times they went shopping with their parents/guardian). At the end of each session the trainee health psychologist, including two other trainers, the children, their parents/guardians all took part together in a physical activity session.

5.1c Assess the cognitive, behavioural and situational determinants of and influence on, relevant current behaviour:

Most of the centres for the CHALK intervention were contacted by the North London NHS PCT via invitations, adverts or contacted directly by telephone or mail merge (Please see Appendix 6 in the practice log book for posters and invites). Those centres that had expressed an interest had the parents/guardians of the children sign consent forms prior to taking part (Please see Appendix 7 in the practice log book for the consent forms) in the intervention**.** In addition to this, all the CHALK trainers that took part, in the programme were volunteers from the local health community centres, primary schools or from other health institutes working within a health professional capacity at these various venues. (Please see Appendix 8 in the practice log book for the invite letters sent to the

trainers). All, the volunteers within in their work place had identified families who had faced challenges in maintaining a healthy weight. At CASAHA, eight families and a total of fifteen children aged between 4 to 7 years registered for the CHALK intervention.

During the intervention, most of the children commented that at home or within their social communities, most of the activities with their friends and family involved eating food such as meats, rice, chili, chips and burgers. Even at home, some children commented that they took very little interest in what their parents cooked and only helped their parents/guardians to cook when they made foods such as pizza, cakes etc. Even within their school, the children said that they were surrounded by unhealthy foods such as pizza, chips, chocolates, crisps and fruit juices. This was also the case when they walked home from school or got the bus they tended to pop into their local sweet shops. There was a very little choice available to them at school regarding healthy food alternatives or options for physical activity. The physical activity that they did do was primarily within the school and involved one or two sessions of physical exercise a week. In addition, as all the children lived in North London, their parents were concerned about their safety and hardly allowed them to play outside alone or go to the park. If they did take part in any sporting activities with their families, it was very dependent on their parent's availability. One of the parent/guardians of a child commented that eating chocolate at home was not frowned upon because the chocolate was given regularly to children aged 2 to 4 years in nurseries especially within Columbia from where they originated from.

All the children and parents/guardians taking part in the CHALK intervention felt that they were ready to make a behavioural change in terms of their eating and physical

activity behaviours and felt that this was the right time to do so. Some of the parents/guardians commented that the local medical practices and the local health clinics or schools had suggested that the children make the change in their food and physical activity behaviours because of health implications in later adult life.

The trainee health psychologist explained to the parents/guardians that she would work together with the children, to raise issues of healthy weight, set learning objectives via knowledgeable creation about food, nutrition and physical activity. Plus, she would also motivate them to take part in interactive games and encourage them to change their behaviour by getting them to maintain a long-term behaviour change plan. The trainee health psychologist made sure that the behaviour change for both the children and their parent/guardian was realistic, manageable and in line with their daily lifestyle and income.

5.1d Develop a behaviour change plan based on cognitive behavioural principles.

The CHALK intervention was based on the theoretical Models of Behaviour. For example, The Determinants of the Health Model (Dahlgren & Whitehead, 2007) and two theories of change e.g., change as learning and method of change consisting of Motivational Interviewing. Several other models of behaviour, learning, and change were considered by the LPHTN for the CHALK intervention and an in-depth review of all these models was provided within a report (Please see Appendix 9 in the practice log book for a report generated by one of the London's University)

The Models of Behaviour, used are as follows:

- The Main Determinants of Health Model **(**Dahlgren & Whitehead, 2007).

Theories of Change as Learning Models, used are as follows:

- Information Motivation Behavioural Skills Model (Fischer & Fischer, 1992).
- Framework for Environmental Education Strategies (Monroe, Andrews, & Bidenweg, 2006)**.**
- Education for Sustainable Development (ESD), ESD1/ESD2 Model (Vare & Scott, 2007)**.**
- Double Loop Learning Theory (Argyris & Schon, 1978).
- Organizational Culture (Schein, 1985)

The Method of Change model, used is as follows:

- Motivational Interviewing (Miller, 1991).

For more information on these models of learning and Behaviour change (Please see Appendix 10 in the practice log book). All the families taking part in the CHALK intervention wanted to make changes to their lifestyles because of concerns regarding their child's future health and thus were ready to make this behaviour change now.

During the sessions, the trainee health psychologist used primarily the CHALK manual in terms of the learning objectives/ outcomes and the practical exercises. However, she also adapted the learning activities based on her previous experience of healthy eating

and physical activity to facilitate the behavioural change of the children aged 6-7 years (For more information on these learning activities for sessions, please see Appendix 11 in the practice log book and Appendix B for summary and reflection of sessions 1-5).

During the physical activity sessions, the children together with their parents/guardians played hopscotch, catching the ball, took part in a mini aerobic routine and engaged in games played in Latin America. At the end of these sessions the trainee health psychologist together with the children discussed the benefits of physical activity combined with healthy eating and thus, children felt more confident in making a behaviour change.

For a more in-depth summary and reflection of sessions (Please see Appendix 11a and 11 b in the practice log book for handouts). In all these sessions, the trainee health psychologist applied the theoretical models of learning and behaviour, encouraged the children to achieve the learning objectives and assisted them in their behaviour change.

5.1e Ensure Monitoring and Support for Behaviour Change Plan.

One way to measure whether the children had understood and applied the learning's from the previous sessions. Was at the start of each session to discuss, what they had done in terms of behaviour change with their families at home, in school and within their communities. The way the trainee health psychologist did this was to allow the children to play for 10 minutes as they entered the room. Once the children had settled down, she then got them to sit down on the floor in a semi-circle and asked them questions for a further 15 minutes about the following:

- The different types of foods they had tried?
- The different new colours of food they liked or disliked?
- What had they had for breakfast, lunch and dinner?
- Had they helped their parents to cook?
- Had they made a pre- shopping list before going out with their parents?
- Had they had a chance to talk about healthy eating with their school friends?
- What projects they could carry out at school and the different types of family fun times they had been involved in during the week?

(Please see Appendix 12 in the practice log book and Appendix C for a list new foods tried and family activities).

In addition, the trainee health psychologist also asked them if they had faced any challenges regarding their behaviour change plan. During the follow-up session, the trainee health psychologist refreshed the children's knowledge and understanding regarding healthy eating and exercise. She explained to them the new learning's and activities for the current session and why it was beneficial to continue with this lifestyle change for future health benefits. No reflective log books or diaries were provided by LPHTN, for documenting any behaviour change during the post session. Any behaviour change that did occur was noted by the trainee health psychologist during the session and was feedback to CASAHA.

Monitoring of The Behaviour Change Plan.

Upon, completion of the CHALK intervention, CASAHA in North London is continuing to run the programme without any financial support. CASAHA has made some minor changes to the programme by deciding to concentrate more on Prochaska's Stages of Change model (Prochaska & Diclemente, 1983). Six families out of eight that had originally taken part in the programme are continuing with the behaviour change programme.

In addition, one other centre in Outer West London is continuing to run the CHALK programme. In terms of measuring a long-term behaviour change or for providing a behaviour change plan for the continuity of this sustained behaviour change with the families. There were no monthly or yearly follow-up sessions organized by LPHTN *for* the future.

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5.1f Evaluate Outcome.

Pre and post telephone questionnaires were assessed and evaluated by LPHTN, for the uptake, process and programme end of the CHALK intervention. The feedback from the children and parents/guardians was that they had tremendously enjoyed the CHALK programme. The post-eight week follow-up calls showed changes both in knowledge, understanding, and attitudes for the majority of respondents in regards to diet, nutrition, physical activity and family time according to LPHTN. The model used in the current CHALK intervention was found to be promising, by using trainers who had no specialist knowledge of obesity/unhealthy weight but did have experience of working with children. Currently, LPHTN cannot say anything about the sustained behaviour change in all the

families that took part in the CHALK intervention (Please see Appendix 13 in the practice log book for the presentation on the evaluation of the CHALK Intervention). In addition, LPHTN plan to run a separate but similar (CHALK intervention) phase 1 study in the future. The time lines for this phase 1 study are at currently unknown.

5.1g Negotiate Completion, Follow-up or Referral as Appropriate.

During the final session of week 5, the learning objectives were again readdressed with the children and because of further discussions, the trainee health psychologist encouraged the children to continue with their behaviour change plan as follows:

- To continue in trying new and different coloured food types.
- To make a pre-shopping list and to go shopping with their parents.
- Help their parents during cooking times.
- To talk to their school regarding projects including healthy food choices.
- Have more family fun-time.

The trainee health psychologist also suggested that the children document in a notebook the different types of behaviour changes they had made and comment on what they liked or did not like about their weekly behaviour change plan.

As the trainee health psychologist was not involved in the initial design, creation or running and completion of the CHALK intervention. But only brought in as trainer in-terms of a trainee health psychologist capacity to deliver the intervention. It was not

possible for the trainee health psychologist, on finalization of the programme to provide any additional support or guidance to the families in continuing with these lifestyle behaviour changes. Nor was it possible, as per the contract with the North London NHS PCT, for the trainee health psychologist to provide the families with additional intensive psychological assistance regarding any future behavioural change strategy. However on reflection, if the trainee health psychologist had been involved in the initial stages during the design, process and in finalization of the programme. She would have made the recommendations, as follows:

- A behavioural change plan to be both agreed and provided to each family at the end of the CHALK programme.
- Five day diary, to be provided to each family, for completion on a weekly basis regarding any behavioural change activities that they had undertaken.
- Follow-up calls to be made every two weeks with the trainee health psychologist and the families.
- Three, monthly face-to face meetings between the trainee health psychologist and the families. To discuss the current behavioural change plan, make any necessary amendments and to suggest any future changes to the plan, according to their lifestyle.
- Telephone numbers to be provided by the trainee health psychologist to the families, in the event the family required further support, encouragement, and guidance throughout the follow-up period, for a year.
- Each family to be awarded for their hard work, at the end of the year. At the end of the year, the trainee health psychologist together with the families to discuss the lifestyle changes they had made, redesign the behavioural change plan and to assess the learning and behaviour models used.

At, the end of the year to provide suitable psychological support and guidance, in the form of support service numbers.

Conclusion.

In summation, the trainee health psychologist found the CHALK intervention to be both challenging (For more discussion on this please see the reflection in the evaluation form provided to LPHTN, for future improvement please see Appendix 14 in the practice log book) and enjoyable. The trainee health psychologist particularly enjoyed working with the children and talking to them about healthy eating and physical activity. The knowledge sharing and practical activity sessions assisted the children to think about behavioural change and to meet the learning objectives, both inside and outside the sessions. In addition to this, the trainee health psychologist adapted the learning activities based on her previous experience of healthy eating and physical activity and set realistic exercises that would be achievable by the children. However, as mentioned above it was not possible to determine if a long-term behavioural change plan was met but it is promising to know that six families have continued with the modified CHALK programme at CASHA. In carrying, out this intervention the trainee health psychologist felt that she had become more confident. She could reflect more in on herself, by questioning how she could apply her newfound experience and skills with different client groups. She also realized that this type of behaviour change intervention was something that she would like to focus in the future.

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Appendix A Exercises Designed by CASAHA.

5.1b Identify and negotiate the behaviour change goals of the clients

Exercises.

Beanbag Contest.

Age: 4+

Preparation:

Divide the children into teams and line them up in rows. Give the child at the front of each row a beanbag.

How to play:

The children must now pass the beanbag from one to the next and back again, in a particular style, which you can decide as appropriate for the age of the children.

For example,

- pass it down the row with the right hand only.
- pass it up the row with left hand only.
- pass it down the row with both hands.
- pass it up the row with the right hand over the left shoulder.
- pass it down the row with left hand over right shoulder.
- pass it up the row under the right leg.
- pass it down the row under the left leg, and so on.

It might be a good idea to have a practise game first! If a beanbag is dropped, you can either make the children start again from the beginning or from the front of the row.

When all the beanbags have been passed correctly, a winner is declared.

Blind Man's Bluff

Age: 6+

You will need:

All you will need is a blindfold and enough space for some excitable children!

How to play:

Choose one child to be "it", and blindfold him or her. Turn her round a few times to disorientate her a little, while the other children group themselves around her. Then let her try to tag one of the other children, who will then become "it".

Variation:

Play as above, but when a child is caught the blindfolded child must try to guess who it is by carefully feeling their face and hair.

Capture the Flag.

A large group of children.

2 flags or markers (anything bright and light-weight, such as a T-shirt, will do).

a large area, which can be roughly divided into two.

How to play:

Split the children into two teams and allocate each team with one half of the area. Each team chooses a base position, where they keep their "flag", and a goal position, where they will keep their prisoners, and makes it known to the other team.

Each team now tries to capture the other team's flag. Whenever a team member ventures onto the other team's territory, he is at risk of being caught (tagged) by the enemy team. When caught, he is taken to that team's gaol, where he must remain until he is freed (touched) by one of his team members.

When someone manages to capture the other team's flag and return it to their own territory, their team wins.

Hints:

Older children will probably organize their teams so that some players guard, others hunt. Younger children will probably run around a great deal and just have fun!

In a large space, especially one with hiding places, this game can go on for an hour or more.

Chase the Rabbit.

All the children kneel on the floor in a ring with their hands on each other's shoulders. One is chosen to be the "rabbit". The rabbit walks around the outside of the ring. He chooses one of the children as he passes them and taps them on the shoulder. That child then has to chase the rabbit around the ring and try to tag him before the rabbit can

kneel down in the child's space. If the rabbit succeeds, the other child becomes the new rabbit. Otherwise, the original rabbit has another go.

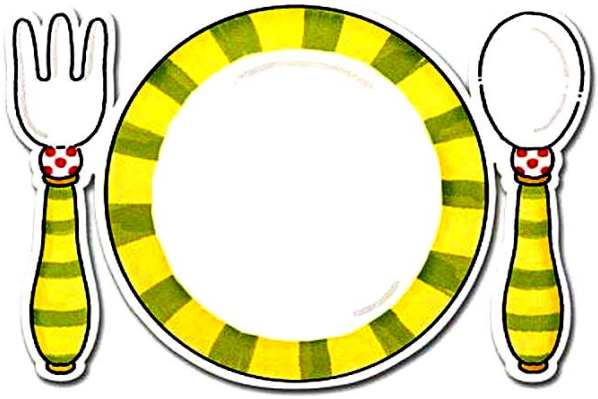
Chinese Ball.

Children stand around in a circle with a ball as appropriate for the age group (such as a basketball).

The ball is thrown quickly around and across the circle. When a child caught the ball, the children on either side must raise one arm - the arm nearest the child with the ball - and hold it in the air until the ball is passed on to another child.

If a child fails to catch the ball or fails to raise the correct arm when their neighbour catches the ball or is too slow to pass the ball along, they drop out. When there are only 5 children left in the circle, they are all declared winners, and the game starts again.

MY PLATE PORTIONS.



Appendix B Summary and Reflection Sessions 1 to 5.

Unit: 5.1d Develop a Behaviour Change Plan Based on Cognitive-Behavioural Principles.

SESSIONS.

As, one of the CHALK trainers at CASAHA, the trainee health psychologist, was responsible for carrying out the intervention with the children in the capacity of a trainee. At the start of session 1, it was quite challenging for the trainee health psychologist to get some of the younger children aged between 4 and 5 years old, engaged in carrying out some of the learning activities. The main reason for this was because nearly all the children aged 4 to 5 years, who had taken part in the intervention, did not read, write or speak English fluently and were only able to converse in Latin American Spanish. This was something the trainee health psychologist had not been made aware of the start of the intervention. Based on this revelation, it was agreed by all the CHALK trainers at CASAHA that it would be far more beneficial for the trainee health psychologist to work with the older group of children aged 6 to 7 years, who were more conversant in English, instead of the younger group of children. It was thus agreed that the other CHALK trainer (a professional Physical Trainer) would work with the younger children age group. This strategy was agreed and continued for the following sessions: 2 to 5. This methodology also assisted both the trainers to work and allowed the trainers to deliver the programme according to the language needs and wants of all the children and to achieve the learning outcomes of the intervention.

Because of the number activities outlined in session 1 and the limited about of time allocated by the CHALK programme of fifty minutes. Both, of the CHALK trainers (including the trainee health psychologist), found that it was not possible during the session 1, to achieve all the learning outcomes or objectives. On reflection, the trainee health psychologist realised that she needed to be better organized, and work smartly during the sessions, to make sure that all the activities carried out not only met the learning outcomes but were strictly timed. One way the trainee health psychologist decided that she could do this was to cut down on the amount of time she spent on explaining to the children on how to do things but instead she could save time by engaging the children in the activity at the same time whilst explaining it to them.

On further reflection, the trainee health psychologist found that some of the practical exercises that had been designed for sessions 1 to 5, did not effectively apply the theoretical models of learning and behaviour in terms of the various age groups of the children aged 4 to 7 years. This was something the organizers of the intervention needed to improve for future learning and this was something the trainee health psychologist needed to feedback to LPHTN. On example of this was in the usage and application of the practical exercises, in some cases the exercises were more suited towards the older child in terms of their learning and objectives, and in other cases less suited for the younger children aged 4 to 5 years. During the practical sessions, not only were the younger age group easily distracted, at times did not want to take part and when they were tested on what they had learnt they were unable to provide any understanding or explain what they had learnt. Often these children commented in Spanish that they did not understand the exercise because it was too hard. However, other factors could have been

at play here, such as the language barriers faced because most of the content was in English and should have been in Spanish. The timings were too long for the younger children who easily got distracted and the timings for the older children were too short. The other factor that could have a bearing was that the CHALK trainer was working in the capacity of a physical trainer instead of a health psychologist. In addition, some of the content provided in the CHALK programme and materials for the older children in regards to healthy eating on several occasions did not increase their knowledge base of the child's learning. On several occasions, the children often commented back to the trainers during the session that the material being presented was too babyish and had already been covered in their school. On reflection, the trainee health psychologist also found that some of the exercises designed by CASASHA were not workable and thus she reflected on her own experience, and used her initiative to use practical exercises of learning which were more suited to the children aged 6 to 7 year olds (For more information on the initiatives used, please see the case-study section: 5.1d Develop a behaviour change plan based on cognitive-behavioural principles). After each session, it was not so easy to determine if there had really been a behaviour change because there were no evaluation forms filled out by the trainers regarding the children's participation and nor were there any diaries provided for the children to record any changes in terms of their physical activity and healthy eating habits. The only way the trainee health psychologist could measure any behaviour change was by setting the children mini projects do at school, home or in their community involving health eating and physical activity.

On, further reflection, the trainee health psychologist found that the resources for the programme did not always arrive in time from. On further observation, the venue where the intervention took place was okay, but had limited facilities, in terms of toilets, the windows at the venue were closed permanently, no air conditioning was available, issues such as health/child safety were not addressed and in the event of an accident happening there was no evidence of first aiders present or available by CASAHA. Plus, the refreshment provided to the children in terms of water on some occasions was very limited bearing in mind that the weather was very hot outside during the months of May and June. This was especially challenging for the younger children who wanted drinks or food. However, most of the constraints were due to extra funding not being available to CASAHA for refreshments during the intervention.

Despite the challenges, the knowledge sharing and practical activity sessions assisted the children to think about behavioural change and to meet the learning objectives both inside and outside the sessions via a series of practical exercises.

As a CHALK trainer, the trainee health psychologist felt that she was more confident, able to reflect more within herself, question how she could apply her experience, skills and improve her health psychology practice.

CHALK SESSIONS 1-5.

Guide to session 1.

SUGGESTED PROGRAMME.

Timing (minutes)	Adults	Children	Refer to Page
0-10	Registration, Welcome, Introduction		2
10-60	- Understanding why weight is important - Exploring. Change4Life - Trying something new.	- Name game. - Active play. - Talking about food	Adults: 3 Children: 8
60-85	Physical Activity		10
85-90	Consent	Warm down	10
90	Close		10

Summary of Session 1.

CHILDREN'S SESSION (50 MINUTES).

ACTIVITY: Name game.

Stand in two rows opposite each other (trainer joins in if numbers are odd).

Say the name of the person opposite.

One row swap with the person to your right.

Say the name of the person opposite.

OR: Trainer point to random people – everyone shouts out their name.

ACTIVITY: **Active Play** (20 mins).

Resources: *Floor size snakes and ladders, hopscotch, crayons, felt pens and paper, chalk boards and chalk.*

4 activities are set out on the floor, spread out.

Ask children to pick an activity – spread out – spend some time.

When I clap / blow whistle/ say 'all change' try a new activity (approx. 6 mins on each activity).

Get children together.

ASK What did you like best? Why?

What do you enjoy doing at home? At school? (Or at Gran's etc.).

When do you eat? Do you like eating at home or at school?

ACTIVITY: On your chalk board draw your favourite food and hold it up.

ACTIVITY: Read a story about food: Smelly Peter.

Read out story – encourage comments – ask questions:

ASK: Is having the same thing every day good for you?

What happened to Peter?

If aliens came to your house what foods would they find most of?

ACTIVITY: Trainer describes a food – colour, size, solid, liquid, sweet, sour, etc. - children have to guess.

Try it in pairs using faux foods – one picks food other closes eyes – describes - colour taste - size – when do you eat it.

Give out Eat well postcards – name the foods.

Lots of different foods- why do we need food? Why do we need a variety of foods?

ANSWERS: To grow.

To stay healthy.

To run.

To jump.

For our bones and hair.

All the different parts of our body need different things.

Key learning points from this activity:
We need food for energy, food to grow, food for activities in the day. Positive images of food, understand the variety of foods

CHILDREN AND ADULTS SESSION TOGETHER (25 MINUTES).

Physical Activity session.

Resources: *safety cones, balls, portable goal.*

Should involve running around, make it fun & competitive. Make sure all adults and children take part – including trainers.

Guide to session 2.

SUGGESTED PROGRAMME.

Timing (minutes)	**Adults**	**Children**	**Refer to Page**
0-10	Welcome back; Physical activity warm-up.		23
10-30	Active Play.		24
30-75	- Change4Life goal setting - Doing tasks with your children	- Why do we need food? - How do we use up energy? - Shopping.	Adults: 25 Children: 28
75-90	Making a shopping list.		30
90	Close.		31

Summary of Session 2.

CHILDREN'S SESSION (45 MINUTES).

Resources: *Eat-well plate postcards/poster, faux foods/blank Change4Life activity cards.*

RECAP: From the last session.

Why we need different foods.

Relate it to the shopping game they were playing earlier.

ASK: Who does the shopping?

Where do you like to shop?

Who decides what you buy?

Do you make a shopping list?

What do you need to eat?

Where can you buy these things?

INTRODUCE. The Eat Well plate.

ASK: What happens if you only eat one or very few foods? Smelly Peter! (story from the last session)

Why do we need food?

Children place faux foods into appropriate food group/Eat well section.

ANSWERS: Need food for our bodies and our minds.

What foods do you like?

Which foods help you to run about, help you concentrate, are good for bones, teeth, skin etc.

ACTIVITY: **Different types of foods.**

(Colours of food: the rainbow).

Let's make a rainbow of foods: on flip chart paper (use the Eat well cards/floor mat to help). Encourage them to name healthy foods.

How many colours can you get on your plate? During the day?

ANSWERS:

Red (tomato, red peppers, red chili, strawberries, apples).

Orange (oranges, tangerines).

Yellow (banana, yellow pepper, corn).

Green (lettuce, cabbage, peas, broccoli, spinach, apples, cucumber).

Blue (blueberries).

Purple (plum, aubergines, blackcurrants, grapes).

ACTIVITY: **LEARNING ABOUT PHYSICAL ACTIVITY.**

Key learning outcomes from this activity:
Energy in must equal energy out (energy balance).

ASK: What activities do we do that use up energy?

When do we use up most energy? Give a list of a few different activities to choose from, e.g. walking, growing, sleeping, swimming (supplement with images cut from magazines etc.).

ANSWERS: Running, jumping, walking, growing, sleeping.

LAY OUT: Fruit and vegetables (fresh & dried). Everybody can try these at their own will. Offer them but don't force anybody to eat them.

ACTIVITY: Get the children to form a line of ascending order of energy use. E.g.: Sleeping--------- Walking ----------Jumping jacks.

Now look at change for life activity cards – somebody picks one – all try it.

Now get into groups of four and make up an activity card.

Share them.

Stations – and do the activity.

After 45 mins: **Children join the adults. Refer to Page 32 of the guide.**

<u>CHILDREN AND ADULTS SESSION TOGETHER (15 MINUTES).</u>

Children & adults together at the table.

ACTIVITY: Making a shopping list.

Do you make a shopping list? – who does?

What do you normally buy?

Swap items and make the list 'healthier'. Draw or write on chalk boards or paper. Give suggestions for 'healthy alternatives' if participants are stuck. Reinforce messages from earlier activities (e.g. colours of food, Eat well plate, fruit & veg).

Resources: *Chalk boards and chalk, paper, and pens.*

Key learning points from this activity:
Doing a task together. Helping each other. Involving adult and child in shopping (part of meal planning.)

BEFORE THE NEXT SESSION, TRY ONE OF THE FOLLOWING:

- Reading with a parent (borrow 'You do' book).
- Drawing with a parent – 'things I like'.
- **Participants are to tell the group about it at the next session.**

ASK: Families to bring in at least one empty food packet for the following session.

NOTE: Trainers should try and bring some of their own to the session, in the case of participants fail to bring their own. Packets can be anything: healthy or not, with labelling or without. The more variety the better the exercise will be.

Key outcomes from this activity:
Try something new, sharing with group, self-esteem, activities together as a family, ideas to reduce screen time

ASK: Any questions?

REMIND: People to come back to the next session!

Guide to session 3.

SUGGESTED PROGRAMME

Timing (minutes)	**Adults**	**Children**	**Refer to Page**
0-10	Welcome Back and plan for the session.		33
10-20	Recap on goals for healthy living.	Warm up.	Adults: 35 Children: 34
20-40	Meal planning.	Breakfast is important	35

40	Designing healthy meals.	40
75-90	Physical Activity.	41
90	Close.	41

Summary of Session 3.

CHILDREN'S SESSION (30 MINUTES).

ACTIVITY: Warm up (10 minutes).

SPLIT INTO TWO GROUPS:

ACTIVITY: **Breakfast is important**

Did you eat breakfast this morning?

What did you have? What is your favourite breakfast? What happens if you don't eat breakfast? What happens if you do eat breakfast?

Healthy breakfast ideas-

Less sugar, less fat, more fruit.

CHILDREN AND ADULTS SESSION TOGETHER (25 MINUTES).

ACTIVITY: Parent and child to design their own menu for a healthy meal or lunch box.

ASK: What do they think makes up a healthy meal?

ANSWERS: Balanced meal which uses the Eat Well plate as a guide. A meal based on starchy foods, with plenty of fruit and veg. Low in fat and sugar etc. Use key dietary messages.

ACTIVITY: Parent and child to prepare a simple fruit salad.

Resources: *Fresh vegetables, paper plates, knives (supervision needed).*

Key learning points from this activity:
Sharing of cooking experience. The child should feel included and valued while building a healthy relationship with parents/carer. Children should be encouraged to handle and try new foods.

CHILDREN AND ADULTS SESSION TOGETHER (15 MINUTES).

(Outdoors if facilities are available).

Physical activity session.

Resources: *safety cones, balls, portable goal.*

Should involve running around, make it fun & competitive.

NB: Some adults may be reluctant to take part in physical activity. Do not force any of them but try and encourage them. It will be fun!

Key learning points from this activity:
Parents and children having fun and encouraging each other to partake in activity for healthy living.

ASK: Any questions?

REMIND: People to come back to the next session!

Guide Session 4.

Timing (minutes)	**Adults**	**Children**	**Refer to Page**

0-10	Welcome Back.		
10-20	Signposting What can we do?	What do you like doing: At home, at school, on weekends, with who? Where do you go?	Adults: Children:
20-40	The FRASH chart Revisiting 'Let's Get Positive!'		
40	Developing the FRASH chart And ideas for rewarding yourself, your children and the family.		
75-90	Physical Activity/food related activity.		
90	Close.		

Guide Session 5.

Timing (minutes)	**Adults**	**Children**	**Refer to Page**
0-10	Welcome Back.		

10-20	What have we done? What are we going to do? What support do we need? What are we going to do?	Healthy eating and physical activity	Adults: Children:
20-40			
40	Check FRASH charts.		
75-90	Rewards and certificates – agreed on next steps.		
90	Close.		

Appendix C A List of New Foods and Family Activities.

Unit: 5.1e Ensure Monitoring and Support for Behaviour Change Plan.

An example of new foods tried at mealtimes and family activities.

Foods:

- **Strawberry.**
- **Mangoes.**
- **Apples.**
- **Bananas.**
- **Yogurt.**
- **Carrot.**
- **Fish.**
- **Broccoli.**
- **Dried Apricot.**
- **Jacket potato.**

Family activities:

- **Football.**
- **Swimming.**
- **Walking.**
- **Playing in the Park.**

Core Unit 1 Generic Professional Case-Study.

Introduction.

In this case study, I will describe and reflect my professional practice as a part-time trainee health psychologist over a seven-year period. This will include areas of reflection within my current and past work posts, and how as a trainee health psychologist, I have enhanced my skills professionally towards the journey in becoming an applied health psychologist. The detailed account will demonstrate how I have developed a range of Generic skills and applied these in the following areas of teaching and training, consultancy and providing psychological advice to others.

Background.

When I started the health psychology doctorate in 2006 I was employed by a Japanese pharmaceutical company as a Clinical Associate Manager within the clinical operations department. My main responsibilities were to oversee a phase III open-label, double blinded, randomized, and controlled drug trial, in moderate and severe Alzheimer's disease from start-up to completion. I led and managed many stakeholders within this consultancy project where I was the sponsor and the research organization (CRO) was the client. My other responsibilities included managing and establishing a 'Process Consultation Model' (Schein, 1999) with other external vendors (laboratory and ECG vendors) and amongst internal departments. I was also involved in the negotiations of the investigator's clinical sites, reviewing client bids proposals and managing 40 million budgets.

During the seventh year of the doctorate programme, I was made redundant and quickly secured new employment with West Yorkshire University. Within this role as a Clinical Project Manager, I managed a targeted ultrasound study in patients with Rheumatoid Arthritis and worked within a multidisciplinary team ranging from academic professors in different country hospitals, ultra-sonographers and research nurses. I collaborated with the finance department, strategic partners like the hospital's research and development department, major stakeholders (one a research organization and the other the funder) and competent authorities. I also adapted myself to the working remits of West Yorkshire University, West Yorkshire Hospital and contributed to writing the research protocol in collaboration with academics at the West Yorkshire hospital (Please see Appendix 1 in practice log book for an anonymized protocol synopsis).

Unit 1.1: Implement and maintain systems for legal, ethical and professional standards in applied psychology.

Whilst working as a trainee health psychologist, I have constantly thrived to implement and maintain good legal, ethical and professional standards within my working practices. One example of this was during my employment with a pharmaceutical company, I carried out a piece of work on the monitoring standards of a research study at investigator sites. The aim of this project was to provide an informative guideline to both the company and its employees in how to monitor, audit and identify whether the patient data generated during a clinical trial at the investigator sites was fit for purpose. For this project, I researched several relevant references related to the auditing, monitoring and good clinical practice (GCP) of clinical studies. I designed a questionnaire on the principles of GCP in regards to monitoring of clinical studies and distributed this questionnaire to forty

company employees for completion. I made sure that the identity of each of the employee was kept anonymous and confidential by thus providing each employee with a number from 1 to 40 with matching numbered questionnaires. I ensured that all previous standards of operating procedures (SOP) were reviewed and I thus liaised with auditors to ensure that the piece of work generated was within the framework of GCP laws (Please see Appendix 2 in practice log book for the anonymized standard operating procedures document on how to monitor clinical trials at an investigator site and presentation). This guideline/SOP was presented by me on a company training day and was implemented by the company.

I have been successful in designing, writing, reviewing and approving the informed consent (ICF) forms for the project in targeted ultrasound in patients with rheumatoid arthritis. For this piece of work, I have collaborated with a variety of stakeholders in the West Yorkshire Universities' legal department, academics and the regulatory department within the clinical research organization. On behalf of the sponsor, I steered the consent form to the client (a regulatory department within the CRO) and outlined both the requirements and legal clauses on behalf of the sponsor. I have acted as a mediator between the client's regulatory and legal contracts department and brought about a better understanding for the sponsor on the ethical legalities of informed consent in different countries. I have also advised the sponsor on the global requirements of informed consent according to the European Directive and in line with international data protection laws. For example, in Spain, the legal requirement is to use the Spanish legal law in consents known as the 'Spanish Decree' and in Spain it is a preference not to use the term abortion or contraception because of the countries religious standing. Another example is Japan

where the laws in this country for patient consent, data, and safety are not governed by the European legislation or data protection laws but according to the Japanese laws. In Japan, the consent form for the patient must be translated into Japanese and the list of all medicinal side-effects within the study need to be documented for the benefit of the patient. In the UK, the requirements of consent are very much governed by the COREC (Central Office of Ethics Committee), (Please See Appendix 3 in practice log book for the examples of the different consent forms, Spain, UK and Japan). All these consent forms were approved by each countries central ethics committees and regulatory authorities. This experience has also assisted me in the design of my own subject information sheet and consent form for my research study.

As a trainee health psychologist in my current work place, I have been instrumental with in my dealings with the central ethic committees by answering all their questions on the scientific rationale of the study design and outcome. I have also been successful in achieving global ethical approvals for the targeted ultrasound project. This approval success has also been granted to my own research study within caregiving and dementia (Please see Appendix 4 in practice log book for the EC application and approved e-mail). In addition, over the past seven years, I have maintained a supervision log documenting my practice and a reflective log.

As a Clinical Manager for the Vascular Dementia project, one of my roles was to source and review language translations of patient reported outcomes. I liaised with the vendor responsible for providing validated patient reported outcomes such as Mini-Mental State Exam (MMSE) , Montgomery Asberg Depression Rating Scale (MADRS), Severe

Impairment Battery (SIB) ,Alzheimer's Disease Cooperative Study-Activities of Daily Living (ADCS-ADL) , Clinician's Interview Based Impression of Severity with Caregiver (CIBIS-Plus), Quality of Life Alzheimer's Disease Instrument (QoL-AD), Euro Quality of Life Instrument (EQ-5D) and Screen for Caregiver Burden Scale (SCB).

Within my work place, I have also designed and implemented the intra and inter-reliability training programme in relation to the CIBIC-Plus. This opportunity allowed me to use my trainee 'hat' as a health psychologist. Here, I was responsible for visiting several investigator sites and working very closely with the clinical raters. I guided and trained the raters on the requirements and how to conduct the 45 minute CIBIC interview. I was responsible for reviewing the completed patient CIBIC-plus scales by the rater and identified areas where the raters could improve when performing the CIBIC-Plus interview by advising them to use more open and less closed questions with the patients. I implemented the patient communication model and guided the rater on how to conduct and facilitate this patient communication during a long arduous interview. In the training phase, I also ensured that the raters understood how to retrieve the patient's answers in line with the principles of the CIBIC scale. I also ensured that the principles of intra and inter reliability was maintained and that the raters understood the reasons for being blinded (to avoid patient bias by the rater) to all other clinical patient data. I collated and assessed all the information and feedback to the rater regarding the rater training, their patient interview technique, the capturing of the CIBIC components and feedback my findings to both the vendor and the Sponsor. This information was then presented as part of lesson learnt session at an Investigator meeting (Please see Appendix 5 in practice log book for the CIBIC-Plus Questionnaire) and was adopted as part of the training

programme in the study of vascular dementia. I have also worked closely with a clinical neuropsychologist and used my trainee health psychologist knowledge to create and implement a treatment expectation and satisfaction questionnaire for carers in the vascular dementia study.

Unit 1.2: Contribute to the continuing development of self as a professionally applied psychologist.

At City University, I have been very fortunate to attend a variety of health psychology workshops as part of my training including psychometrics, systematic review consultancy, counselling skills, teaching and training, Cognitive Behavioural Therapy (CBT), generic and professional. I believe that these workshops have been invaluable in providing me with a firm foundation, in increasing my confidence, enhancing my skills and thus assisting me in my professional development as a trainee health psychologist (Please see Appendix 6 in practice log book for the workshop certificates of completion). These workshops have also allowed me to be more open and reflective within my practice and encouraged me to be more interactive with other trainees and health professionals.

I have attended several British Psychological Societies (BPS) conferences within health psychology, primary healthcare events, investigator meetings, training courses and therapeutic training. These conferences have all assisted in the further enhanced my knowledge and skills in the areas of academic writing, interventions, project planning and my ability to conduct a systematic review. As I have progressed through the doctorate programme I have continued to develop and grow as an applied psychologist.

Publication.

In one of the Doctorate work-shop sessions, I with two other fellow trainee health psychologists were made aware that the BPS Health Psychology Update journal was looking for trainees to submit an article to the journal detailing their experience whilst undertaking the stage two health psychology doctorate programme. In collaboration with two other fellow trainees, I wrote a joint article on our experiences of undertaking the Health Psychology Doctorate at City University. This article was published in the Volume 16, Issue 4, 2007 in the special issue entitled *Teaching and Training of Health Psychologists*. (Please see Appendix 7 in practice log book and Appendix A for the British Psychological Society, Health Psychology, Update Journal). This was my first publication and even though this was based on the experiences of trainees on the doctorate programme and not an academic piece of work, it was still approved for publication. This opportunity has undoubtedly provided me with the experience, confidence and the desire to write more academic papers in the future for publication.

Developing my skills as a consultant.

My first consultancy experience comprised of an eight-week health eating programme being delivered to 11-12 years at a semi-professional football club in North Middlesex (Sponsor). The aims and objectives of the consultancy were to target children aged 11-12 years along with their parents/guardians by making them all aware of what the children should or should not be eating and to identify as to whether there was a difference in the 11-12 year olds physical performance by the eighth week.

My second consultancy included delivering a physical activity and healthy eating programme to nurses and clinical professionals at a North London Primary Care Trust. The third consultancy/intervention included delivering and implementing a Creating Health Active London Kids (CHALK) programme on healthy eating and physical activity behavioural change which was run by the London Teaching Public Health Network.

The consultancy workshops at City University have assisted me by providing me with the core principals and the confidence to conduct more consultancy work within the local community. I have been able to apply various psychological models of consultancy and behaviour change theories within my health psychology practice and these are the type of health behaviour change interventions that I would like to focus more on in the future as part of my continuous professional development. This experience has been extremely beneficial in my working with both the client and the sponsor. On further reflection, I have realised that in all future consultancy work I need to carefully plan the project timelines, cost and build in extra time for any potential delays and any additional out of scope services. On further reflection, I have realised that even though, I had billed the contact client for the services provided, I had not billed the contact client for my time in the preparation and design of the work. This is something that I need to implement in all future consultancy work. In addition to this, the other learning point for me during this consultancy/intervention process was to identify the needs, wants and expectations of all the stakeholders early in the project and to provide suitable support and training during the consultancy process. Whilst doing the doctorate programme I have learnt that consultancy work is something I thoroughly enjoy.

My experience in teaching training has been based on a variety of clienteles within my workplace. This has varied from delivering training to principle investigators participating in a research study at investigator meetings to conducting a communication skills training to laypeople at North London Primary Care Trust. In the training sessions, I discovered that I had achieved all the learning outcomes in terms of increasing the trainee's confidence and making them aware of matters of sensitivity. I also assisted them to identify both good and bad communication and applied these communication skills within a community based setting. However, there were other components of the training session that as a trainee health psychologist I could have improved which are part of the future learning especially in regards to my training and my delivery style.

My teaching and training included delivering a lecture on gender, culture, and health to the MSc students at City University. I realised that even though I had enormously enjoyed delivering the teaching session. I further discovered that I particularly enjoyed the group-work in the teaching session and this is something that I would further like to develop. The whole experience has been extremely useful in my continuous professional development.

Unit 1.3 Provide psychological advice and guidance to others.

My first experience of providing psychological and guidance to others was when I carried out the 8-week health eating intervention with 11-12 year olds already involved in a physical activity at a local football club.

Not only did I design and deliver this programme. I also provided psychological advice to the parents/guardians, the 11-12-year-old boys, the sponsor and the club caterer on healthier eating options. I also attended the football training sessions and football matches to support, advice and answer any questions, on healthy eating options before and after a football match. I met up with external bodies such as the South London Health Promotion Department, the press office at the Food Standards Agency and two health professionals at a North London Primary Care Trust. In the pursuit of knowledge share and exchange, I also sought psychological advice from nutritionists and health psychologists to further strengthen my experience as an applied psychologist.

Over the years, I have been involved in providing advice on a one to one basis especially in my workplace where I have provided expert advice in how to set-up a research protocol study, how to manage the study in the interim period, treatment and follow-up phases to close down.

Unit 1.4 Provide feedback to clients.

Part of my doctorate programme has consisted of communicating on the processes and the outcome of the consultancy for the 8-week healthy eating programme. The advice and feedback I provided to the contact client were received well and it was also a lesson learnt (health eating) for the Semi-Professional Football Club. The contact client on behalf of the sponsor suggested that they would like to see the intervention carried out in the future with an older age group of players and would recommend it to other clubs. The contact client also mentioned that the club caterer was offering healthier options in the club house

and the club had fresh fruit was on sale during the match days. For me, this was a successful intervention as the club had taken on board the advice provided by the trainee health psychologist on healthy eating options.

Lessons Learnt.

Over the seven years, I have gained a wealth of knowledge, skills and confidence as a trainee health psychologist. There are several lessons I have learnt and one prime lesson is when I conducted the Systematic Review: looking at the Psychological and Health Benefits of Motivational Interviewing as an Intervention in the Management of Type 1 and Type 2 diabetes. Here I discovered that you need to first define the parameters of your systematic review in terms of the research question. Secondly, the aims, objectives, the methodology, strategies and outcomes of the review. My systematic review took a period of two years to complete mainly because the topics I decided to research or select had either already been systematically reviewed or there were not enough research papers to warrant a review. From this experience, I learnt that effective planning, time management, and back-up strategies were paramount when performing such a task. Despite the challenges, through the continuous guidance of my supervisor I eventually started my systematic review and towards the end of the process, I thoroughly enjoyed completing this case-study. I am more confident in conducting systematic reviews soon.

Teaching and Training.

The teaching and training skills that I have developed over the seven years have been tremendously enhanced by me attending the Teaching and Training workshop in the

doctorate programme but also from carrying out teaching and training in practice. When preparing, for future training material I have learnt that I need to consult all sources of information both old and current. That I need to plan in detail when delivering any teaching and training, that the presentational material needs to be clear, concise and like a story which has a start, middle and end. Also, the other lesson I have learnt as a trainer is that I need to prepare for unexpected questions from the audiences because despite their different learning styles some audience members are well versed in the topic area in the given topic area. However, having changed my practice, I no longer experience these challenges.

Other Areas.

Over the past years despite enjoying the health psychology programme, the only regret I have is that I wish I could have had more opportunities to carry out and expand my health psychology practice within in my work place. Having said that the skills I have developed have given me the confidence to advise my current employer West Yorkshire University in the area of generic skills, the consultancy processes in terms of milestones and budgets and intervention and outcomes. Because of this, I have been given the responsibility and autonomy to make informative decisions on behalf the sponsor in relation to various stakeholders and decisions in collaboration with the sponsor. In addition, to this my skills have equipped me being more confident when speaking publicly to others at a conference or venue (see Appendix 8 in practice log book for the presentation material to be presented at the Rheumatoid Arthritis investigator meeting in Europe).

Conclusion.

When I first began the doctorate in 2006 and started my training as a trainee health psychologist I was extremely anxious. The main reason for this anxiety was because firstly my place of work was not within an NHS setting and secondly all my fellow trainee health psychologists on the doctorate programme all had a wealth of experience in relation to health psychology within the working remit of the NHS. As the years progressed, and my learning became more and more consolidated through a series of doctorate trainee work-shops and practice. I become more confident in my skills and abilities and I realised that I could implement the knowledge into practice. I also realised three poignant facts: one I did not need to work within a conventional NHS setting to avail and promote health psychology, secondly the skills and knowledge I had obtained as result of practice were transferable and thirdly as long I had the confidence or pragmatic approach I could apply it anywhere.

As a trainee health psychologist, I have become more open, and reflective in myself and in my practice allowing me to adapt the way I work which has resulted in me being a more proficient and experienced trainee health psychologist. As my confidence, has grown I become more proactive in looking for new opportunities at work within a generic and consultancy fields which I am competent in. I have also gained a wealth of experience by having the opportunity to work and communicate within a multi-disciplinary team of professionals which is important when working as an applied health psychologist.

The experience I have gained over the seven years as a trainee health psychologist has been extremely invaluable. At times, to be honest it has been challenging and also at times it has been rewarding and the prospect to work as a Chartered Health Psychologist in the near future is indescribable. To prepare me for this final journey last year I set-up a limited company so that I could seek more consultancy work in the field of health psychology and consultancy as an applied health psychologist.

References.

Schein, E. H. (Eds.) (1999). *Process Consultation Revisited. Building the Helping Relationship.* Reading, MA: Addison-Wesley.

Appendix A British Psychological Society Health Psychology Update Journal Volume.

Unit 1.2: Contribute to The Continuing Development of Self as A Professional Applied Psychologist

Publication: Khokhar, F. et al. (2007). Teaching and Training of Health Psychologists. BPS Health Psychology Update Journal Volume 16, Issue 4, Special Edition.

The Stage 2 "City" Experience: Three Trainee Perspectives.

What made us decide to do it?

Our reasons for applying for the Stage II Health Psychology Doctorate were very similar. Having completed the Stage I programme, we were very clear that gaining chartered status was our goal in pursuing careers as Health Psychologists. Having investigated the BPS route, the Doctorate route was chosen as we also felt that in addition to having chartered status within this growing field, that Doctorate status would strengthen our position for being recognised as professional Health Psychologists.

Our initial impression of the Doctorate programme at City University London was that the route for gaining chartered status was clearly defined, structured methodically and flexible in offering both full and part-time routes. We were also extremely impressed by the timetabled workshops spanning across a two-year period covering the core Stage II

competencies (both theoretical and pragmatic dimensions). The very interactive workshops provide trainees with an opportunity to practice and develop skills, which assist trainees in completing the competencies. The workshop facilitator gives feedback on the development needs of trainees and they end with time for reflexion. In addition, they provide trainees with an excellent opportunity to meet on a regular basis to share experiences and to gain peer support for what can sometimes feel like a very lonely journey. The workshops have proved to be invaluable in keeping us motivated along with regular supervisions with our supervisor.

So where do we work?

Two of us work for London-based Primary Care Trusts in the roles of Primary Care Facilitator for Smoking Cessation and Public Health Strategist for Long Term conditions, leading on obesity and physical activity. The third works as a Senior Clinical Research Associate for a Pharmaceutical Company. This involves organising and managing clinical trials in the areas of Dementia and Alzheimer's disease, which means that some competences have been gained outside of this role.

Progression.

Trainee	**Research**	**Generic & Prof.**	**Teaching & Training**	**Consultancy**	**Option 1**	**Option 2**
1 (Julie Pearson)	Qualitative study using Interpretative Phenomenological Analysis: Smoking cessation in pregnant and postpartum smokers and why pregnant and postpartum smokers relapse.	Writing a grant proposal, attending conferences, seeking out opportunities to develop as a health psychologist, presenting at conferences, exploring new areas in smoking cessation, e.g. prisons.	Delivery of a lecture for MSc Health Psychology students on how health psychology is implemented within the workplace. Delivery of a two-day course on smoking cessation for health care professionals	Evaluating a health intervention for a London PCT aimed at reducing salt consumption amongst black and minority ethnic groups at increased risk of cardiovascular disease using qualitative methodology (Interpretative Phenomenological Analysis).	Unit 5.1 Delivering an intervention for a pregnancy client giving up smoking, and working with the client in the postpartum period.	Unit 5.2 Observing and supervising a practice nurse delivering smoking cessation interventions over a four-week period.

2 (Farah Khokhar-Cottrell)	Quantitative and qualitative study (using Interpretative Phenomenological Analysis): Exploring various types of satisfaction experienced by male and female caregivers who are caring for patients with dementia within the home environment.	Addressing issues of patient consent and data protection, providing feedback on research proposals submitted to ethics committees, attending conferences, delivering presentations /training.	Delivery of a lecture for MSc Health Psychology students for the Life Span, Gender and Culture module. Plan to deliver physical activity promotion training for primary health care professionals.	8-Week Healthy Eating Programme for Children aged 11-12 years at Semi-Professional Football Club. Providing a healthy eating and behaviour change programme for an individual footballer at a semi-professional football club.	Unit 5.1 Delivering an 8-week healthy eating intervention aimed at children aged 11-12 years and their families who attend a semi-professional football club.	Unit 5.3 The processes and outcomes of the 8-week healthy eating consultancy and intervention to be communicated and disseminated back to the clients, i.e. parents/children and the semi-professional football club).

3 (Vanessa Bogle)	RCT – The efficacy of Motivational Interviewing and Implementation Intentions for a Physical Activity Referral Scheme.	Attending conferences, delivering presentations/ training, attending project management course, providing psychological advice relating to obesity and physical activity.	Delivery of a 2-day Motivational Interviewing course for health professionals 1-hour workshop for work-based health physical Activity initiative.	Providing behaviour change training as part of a Department of Health pilot (Primary care physical activity care pathway). Providing psychological advice across the local obesity network for the development of an obesity resource pack for use in primary care by health professions to assist them in addressing issues of overweight and obesity in their work with patients.	Unit 5.8 Successful grant application for a community-based physical activity initiative using behaviour change approaches aimed at those at high risk/with established cardiovascular disease within 3 deprived wards.	Unit 5.6 Development of an Obesity Strategy/obesity care pathway and disseminating knowledge in this area via a local Obesity Conference.

Top tips for potential students.

- Book frequent supervisions with your supervisor.
- Keep in regular contact with fellow trainee health psychologists on your course or form a more formal trainee support group.
- Make contact with second year trainees to benefit from their experiences.
- Attend the workshops.
- Complete your log book on a weekly basis to avoid the creation of a backlog.
- Seek out opportunities outside/within your workplace to complete the competencies.
- Look for opportunities for funding through staff development grants/bursaries.
- Seek training and teaching opportunities at universities/within the workplace.
- Seek opportunities to carry out consultancy work.
- Explore opportunities to present your work, e.g. Conferences.
- Early submission of your COREC form for your thesis is recommended.

  Ensure you receive feedback from your supervisor prior to submission.
- Explore opportunities for flexible working within your workplace.

Challenges.

- Good time management skills are required to enable you to manage the work and life balance.
- If you're current employment does not provide you with opportunities to cover all competencies, it can be a challenge to fulfil these competencies elsewhere.
- Completing the COREC form is a major piece of work. Do not underestimate the complexity and time required for completion.
- The need to use annual leave to complete the Doctorate within the given timeframe.
- Raising awareness of the importance of health psychology and its relevance within the workplace, e.g. in implementing the 'Choosing Health Agenda'.
- Raising awareness and the profile of health psychology, e.g. the generic skills we have as health psychologists.
- Lack of funding for training compared to other health professionals.

Developing as a Health Psychologist.

- Increased confidence in designing and delivering health interventions.
- Enhanced skills to carry out research and in evaluating health initiatives.
- More reflective in our practice.
- Increased confidence in delivering teaching and training.
- Confidence in ability to act as a consultant.

Next Steps!

We look forward to working as Chartered Health Psychologists. The field of health psychology is developing rapidly and we feel that the Doctorate will open a diverse range of opportunities for health psychologists within this new and exciting discipline.

Recommended reading:

1. Exley, K. & Dennick, R. (2004). *Small Group Teaching: Tutorials, Seminars and Beyond.* London: Routledge.
2. Michie, S. & Abraham, C. (2004). *Health Psychology in Practice.* Oxford: Blackwell, Publishing Ltd
3. Schein, E. H. (Eds.) (1999). *Process Consultation Revisited. Building the Helping Relationship.* Reading, MA: Addison-Wesley.

Correspondence:

Trainee Health Psychologists: -

Vanessa Bogle [redacted]

Farah Deba Khokhar-Cotterell [redacted]

Julie Pearson [redacted]

City University London

School of Social Sciences

Department of Health Psychology

Northampton Square

London

EC1V 0HB

SECTION D

Core Unit: 2.1: Conduct a Systematic Review.

Title: The Psychological and Health Benefits of Motivational Interviewing as an Intervention in the Management of Type 1 and Type 2 diabetes: A Systematic Review.

2.1a Define Topic and Search Parameters.

Background.

Diabetes Mellitus is a chronic disease which per the World Health Organisation (2014) is reported to affect 346 million people in the world. Diabetes is a group of diseases which is characterised by high blood glucose level in the human body due to a deficiency in the production of insulin, insulin action or both (Eiselein, Schwartz, & Rutledge, 2004). The incidence of diabetes is increasing because of the aging population and the way people live their lifestyles (Wild, Roglic, Green, Sicree, & King, 2004). The number of deaths resulting from diabetes is projected to double between the years of 2005 to 2030 and of these 80% of these diabetes deaths will have occurred in low and middle-class income countries (WHO, 2014). Diabetes was currently reported to be the cause of 1.5 million deaths in 2012 per the World Health Organisation (2014) and 4.9 million deaths in 2014 (International Diabetes Federation, 2014) and estimates suggest that it will be the 7th leading cause of death in 2030 (Mathers & Loncar, 2006)

Diabetes Type 1 (insulin dependent) accounts for 10% of the population affecting the younger population with the peak age being around 14 years old (Eiselein et al., 2004). This type of diabetes is a T-cell mediated autoimmune disease where the insulin producing beta cells of the pancreatic islets of Langerhans are destroyed (Eiselein et al., 2004). Diabetes Type 2 (non-insulin dependent), is caused by the inadequate production of the hormone insulin or a lack of response to insulin by various cells in the human body (Skelly, 2006). Type 2 diabetes is predominately seen in the adult population after the age of 30 (Skelly, 2006). It is seen to be increasing rapidly in children, adolescents, young people from different ethnic groups from developing countries such as the South Asian and the Afro-Caribbean communities within the UK (Riste, Khan, & Cruickshank, 2001; Skelly, 2006). Genetics, environmental factors obesity, and a sedentary life are all factors liked to Type 2 diabetes (Skelly, 2006).

Diabetes Mellitus is seen to continue for the duration of the patient's life and can cause long-term health related effects such as various infections, peripheral neuropathy causing foot ulcers, Charcot joints amputation, autonomic dysfunction resulting in sexual dysfunction, nephropathy leading to renal disease and retinopathy resulting in blindness (Alberti & Zimmet, 1998). Complications associated with diabetes mellitus effect economies of countries, their health systems, the individual diagnosed with the disease and their families (WHO, 2014). Early screening interventions, such as blood testing have helped in the diagnosis and treatment of diabetes. Other measures such as maintaining a healthy body weight, regular and moderate exercise of 30 minutes a day, eating healthy and smoking cessation have all contributed in helping in the management of diabetes. Despite these recommendations, many patients have found themselves unable to adhere

to these recommended lifestyle changes (Minet, Moller, Vach, Wagner, & Henriksen, 2010).

Minet et al. (2010) carried out a meta-analysis by looking at forty-seven randomised control trial papers, regarding the effects that self-management interventions had on in improving glycemic control in Type 2 diabetes. Minet et al. (2010) found that the failure of the patient to adhere to certain treatment regimens was a result of psychological and motivational influences rather than an educational style. Other studies carried out have also supported this point of view in that educational awareness of lifestyle changes have not always contributed to behaviour change (Minet et al., 2010; Stead, Cooke, & Newman, 2003; Danish Health Technology Assessment, 2003). In this meta-analysis, it was found that patients with Type 2 diabetes who had received self-care management treatment combined with an educational intervention benefitted from small improvements both in glycemic control and behaviour change. Minet et al. (2010) concluded that there was a need to challenge the impact of diseases such as diabetes in line with other psychological methods and motivational interviewing interventions. It was also suggested that future research needed to be conducted looking at the duration and frequency of an intervention which influenced self-care management in Type 2 diabetes patients.

Motivational Interviewing as an Intervention in Diabetes Care.

Motivational Interviewing (MI) was originally developed by R. Miller in 1983, from his experience of working with individuals that were alcoholics. It has been implemented and tested in various psychological, health and research settings where MI efficacy as an

intervention has been evaluated and demonstrated. The most recent definition of Motivational Interviewing is as follows:

"A collaborative, person-centred form of guiding to elicit and strengthen motivation for change." (Miller & Rollnick, 2009).

As motivational interviewing is a client-centred directed approach it targets the individual's internal motivations and explores the individual's unwillingness to make a behaviour change (Miller & Moyers, 2006). Motivational Interviewing in its collaborative spirit guides the individual rather than directing them and assists the individual by listening to their reasons rather telling them what to do. It supports the individual and gets them to understand their diverse emotions regarding the desired behaviour change so that they can internally drive the change and thus in this way motivational interviewing respects the patient's autonomy (Rollnick, Miller & Butler, 2008).

Motivational Interviewing as an intervention is based on the transtheoretical model of behaviour change (Prochaska & DiClementine, 1982). It is also known as the *stages of change model* (DiClemente, Prochaska, Fairhurst, Velicer, Velasquez, & Rossi, 1991; Prochaska & DiClementine, 1984; Prochaska, DiClemente, & Norcross, 1992) this theory of behaviour change describes people's eagerness to change with five potential stages:

- **Pre-contemplation:** Does not have enough information to identify a problem/ believe in the inability to change.

- **Contemplation:** There is an openness to consider that a problem exists; however, a commitment has not been made yet.
- **Preparation**: The individual has made the decision to make the change and prepares the course of action.
- **Action and Maintenance:** The person recognizes that there is a problem and decides to do something about it. In maintenance, the individual recognizes the benefits of change.
- **Relapse:** The individual must be aware of triggers that cause him/her to relapse.

West (2006) openly criticised the stages of change model, despite its preference amongst health professionals. Suggesting that it was flawed in its concept of stages because of its random, insignificant, false divisions between the stages. He called for the model to be operationalized and that a new model of change to be introduced. The new model of change he commented needed to be broader, to allow more choice making and have more motivational processes that were not cognisant. West (2006) also argued that the new model needed to understand how individuals, create, maintain and discard behaviour by involving more stable factors such as biological, psychological and social/environmental. Prochaska (2006), responded to West's comments and found that he had focused largely on the principles related to the stages in terms of labels and time frames instead of the model of change itself. Prochaska (2006), further commented that as the model had assisted early interventions, treatment for individuals and health care services it thus should not be abandoned nor replaced.

However, in recent years the rise in MI has significantly been seen in the treatment of smoking cessation, weight loss, physical activity, asthma, diabetes and in the adherence of treatments for these health/medical conditions (Rubak, Sandbaek, Lauritzen, & Christensen, 2005). MI has typically been delivered by various health care professionals such as mental health counsellors, clinical psychologists and social workers who are not always trained in diabetes and who are also not part of the primary care setting (US. Department of Health and Human Services, 2007). MI as a method of intervention has also been adopted by general practitioners, nurses and midwives (Rubak, Sandbaek, Lauritzen, Borch-Johnsen, Christense, 2009). Diabetes-related research studies using MI-based therapies have shown a variety of results ranging from significant, marginal or conflicting findings (Ismail, Maissi, Thomas, Chalder, Schmidt, Bartlett, Patel, Dickens, Creed, & Treasure, 2010).

Most research studies with diabetes have looked at MI in combination with other therapy interventions. The most successful lifestyle intervention programmes in Type 2 diabetes with MI have combined dietary restriction, exercise, and behaviour modification programmes (Wing, 1993). There have been several systematic reviews carried out in the field of motivational interviewing, one such review is by Campbell and Madson (2006). In their paper, several studies were reviewed looking at the therapist's adherence and competence to empirically supported MI interventions in the areas of substance abuse and behavioural problems. However, some of these studies raised concerns in regards to the fidelity of MI and the way it was implemented in relation to training, supervision, and monitoring of the therapists and thus was not always seen to coincide with spirit of MI (Moyers, Martin, Catley, Harris, & Ahluwalia, 2003; Rollnick & Miller, 1995). Campbell and Madson (2006), found that there was a need for researchers and clinical supervisors

to evaluate such evidence-based interventions. This would ultimately enable clinicians to obtain a better understanding of the principles of an intervention but also assist clinicians in their skills development. For such an intervention to work it must be provided with *'skill and reliability'* (Campbell & Madson, 2006).

Rubak et al. (2005) carried out a systematic review and meta-analysis of randomised controlled trials to examine the effectiveness of motivational interviewing in the various areas of physiological and psychological diseases. The meta-analysis showed a significant effect in that motivational interviewing within a scientific setting was seen to be more successful in comparison to traditional treatment advice on a range of behavioural problems and diseases. The paper suggested that large-scale studies are needed to demonstrate whether motivational interviewing could be implemented within a 'clinical, primary and secondary health care setting' (Rubak et al., 2005).

Aims and Objectives of the Systematic Review.

The aim of this systematic review was to look at the psychological and health benefits of motivational interviewing as an intervention for diabetes in adults and the influence that motivational interviewing had on the patient's everyday management of diabetes (Type 1 and Type 2).

Methodology.

Criteria for inclusion of studies in the review.

This systematic review only considered research studies from 2000 until 2015 that were randomized control trials. The inclusion criteria focused on all relevant studies that were both experimental and evidence based. Studies from any country were included if published in English. Studies using MI with adults were considered solely for this systematic review and studies with children or adolescents were not considered for this review. The main reason to exclude children and adolescent studies was because there had been very few studies carried out in MI with both adolescents and children and none of these studies were randomised control trials.

Setting.

This systematic review focused on interventions that have been implemented within a primary care, health care community centres, clinics, university research departments and hospital settings.

Types of Participants.

All the studies included adults aged eighteen years plus at the start of the study, consisting of both male and female genders with a confirmed diagnosis of Type 1 or Type 2 diabetes.

Types of Intervention.

All studies that included motivational interviewing as a stand-alone intervention or part of a component for another intervention in the self-management of diabetes were considered in this systematic review. Studies that included counselling, CBT, self-diabetes management therapies or health promotion interventions as stand-alone interventions and did not include motivational interviewing were excluded. Also, neonatal and gestational diabetes studies were excluded.

Outcome Measures.

The studies included from the literature research needed to contain the outcome measurements of how the intervention had affected the health or wellbeing of the participants. The inclusion criteria for these health outcomes were as follows:

- Physical health.
- Mental health and well-being.
- Self-efficacy.
- Adherence to treatment.
- Glycemic control

2.1b Conduct a search using appropriate databases and sources.

Search Strategy for the identification of relevant studies.

The following academic research databases were targeted for published literature between the period of ten years and more from 2000 until 2015 as follows:

- CINAHL (E-Journals database, Library, Information Science & Technology Abstracts (LISTA), Library, Information Science & Technology Abstracts with Full Text, Psychology & Behavioural Sciences Collection, Psych Articles and SocINDEX)
- Medline.
- Psych info
- Embase
- EMB Reviews (ACP Journal Club, Database of Abstracts of Reviews of Effectiveness and Cochrane Database of Systematic Reviews)
- Cochrane Controlled Trials Register (CCTR)
- Scirus.

The following databases were also searched for unpublished literature:

- Ethos and Index thesis.

Journals were manually hand searched for a detailed review and dissertation abstracts for their relevance and to ensure that articles that might have been missed via electronic

searching might be discovered. Other sources such as the internet, conference papers, and books were also reviewed.

The Websites and other URL's that were examined for their relevance are as follows:

- <http://www.who.int/diabetes/en/index.html 2012>

- www.**diabetes**.org.uk/Information 2012

- *spectrum.**diabetes**journals.org/content/19/1/5.full*

- www.**motivationalinterview**.org/documents 2010

- http://www.fhi.se/Documents/ICMI/Dokumentation/June---6/Miller---and---Rollnick---june6---pre---conference---workshop.pdf

- *Conference*www.lib.ncsu.edu/databases/more_info.php?database=29889 *2012*

The search terms used are detailed in full below:

Diab* OR Diabetes OR Diabetes Type 1 OR Diabetes Type 2 or Type 1* OR Type 2*

AND

Motiv* OR Motivational Interviewing OR Motiv* and Diabetes OR Motivational Interviewing OR Diabetes Type 1 OR Type 2

AND

Adult* OR Over Eighteen OR Adult Male OR Adult female.

AND

randomised control* trial OR randomized control* trial OR rct OR rcts OR random allocation OR controlled clinical trial.

Data Management.

A record was maintained on an on-going basis detailing the names of databases viewed and the keywords searched. Research papers with titles, abstracts, and full text were considered and recorded with details of where the article had been found. Relevant studies were filed per the inclusion and exclusion criteria. Full details of electronic searching and the search results were recorded.

Review and Selection.

Articles were selected after the keywords have been searched. The relevant titles and abstract were read by the first reviewer (trainee health psychologist) to ensure that the study meets the inclusion criteria. Studies that met the inclusion criteria had their full-text

read. To ensure that all potential studies were included in the systematic review, therefore when it could not be ascertained as to whether the abstract satisfied the inclusion criteria, the full article was obtained for a further review. Abstracts of articles that did not meet the inclusion criteria were excluded. In parallel to this search, citations were followed up and authors/experts within the field of the intervention and who had already published studies were also contacted for details of any further published and unpublished studies.

Studies Included in the Review.

The original search when using the research terms diabetes and motivational interviewing singly identified 18,112 papers and with the use of keywords and search terms such as diabetes Type 1 and Type 2, Adult or over 18 years and randomized controlled trials the number of papers was reduced systematically down from 1202 to 754 and 413. Of the 413 papers identified, the abstracts of these papers were reviewed for further perusal and a total of 23 papers were included. No additional papers were found from citations and handheld searches. The 23 papers were reviewed in line with the aims/objectives of this systematic review, the psychological and health benefits of motivational interviewing as an intervention, and the influence that motivational interviewing had on the patient's everyday management of diabetes (Type 1 and Type 2). A total 15 studies were not included in the review the main reasons for this were as follows: non-RCT studies, protocol studies, research studies that did not present the results, purely GP studies, studies not including motivational interviewing and studies that provided a description of the studies already included in the review.

A total of eight studies were found to satisfy the inclusion criteria and were included in the review. The period of the studies ranged from 2007 to 2015. The length of the studies varied from 6 months to 18 months and the sample sizes varied from less than a 100 to 600+(Please see Appendix 1 in the practice log book and Appendix A for the summary of the papers included in the data extraction table).

Assessment of Methodological Quality:

An assessment of the quality of the studies was carried out by two reviewers (first reviewer: trainee health Psychologist) and (second reviewer: health psychologist). The study quality was assessed under two categories, namely methodological quality and reporting quality.

The first reviewer assessed the studies identified for inclusion using the quality assessment measure. The relevant articles were then forwarded to the second reviewer for review and a critical appraisal. At the end of this process, both reviewers discussed the papers that they had independently graded, compared the rating and discussed any discrepancies that they may have come across and agreed upon the results. If the there was more than a 2-point difference in the grading the reviewers corresponded to resolve these and agreed on the further rating. In cases where there was a less than a two-point difference, it was agreed by both reviewers that a decision would be made by the first reviewer and the quality assessment question would be re-assessed by the first reviewer. Of the eight papers reviewed, five papers had a discrepancy of one and three papers had no discrepancies. For more information on the quality assessment rating system (please see Appendix 2 in the practice log book for the Quality Assessment form).

An Overview of the Studies in the Review.

Seven of the studies included were of Type 2 diabetes studies and one of the studies included only Type 1 diabetes. A total of 3223 participants took part in the eight studies and three of the studies also included GP's (263 GP's in total). One of the studies was conducted in the UK, two in Denmark, one in Holland, one in Thailand and three in the US. The studies included were as follows: Dale, Caramlau, Sturt, Friede, & Walker (2009); Rubak et al. (2009); Rubak, Sandbaek, Lauritzen, Borch-Johnsen, & Christensen, (2011); Welch, Zagarins, Feinberg, & Greene (2011); West, DiLillo, Bursac, Gore, & Greene, (2007); Jansink, Braspenning, Keizer, Van der Weijden, Elwyn, & Grol, (2013); Wattanakorn, Deenan, Puapan, & Schneider, (2013); Ingersoll, Banton, Gorlin, Vajda, Singh, Peterson, Gonder-Frederick, & Cox, (2015). The studies were carried out in a variety of settings ranging from general practices, clinics, diabetic clinics, and universities.

All the studies in this review used motivational interviewing as an adjunct to other treatments for diabetes. Rubak's et al. (2009) examined whether MI trained GP's could improve Type 2 diabetes patients understanding of diabetes, belief regarding prevention, treatment and motivation for behaviour change. Rubak et al. (2011) examined whether a course in MI for GP's improved patient's adherence to intensive treatment based on risk parameters and adherence to prescribed medication in people with Type 2 diabetes mellitus (T2DM) detected at screening. Both, Rubak et al. (2009) and Rubak et al. (2011) studies were follow-up studies to a randomised controlled trial (RCT) study. Welch et al. (2011) looked at whether glycemic control could be improved when motivational interviewing (MI) was used inconjunction with Diabetes Self-Management Education (DSME) compared to DSME alone. West et al. (2007) evaluated whether adding MI to a

behavioural weight control programme improved weight loss outcomes and glycemic control for overweight women with Type 2 diabetes. Dale et al. (2009) measured the effectiveness of a peer telephone intervention to enhance self-efficacy in Type 2 diabetes patients. Jansink et al. (2013) assessed a comprehensive diabetes programme in general practice by the integration of MI by looking at the effects this had on the clinical parameters of lifestyle, the patient's readiness to change lifestyle and on their quality of life. Wattanakorn et al. (2013) looked at the effects that an Eating Behaviour Modification Programme (EBMP) based on the self-regulatory theory and motivational interviewing had on Thai people with diabetes and obesity. Whereas Ingersoll et al. (2015) looked at a telephone motivational intervention targeting completion of an internet intervention for drivers with Type 1 diabetes and compared the utilization of the programme by those randomised either into intervention plus MI, intervention without MI and control group.

Four of the papers examined whether there was an improvement in the level of glycated haemoglobin (HbA1c) between the intervention group and the control group (Dale et al., 2009; Rubak et al., 2011; Welch et al., 2011; Wattanakorn et al., 2013) and one examined HbA1c in line with diet and physical activity (Jansink et al., 2013). One paper looked at self-efficacy (Dale et al., 2009) and two papers looked at distress (Dale et al., 2009; Welch et al., 2011). Other outcomes measures evaluated by the papers were medication adherence (Rubak et al., 2011), level of cholesterol (Rubak et al., 2011; Jansink et al., 2013), BMI (Rubak et al., 2011; West et al., 2007; Jansink et al., 2011 & Wattanakorn et al., 2013), psychological and behavioural measures (Welch et al., 2011). Wattanakorn et al. (2013) looked at also body fat percentage, waist circumference, illness representations and eating behaviours. While Ingersoll et al. (2015) looked at internet intervention usage,

its adherence and maintenance by users, programme completion in regards to benchmarks including assignments and eleven to twelve month diaries.

Methodological Critique of Quality

Five of the studies satisfied most of the quality criteria and were given a score of 13 (West et al., 2007; Wattanakorn et al., (Ingersoll et al., 2015) and 12 (Rubak et al., 2009 & Jansink et al., 2013) during the assessment quality rating as described above in section 2.1b and were defined as being of high quality. Three studies had a score rating between 10 and 11 and were defined as being of a medium quality (Welch et al., 2011; Rubak et al., 2011; Dale et al., 2009).

All the eight studies included in the review were randomised controlled trials. Seven of the papers gave a description of randomisation (Dale et al., 2009; Ingersoll et al., 2015; Jansink et al., 2013; Rubak et al., 2009; Rubak et al., 2011; Wattanakorn et al., 2013; West et al., 2007). Three papers stratified randomisation per county and size of GP practices (Jansink et al., 2013; Rubak et al., 2009; Rubak et al., 2011) in their studies. One of the papers provided no description of the process of randomisation (Welch et al., 2011).

Sample sizes.

The sample sizes in the studies were more than 100 in all the six studies apart from two (Dale et al., 2009; Wattanakorn et al., 2013). Six studies provided justification for the sample sizes per group and the power analysis calculations (Dale et al., 2009; Ingersoll et

al., 2015; Jansink et al., 2013; Rubak et al., 2011; Wattanakorn et al., 2013; Welch et al., 2011; West et al., 2007). One paper did not fully describe how the sample sizes per group were compared and assessed to obtain the power calculations and p-values (Rubak et al., 2009). In one paper, the patient number per arm was greater than a 100 in comparison to the number of GP's taking part in the study which was less than a 100 (Rubak et al., 2011; Wattanakorn et al., 2013; Jansink et al., 2013).

Response sizes.

Two of the studies reported on the response rates (Rubak et al., 2011; Rubak et al., 2009). Welch et al. (2011) reported an attrition rate of 35% while Rubak et al. (2011) reported that two practices (6 GP's) and 2 Type 2 diabetes patients dropped out after randomisation. Rubak et al. (2009) reported 2 practices (6 GPs) dropped out after randomisation, two Type 2 diabetic patients dropped out after randomization and 13 participants in the control group and 18 in the intervention group did not complete one-year follow-up. West et al. (2011) in his paper reported a modest attrition (93% retention at 18 months). Dale et al. (2009) allowed an attrition rate of 20%, with the aim to recruit 125 subjects from each arm of the trial (i.e. 375 patients in total) but this attrition rate was not fully reported. Jansink et al. (2013) reported that 4 practices in the intervention and 2 practices in the usual care group dropped out. Wattanakorn et al. (2013) reported an attrition rate of 10% and Ingersoll et al. (2015) reported a drop-out rate of zero.

Baseline Data.

Welch et al. (2011) compared the study groups at baseline on demographics and treatment variables (age, gender, race/ethnicity, education level, marital status, diabetes duration,

HbA1c, questionnaire scores, medication use). He found that that the groups at baseline differed in terms of demographics and treatment variables. Rubak et al. (2009) found no differences at baseline between the intervention group and control group for the participants (newly diagnosed patients). West et al. (2007) found no differences in the baseline demographics factors between dropouts (weight, or diabetes control) compared to study completers. Dale et al. (2009) collected baseline data after randomisation and no differences were found between the three groups in the primary outcome measured by Diabetes Management Self-Efficacy Scale (DMSES). Rubak et al. (2011) study had included data obtained from baseline data and at one year follow-up: risk profile of glHbA1c, height, blood pressure, health care services (Prescribed medication was reported by the GPs on case record forms) and self-reported data (Data from patient questionnaires on smoking and exercise in leisure time and at work); there was no difference in the groups. Jansink et al. (2013) looked at the baseline features of general practice, nurses, patients and the baseline values in regards to lifestyle and quality of life and found no differences between the intervention (diabetes care programme with MI) and the control group (usual care programme). Wattanakorn et al. (2013) found no meaningful differences in the demographic characteristics and outcome variables at baseline between the Eating Behaviour Modification Programme (EBMP) intervention and the control group.

Intervention described and Primary Outcomes.

All the eight studies described the interventions in full (Dale et al., 2009; Ingersoll et al., 2015; Jansink et al., 2013; Rubak et al., 2011; Rubak et al., 2009; Wattanakorn et al., 2013; Welch et al., 2011; West et al., 2007) and these described the primary outcomes in their papers. Self-efficacy and HbA1c were reviewed in Dale's et al. (2009) paper. Rubak

et al. (2009) reviewed the percentage rate to questionnaires between the MI in comparison to the control group. Rubak et al. (2011) examined the HbA1c. Also in this paper medication adherence and GP's intervention (where 1.7 out three MI consultations were used) were evaluated. Welch et al, 2011 looked at the primary outcome of HbA1c within the MI intervention and non-MI group (Control group). West et al, (2007) reviewed weight, BMI, and AIC within MI and non-MI groups at 6 and 18 months. Jansink et al. (2013) examined HbA1c, on the aspects of lifestyle in regards to the diabetes outcomes measures and quality of life in both the intervention and the control group. Watttanokorn et al. (2013) compared differences between the intervention and control group for BMI, waist circumference, blood sugar levels, illness representation and eating behaviours. Ingersoll et al. (2015) examined internet intervention usage, adherence, maintenance of changes during intervention and programme completion in terms of benchmarks assignment and monthly diaries between the Diabetes drivers.com plus MI (DD.com plus MI) intervention between the intervention without MI (Diabetes drivers.com (DD .com only) and the control group (usual care).

2.1c Summarise findings from the review.

Results.

The results of this review will be discussed below in relation to the intervention approach provided.

Evaluating telephone peer-Intervention for diabetic patients.

Dale et al. (2009) tested the study design by comparing the effectiveness of peer telecare support through the enhancement of self-efficacy in Type 2 diabetes in comparison to nurse telecare provision (who were trained on MI) or routine care alone.

Telecare support was intended to compliment routine care by *'motivating adherence'* in terms of the advice provided by the general practitioner or practice nurse at the *'time of change'* in relation to the patient's lifestyle and their prescribed medication. Most of the patients found the telephone support, whether provided by peer or Diabetes Specialist Nurses (DSN) was more useful than routine care. Telecare peer support was seen to be less valued when provided by DSN. The study failed to demonstrate any impact on the physiology and psychological measures of well-being for both peer and patient.

The results of the effect sizes, when compared to six months of the intervention, were small for the primary outcome for both PS and DSN when compared with the control group. The effect sizes for PS and DSN, when compared with the control group were small for the secondary outcomes for Problem and Distress scale (PAID) and HbA1c. Therefore, the overall effect sizes for all groups was small. There were no overall clinical significant differences shown for the primary outcome of self-efficacy and Hb A1C or other secondary measures at six months for the intervention group. Even though no significant differences were shown in peer support group for self-efficacy and secondary outcomes of HbA1C or PAID in comparison to the control group. There were small differences shown between the groups and DSN for self-efficacy and HbAIC which were not significant.

Intervention examining whether GP's trained in MI can affect positive attitude to behaviour change in Type 2 diabetes.

The study inspected whether GP's trained in MI could affect the behaviour of type 2 diabetic patient in their understanding of the disease, their beliefs regarding prevention and treatment and motivation for a behaviour change, Rubak et al. (2009). The GP's were randomized into two groups, the intervention group received training on MI and the control group received no training on MI. However, both groups received comprehensive training on target driven approach to treating Type 2 diabetic patients Rubak et al. (2009). The assessment questionnaires used in the study were previously validated in primary care with Type 2 diabetic patients and area as follows: The Health Care Climates questionnaire (HCCQ) consisting of six items which evaluated the patient-doctor relationships; the Treatment Self-Regulation questionnaire (TSRQ) which evaluates degrees to which behaviour is self-determined was subdivided into three subscales autonomous regulatory style; the controlled regulatory style and amotivation style. Diabetes Illness Representation Questionnaire (DIRQ) which assess beliefs and understanding of Type 2 diabetes and Summary of Diabetes Self-Care Activities (SDSCA) related to Type 2 diabetes.

The results showed that the effect sizes for the HCCQ questionnaire were small for the intervention. The effect size for the TSRQ was also small and there was not a significant difference between the groups. For the TSRQ Autonomy subscale the effect size was small but despite this, the intervention group was more autonomous in bringing about a change in behaviour. In the TSRQ 'amotivation' the effect size for the intervention group was larger in comparison to the control group. There was a significant difference in that the patients in the intervention group were more motivated. The effect size for TSRQ

Index (relating to self-determination, control and help) was small and showed no significant difference between the groups. The effect sizes for DIRQ and Timeline was small for both intervention in terms of control prevention: threat and impact and had no significant difference. The study showed a response rate to the patient questionnaire of 87% in the intervention group compared to 90% in the control group. Also, the study showed was that the patients in the intervention group were more independent and motivated to change their behaviour after one year, also patients in the intervention group were more likely to be more significantly aware when supervising their diabetes and significantly had a better understanding of how to prevent complications relating to their diabetes in comparison to the control group. MI improved Type 2 diabetes patient's beliefs regarding treatment aspects, their contemplation and their motivation for behaviour change. GP's in MI group were found to give more advice on diet, exercise, and self-control of diabetes than GPs in the control group.

Intervention examining the effect of MI on Type 2 diabetic treatments and target driven intensive treatment.

The study evaluated whether GP's trained in MI could improve a patient's adherence to intensive treatment based on risk parameters and adherence to prescribed medication in people with Type 2 diabetes detected by screening. The GP's were randomized into two groups, the intervention group received training on MI and the control group received no training on MI. However, both groups received a comprehensive training on target driven approach to treating Type 2 diabetic patients Rubak et al. (2011). Rubak et al. (2011). In this study the risk profile HbA1c was analysed, height was measured, prescribed medication was reported to GP's on the case record forms (Health Care Services). Blood samples were obtained from the Nation Health Services Registry in Denmark. The

assessment questionnaires international Physical Activity Questionnaire (IPAQ) and (Summary of Diabetes Self-Care Activities (SDSCA) were used in the study were previously validated and used to obtain data on smoking, exercise in leisure and work time.

The effect sizes after 12 months were small, for, HbA1c, BMI, T-Chol, HDL and LDL for the intervention group. For the effect size for both the intervention was small and insignificant. The effect sizes for the activity per week aerobic and moderate exercise the intervention group was small and showed no statistically significant difference. Insufficient data was available to calculate effect sizes for medication adherence.

Therefore, in conclusion, the study found no effect of MI on metabolic status or on adherence to medication in people that were screen detected with Type 2 diabetes. However, one year after the study had been completed another follow-up there was carried out and showed significant improved metabolic status and adherence to treatment in the intervention group.

Intervention: Motivational Interviewing combined with Diabetes Self-Management Education (DSME).

The aim of the study was to create a DSME intervention by combining an MI counselling approach with *'practical teaching of diabetes knowledge and skills training'* Welch et al. (2011). Its other aim was to see whether blood glucose control HbA1c was improved when used in conjunction with DSME or when DSME was used alone.

Four CDE's (Certified by the American Association of Diabetes Educators Diabetes Education Accreditation Programme) from the hospital's diabetes programme took part in the study. Two of the diabetes educators were randomised to receive MI training from MI trainers and two of the diabetes educators did not receive MI training. Patients were randomised into four groups as follows: MI, MI and patient self-management assessment report, DSME (Control group) and DSME plus Summary Report (Control group) and attended four intervention sessions (Mean 3.4).

The effect size for two MI trained groups first one only using MI alone was large and the second group using MI with a report was medium. The mean change in the primary outcome for HbA1c over the intervention showed a clinically significant improvement in blood glucose control overall in patients. The mean change amongst the two MI trained group was significant. However, multiple regression did demonstrate that those patients receiving MI had a mean change in HbA1c which was relatively lower in comparison to the control group. For behavioural and psychological changes, no differences were found between MI of patients. For mediators of HbA1c, no differences were seen in the MI intervention group for self-care behaviours, diabetes distress, and self-efficacy. DSME improved blood glucose control which was beneficial for the management of Type 2 diabetes but DSME, when combined with MI, was seen to be less effective in comparison to the control group then when DSME was used alone. Despite, the CDE's reporting professional satisfaction with the MI training provided. MI alone did not improve blood glucose control when compared to Non-MI.

Interventional Motivational Interviewing combined with Behavioural Weight Control Programme.

The study examined whether by adding motivational interviewing to a behavioural obesity weight control programme improved glycemic control and weight loss in overweight women with Type 2 diabetes West et al. (2007). The female patients included in this study were randomised into two groups, those receiving individual sessions of MI and those receiving attention placebo as an adjunct to the weight control programme.

The effect sizes, for weight change at 6 months, 12 months and 18 months ranged from medium to large. For uncontrolled diabetes (AIC) the effect sizes at 6-months, 12 months and at 18 months were small. The effect sizes for both primary outcomes showed a significant reduction from 6 months to 18 months and ranged from large, medium to small.

Larger significant reductions were seen in AIC (uncontrolled diabetes) in those undergoing MI at 6 months in comparison to 18 months. What the study showed was that Women in MI group lost more weight significantly at 6 months and at 18 months. Increased weight losses with MI were affected by enhanced adherence to behavioural weight loss programme. African American women lost less weight than White American overall and appeared to have a diminished benefit from the addition of MI. MI at 6 months and 12 months resulted in weight loss in African American but dissipated at 18 months. Whereas, the White Americans weight loss until the end of the programme. In general participants in the MI group, had significantly better involvement in the behavioural weight programme at all adherence measures and better attendance at MI sessions was

observed at 6 months but this gradually decreased after the MI sessions had ceased and there were no significant differences between the individual MI groups in comparison to the control group. The study found that MI was favourable when combined with a behavioural obesity treatment for women with Type 2 diabetes, although this benefit was not seen amongst the African American women at 18 months.

Comprehensive diabetes programme in general practice integrating counselling and MI.

The study examined patient-centered MI counselling in comparison to a comprehensive diabetes programme within general practice. Both programmes were evaluated in relation to the effect they had on the clinical parameters of lifestyle, on the patients (Type 2 diabetes) readiness to change lifestyle and their quality of life (Jansink et al., 2013). The patients included in the study were Dutch nationals and were randomised into two groups those receiving standard care for diabetes and those receiving a diabetes programme combining MI.

The nurses who delivered the intervention in the study received four and a half days of training sessions (total of 16 hours) over 6-months on lifestyle counselling based on MI and introduction to tools based on diabetes care. Another training was provided at post 6-months and at post measurement after 14-months, this consisted of record keeping, agenda setting, and telephone follow-up with diabetes patients and feedback sessions.

For the diabetes programme integrating MI compared to the usual care programme for diabetes, there was not a significant difference in outcomes measure for HbA1c, blood

pressure, cholesterol, and BMI between the treatment and control group and the effect size of the intervention. The effect sizes for the outcome measure cholesterol outcomes and LDL (low-density lipoprotein in other words good cholesterol) in the intervention even though being small indicated some small changes in the fat levels in the intervention group but did not generate significant changes in the intervention group when compared to the usual group. For consumption of alcohol, fat, vegetables, fruit and physical activity the effect sizes were very small in the intervention. Even though physical activity demonstrated different outcomes when measured by questionnaire, personal meter, and diary none of these outcomes showed significant differences in the intervention and usual care groups.

In the 14-month follow-up, the intervention showed the effect sizes for, vegetables, fruit pieces, and physical activity were small and for the fat level, the effect size was negative indicating no difference between the intervention and usual care groups. Only alcohol consumption showed a large effect size in the intervention. But overall the results indicated that the intervention did not change any of the patient's readiness to change their lifestyle, nor was it seen to influence the diabetes outcomes and nor did have any impact on the patient’s quality of life.

What this study found is that patients who had Type 2 diabetes in the intervention group were no more ready to change their lifestyle in comparison those patients in the usual group. What the study did find is that it allowed patients to have regular screening checks in relation to their diabetes, blood pressure and cholesterol levels values which were useful in practice.

Intervention: Randomised Control Trial combining Motivational Interviewing with an Eating Behaviour Modification Programme (EBMP).

The aim of the study was to evaluate the effects of an Eating Behaviour Modification Program (EBMP) based on the self- regulation theory and motivational interviewing on Thai people with diabetes and obesity (Wattanakorn et al., 2013). The programme was developed to improve healthy eating behaviour and the various outcomes: eating behaviours, BMI, blood sugar level body fat percentage and waist circumference was examined via the Brief illness perception questionnaire, the three-factor eating questionnaire, and the seven-day physical activity questionnaire. The participants were divided into the intervention group EBMP combined with MI and self-regulation theory and the control group EBMP alone.

The intervention was delivered by a Principal Investigator (PI), registered nurses and research assistants. The PI received an MI skills-based training course and work shop offered by a Clinical Psychologist and the researcher'scompetence in regards to MI fidelity was also verified in the study by a medical psychiatrist. The research nurses were trained on accuracy and collection of correct data. Both the research nurses and research assistants independently collected baseline measures on the initial ten patients to determine inter-and intra-reliability of the data collected. This training continued throughout the study until completion.

In the study, it was impossible to calculate the effect sizes for the outcome measure and the P values because of insufficient data presented.

What the study did find was by that by combing EBMP with MI and self-regulation theory produced significant positive effects in the intervention group in regards to the participant's health behaviours and significant effects in the intervention group for the outcome measures such as low BMI, body fat percentage, waist circumference and blood sugar levels in comparison to the control group. The study recommended that the EBMP combining MI and self-regulation theory needed to be adopted by nurses in the practice and needed to be demonstrated to various clientele groups over a long period.

A telephone motivational intervention combined with therapist support comparing the internet Intervention completion and utilization for drivers with Type 1 diabetes.

The aim of this study was to carry out a telephone motivational intervention via the support of therapists for drivers with Type 1 diabetes and to examine the programmes adherence, utilization in comparison to the completion of the programme in regards to the internet intervention benchmarks (completion of training modules called cores, progress notes, and monthly diaries). The diabetic drivers were randomised into the following group's intervention diabetes drivers.com (Type 1 diabetes) plus MI or diabetes drivers (Type 1 diabetes) without MI or usual care (control) (Ingersoll et al., 2015). The other aim of this study was to ensure that by the time the participants reached core 4, they would be able to apply the important skills learnt during the training session to prevent a hypoglycemic attack occurring whilst driving.

The intervention was delivered by interviewers who were psychology students and postdoctoral clinical research fellows. Interviewers in the training part of the study were two post-doctoral fellows, one graduate student, and 2 undergraduate research assistants

who were experienced with working with participants and patients with Type -1 diabetes. Training included four to two-hour sessions on MI skills and 2-hour session to practice full MI session. MI telephone sessions were conducted at post questionnaire completion and MI fidelity was measured on 10% of the sessions. The interviewers achieved competency levels in both MI characteristics and percentages based on behaviour counts with very little difference in global rating. What the results showed was that even the sessions were not perfect in terms of the spirit of MI but the interviewers achieved a decent level of MI practice.

Effect sizes for outcomes relating to completion of aspects of the intervention were small to medium. For days and completion of cores, the effect sizes ranged from negative values, small to medium.

The aim of the pre-intervention sessions was to motivate the participant to complete the internet intervention and all the assignments. Whereas the goal of the post-treatment sessions was to plan and maintain changes made during the intervention. The study found that those participants in the DD.com plus MI intervention in comparison to the DD.com without MI and control completed the core 4 significantly sooner. Adherence was also significantly greater in the intervention regards to completion of cores 0-4. Those in the DD.com plus MI intervention submitted the same number of monthly diaries but were found to submit them significantly sooner for the 11 to 12-month diaries and for the post-during the treatment follow-up in comparison the DD.com without MI intervention and the control group.

Discussion.

The aim of this systematic review was to look at the psychological and health benefits of motivational interviewing as an intervention and the influence that motivational interviewing had on the patient's everyday management of diabetes (Type 1 and Type 2). The intention of this systematic review was to focus on interventions that had been implemented in a range of clinical settings. All the eight studies included in this systematic review included motivational interviewing as part of a component for another intervention in the self-management of diabetes. As the samples of these studies were small to medium and based on a variety of outcomes a meta-analysis was not conducted. However, there were some studies included in this systematic review that had the same outcomes in terms of HbA1c and self-efficacy.

In this review, it was indicated that telecare support was meant to compliment routine care by 'motivating adherence' to the guidance given by the general practitioner or practice nurse at the 'time of change' in terms of the patient's lifestyle and medication in relation to their diabetic care (Dale et al., 2009). No evidence was found that such support was associated with an improved outcome. The purpose of the study was to *'encourage'* and *'motivate'* patients in their self-management of diabetes. However, patients were found to be resistant to setting goals and were in a *'state of denial or avoidance'*. Also, not all the outcome measures such as the DSME for self-efficacy were found to be effective.

It was suggested in this review that MI significantly enabled more of the patients to enter the contemplation stage in the intervention than in the control group and it was also

implied that patients in the intervention were more motivated to change behaviour (Rubak et al., 2009). However, this study found that the initial benefits of MI intervention reduced overtime at follow-up which could have been influenced by the *'inclusion'* in the study which made the patients more aware of their lifestyle behaviour changes in both the intervention and control groups. The GP's in the intervention group were found to give more advice on diet, exercise, and self-management of diabetes than the control group. In this study, GP's used MI to increase patients understanding and *'need for behavioural changes in lifestyle and adherence to diabetes prevention and treatment'*. But overall patients understanding, beliefs about treatment and motivation to change behaviour were a result of MI.

The results of this review indicated that MI could influence GP's professional behaviour, although this did not appear to have an impact on adherence to medication, or health outcomes, of their patients with Type 2 diabetes (Rubak et al., 2011). Only after one year in both Intervention and control group was there a significant improvement in metabolic status and adherence to treatment. One explanation provided was that the GP's in the control group used core elements of MI than those in MI group who used less than 2 out of 3 MI consultations.

The results in this review found that MI itself on its own did not improve blood glucose when compared to the control group (Non-MI) (Welch et al., 2011). It was also shown that the mean change in HbA1c for the intervention was lower in comparison to the control group. Self-efficacy (MI) as one of the factors did not specify a mediating change in HBA1c. Whereas DSME was seen to improve blood glucose control and when

combined with MI. A less effective and weak support was found for the clinical utility of MI in the management of Type-2 diabetes delivered by diabetes educators. In this review, African American women lost less weight in comparison to White American overall (West et al., 2007). Afro-America women also seemed to have a diminished benefit from the addition of MI in comparison to White American who continued until the end of the programme. MI as an adjunctive intervention was significant in both glycemic control and weight loss among overweight women with Type 2 diabetes. This was apparent after two sessions of MI at 6 months and weight loss at 18 months.

In this review, it was found that when a comprehensive diabetes programme was combined with counselling based MI it had no influence on HbA1c or lifestyle related to diet, physical activity and quality of life (Jansink et al., 2013) The patients with Type 2 diabetes in the intervention were no more likely to make a lifestyle change in comparison to participants in the usual a group. Also, the nurses who carried out the intervention even though attending the MI training session were less adherent to follow-up sessions of MI. The paper questioned the benefits of MI in diabetes care and general practice and called for future research on lifestyle counselling in primary care, interventions on diabetes care and suggested that lifestyle counselling is

tailor-made by genetics and other information such the benefit received by the patients and nurses delivering such methodology in practice to be more focused.

It was found in this review that when MI and self-regulation theory were combined with EBMP, they had a positive effect on the participant's health behaviours and physiological outcomes (Wattanakorn et al., 2013). The study also concluded as the nurses carrying out

the intervention applied a client a client-centered approach via MI they presented a much more of a wholesome nursing care style towards the participants which promoted healthy behaviours for people with diabetes and obesity.

In this review, it was found that those who had received MI support in regards to programme adherence completed the intervention benchmark (Cores) quicker. This was particularly noticeable in the intervention group who completed the core four diaries and the nine follow-up diaries quicker (Ingersoll et al., 2015). Even though the results did not achieve a statistical difference overall, it did find that those receiving MI support in comparison to those that did not receive MI, at each point of the intervention achieved the benchmarks quicker. Also, what Ingersoll et al. (2015) found was that the MI telephone support sessions including the four processes (cores) could be delivered successfully before and after internet intervention. Also, what this study found was that MI can achieve good MI fidelity when delivered by interviewers who are moderately trained but experienced by the patient population.

The eight studies in this review showed a mixed range of effect sizes where five of the studies showed effect sizes being small, one small to medium and two of the studies showed the effect sizes ranging from medium to large. Five of these studies showed that MI did not have an effect in bringing about behaviour change and three studies showed that when MI was combined with another adjunct therapy that it did have a significant change in behaviour. This is in line with other literature studies where MI's usefulness within a variety of cultural and clinical settings; its application in a range disease populations is evident when it is combined with small interventional measures. One other

usefulness of MI is that its basic principles can be comprehended and applied by health care professionals' in their busy clinical settings involving medical interventions and its supervisory style can be applied in daily practice (Welch et al., 2006). On the other hand, MI is seen to display a close affinity to several models of behaviour change and to the Health Belief Model (HBM), where health behaviour is marked by the patient's belief, perceptions, influences, the consequences and social implications when engaging in a behaviour. MI with its patient centred approach coincides with these principles of the HBM and promotes these both within the patient by the health practitioner (Britt, Hudson, & Blimpier, 2004). Also, MI's close relationship to the stages of change model and its emphasis on the concept of readiness might provide an answer that by simply giving advice to a patient who is not ready to make a change in their behaviour might be soon to be unsuccessful and result in the patient not acting (Rollnick, Kindersley, & Stott, 1993) which could also affect the studies in this review.

MI displays a degree of frailty, in that there are very few MI RCT studies available in the literature that can be compared because of efficacy and validity. Where MI has been used in studies as interventions most of these are not robust or empirically based or are in early stages of the study protocol development. Also, the MI interventions do not describe the intricacies or applications of these programmes across different patient population groups and the reliability of MI assessments is questioned in terms of its novelty. It is still unclear as to how beneficial MI is, how sessions should be structured, what methodologies should be used and what patient will '*benefit from MI and what MI interventions are beneficial for which patient'* Britt et al. (2004).

Limitations of the Review.

Some of the studies showed some small effects while other studies showed a mixed range of effects which made it challenging to make assumptions. Also, the studies included in this review concentrated on MI combined with adjunct therapies. There are no studies that have looked at MI purely in its own right. Also, the studies reviewed in this paper concentrated on in Type 2 diabetes and only one study looked at Type 1 diabetes. In all the studies a wide range of outcome measures was used and in some cases, inadequate or insufficient data was offered. Another limitation of the review was that the follow-up of participants was small to assess the effect on a long-term basis.

For the future, more RCT studies need to be conducted in MI. Some studies were not included in this review because they either lacked the true *'spirit of MI'* or because they were in early stages of study protocol development and did not present robust results. More tailor-made studies in MI and longitudinal studies, in both Type 1 and Type 2 diabetes are required.

The results of the review indicate that even though the concept of MI is seen to be a desirable form of intervention amongst clinicians or practitioners within a clinical health setting in practicality. MI in this review was not seen to be an effective intervention on its own and was only seen to be sensitive when it was combined with another therapy. Even core components of MI such as self-efficacy were not seen as effective outcome measures in having the desired effect on the metabolic status of the disease. MI was seen to be only successful when the validity of MI was tested in terms of its fidelity and MI competency evaluated in regards to clinician or health practitioners delivering it and only

two studies in this review looked at the fidelity of MI. There were several gaps identified by the authors in the type of MI training provided, the length of the training and by who provided the training and the application of the teaching method. Another question arises is that the kind of professionals that were trained and delivered the MI such as GP's and diabetes educators might not be the right brand of clientele to bring about a lifestyle change in patients. Another finding is that even though the patients were *'encouraged'* and *'motivated'* to bring about a lifestyle behaviour change in their management of diabetes, there were far more underlying contributory factors that determined the patient ability it bring about a change especially in relation to their daily living, cultural, physiological, psychological and external social stressors that need to be considered. Where MI had been delivered over a longer period there were limited effects and this was specifically identified amongst Afro-American women. Ethnicity is another area that could possibly have influenced the efficacy of MI in certain population groups. MI did not demonstrate a significant effect on the physiological or psychological measures of well-being. Where MI succeeded was when additional advice or support was provided to patients and more patients were found to enter the contemplation stage. Also, other areas to consider is that in these studies there were multiple ranges of behaviours considered and these behaviours were pre-determined by the intervention or the researchers carrying out the intervention and not the participants themselves. MI possibly might be seen to be less effective when used for multiple behaviour changes and future studies need to target MI with single behaviours and interventions need to be solely dedicated to MI.

Conclusion.

In conclusion, none of the MI combined interventions were implemented or adopted in practice universally. With the rapid rate at which diabetes mellitus (Type 2) is affecting the younger patient population, it is inevitable that the above factors outlined need to be considered and in addition, more improved and longitudinal studies need to be conducted using MI for future development and its application in practice.

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Table for Appendix A Extraction Systematic Review.

Table 1 Characteristics, Methodology, Design, Effect Sizes Outcome and Results for investigating the effects of Motivational Interviewing Interventions for Patients with Type 1 and Type 2 Diabetes.								
General	**Participants Characteristics (Age, gender, disease etc.)**	**Intervention:**	**No. of conditions:**	**Training for delivery MI.**	**Outcome (Measures)**	**Effect Size**	**Test Used**	***P***
1-Information on Study (Authors Name). 2-Country.	1-Entry Criteria. 2-No of participants. 3-Demographics	1-Type of intervention: 2-Delivered by 3- Duration	Intervention and Control			Effect Size for Intervention	Statistical analysis used.	P Value for Intervention/ Control
1-West et al. (2007) 2-USA	1-Type 2 diabetes. 2-N=217 3-Aged 53± USA Citizens.	1- Motivational Interviewing (MI) combined with a behavioural weight programme. 2- Behaviourist, nutritionist, exercise psychologist, and diabetes educators. 3- 42 sessions weekly and then 6-months, then over a period of 18 months.	Group 1: Individual sessions with MI. Group 2: Placebo as an adjunct to the weight control programme.	5 x MI sessions delivered by licensed Clinical psychologists for 45 minutes prior to group therapy at 3,6, 9 & 12 months to the delivery team.	Beam scale-Weight and BMI 6-months 12-month 18-month Glycaemic control HbAIC BMI 6-months 12-month 18-month	 3.40 3.38 2.85 -9 -1 0	2- Way Anova repeated measures) 3- Way Anova ANCOVA with Tukey- Kramer Pearson correlation- Two sample Student's t tests Multivariable regression models	 P=0.01 P=0.04 P=-0.02 P=-0.02

1-Dale et al.(2009) 2-UK	1-Type 2 diabetes. 2- N=231 3-Aged under 50, 50-70 & 70. UK Citizens	1- Telephone Support (Self-efficacy and Motivational Interviewing) 2- Peer Supporters and Diabetes Specialist Nurses (DSN) 3- 6-month intervention and 6 months follow-up .	3 groups Group 1-telecare provided by peer supporters (PS) Group 2-telecare support by diabetes specialist nurses (DSN's) Group 3-Control Group (CG)-routine care	Two day training programme on MI	DMSES and self-Efficacy. PS/CG: PS-DNS DSN/CG PAID) and Distress PS-CG PS-DNS DNS/CG P HbAIC PS-CG PS-DNS DNS/CG P Cholesterol, BMI 6-months DMSES +self-Efficacy. PS/CG: PS-DNS DSN/CG PAID/distress PS/CG: DSN/CG HBA1c PS/CG: DSN/CG:	 0.05 0.1 -0.34 0.19 0.23 0.15 0.16 0.06 0.02 0.31 0.09 0	Linear mixed effects models. SD, X^2 test, SAS version 9 and NVIVO	 P=0.28 P=45 P=94 P0.27, P=0.81 P=0.55 P=0.33 P=0.44 P=1.00

1- Rubak et al. (2009) 2- Denmark	1- Type 2 Diabetes 2-N=65 GP's N=265 3-Aged 40-69. Danish.	1- MI training to General Practitioners (GP)and affects of behaviour change in patients. 2-General Practitioners (GP) 3- 12-month Follow-up	Group 1: MI trained GP's Group 2: Non- MI trained GP's	1½- day training programme on MI and ½- day follow-up twice a year.	HCCQ TSRQ I+C TSRQ Autonomy MI I +C TSRQ amotivation I +C TSRQ Index I +C DIRQ Timeline control prevention: threat: Impact SDSCA and DSCA No of smokers Cigarettes/average per day? Last visit/smoking status? Last visit/counsel to stop-smoking programme? Motivation to stop smoking	0.19 0.06 0.21 0.53 +0.11 0.08 -0.04 0.22 0.17 0.02 0.02 Mean and SD not available.	SPSS, Mann Whitney Test + t-test	P=0.26 P=0.75 P=0.03 P= 0.014 P=0.34 NS P=0.21 P= 0.27 P=0.001 P=0.046 P= 0.73.

					Alcohol measurements: Beers/average per week? Wine average per week? Health, lower your alcohol intake			 P= 0.27 P= 0.24 P= 0.27

1- Rubak et al.(2011) 2-Denmark	1-Type 2 Diabetes 2-N=140 GP's N=628 3-Aged 40-69. Danish	1- MI effects on quality care of patients with Type 2 diabetes. 2-GP 3- 12 Month follow-up	Two Groups. Group 1: MI trained GP's Group 2 Non- MI trained GP's	1½- day training programme and ½- day follow-up twice a year.	Blood Total Cholesterol (T-Chol) HDL LDL I=C BMI I + C Exercise Activity per week aerobic I + C Moderate: I+C HbA1c International Physical Activity Questionnaire. SDSCA	-0.9 0.1 0.6, 0.7 0.8, 0.9 0.9, 3.5 0.6, 3.5 0.7	SPSS, Mann Whitney t-test No data Mean and SD not available. Mean and SD not available.	NS No data NS NS

1-Welch et al., (2011). 2-United States	1-T2DM patients with (HbA1c 7.5%), 2-N=234. 3-Aged 30-70 years. USA Citizens	1- DSME with [patient centered strategy MI. 2- Certified Diabetes Educators (CDE) MI trained and CDE Non MI trained 3-6-month intervention 6-month follow-up	Group 1: MI Group 2: DSME Group 3: MI + patient self-management assessment report (-DSME) Group 4: -DSME +Summary Report (web tool)	2- day Training workshop plus in-person and group conference call sessions (twice a month in one year and then monthly sessions) x three year intervention phase of the study. Training: phone based and feedback coaching every 2-4r hours a month then monthly combined with a full day training sessions with a trainer	PAID, DSCP, SCI-R, DTSQ-C, CES-D, DSCQ DSME alone and MI alone DSME with report and MI with report DSME not using MI and DSME using MI HbA1C Within MI groups Non- MI groups MI change in HBA1c Vs non-MI groups	No Data -0.80 -0.47 -0.31 SD Values not available.	T-Tests (MI & non- MI trained. Anova, Chi-square test (HbA1C) Multiple regression analysis variance (Strata version 10.3 a model for change for HbAc1). Sobel-Goodman mediation tests. (Psychological and behavioural HbA1C)	NS P <0.01, P= 0.04 P= <0.01, P= 0.14 P <0.01 P= <0.01 P= <0.01 P= 0.01. P= <0.01 Vs P=0.037

1-Jansink et al., (2013) 2-Holland	1- Type 2 diabetes (with a HbA1c above 7% and body mass Index (BMI above 25kg/m² 2-N= 422 Intervention N= 518 usual care 3-Aged 80 years and younger. Dutch.	1-RCT 2-Diabetes care programme including MI: 3-Nurses. 4-12-months and follow-up 14-months	Two Groups. Group 1 Intervention: Diabetes Care programme with MI. Group 2: Usual Care	4 and a ½ day training session (total of 16 hours) for nurses over 6-months for training on life-style MI counselling based plus tools based on diabetes care. Post 6-months and post measurement after 14-months on record keeping, agenda setting, telephone follow-up and feedback sessions.	HbA1c Systolic BP Diastolic BP LDL Total Cholesterol BMI HbA1c/diet Alcohol Fat score g/day Vegetables /day Fruit, pieces/day Physical activity: Minutes /activity per day Personal Activity Meter Score (PAM) Low activity/mins/ day Med activity/mins/ day High activity/mins/ day	124 0.193 0.195 0.331 0.2 0 0.09 -0.267 0.0064 0.091 0.11 0.24 0.94 0.97 0.5 0.0167	Means, standard deviation Multilevel linear regression in SPSS	NS

					Diary/activity, minutes/day7			
					Vas Score	0.62		
					14- Month follow-up:			
					HBA1c	0.112		P 0221
					Systolic BP	0.197		P=0.279
					Diastolic BP	0.216		P= 0.294
					LDL	0.294		P 0.081
					Total Cholesterol	0.3		P =0.051
					BMI	0.068		P= 0.198
					Alcohol	0		P= 0.647
					Fat score g/day	-0.05		P =0.708
					Vegetables /day	0		P=0.518
					Fruit, pieces/day	0.86		P= 0.884
					Minutes/ activity per day			
					PAM	0.062		P =0.839
					Low activity/mins /day	0.013		P= 0.498
					Med activity/mins/ day	0.004		P =0.592
					High activity/mins /day	0.043		P =0.669
					Diary/activity, minutes/day	0.049		P= 0.066
					Vas Score:	0.123		P=0.441

					Readiness to change 14 month Alcohol Fat score g/day Vegetables, Tbs/day Fruit, pieces/day Physical activity: Minutes/ activity per day	 0.606 0.37 0.254 0.142 0.131		 P=0.471 P= 0.901 P=0.228 P=0.597 P=0.563
Wattanakorn et al. (2013) 2-Thailand	1- Type 2 diabetes and obesity (BMI≥25kg/m²) 2- N=76 3-Aged 20 to60., Thai citizens.	1-EBMP 2-Principal Investigator (PI), registered nurses and research assistants. 3-Intervention Group= 4 weeks. Control group: 7 days. 15 minutes' meetings x 3 months.	Group 1: EBMP MI + Self-regulatory. Group 2: EBMP only.	MI skills based training course + work-shop delivered by clinical Psychologist for (PI) and MI fidelity verified. 30-45miniutes x 4 Sessions including MI aspects on eating behaviours,	Brief Illness perception questionnaire (BIPQ). Three factor Eating questionnaire (TFEQ)and seven-day physical activity recall (PAR) weeks 0,5, 9 and 13.	Insufficient data to work out effect sizes.	Chi-tests T-tests Repeated MANCOVA	Insufficient data to work out P-values.

		Follow-up weeks 5, 9 and 13.		goal setting, self =monitoring and self confidence and self-efficacy.	Illness representation Eating behaviours BMI Blood Sugar Level Body fat percentage Waist circumference		Repeated MANCOVA.	
1-Ingersoll et al. (2015) 2-USA	1- Type 1 diabetes patients for a year + RADD 2- N=632 3-Aged ± 50 to 70.2. ± USA Citizens	1-Motivational Interviewing support for a behavioural health intervention for drivers with type1 diabetes. 2-Psychology student, post-doctoral and research fellows. 3- 70 days and Monthly (duration 12 months)	Group 1: Routine care (RC). Group 2: Diabetes drivers.com plus (DD.com plus MI) Group 3: Diabetes drivers.com (DD .com only)	4x 2 hour sessions on MI skills and 2-hour session to practice full MI session. MI telephone sessions post questionnaire completion.	Internet intervention usage and adherence Core Completed 1-4 in day 70 Maintenance of changes during the intervention. DPN Programme completion benchmarks-assignment and 1/12 monthly diaries. DPNs Core 3 DPNs Core 4 DPNs Core 5	 0.137 0 0.104 0 0.182	CHI Square T-test	 p = 0.03 NS NS NS NS

					MDD 1 completion day	0.334		P=0.01
					MDD 2 completion day	0.312		P = 0.02
					MDD 3 completion day	0.269		P = 0.04
					MDD 4 completion day	0.261		P = 0.05
					MDD 5 completion day	0.309		P = 0.02
					MDD 6 completion day	0.327		P = 0.02
					MDD 7 completion day	0.271		P = 0.04
					MDD 8 completion day	0.358		P = 0.005
					MDD 9 completion day	0.31		P = 0.02
					MDD 10 completion day	0.394		P = 0.004
					MDD 11 completion day	168		P = 0.16
					MDD 12 completion day	0.248		P = 0.05
					MDD 15 completion day	-0.164		P=0.33

Note: Negative effect sizes do not represent significant results.

Key Measures: EBMP=Eating Behaviours Modifying Programme, BMI= Body Mass Index, Glycaemic control HbAIC= (Glycated Haemoglobin). DMSES= Data Management Self-Efficacy Scale, PAID= Problem Areas in Diabetes Scale, * HCCQ= Health Care Climates Questionnaire, *TSRQ= Treatment Self-Regulation Questionnaire, DIRQ=Diabetes Illness Representation Questionnaire, DSCA= Summary of Diabetes Self-Care Activities & Diabetes Self-Care Activities, Brief Illness perception questionnaire (BIPQ). TFEQ=Three factor Eating questionnaire. PAR Physical Activity Recall, PAID = problem areas in diabetes; SCI = self-care inventory; CES-D = centre for epidemiologic studies depression scale; DSCQ = diabetes self-care questionnaire, RADD =assessment of Diabetic Drivers and DSCP= Diabetes Self Care Profile, DPN= daily Progress Notes, MDD= Monthly daily diaries, Tbs=Table Spoon, High density lipoprotein(HDL), Low density (LDL) Lipoprotein, I=Intervention and C=Control, USA= United States of America & UK=United Kingdom.