National College of Ireland

'A study of the importance of establishing a relationship between emotional intelligence and dementia care for the provision of person-centred care by home care workers in the non-for-profit sector'

MSc in Management

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Abstract

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Title: 'A study of the importance of establishing a relationship between emotional intelligence and dementia care for the provision of person-centred care by home care workers in the non-for-profit sector'

Three interventions were applied to this research 1) The delivery of Ireland's National Dementia Offices dementia training "Understanding Dementia for Homecare Workers" to 52 home care workers (HCW's) and 6 members of Company A's community management team (CMT), 2) The completion of three questionnaires regarding dementia, emotional intelligence (EI) and training delivery; and 3) The facilitation of two focus groups. Group one consisted of 7 HCW's while group two consisted of 6 members of the CMT and their service manager.

An extensive literature review indicated that despite a suspected 55,000 people currently living with dementia in Ireland, there is a vast educational deficit in dementia care. The lack of dementia knowledge and skill-sets to deliver person-centred care is of public concern and national priority. There is a recognition for change readily reported by government bodies however, minimal evidence is available to suggest where changes had been made or when the implementations for change will commence.

The research methodology undertaken is underpinned by a mixed methods approach, conducted in a systematic sequence and order.

The study highlights the need for dementia training that moves beyond traditional didactic models of training, to training that captivates the importance of EI. Current training deficits and the restraints of homecare tender specifications, do not incorporate the psychological needs of a person living with dementia.

Further research is required to capture what impact adequately trained HCW's have on people living with dementia, if such training develops the EI of HCW's and how best to address the lack of specialisation and flexibility in the provision of dementia care.

Declaration

Submission of Thesis and Dissertation National College of Ireland

Name: Deborah Rooney

Student Number: X16122224

Degree for which thesis/dissertation is submitted: MSc in Management

In respect of the material submitted for award, I hereby declare that:

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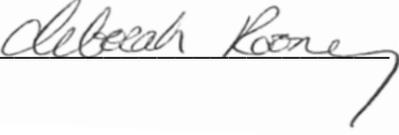
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To the board of management and all at Company A, thank you for allowing me the opportunity to complete this piece of research. Special appreciation and acknowledgement for your generous contribution, your sharing of knowledge and expertise; and for making the completing of this dissertation a pleasurable experience.

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List of abbreviations

IPA	Interpretative Phenomenological Analysis
CHO9	Community Healthcare Organisation 9
CMT	Community management Team
DCU	Dublin City University
DKAS	Dementia Knowledge Assessment Scale
EI	Emotional Intelligence
HCP	Home Care Package
HCW	Home Care Worker
HH	Home Help
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
IHCPs	Intensive Home Care Packages

Chapter 1: Introduction

1.1 Background

In today's Ireland, people with dementia are at crisis point before support services are engaged with. While there are many reasons for this, this is not the focus of this piece of research, it is merely a contributing factor. General misperceptions are held that home care workers (HCW's) have the skills and knowledge to cater for those with dementia. There are continuous reports of sub-standard care being provided within the acute and community setting. This piece of research focuses only on the community setting, with attention given to the provision of homecare. While there are many titles held by those employed to provide care and support to a person with dementia e.g. carers, care givers, support workers etc. In this document the title applied will be HCW.

Consent for participation in this research (see appendix 1) was sought by a non-for-profit company, solely funded by the Health Service Executive (HSE), located in the north of Dublin. For anonymity purposes the company will be known from here on as Company A. Company A provides an annual average of 220,000 hours of care and support in the community, with an average turnover of €5 million. Established in the early 1970's, the company has a team of 220 staff, primarily built up of 200 HCW's and 20 staff allocated to the care and support management team. The organisation has a client list of approximately 600 service users; however, these numbers vary depending on funding available from the HSE. The targeted group for this research was 52 HCW's, along with 6 members of the community management team (CMT) and their service manager.

Despite the growing demands for skilled dementia HCW's, Company A did not have a dementia training programme in place. The organisation suggests that budget restructuring within the HSE has put excessive demands on the

organisation for upskilling of HCW's to meet the complex needs of people living with dementia in the community. This in turn has created an influx of HCW's reporting excess stress, exhaustion and an inability to provide adequate care. HCW's have indicated that their current skill-sets and academic qualifications are insufficient when providing care and support to a person with dementia.

To conduct this piece of research, from September to December 2018, I attended DCU's Person Centred Dementia Champions QQI Level 8 training. Successful completion of this course awarded me the criteria to attend the train the trainers course for "Understanding Dementia for Homecare Workers", facilitated through Ireland's National Dementia Office in February 2019 (see appendix 2). Permission was granted by Company A to train the target group of 52 HCW's, with an understanding that the remaining 148 HCW's would be trained once this dissertation was complete.

1.2 Motivation for research

When there is little, or no short-term memory and the facts are misplaced in a person's mind, feelings are often the best place to focus when engaging in the provision of person-centred care. The "Understanding Dementia for Homecare Workers" focuses on this concept but not just for the person with dementia, it includes the HCW. For this reason, it was deemed fitting to incorporate the concept of emotional intelligence (EI) into this piece of research.

The literature presented in this dissertation is mainly built up by academic and government publications, both noting the significance of such an intervention. This piece of research concurs with current available research, suggesting that there is a vast educational deficit in dementia care; and the impact this is having on HCW's and those living with dementia. The following figure brings clarity to the importance of research in this area, illustrating the estimated and projected numbers for people with dementia in Ireland, living in the community, 2011-2046:
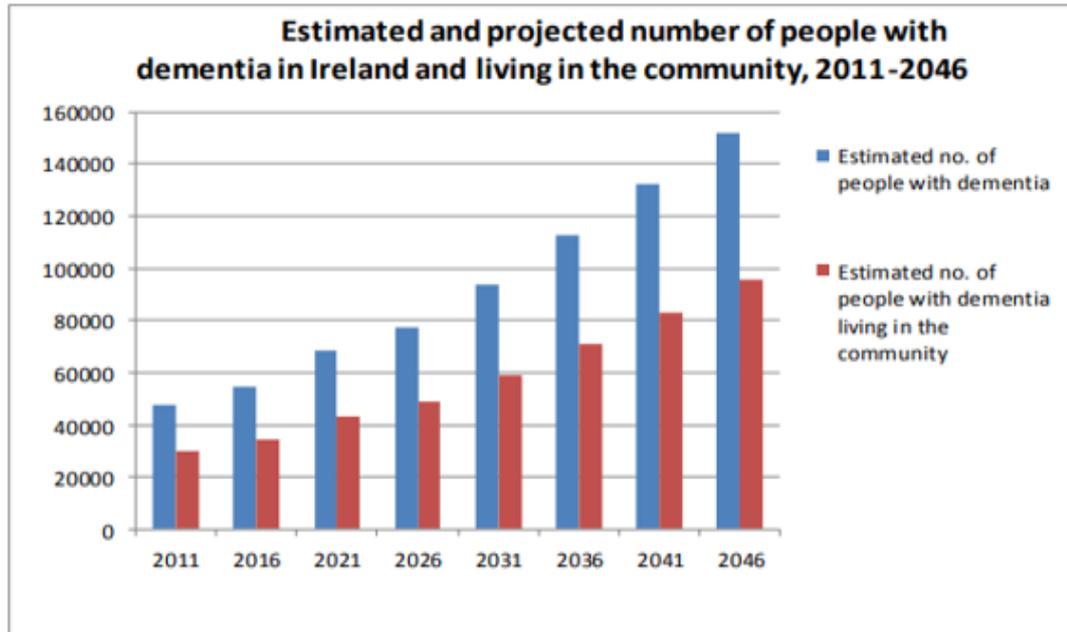
Figure 1: Estimated/ projected number of people with dementia 2011-2046

(Source: Pierce *et al.*, 2014. Prevalence and Projections of Dementia in Ireland, 2011-2046).

1.3 Structure of dissertation

The main body of this dissertation is divided into 5 chapters:

Chapter 1: Introduction – gives a brief introduction to the study and the motivational reasons for conducting this piece of research.

Chapter 2: Literature review – an exploration of academic and government publications that delve into the common themes associated with the research question, with particular reference to the significance of such an intervention.

Chapter 3: Methodology – outlines the research methodology and the approaches taken for the purpose of collecting primary data.

Chapter 4: Research findings and discussion – provides a descriptive analysis of the research findings and discussions, outlining participants response, experiences and opinions of the intervention.

Chapter 5: Conclusion – gives an overall conclusion of all work completed to produce this dissertation, along with proposed future research.

Chapter 2: Literature review

2.1 Dementia

2.1.1 Dementia as a crisis in Ireland and global

According to Mitchell et al. (2013) due to the lack of formal diagnosis it is difficult to determine the actual number of people with dementia. There is an estimated 35 million people living with dementia worldwide, an estimated 55,000 living in Ireland; and this figure is expected to escalate dramatically (O'Shea and Monaghan, 2016). Two thirds of these 55,000 are living in our communities (Pierce, Cahill and O'Shea, 2014). The World Health Organization (2012) alludes to how governments must plan accordingly for dementia care and the necessary financial supports. The Irish National Dementia Strategy (Department of Health, 2014) identifies dementia as a national priority and indicates its intention to care for people with dementia in their own home, for as long as possible.

The absence of data in the area of dementia and the available services to those with dementia is a key constraint to priority-setting (Cahill et al. 2012). While the Cahill et al. (2012) report focuses on figures relating to 2010, the data does not correlate with other reports. For example, according to Wimo et al. (2011) the Northern Europe annual estimated cost per person with dementia is €36,000. Whereas, Knapp and Prince (2007) working off 2005/6 figures report the average annual cost per person with dementia in the UK as that of £25,000 (€29,000). In the Cahill et al. (2012) report the annual cost is reported at €22,000. Such reporting discrepancies make it difficult to present the actual associated cost to a person living with dementia, which highlights a requirement for present-time data collection.

2.1.2 What is dementia?

According to OECD (2015), dementia is the second largest cause of disability in people over the age of 70. O'Shea and Monaghan (2016) describe dementia as:

"a neurodegenerative disease characterised by a progressive loss of cognitive and functional abilities and social skills, often impinging on quality of life and the individual's capacity for independent living" (p. 4).

Dementia is an umbrella term used to describe a person who experiences cognitive loss, social abilities and behavioural changes (Pierce et al. 2014). In many cases resulting in a person's inability to complete day-to-day activities and navigate through physical environments (Parson, 2001). When providing care and support to a person with dementia there are six psychological needs that must be considered (Kitwood, 1997b). These are illustrated below, in a diagram often referred to as Kitwood's flower of emotional needs:
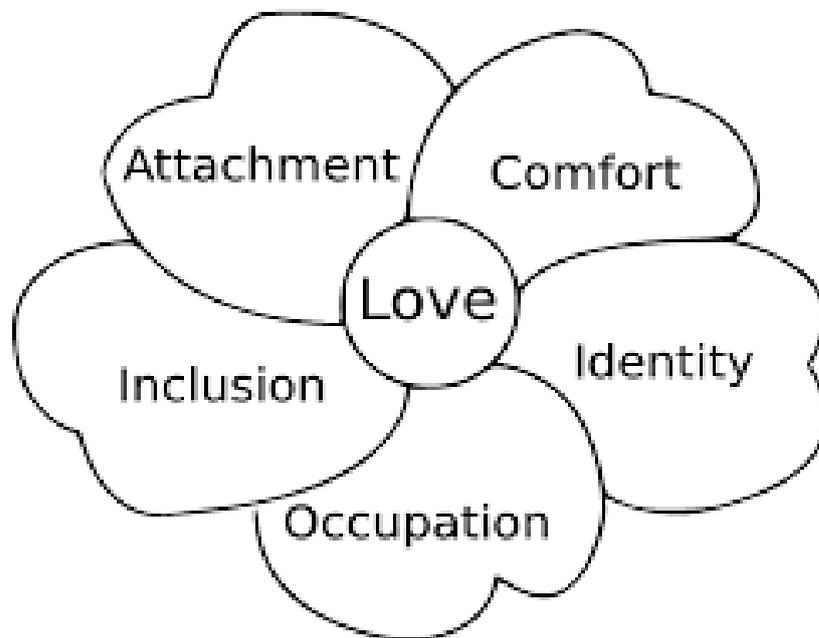
Figure 2: Kitwood's flower of emotional needs

(Kitwood, 1997b: p. 82)

According to Kitwood (1997b) the following come together to meet the central need for love:

- Comfort - the need for being close to another.
- Identity - knowing who you are in cognition and feeling.
- Occupation - engaging in a project, activity and a general need to help others or to just get involved.
- Inclusion – ensuring face to face interaction and the encouragement of activities.
- Attachment - loss of attachment undermines a sense of security which can have a devastating effect on the person with dementia.

2.1.3 Dementia training

There is slow recognition of the vast educational deficit in dementia care (Kitwood, 1997a). While there is much research and literature available regarding the importance of delivering dementia training, no literature was found to support the impact that qualified dementia HCW's have on a person with dementia. Dementia training needs to be tailored for specialist roles within services that embodies the incorporation of both knowledge and experience to apply learning (Surr et al. 2016). None of the existing training available appropriately addresses the challenges arising in dementia care (Kitwood, 1997a). It is of international concern that HCW's lack informed and effective dementia training (Surr et al., 2017). Conventional papers/ qualification may mean nothing when specific training on dementia care has not been availed of (Kitwood, 1997b). There are many complexities to dementia, both the complexities and negative attitudes pose challenges when a person with dementia is presented (Crabtree, J. et al., 2010). The scale of this problem is gigantic (Kitwood, 1997a). HCW's are the direct providers of care and support to those with dementia, therefore they must be upskilled to manage the demands of working in this area (Jansen et al., 2017). Dementia specific training is often delivered quantitatively, looking at training large numbers rather than looking at the quality of the dementia training. Mustafa et al. (2013) propose that the educating and training of those working with people with dementia is a global challenge. That although some organisations offer

training, the training is delivered in a 3-hour slot, which trainers themselves believe to be inadequate and therefore do not exert the delivery. Dementia training should focus more on improving outcomes for both the person with the dementia as well as the HCW's (Surr *et al.*, 2017). Adler *et al.* (2015) refers to the lack of dementia training to be that of a public health concern, describing the implementation of dementia training to HCW's as paramount for achieving clinical competence. Smyth *et al.* (2013) describe HCW's as the target population for dementia awareness and education. Kitwood (1997b) describes how person-centred care can be found when personhood is catered for. Personhood is the acknowledgement of a person's authentic self, their right to have an ethical status and their right to be treated with respect (Kitwood 1997a). Understanding personhood is a key requirement when providing support to a person with dementia (Kitwood, 1997b). Other than the "Understanding Dementia for Homecare Workers" training provided in this research, personhood is not covered in current academic HCW training in Ireland. It is within personhood that the importance of a HCW being emotional intelligent is explored.

2.2 Emotional intelligence (EI)

2.2.1 The concept emotional intelligence

EI is undervalued by society (Whitmore, 2010). EI is just a different way of being smart (Goleman et al., 2017). Often considered to be a non-intelligible concept rather than a cognitive concept, it is continuously becoming more prevalent in today's society. There is much research that claims that EI is just as important as IQ. Gibbs (1995) proposes that in a work environment it is IQ that gets you hired but that it is EI that gets you promoted. As little as 4% of IQ contributes to a person's success (Cooper and Sawaf, 1997). EI has been defined as:

1. *"The capacity to reason about emotions to enhance thinking. It includes the ability to accurately perceive emotions, to access and generate emotions so as to assist thought, to understand emotional knowledge, and to reflectively regulate emotions as to promote emotional and intellectual growth" (Mayer, Salovey and Caruso, 2004, p. 197).*

2. *"The ability to monitor one's own and others feelings, to discriminate among them, and to use this information to guide ones thinking and action"* (Salovey and Mayer, 1990, p. 189).

3. *"The capacity for recognizing our own feelings and those of others, for motivating ourselves, and for managing emotions well in ourselves and in our relationships"* (Goleman, 1998a, p. 317).

2.2.2 Strengths within emotional intelligence

EI is not stagnant and can therefore be developed over time (Convey, 2004). A person can improve their EI through personal development and training (Cherniss and Caplan, 2001). People with higher EI are better at establishing and maintaining close relationships (Saarni, 1999). This is particularly important when providing support to a person with dementia. A person's cues and general communication techniques experience patterns of disturbance, often making communication difficult for someone with dementia. Empathy is a way of capturing or sensing what others are trying to communicate at a higher level, without saying so (Goleman, 1998b). As humans, we have the ability to transmit our moods. While it often happens unnoticeably at first, we will always recall our interactions with someone as uplifting or deflating. Goleman (1998b) describes this as a powerful tool that is often invisible, subtle and contagious; but suggests that there is great importance here as EI accounts for 67% of the abilities to be a successful leader. Moreover, many organisations 80-90%, sometimes 100% report that the competencies that set apart their top leaders are based on EI (Goleman et al., 2017).

2.2.3 Emotional intelligence and leadership

Leadership is a foundation that is built from trusting relationships (Kouzes and Posner (2002). Given the nature of the industry, in homecare leadership is expected at all structural levels and within all roles. The high prevalence of lone working can have an impact on the level of leadership management applied to HCW's. Wheatley (2017) describes the importance of not micro-managing and suggests that if increased productivity is desired, management

must engage emotionally with staff, that it is through this type of engagement that commitment, buy-in, creativity and imagination is achieved. Furthermore suggesting that it is not about being a leader that is liked, but a leader that helps others to discover their capabilities and potential to deliver organisational purposes. Much research suggests that if we enforce fear on individuals that we suppress their emotions. In homecare emotions are what drive person-centred care. Wheatley (2017) believes that it is this shift from hero to host whereby people feel like they are a necessity within the workforce.

Asking a workforce to change from how they currently support a person with dementia, to that of a more emotionally engaging approach will require emotional intelligent leadership. Developing the EI of leaders and mentors enhances the emotional competencies within an organisation (Sosik and Magerian, 1999). EI is a contributing factor in almost 90% of successful leadership positions (Chen et al., 1998). Emotionally intelligent leaders have the ability to effectively address underlining feelings and emotions with a person (Mayer and Caruso, 2002). Therefore making EI an essential element for the provision of person-centred care.

2.2.4 Emotional intelligence as a theory/model

According to Goleman (2015) high EI, rather than cognitive abilities can be linked to effectiveness and strong performance in the workplace. Goleman suggests that there are 5 components within EI: 1) Self-awareness, 2) Self-regulation, 3) Motivation, 4) Empathy, 5) Social skills. The following is a chart giving explanation behind his theory:

	Definition	Hallmarks
Self-Awareness	the ability to recognize and understand your moods, emotions, and drives, as well as their effect on others	self-confidence realistic self-assessment self-deprecating sense of humor
Self-Regulation	the ability to control or redirect disruptive impulses and moods the propensity to suspend judgment – to think before acting	trustworthiness and integrity comfort with ambiguity openness to change
Motivation	a passion to work for reasons that go beyond money or status a propensity to pursue goals with energy and persistence	strong drive to achieve optimism, even in the face of failure organizational commitment
Empathy	the ability to understand the emotional makeup of other people skill in treating people according to their emotional reactions	expertise in building and retaining talent cross-cultural sensitivity service to clients and customers
Social Skill	proficiency in managing relationships and building networks an ability to find common ground and build rapport	effectiveness in leading change persuasiveness expertise in building and leading teams

Figure 3: Goleman's five components of emotional intelligence at work

(Goleman, 2015: p. 6)

2.2.5 Goleman' five components applied to home care workers

2.2.5.1 Self-awareness

The ability to read one's own emotions and draw judgements on their potential impact is found within the self-awareness component (Goleman, 1998a). People with high self-awareness are more capable of working with people who make high demands, whereas a person with low self-awareness makes decisions that brings on inner turmoil based of buried values (Goleman, 2015). HCW's struggle in the absence of self-awareness due to the complexities of supporting a person with dementia in an often reactive and unpredictable working environment. Providing care and support can be emotionally challenging. Being self-aware is knowing one's strengths and limitations (Goleman, 1998a). Self-aware HCW's who have a good understanding of their capabilities, can make good judgement calls and are less likely to set themselves up to fail.

2.2.5.2   Self-regulation

Impulses drive our emotions, self-regulation frees us from our own feelings, often allowing for better moods and the ability to consider mitigating factors in challenging situations (Goleman, 2015). HCW's are by nature lone workers and therefore often have very little supervision or support. Without self-regulation HCW's would be more likely to react in a negative manner to the daily challenges of providing care and support. In addition, Goleman (2015) proposes that self-regulation enhances integrity and it is only when the opportunity arises that a person with low impulse control abuses power for selfish ends. HCW's are often exposed to situations of temptation e.g. handling service user's finances. When someone is self-regulated they can say no to impulsive urges.

2.2.5.3   Motivation

While many people are motivated by power, salaries etc. some are motivated by a passion for the work itself. Motivation can be seen in someone who just wants to do things better (Goleman, 2015). Research in this area has shown that this is very typical of HCW's. While hourly pay in Company A is by average higher, a HCW's weekly take home salary can decease without warning. For example, if the person with dementia becomes ill and is admitted into hospital the HCW does not get paid for the hours he/she has lost. Therefore, this indicates that money is not the real motivator for doing this type of work. Goleman (2015) argues that when people love the work they do, they are often committed to the organisation, even when they are headhunted by others. Known as a reputable company, HCW's at Company A are consistently offered employment elsewhere in the private and black market industry. Company A has managed to retain staff with approximately 70% of the workforce employed by the company for 10 years plus, while others are employed for 30 years plus.

2.2.5.4   Empathy

Empathy is a key requirement when support a person with dementia. Empathy is were meaningful relationships are built. It requires HCW's to have real conversations were the sharing of knowledge and experience takes place. By being empathetic a person can establish relationships with people with diverse backgrounds (Goleman, 2002). An important aspect of person-centred care is establishing a connection that will enhance long term respectful working relationships (Kitwood, 1997b). Due to the requirement for intimacy and empathetic engagement, the provision of care and support can be a vulnerable place for both the HCW and the person with dementia. Goleman (2015) refers to empathy as an antidote, proposing that people who are empathetic are attuned to subtleties in body language; and can hear real messages beyond the words been spoken. An important skill when supporting a person with dementia, particularly when that person is non-verbal.

2.2.5.5   Social skills

Social skills are not just about being friendly, socially skilled people have a knack of finding mutual or common ground with people; and the capability of moving people in the direction that they desire (Goleman 2015). Given the nature of the tasks that is required in the provision of care e.g. personal care (washing/dressing) it is important for HCW's to have social skills. People with social skills are adept in influence and persuasiveness (Goleman, 2002). As expert influences and persuaders, HCWs use their social skills to effectively manage difficulties, in often challenging situations, particularly when collaborations are required.

2.3 Homecare

Company A, on behalf of the HSE provides Home Help (HH), Home Care Packages (HCP) and Intensive Home Care Packages (IHCP), delivered by HCW's in the Dublin 1, 3 & 7 area.

2.3.1 Home help

According to the Haslet et al. (1998) HH was introduced in 1972 and was one of the key community services for older people. HH expanded over the years to incorporate other persons within the community that required supports e.g. family support (young children in crisis) and to those with a disability. In summary the HH cliental could be expanded to capture any person within the community whom required assistance to maintain their independence; or as a deterrent for engagement in other already overwhelmed systems e.g. social work. HH was later followed by the HCP scheme, which over time would see the dramatic reduction of HH budgets.

2.3.2 Home care packages

The HCP scheme was introduced in 2006. According to the NESF (2009) report as an administrative scheme, there was no automatic rights to avail of a HCP. Instead HCP's are typically made available to people over the age of 65, in accordance with the HSE's entrance criteria, based on their levels of care and medical conditions. HSE budget restraints are reported nationally, detailing hospital bed restraints, all of which have an impact on the quantity of HCP's distributed to companies like that of Company A. Such budget restraints can be a deciding factor as to whether or not a person is allocated a HCP, despite their current requirement for support. When a case of advanced dementia is presented, the HSE can apply for an alternative budget through the Intensive Home Care Package (IHCP) scheme.

2.3.3 Intensive home care packages

To date, Company A has only received 5 IHCP's. All of which they report as being near crisis point when referred. In 2015 Genio, supported the HSE in the implementation of up to 500 IHCP's. IHCP's were initiated after agreement with the Department of Health and the Atlantic Philanthropies. Genio was commissioned by the HSE to complete a mixed methods piece of research on the roll-out of these IHCP's. The research was completed between 2016-2018. Research findings have not yet been published. The process for distribution

of these IHCP's are allocated outside that of the HSE's National Tender process.

2.3.4 National tenders

Since 2016, homecare providers are required to tender through the HSE's procurement department for all new HCP's. HH is no longer in distribution. As a successful tenderer, all new referrals to Company A must be referred through the HSE's national tender service specification criteria. All homecare providers who were not successful in application can now no longer be in receipt of new HSE HCP referrals. The HSE (2018) Service Specification for Home Support is overwhelmingly based on standards that do not drive person-centred care, despite setting a requirement for all homecare providers to ensure the provision of person-centred care to all in receipt of HCP's. The style of care required in the provision of person-centred care is time consuming; and therefore does not fit into the task orientated medical model of the HSE. Kitwood is the most widely referred to expert in the provision of care to people with dementia. Kitwood (1997b) proposes that people will not flourish in cases like that of the medical model, that they will instead be reduced to isolation, despair and what he calls 'social death'. This style of delivery does not promote person-centred outcomes and fails to look at satisfaction levels of the person with dementia. Furthermore, despite the requirement for such standards specified in the HSE's service specification, the HSE rarely conduct inspections of homecare providers to gauge whether or not person-centred care is being provided.

2.3.5 Standards and the provision of care

Prior to 2019, inspections completed by the HSE were minimal. Since its establishment in the 1970's, Company A was inspected on two occasions. Once in 2011 and again in 2013. The HSE have suggested that a team of inspectors have been employed and that they plan to inspect homecare providers nationally. No literature could be found indicating such inspections. Nursing homes are subject to the statutory regulatory framework provided

through the Health Information and Quality Authority (HIQA), homecare is not. Therefore, outside homecare provided through national tendering, there are no set boundaries for the provision of homecare. The rationale behind this is that there is no legal framework that allows for organisations like HIQA to regulate homecare. Regulation will require a change in legislation or the amendment of a respective piece of legislation e.g. the Health Act 2004.

2.3.6 Lack of regulation

History will suggest that the lack of regulation leaves vulnerable people at risk in their own homes and yet nothing has changed. In 2010 and 2012 RTE's "Primetime Investigates" exposed many of these organisations for sub-standard provisions. While many organisations have since closed or been taken over by new management, part of the recommendations at the time were for the implication of new standards. According to the OECD and the European Commission (2013) heavy administration costs associated to standards can often prove to be a burden for providers. However, it could be argued that there is no cost too great for the provision of quality care to our most vulnerable in society, particularly those living with dementia who are less likely to complain about sub-standard care provision.

2.3.7 Sub-standard care

Homecare providers have the potential to improve sub-standard care that is currently being provided to those with dementia living in our community. This type of intervention would help to overcome the high turnover of HCW's as well as meeting the complex needs of those with dementia (Bölenius *et al.*, 2017). HCW's need to be equipped not only with regards to the physical work but also the psychological tasks associated with providing support to those with dementia (Kitwood, 1997a). Unskilled workforces contribute to the delivery of sub-standard care. When HCW's are more adequately trained in the area of dementia care, this reduces the high turnover of staff, reduces stress and brings about personal and professional job satisfaction (Brooker

and Latham, 2015). Enforcement of training standards require the production of government strategies and financial support for implementation.

2.3.8 Governmental training strategies

According to Healy *et al*. (2019), there is government recognition for the need for dementia training. Ireland's National Strategy for Dementia published in 2014 indicates that funding has been promised to three priority areas 1) intensive home care supports, 2) GP education; and 3) training and dementia awareness. Ireland's current infrastructures does not capture the required person-centred approach to delivering dementia care. O'Shea and Monaghan (2016) argue that there is a narrowness to providing dementia care through a medically driven model and that this approach runs the risk of diminishing the personhood of the individual. There is also a clear indication that the current model of service provision for people with dementia lacks specialisation and flexibility, all of which are essential in the delivery of person-centred dementia care. Kitwood (1997a) suggests that the delivery of dementia care brings about its own special organisational issues, but specifies that when employees experience support and encouragement they will take their own sense of well-being into how they operate/interact in the workplace. In order to capture the complexities of person-centred care, skilled specialised trainers outside that of the typical academic field, are required for dementia training delivery.

2.3.9 Shortfall of specialised trainers

According to Sheard (2008) management is drowning out dementia care, that there is no focus on the individual's feelings and instead we are focusing on the delivery of care from a patchwork quilt perspective filled with restrictions and controls. Company A has recently invested in the training of two dementia facilitators and agreed to pay all HCW's who attend the training. This is rare in homecare as most organisations do not provide training that is not specified in the national tender specification. Kitwood (1997a) suggests that the scale of the problem is gigantic and that there is a need for approximately 2000 trainers in the professional dementia setting and likewise a need for an additional 2000

people to help support those in the less formal setting e.g. family carers. This is a real indication of the crisis in today's society. Two day training initiatives are often considered time-intense and have an expense associated with them, but while this may be the case, the delivery of effective training requires that investment (O'Brien *et al.*, 2018). Research suggests that the making of such investment enhances the working environment of the HCW.

2.4 Home care workers

2.4.1   Informal carers (family carers)

Many HCW's assigned to HCP's work directly alongside informal carers. Typically made up of family members, informal carers often act as the required second person in high dependency cases. This practice is common when funding for more hours is not made available by the HSE, resulting in the two types of carers coming together for the provision of safe, quality care. The below chart suggests an average governmental cost associated to informal carers to the value of €807 million. The same report gives an estimated value of €33 per hour for a HCW which indicates that in the absence of government support there is a national saving of more than ⅔. However, this saving does not capture the cost associated with the adequate provision of dementia care as it is not yet a requirement.

	Number with dementia in the community	Care hours per day	Cost per hour (€)	Total annual cost (€)
<65	3,046	8.33	10	92,627,309
65-69	2,177	8.33	10	67,489,634
70-74	5,363	8.33	10	166,273,983
75-79	1,766	8.33	10	54,747,957
80-84	5,764	8.33	10	178,696,872
85+	7,988	8.33	10	247,663,374
All	26,104			807,499,128

Figure 4: Informal carers

(Cahill et al. 2012, p:53)

2.4.2   Recognised qualifications

As part of the HSE (2018) national tender specifications in order for a HCW to be allocated work under HSE tendered contracts they must ideally obtain a relevant major award (e.g. QQI) at level 5 or higher. As a new entrant to homecare, HCW's must have two minor awarded modules "Care Skills" and "Care of the Older Person". Existing HCW's with a minimum of 1 years paid employment are required to engage in acquiring at least the two minor awards. Dementia care is not considered in this training. Traditional forms of training has been criticised for not capturing the practice learning required to be empathetic towards a person living with dementia (Cowdell, 2010). Inadequate training is commonly reported as a contributing factor to HCW burn-out. People who work directly in the capacity of helping others often experience vulnerabilities, usually resulting from a lack of vocational qualities (Chernis, 1980).

2.4.3   HCW burn-out

Burn-out is a common theme in the provision of homecare and tends to increase when supporting a person with dementia. Kitwood (1997a) refers to burn-out as being significantly different to that of exhaustion, suggesting that when a person experiences exhaustion that this can be remedied through rest or even recreation, but that burn-out is often dramatic and results in people not being able to return to work. EI influences a person's ability to effectively cope with everyday demands and pressures (Bar-On & Parker, 2000). There needs to be a comprehensive approach taken to relieve such stresses experienced by HCW's (Butcher, Hooley and Mineka, 2015). Due to the reinvestment ethos of non-for-profit organisations financial support is more likely to be make available to meet these requirements.

2.5 Homecare non-for-profit organisations

Established since the 1960's, homecare non-for-profit organisations are typically set up as charities and governed by a voluntary board of directors. Due to ongoing cuts and resource scarcity non-for-profits generally have to be more creative in their spending allocations, yet like that of for-profit companies they strive towards achieving their goals and objectives (Pinho, Rodrigues and Dibb, 2014). Non-for-profits have been exposed in many scandals that have raised questions regarding their professionalism. Success in non-for-profits can be seen when a learning is adopted as a culture and primary goal (Marino, 2011). As a non-for-profit organisation Company A has been in a position to reinvests all surplus finances gained from the new HSE tendering process back into the organisation, particularly in the area of training. In a comparison study of non-for-profit and for-profit companies completed by Birdi et al. (2007) the findings suggested that employees reported more training opportunities within non-for-profit organisations, which was a contributing factor for organisational performance.

2.6 Literature conclusion

While there has been considerable literature published with suggested figure's, no real-time data could be found to support the actual total number of people living with dementia in Ireland. Over the last two decades, a number of researchers and government publications have sought to determine the negative impact that unskilled and inappropriately educated HCW's will have on the provision of person-centred care to people with dementia. Moreover, while researchers have examined the importance of delivering dementia training, no literature was found to support the impact that appropriately qualified dementia HCW's would have on a person living with dementia.

Research alludes to the importance of establishing a relationship between EI and dementia care for the provision of person-centred care by HCW's. EI is now widely excepted as an important aspect of supporting a person with

dementia. Concurrent developments suggest that EI has been linked to effective leadership, a quality that is required amongst HCW's, particularly in their often lone working environment. Effective leadership, strong performance in the workplace; and Goleman's five components within EI correlate to form an adequate foundation in the provision of dementia training. All important aspects for the provision of homecare.

The presented literature explored the types of funded care distributed by the HSE to Company A for subsequent allocation to HCW's. Research suggests national and global acknowledgement of identifying dementia as a priority. Despite much government publications and research findings, minimal implementations to support appropriate dementia training have been reported. Moreover, literature suggests that current medically driven models of homecare do not encourage person-centred care. It instead creates a narrowness in the provision of care and support that lacks specialisation and flexibility; causing a sub-standard delivery of care services through an inadequate financially resourced system. Which in turn has been a contributing factor towards HCW burn-out and service delivery dissatisfaction.

Chapter 3: Methodology

3.1 Introduction

For the purpose of gaining new knowledge in the subject area, research was conducted in a systematic sequence and order. Research is a well-coordinated activity that allows for the contribution of further knowledge to an existing body of knowledge (Fellows and Liu, 2008). This chapter provides information on the research methods used for the collection of data throughout the study. The study was designed to establish a relationship between EI and dementia care for the provision of person-centred care by HCW's in the non-for-profit sector. The present chapter will discuss the methodology for the study.

3.2 Proposed research methodology

The Onion Model developed by Saunders, et.al (2009) was adopted as one of the guiding frameworks for this study.
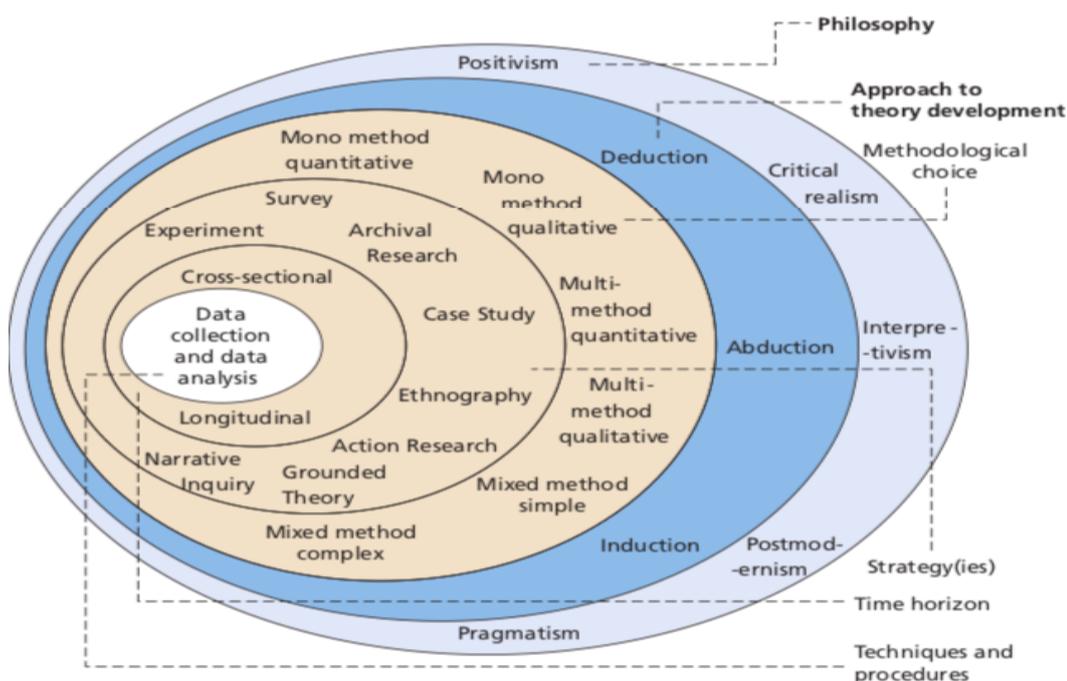
Figure 5: The research onion

(Saunders, Lewis and Thornhill, 2019, p. 130)

The rationale behind the adoption of this model was that it allows the researcher to break down the philosophy into more detailed sections, giving detailed structure to the research. Sinha, et al. (2018) describes the research union as a metaphor that uncovers layers of meaning which enables the researcher to understand the phenomenon they are researching.

The second chosen guiding framework for this study was a phenomenological approach which allowed for a Interpretative Phenomenological Analysis (IPA). Smith and Shinebourne (2012) describes phenomenology as *"the philosophical movement primarily concerned with human lived experience"* (p. 73). In summary, phenomenology is a holistic approach to research whereby the researcher engaging in a process of interpretation, trying to gather information about the human lived experience that can never be truly transparently extracted. It is important to note that by applying IPA the researcher only has access to the participants human life experiences as provided by the participant; and that it is for this reason that transparency is not always present. Most research takes qualitative and quantitative approach whereas IPA looks at the individual. Therefore, it was deemed fitting to incorporate IPA into this study, as part of a mixed-methods approach and not that of a sole approach.

3.2.1 IPA applied to focus group sessions

Participant in this part of the study were selected purposely. This is in line with the theoretical underpinning of IPA. There are 2 focus groups in total, all of whom are working in Company A in the study area and had a new knowledge base of dementia. The first focus group participants were the CMT and their service manager (7 participants), whereas the second focus group consisted of HCW's (7 participants). Both focus groups were audio recorded and transcribed verbatim (see appendix 4). Transcripts were evaluated to review similarities and differences. Due to its complexity, Smith and Shinebourne, (2012) suggest that it is useful to describe IPA in distinct stages. For illustration purposes the following figure has been devised:

Stage 1	Stage 2	Stage 3	Stage 4	Stage 5
Researcher immerses in data (transcripts) noting observations, reflections and potential significances	Researcher explores emerging themes	Researcher evaluates emerging themes for connections and similarities	Researcher produces data making decisions on the prevalence of the data and pertinence of the themes	Researcher writes a narrative account of the study

Figure 6: IPA 5 stages

3.3 Research philosophy

"The Research Onion" considers the research philosophy as the first layer of the onion. "*Research philosophy refers to a system of beliefs and assumptions about the development of knowledge*" (Saunders et al. 2019: p. 130). Throughout the journey of research the researcher makes several types of assumptions about the research matter (Burrell and Morgan 2016). Williams and May (2002) refer to these as philosophical values; and suggest that these values are defined by varying disciplines which are the basis for research. These are categorised in 3 philosophies: ontology, epistemology and axiology. The following was devised a way of showing a simplistic understanding of the 3 philosophies.

Philosophies	Explanation
Ontology	Ontology looks at knowledge or knowing and what it is that we know about the world? From a researchers perspective ontology asks questions like 'what is the reality?' and 'what actually exists within a particular field of research?' Researchers use this concept to explore questions to further the ontological status of the world, often looking to group similarities together into categories.
Epistemology	Epistemology is concerned with the nature of knowing. It is an approach often used by researchers who want to explore how we know what we know, and how we get to know the things that we find out through research? For this reason this concept is often used by researches to gather human knowledge e.g. measuring data through the use of questionnaire for personal testing e.g. emotional intelligence testing.
Axiology	Axiology looks at what could be described as the ethical behaviour of the researcher. It asks questions like 'what are the values of the researcher?', 'is the researcher neutral?', or 'is the research shaped by the values of the researcher?'

Figure 7: 3 Research philosophies- Ontology, Epistemology, Axiology

The position adopted in this dissertation is that of both Ontology and Epistemology. By adopting the position of Epistemology it allowed for the collection of data/knowledge uniquely held by participants completing the training, findings within the EI questionnaires and those also participating in the focus groups. Whereas, the adoption of the position of Ontology was chosen when participant were ask to complete a before and after DAK questionnaire to establish the knowledge held relating to dementia prior to and after the commencement of training.

3.4 Research approach

Both deductive and inductive approaches were used when conducting research in the subject area. While deductive and inductive approaches are considered to be direct opposites, it was necessary to apply both due to the application of both quantitative and qualitative research methods in this study. Quantitative data is collected from studies that are deductive, whereas qualitative data is collected from studies that are inductive (Horn, 2009). The topic of dementia requires a more indebt approach to gathering information. Levin-Rozalis (2004) refers to this combination as abductive. The combination of both approaches are perfectly possible and often advantageous, within the same piece of research (Saunders et al, 2009). Furthermore, Horn (2009) suggests that applying a deductive only approach could cause the data generated to be flat, whereas by applying both deductive and inductive this can have a more dynamic and creative effect.

Saunders et al. (2009) refers to three types of study approaches: exploratory, descriptive and explanatory. The mixed methods approach of quantitative and qualitative taken in the dissertation makes suitable application of all three studies. For the purpose of application of theory to the intervention the following figure was developed highlighting Saunders et al. (2009) three types of study approaches (exploratory, descriptive and explanatory), applied to this piece of research:

Approach	Application Narrative
Exploratory	The training intervention of this piece of research is applicable to Saunders et al. (2009) theory of an exploratory study. Descriptions are given whereby the research allows the researcher to explore what is actually happening and to seek further insight, asking questions that will bring new light to the phenomena.
Descriptive	The DKAS questionnaires were performance related to give an accurate portray of the participants profile of learning prior to and after the completion of training. Saunders et al. (2009) describes this method of researching as a descriptive study.
Explanatory	For the purpose of this research an extensive literature review was completed along with the engagement of focus groups. According to Saunders et al. (2009) the explanatory study incorporates these two methods of research.

Figure 8: Research application of Saunders et al. (2009) three types of study approaches exploratory, descriptive and explanatory

3.5 Research strategy

This layer of the Research Onion refers to strategies such as experiment, survey, archival research, case study, ethnography, action research, grounded theory and narrative inquiry. For the purpose of this piece of research the following research strategies were applied:

- Survey Research: A validated DKAS Questionnaire and validated 33-Iiem assessing emotions scale (Self Evaluation Questionnaire) was used to enable the collection of quantitative data.

- Action Research: An intense literature review was completed looking for common themes amongst the relevant literature. As well as a training intervention that promoted change within the organisation, looking at the need of the researcher, whilst giving a new knowledge base to the sponsor (Company A).

- Grounded Theory: In summary the grounded theory is used to predict and explain behaviour, for the generation of data through observation and interaction.

- Narrative Inquiry: This approach is also aligned with the previously discussed Interpretative Pneumological Analysis (IPA) whereby the researcher gathers information about human lived experiences.

3.6 Research choice

Academically, the widely accepted research methodologies are: quantitative, qualitative and mixed-methods (Creswell, 2014). The research approach adopted in this study will take the form of a mixed-method design. Saunders et al. (2009) refers to a single data collection method being called a mono method and a more than one approach to data collection as a multiple method, but argues that there are many opportunities with applying a multiple method approach.
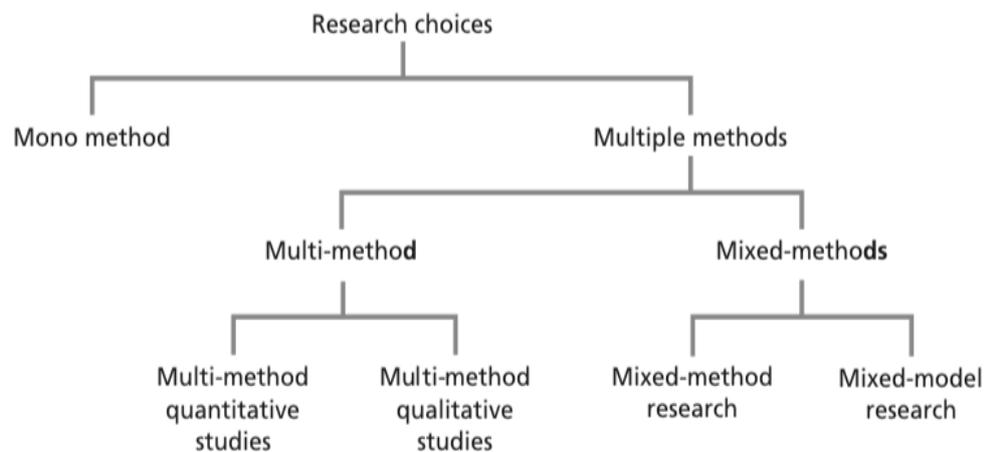
Figure 9: Research choice

(Saunders et al., 2009: p. 152)

Amaratunga et al. (2002) suggests that by applying the mixed methods approach, the weaknesses of both quantitative and qualitative are complimented by the strengths of the other method. For the purpose of addressing the research area, quantitative and qualitative research was

conducted concurrently. This mixed method approach was chosen as a way of bringing positive value to the research. To complete only one method of research, would have applied limitations to accessing the required data.

3.7 Secondary data collection

For the purpose of conducting a literature review a secondary data collection was completed. Saunders et al. (2009) classify secondary data in three classified groups: documentary, multiple source and survey:
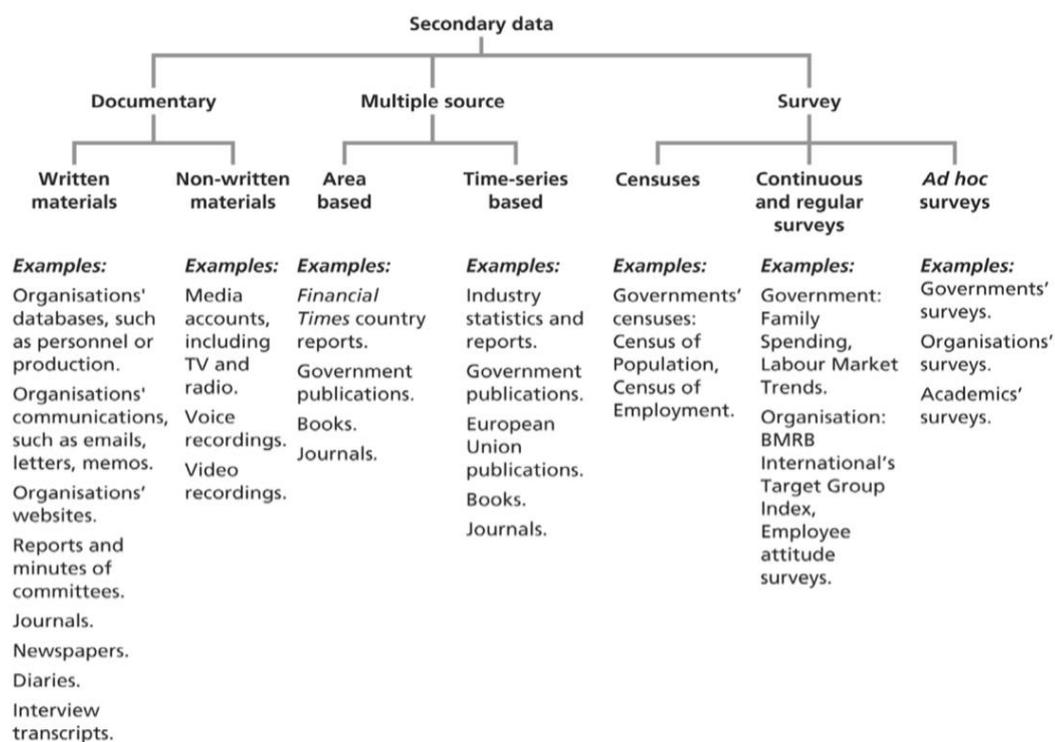
Figure 10: Three types of secondary data: documentary, multiple source and survey

(Saunders et al. 2009, p. 259)

In accordance with the three classified groups, a multiple source and survey approach was taken. Data sourcing was completed through a combination of accessing academic journals, web reports, articles and text books through formal data sources e.g. library and online facilities. Once the data had been sourced a data downsize approach was taken and a forensic critique was carried out to analysis the arguments presented in the literature. While there

are many advantages to the collection of secondary data (easy accessibility of high volumes of quality data) there are also some disadvantages (complexities associated with data e.g. core research subject may not be a current topic, limiting the data available).

3.8 Quantitative and qualitative research

Quantitative research is mostly used in scientific research, but it is qualitative research that contributes to a body of knowledge (Willig, 2019). Quantitative data generally involves analysing a set of descriptive statistics, whereas qualitative data is interested in exploring meanings, perceptions and understandings (Horn, 2009). This piece of research involved the use of both quantitative and qualitative research.

3.8.1 Quantitative research

Quantitative research often involves the collection of predominately numerical data and opinion, testing whether or not views are correct; and the reporting of relationships between one variable and another (Horn, 2009). While reporting such data in this piece of research was considered important, limiting the collection of data to only that of quantitative could have limited the substance in the research findings.

3.8.1.1   Quantitative data primary collection: questionnaires

The quantitative data collection methods chosen were two questionnaires and a training evaluation sheet. The two questionnaires were both validated questionnaire therefore strengthening their validity. Whereas, the training evaluation sheet was produced as part of the training delivery pack.

3.8.1.2   Validated 25-item dementia knowledge assessment scale (DKAS)

Data analysis was conducted using the dementia knowledge assessment scale (DKAS) (Annear, 2018). The DKAS was developed to measure dementia knowledge amongst people providing care to individuals with this complex syndrome (Annear, 2018). This is a self-report questionnaire that measures and identifies a base-line understanding of the HCW's prior to and after the delivery of the training intervention. Annear *et al.* (2017) describe DKAS as a reliable and valid measure when collating knowledge across four domains:

1. Causes and Characteristics
2. Communication and Behaviour
3. Care Considerations
4. Risks and Health Promotion
   (Annear *et al.*, 2017)

3.8.1.3   Validated *33-item assessing emotions scale (self-evaluation questionnaire*)

The assessing emotions scale questionnaire was chosen as a method for assessing the EI of the participants. The rationale for using this questionnaire was due to its recognised validity and the scoring mechanism applied. Findings could then be captured through the use of SPSS allowing for the identification of EI levels within the research sub-groups. EI is strongly represented in the dementia training, therefore making the analysing of EI an interesting factor in this piece of research. Ciarrochi et al. (2001) identifies four most widely used sub scales from the 33-item assessing emotions scale:

1.   Perception of emotions (items 5, 9, 15, 18, 19, 22, 25, 29, 32, 33)

2.   Managing emotions in the self (items 2, 3, 10, 12, 14, 21, 23, 28, 31)

3.   Social skills or managing other's emotions (items 1, 4,11,13, 16, 24, 26, 30)

4.   Utilizing emotions (items 6, 7, 8, 17, 20, 27)

Reverse coding was applied to questions 5, 28 & 33. Scores ranged from 33 to 165, with the higher scores indicating more characteristics of EI.

3.8.1.4 Training evaluation sheet

The training evaluation sheet is a traditional method used for analysing whether or not participants found the training intervention to be successful or not. Unlike the questionnaire the training evaluation sheet was anonymous. While it may have been interesting to show some statistical research results on whether satisfaction was as a result of learning, this was not to be the case due to the anonymous stipulations set out in training delivery requirements.

3.8.2 Qualitative research

Qualitative research may fill a void in literature, and has the potential to establish a new line of thinking in the area of research (Creswell, 2007). Three methods of qualitative research were chosen 1) focus groups, 2) the training evaluation forms comment section; and 3) through the process of receiving feedback during the delivery of training to the HCW's and the CMT members. By engaging in qualitative research, this allows for narrative story telling. Glesne and Peshkin (1992) describe this process as a process that blurs the lines between fiction, journalism and academic studies.

3.8.2.1 Qualitative data primary collection: focus groups & feedback from training

Focus groups and feedback from the training intervention were chosen as methods for this study as it allows for the gathering of data that reflects interaction and insight into why opinions are held. Focus group research is not static and has become ever changing over time; resulting in the collection of real data from such engagements (Krueger, 1994). Researcher's need to be careful when engaging in focus groups, and ensure that no imaginative data is used after transcribing (Freeman, 2009).

3.8.3 Reflective statement

Assumptions can lead and mislead research. At every stage of research engagement the researcher makes a number of assumptions (Burrell and Morgan, 2016). These assumptions inevitably shape our approaches to research and the methods in which we interpret findings (Crotty, 1998). For this reason, at the end of each research intervention, an evaluation of findings was completed, for the purpose of establishing real facts.

On reflection the training delivery showed that there had been a pathway of change. The pathway of change consisted of 3 stages 1) training delivery, 2) reflection on practices; and 3) EI. The training generated a reflection on practices, which brought about a real focus on the importance of EI for participants.
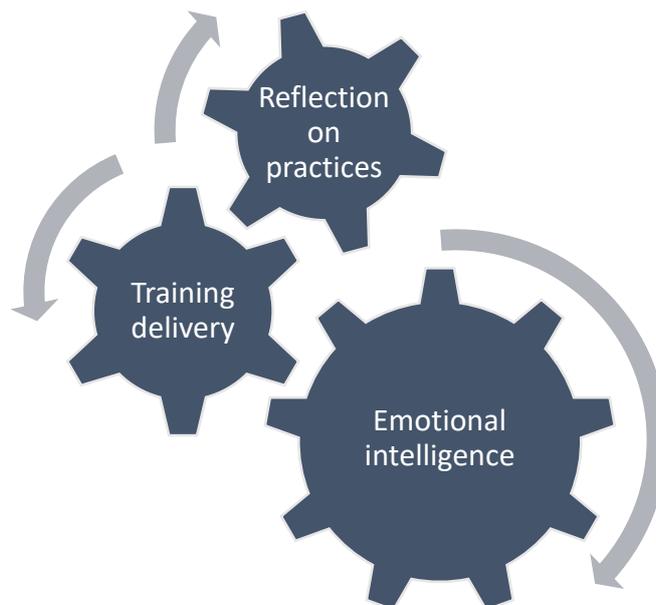
Figure 11: Pathway for change

It is for this reason that the pathway for change would become the centre point for the focus groups. The focus groups were an opportunity to establish the relationship between EI and dementia care. Goleman's (1998a) identified five basic emotional and social competencies to EI.
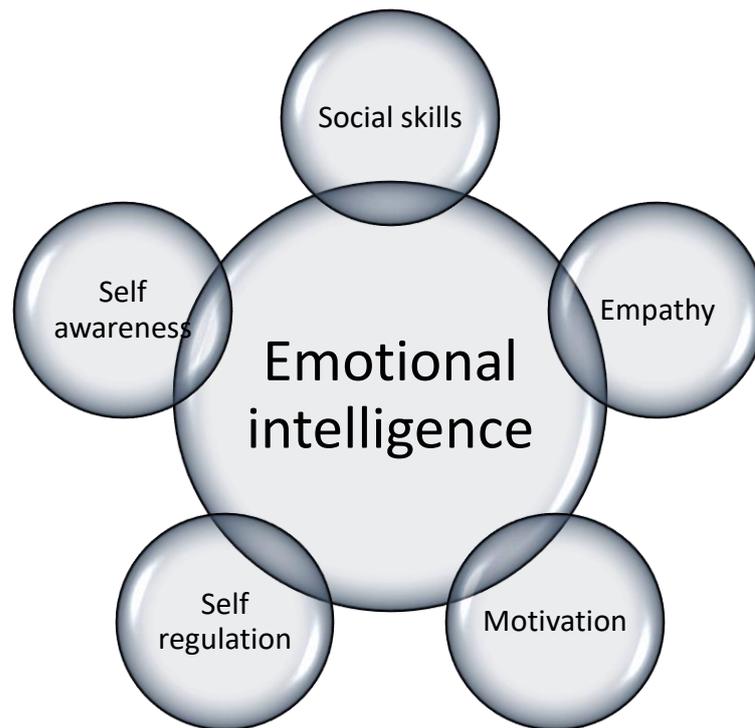
Figure 12: Goleman's (1998a) identified five basic emotional and social competencies to EI

Using the five identified basic emotional and social competencies to EI, statements and questions applied to the dementia training, were developed to formulate focus group discussions. This topic is discussed in more detail in Chapter 4: 4.6 Focus Groups.

3.9   Quantitative and qualitative data

The population for quantitative and qualitative data were a targeted group of 52 HCW's, 6 members of the CMT and their service manager. Bringing the total amount of participants to 59. The HCW's were chosen by Company A's care coordinators based on their clientele, an expressed interest in completing the dementia training, or through a random selection process based on availability. The 6 CMT members and the service manager were approached directly as they are line managers to the HCW's.

3.10 Population for analysing quantitative and qualitative data

The most appropriate methods for analysis quantitative and qualitative data were chosen. SPSS was chosen for the analysing of the quantitative data (questionnaires and evaluation sheet), whereas a narrative/story telling approach was taken for the analysing of the qualitative data presented (focus groups and feedback from the training intervention).

3.10.1 Analysing quantitative data

SPSS was used for the purpose of analysing all chosen questionnaires. Descriptive statistics (means and standard deviations) were calculated for all variables. These statistics will be discussed later in chapter 4. In chapter 4, exploration is provided regarding population demographics and overall results of the statistical analysis. Out of the 58 participants who completed the EI questionnaire, 7 individuals had left one question blank each. These missing data cells were assigned the mean value for that question so as not to distort the results. Shrive et al. (2006) assesses multiple methods for dealing with missing questionnaire data and found mean substitution to be simple yet accurate.

With regards to the DKAS questionnaire a paired t-test was completed. The t-test allows for a comparison to be completed between the two sets of results from the same person. The only difference is that the results were taken at two different time points – T1 before and T2 after the training had been given. The purpose of doing same was to compare the results to see if there was a statistically significant difference when subtracting participants after and before result. From this an average of these differences was generated.

3.10.2   Analysing qualitative data

The analysing of the qualitative data was achieved through the process of identifying important feedback provided in the focus groups, through comments made in the training evaluation forms; and throughout the training intervention. This method was chosen for this study as it allowed for the gathering of data that reflects interaction and insight into why opinions are held on the subject matter. Through such engagements a narrative was developed for the purpose of telling a story of the participants experiences to date. Narrative is a fundamental way in which human thoughts are processed (Hogan et al., 2009). By gathering feedback through these processes it allowed for real life experiences to be heard. This was identified as a gap in literature, particularly with regards to the research subject.

3.10.3   Quantitative and qualitative population demographics

Basic demographic information was analysed using descriptive statistics. Results are presented as mean values ± standard deviations and % proportion of the overall group are displayed within the brackets. Throughout the research process there were 59 participants in total. This figure only changed from 58 to 59 when Company A's service manager was included in the CMT focus group. All of which is discussed in detail in chapter 4.

3.11 Sample

For the purpose of gathering data on the research matter, theoretical sampling was applied. Theoretical sampling is concerned with the obtaining of data from best candidates, with a particular focus on exploring participant views and listening to their stories (Qureshi, 2018). As part of the research proposal a sample intervention was completed. The purpose of this sample intervention was to get a real life understanding as to whether or not there was a requirement for research in this area. To ensure that the participants in the sample intervention could not be identified they were each given a pseudonym: Service User Susie, HCW Mary and HCW Anne.

The pilot intervention involved identifying one person (Susie) with dementia, living in the community; and two of her HCW's (Mary and Anne), all of whom agreed to participate in the pilot (see appendix 5). Once agreement was obtained a pilot training course was delivered and an observation of behaviours prior to and after the training was conducted. The findings were that, based on the polit study, conditions for the person with dementia improved and there was a reduction in the burden effect of those providing care and support for the HCW. The literature reviewed highlighted dementia as a global concern, with governmental recognition of the requirement of service delivery change, along with the current sub-standard homecare service not meeting the intrinsic needs of those living in the community with dementia.

3.12 Ethical issues

While ethically drawn to this type of invention, the research intervention and findings will add knowledge and substance to Company A's plans for service improvement to those with dementia. Cooper and Schindler (2008) define ethics as the *"norms or standards of behaviour that guide moral choices about our behaviour and our relationships with others"* (p. 34). From a moral perspective it is vital that research is completed in the area of dementia, particular given the statistics regarding the increase of dementia cases discussed in the introduction section of this dissertation. However, given the nature of the disease the topic of dementia is complex and can often raise concerns regarding consent for those with dementia. This was only presented as a caution during the sample intervention (pilot study) as no other Service User participation was required in this research. Concerns are often raised as to whether informed consent has been considered when a person is invited to participate in research (Sherratt, Soteriou and Evans, 2007). This is particularly more prevalent when a person has dementia.

3.13 Limitations to research

One of the major limitations to this piece of research is the use of convenience sampling from only one organisation. This limits the generalization of the results, given that the study only represents the current service delivery and skillsets of HCW's and CMT members of Company A. Participants may also have felt cautious about divulging information about current service delivery and skillsets, which may have led to limited participant throughout the research.

3.13.1   Section process

From a research and findings perspective all participants were treated as anonymous individuals, informed of their right to withdraw from the research if they wished to do so. Participants were selected based on their current clientele (if any had dementia), based on an expressed desire to attend dementia training and randomly selected based on availability. Consent and financial approval was obtained by the Board of Management of Company A. As part of giving authorisation to the research and funding the delivery of training, all findings were reported back to the Board of Management for review. However, no individual findings were reported, therefore respecting the anonymity of all participants.

3.13.2   Literacy

Throughout the intervention it became apparent that there were concerns raised regarding the literacy levels of participants. For the purpose of allowing these individuals remain anonymous to the wider group each intervention group were advised that if they wished to repeat the questionnaires on a one to one basis that they could put a star in the corner and they would be approached separately, which they did.

3.13.3 Implementation of new training

The training delivered is newly developed by the National Dementia Office, the HSE and DCU. Like all new training there was unexpected situations that arose. This was particularly seen when participants were referring to personal experiences/memories, which appeared to open up old wounds during the feedback sessions of the training. It therefore became apparent that the training was not a stand-alone course and that there was a real need for future supports to be put in place, either from a group or one-to-one perspective, pending on the disclosure and need of the participant.

Chapter 4: Research findings and discussion

4.1 Participant profiles

A total of 58 participants took part in the training and the completion of questionnaires, with a breakdown of 51 Females (87.9%) and 7 Males (12.1%). The participants consisted of 6 members of the CMT and 52 HCW's. There was a Mean Age of 43.17 ± 12.34 years (Youngest: 20, Oldest: 73). The length of service in Company A had a mean of 9.45 ± 7.81 years (Min 6 months, Max 34 years). Throughout the process the CMT consisted of 6 members except when joined by their service manager (female, aged 36, length of service: 16 years) in the focus group. Bringing the total amount of participant to that of 59.

4.2 DKAS

4.2.1 DKAS scores

As discussed in the methodology chapter results are presented as mean values ± standard deviations. These values were obtained using descriptive statistics on SPSS. The following figure will show a comparison between DKAS T1 and DKAS T2. DKAS T1= The first time the dementia questionnaire was completed, which was before the participants commenced in the dementia training. Whereas, similarly DKAS T2= the second time the participants completed the dementia questionnaire, which was directly after the completion of training.

DKAS T1				DKAS T2			
Mean Score	Std. Deviation	Min. Score	Max. Score	Mean Score	Std. Deviation	Min. Score	Max. Score
28.14	± 6.86	12	42	34.20	± 7.24	18	48

Figure 13: A comparison between DKAS T1 and DKAS T2

A paired sample t-test was used to compare the mean values for before and after the intervention (dementia training). The findings suggest that:

- The scores at DKAS T1 and DKAS T2 were weak but positively correlated (r= 0.283, p = 0.032)
- A significant difference was observed between the scores before and after the training (t_{57}= 5.455, p<0.001)
- The mean difference in DKAS T2 vs DKAS T1 scores was 6.05, meaning that on average individuals scored 6 points higher on the second test. (95% CI [3.83,8.27]).

DKAS T1: Subscale	Mean	Std. Deviation	Min.	Max.
A: Causes and characteristics	7.45	± 2.73	1	14
B: Communication and behaviour	6.88	± 2.70	0	12
C: Care Considerations	8.81	± 2.45	3	12
D: Risk factors and health promotion	5.00	± 2.25	0	9
DKAS T2: Subscale	Mean	Std. Deviation	Min.	Max.
A: Causes and characteristics	8.98	± 2.72	3	14
B: Communication and behaviour	9.09	± 2.38	4	12
C: Care Considerations	9.52	± 2.41	4	12
D: Risk factors and health promotion	6.60	± 2.63	2	12

Figure 14: A comparison of the subscale results before and after the intervention using paired t-test

Findings of a comparison of the subscale results before and after the intervention using paired t-test show that:

- Sub A (Causes and characteristics): Mean Difference: 1.53 ± 3.57 (improved on average by 1.53 points) p = 0.002

  T_{57} = 3.274, Upper and Lower CI [0.60, 2.47]

- Sub B (Communication and behaviour): Mean Difference: 2.21 ± 3.27 (improved on average by 2.21 points) p = <0.001

  T_{57} = 5.140, Upper and Lower CI [1.35, 3.01]

- Sub C (Care Considerations): Mean Difference: 0.71 ± 2.77 (improved on average by 0.71 points) p = 0.057

  T_{57} = 1.942, Upper and Lower CI [-0.02, 1.44]

- Sub D (Risk factors and health promotion): Mean Difference: 1.6 ± 2.80 (improved on average by 1.6 points) p = <0.001

  T_{57} = 4.366, Upper and Lower CI [0.87, 2.34]

4.3 Emotional intelligence

By measuring EI this gave an understanding of whether or not a HCW could sustain the pressures of supporting a person with dementia (discussed further in 4.6).

4.3.1 Overall results of the assessing emotional scale questionnaire

A total of 58 participated in the completion of the Validated 33-Item assessing emotions scale questionnaire. With the highest possible overall score of 165 the overall participant mean= 136.86 ± 13.78 (standard deviation). The minimum possible score for participants was 33, however the lowest participant score in this study was recorded at 96 with a maximum score of 164. The following table has been produced to show an understanding of the different subscale mean associated findings.

Subscale	Maximum Possible Score	Mean	Std. Deviation
Perception of emotions	50	40.28	5.00
Managing emotions in the self	45	36.88	5.01
Social skills or managing other's emotions	40	34.36	3.55
Utilizing emotions	30	25.34	3.05

Figure 15: Participant results of 33-item assessing emotions scale questionnaire

Below is a comparative between the CMT's and HCW's:

Group Statistics				
Role	N	Mean	Std. Deviation	p-Value
Sum_ Total Participants				
CMT	6	140.3333	10.63328	0.520
HCW	52	136.4615	14.14832	
Managing emotions in the self_ Sum				
CMT	6	38.8333	5.30723	0.323
HCW	52	36.6538	5.04445	
Social skills or managing other's emotions_ Sum				
CMT	6	34.0000	1.78885	0.795
HCW	52	34.4038	3.71145	
Utilizing emotions_ Sum				
CMT	6	26.0000	3.28634	0.583
HCW	52	25.2692	3.04937	

Figure 16: Group statistical results of 33-item assessing emotions scale questionnaire

4.4 Training evaluation feedback

4.4.1 Results through SPSS

All 58 participants reported that the content of the programme supported their knowledge development on dementia. The majority of participants (94.8%) rated the programme as very good in terms of content, presentation, handouts and reading material supplied. All 58 participants reported that they would recommend the dementia training to a colleague.

4.4.2 General overview of feedback comments

Positive Feedback
"Really enjoyed the course, full of knowledge and advice on moving forward with my clients with dementia"
"I found the course beneficial, interesting and very relevant"
"Excellent course, brilliant delivery"
"Lovely class with an easy learning environment"
"I'll remember what I learnt for a very long time"
"Very intense, good group interactions"
"Great job, thanks for all the new knowledge"
"Thought provoking"
"Overall very informative"
Suggested Improvements
"More colour and contract in the slides"
"Family members would really benefit from this course"
"Too much words on the slide"
"More relevant video's"
"Real scenario's"
"Bigger room with more participants"

Figure 17: Training evaluation- positive feedback and suggested improvements

4.5 Themes generated from training delivery

4.5.1 Description of dementia

On Day 1 of the "Understanding Dementia for Home Care Workers" training participants were asked what words they associate with dementia. The description provided was negative and showed little hope for the person with dementia.
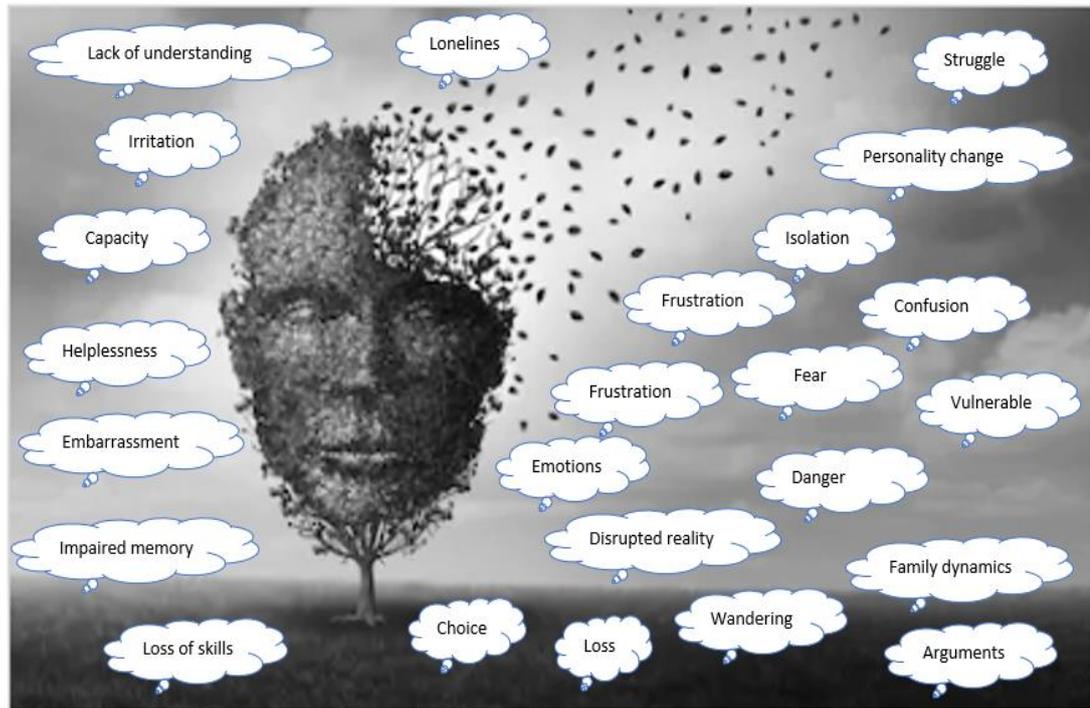
Figure 18: Trainees description of dementia

4.5.2 Ageism

Throughout each training session there appeared to be a generalised set of beliefs that legitimised ageism amongst the group. While predominantly from a protective perspective (protecting from danger and in some cases further injury), the assumptions made placed limitations on the person with dementia's engagement in activities due to their perception of the person being old. The concept of ageism has been around for over 50 years. It has been suggested that the term was first introduced by Butler (1963). There have been several books published since then, however the term ageism is still relatively young and an unchartered field of research. Bytheway (1995) suggests that older people are often categorised as being incompetent, ugly and burdensome. Again a description that shows little hope for the person with dementia.

4.5.3 Quotes from training participants

"In all my years of working with older people I never thought that I was ageist, but now I have to question that" (Participant 42, aged 62, female, HCW, length of service: 23 years)

"Feel like I have been doing everything wrong until now" (Participant 8, aged 52, male, HCW, length of service: 7 years)

"Never thought that people with advanced dementia could still be able to communicate" (Participant 33, aged 32, male, HCW, length of service: 5 years)

"Until now I never would have thought that keeping someone safe could actually be stopping people from making decisions for themselves" (Participant 1, aged 58, female, HCW, length of service: 7 years)

"Wow, never really thought of the differences between empathy and sympathy, but only ever wanted for the person to feel better. It all makes sense now" (Participant 54, aged 39, female, Community Supervisor, length of service: 11 years)

"I have been working in Company A for 34+ years and I have just learnt to get on with it. It's never about the money for me, when I started we got £20 a week despite what hours we did. I don't take the job personally, I just do whatever needs to be done" (Participant 44, aged 73, female, HCW, length of service: 34 years)

"Treachery is a common part of how I engage with people with dementia, it's a way of calming people with dementia down" (Participant 22, aged 38, female, HCW, length of service: 1.5 years)

"Until now I never thought about the importance of putting the persons needs first, I have always thought that we had to do what the family wanted" (Participant 2, aged 41, female, HCW, length of service: 3 years)

"I am always taken advantage of, one woman gets me to walk in front of her so that I break her fall if she falls down the stairs. Never realised until now how I allowed people to do this to me" (Participant 28, aged 33, female, HCW, length of service: 11years)

"This training will makes me look at things very differently, it's exciting" (Participant 34, aged 24, female, HCW, length of service: 1 year)

"I knew I was doing something wrong, this training will all help me feel more confident in my role" (Participant 47, aged 33, female, HCW, length of service: 3 years)

"I never thought there could be a problem with a therapeutic white lie" (Participant 5, aged 43, female, HCW, length of service: 17 years)

"People tend to see the dementia before the person" (Participant 53, aged 43, female, Community Supervisor, length of service: 6years)

Figure 19: Quotes from training participants

4.6 Focus groups

As discussed in Chapter 3.8.3 Goleman's (1998a) five competencies to EI were applied to the dementia training for the purpose of compiling statements and questions to be used in the focus groups (refer to appendix 4). According to Krueger (1994) the ideal size for a focus group is typically between 6 and 9. For this reason two groups of 7 participants were chosen. The 5 stage Interpretative Phenomenological Analysis (IPA) guiding framework was then applied to analysis the scripts of the focus groups:

Stage 1:   The intervention involved both qualitative and quantitative research, each producing interesting findings strengthening each research method approach. While it was noted that there was much research sourced material regarding EI, none could be obtained showing the importance of establishing a relationship between EI, dementia care and HCW's.

Stage 2:   Emerging themes were found throughout the training delivery and focus groups, all of which are detailed in this chapter.

Stage 3:   The connecting of emerging themes and similarities was particularly relevant when completing a comparison between the two focus group as detailed below.

Stage 4:   The production of data was divided into two sections, the chaptered section of the dissertation and the appendix section. The data entered in the chaptered section was considered to be most prevalent with pertinent themes.

Stage 5:   This stage is outlined below, illustrating a summarised narrative account of the research.

4.6.1 Objective 1: Self-awareness

CMT focus group

Synopsis of the CMT feedback regarding self-awareness:

Being self-aware is important. Goleman (1998b) suggests that being self-aware assists in decision making and gives realistic assessment of a person's abilities. When a HCW is not self-aware this can bring about confusion for a person with dementia. People with dementia can feed off a HCW's confidence and general mood. Therefore, a HCW's mood can impact on how that person with dementia's day will go. Self-awareness brings consistency. Moreover, it is important to create boundaries and stay within a care plan. The person must come before the dementia, the dementia is just the illness, not the person. It is important that HCW's maintain at the person with dementia's level, adapting their way of doing things to suit their audience, while reassuring the person that it is okay to make mistakes. Things can get very distorted for a person with dementia therefore it is important to make life as normal as possible for them. Humour is a good way of keeping things normal. By bringing humour into care, it helps to form a connection with the person. Without laughter a HCW would not survive. The absence of laughter will lead to a HCW beating themselves up. Laughter is a great way of acknowledging limitations. People who are self-aware know their limitations (Goleman et al., 2002).

HCW focus group

Synopsis of the HCW's feedback regarding self-awareness:

HCW's suggest that not being self-aware can cause confusion and frustration for the person with dementia. It is important to recognise our inner signals (Goleman et al., 2002). A HCW's role requires them to be confident particularly due to the importance of building a trusting relationship. If you are not confident

in your role the person with dementia will sense this and will not be comfortable in you supporting them. Reference was also given to the importance of humour and how this can break down barriers and help people feel comfortable in uncomfortable situations e.g. personal care- toileting, washing and dressing. Laughter is a great way of dealing with the challenges associated with supporting someone with dementia. It can lighten difficult conversations that have to be had and reduce tensions. Laughter is what makes the job easier and the person's environment happier; having the potential to set the mood for that person. When a person with dementia is more relaxed it deduces the complex challenges of providing support. Goleman et al. (2002) describes this as 'the open loop in operation', suggesting that this is something people are conditioned with, that we cannot help but lighten our moods when we are introduced to laughter. Some people with dementia scream a lot. Singing and laughter creates connections, helping change a person's mood. When you laugh, she laughs, when you sing, she sings. When a person with dementia is laughing or singing they can complete tasks that they would otherwise see as difficult. This type of engagement with a person requires much confidence particularly when family or community members are around. Some people struggle to understand this. Being self-aware assist's you assessing a person's needs and wants.

4.6.2 Objective 2: Self-regulation

CMT focus group

Synopsis of the CMT feedback regarding self-regulation:

The CMT's describes not being trustworthy as abusive and gives emphasis to the importance of building a trusting relationship. Noting that without a trusting relationship people with dementia would not allow HCW's to provide care and support. That the person would express fear, therefore keeping their distance. Closeness is formed by respecting a person's values and working alongside them. This can be time consuming and difficult for a HCW's but it is important

not to sway a person from their values. Doing so takes away their choices and power. Moreover, this can have a diminishing effect on a person's independence and their control levels in life. By being self-regulated a HCW always puts the person first, respects their wishes, even when there is persistent family members pushing their own values to the forefront. Self-regulation allows a person the opportunity to handle their emotions, which in turn avoids interference and offers facilitation to the task at hand (Goleman, 1998b). Disregarding a person with dementia's emotions can trigger behaviours such as anger, frustration, etc. HCW's must remember that they are there in service of the person with dementia and not the family. The is particularly prevalent with regards to the person's privacy. CMT members describe how family members and friends would often read over a person's home care file without the permission of the person, despite it containing some of their most private details. Sometimes we just act without thinking. Old urges can come into practice, making it difficult to self-regulate our actions (Goleman et al., 2002). Nevertheless, people with dementia don't always speak up about their wishes even when doing so makes them feel empowered and liberated.

HCW Focus Group

Synopsis of the HCW's feedback regarding self-regulation:

There was a general consensus held that it was important to ensure the happiness of the person with dementia. By being self-regulated HCW's can ensure that they do not engage in supporting someone with dementia while still holding onto their own person issues. Providing support can be challenging for both the HCW and the person with dementia and often exposes a HCW to situations of temptation e.g. financial irregulating. People with dementia often offer money as a way of showing gratitude. However, it is important that a HCW remains self-regulated and professional, advising the company of such activities so that they can be protected should an allegation be raised. It is also important to regulate your feelings and behaviours as a HCW. When a person

is self-regulated they are not using mental energy to fight off urges, instead efforts become automatic, taking away the pressures once held (Goleman et al., 2002). It was acknowledged that sometimes supporting a person with dementia can help you forget your own issues, but that it did take a certain type of person to work in this industry. Supporting someone with dementia can come with its frustrations and be upsetting. Therefore, it is important to stay professional and be mindful of burn-out. Burn-out can be found in both HCW's and family carers. Self-regulation is important for managing challenges. Self-regulation helps a person to recover well from emotional distress (Goleman, 1998b). While it is important to understand that the family may also have challenges, self-regulation assists a HCW in choosing how to address challenges from family members should they arise. Furthermore, there has to be a balance, the person with dementia has to come first, particularly given the limited time allocation of calls.

4.6.3 Objective 3: Motivation

CMT Focus Group

Synopsis of the CMT feedback regarding motivation:

The CMT members were adamant that this type of job was never about money. While some members recalled how the working hours and wages were enticing, all agreed that it was the personal rewards that encouraged them to stay. Emphasis was placed on the importance of building a trusting relationship with the person with dementia and how this could not be achieved with only a financial incentive. A belief was held that HCW's whom solely worked for financial gain, were clinical, therefore not meeting the individual needs of the person with dementia and would never be motivated enough to do the job right. When we understand the source of discontent this can motivate us to act (Goleman et al., 2002). CMT members collectively agreed that when providing support to vulnerable people, that person must be of caring nature. That this is a requirement for good relationship and engagement

which is achieved through the provision of quality care. People with dementia can have heightened senses, they know when a person is engaging with them just for financial purposes. This often makes it difficult for them to connect, which makes general tasks difficult to complete e.g. washing, dressing and bathing. In some cases it can take a long time for a person with dementia to connect with a HCW but these connections are usually the ones that last the longest. Opinions were voiced, suggesting that homecare companies place more value on HCW's who work excessive hours, despite this creating burnt-out for the employee and a devalued service provided to the person with dementia. Goleman (1998b) suggests that motivation guides us towards achieving goals particularly when faced with challenges. CMT members propose that it is the people and the personal rewards that motivates HCW's to stay working in homecare. All agreed that seeing a smile on someone's face when you arrive and leave can be gratifying for a HCW.

HCW Focus Group

Synopsis of the HCW's feedback regarding motivation:

The HCW's proposed that HCW's must be motivated in order to motivate others. Being motivated gets the job done right e.g. a lack of motivation when washing someone could lead to a person getting sores. When we are truly motivated we are tapping into our own values and wishes for the future (Goleman et al., 2002). Challenges within dementia care can require you to take deep breaths and centre yourself before going into a call, but in general it is a very rewarding job. Motivation helps a person to take initiative and strive to improve situations despite being faced with frustrations or setbacks (Goleman, 1998b). The slightest little improvement in a person can motivate you to do more. Their appreciation for what you do motivates HCW's. It makes you feel good about yourself. Due to the exposure of vulnerabilities, HCW's bond quickly with a person with dementia. When a HCW is going on holidays they make preparations for their absence e.g. ordering medication, ensuring

there is an adequate supply of gloves, shopping etc. The HCW's stated that working in homecare is often considered a vocation, but there was a difference in working for a private company and a non-for-profit company. Further suggesting that in their company (non-for-profit), unlike private companies, that appreciation is shown in other ways e.g. that they have a team of mentors to support new staff members, get paid more, receive sick pay, Christmas vouchers and occasional gifts like chocolates for 'just because' etc. Again it is not the money that motivated HCW's, but rather the thoughts of them being appreciated by the company.

4.6.4 Objective 4: Empathy

CMT Focus Group

Synopsis of the CMT's feedback regarding empathy:

Strong beliefs were held that empathy was an important aspect of providing support to a person with dementia. That a person's independence needed to be supported and their choices/wishes treated with dignity and respect. Emphasis was given to the importance of holding onto these choices/wishes even if they appear small in comparison to those choices/wishes being expressed by family members on their behalf. It was described how HCW's needed to step back and observe a person with dementia's capabilities, allowing them to do what they can instead on jumping straight in. Agreement was held that this allows the person to maintain their independence as much as possible. People see the dementia before they see the person. It is important to approach a person with an empathetic attitude instead of a sympathetic attitude. People with dementia should be able to show their emotions and HCW's should not be distracting them from doing so. By being empathetic HCW's encourage people to show their emotions, which in turn helps a person to understand their emotions. Naomi Feil, a leading expert in dementia care refers to the expression of empathy as 'validation' (Laing 1967). When a person with dementia's feelings and emotions are 'validated' they feel

more alive and connected in real life (Kitwood 1997b). This eases the frustrations of HCW's, particularly around repetitive behaviours. The training illustrated that this helps people with dementia work through their frustrations and find the causes of same. Being empathetic does not just lie with the person with dementia it is also important to be empathic with the family. The family would benefit 100% from participating in the dementia training. Not having knowledge in this area makes it difficult to understand the complexities of the illness. The training has made HCW's more conscious of being empathetic and how they interact.

HCW Focus Group

Synopsis of the HCW's feedback regarding empathy:

Goleman (1998b) refers to empathy as a way of sensing a person's feelings and the ability to build rapport with people of all diversities. Agreement was held that empathy was an everyday part of the role of a HCW and that if a person does not have empathy, that this would not be fair on the person with dementia. The persons feelings are too important to be ignored. To be empathetic with a person with dementia there has to be a focus on the emotions not the facts. Family members often struggle with the difference between being empathetic and sympathetic. One HCW recalled a heart breaking situation whereby a daughter would tell her mother on a daily basis that her husband was dead, which resulted in the woman going through a new bereavement every day. The HCW described how it took several weeks to get the family to explore a different approach. While it was obvious to the HCW that there was no real harm intended, it was challenging considering that the family had been told by a medical professional to be honest with their mother. Being empathetic can be successful when offering constructive advice (Goleman et al., 2002). Others recalled how some of their dementia clients had appeared miserable and how working through their feelings made them feel better. It is about just being there for them, being present, not saying

anything, respecting their regression age and treating them appropriate to their needs at this age e.g. some people with dementia display childlike behaviour like wanting to be cuddles and tickled.

4.6.5 Objective 5: Social skills

CMT Focus Group

Synopsis of the CMT's feedback regarding social skills:

Communication is vital in any relationship, if a HCW is not engaging with a person with dementia they can become more reclusive. Having social skills makes a HCW feel more positive about what they do, creates a sense of ease for the person with dementia and gives a level of trust to families and their networks. Applying social skills helps a HCW's listen and observe more, which overtime helps the person with dementia build a picture of what they are trying to communicate. Lewis et al. (2000) describes this process as two people harmonising their mental state. Social skills assist HCW's in identifying when they are trying to stop the emotion of the person with dementia due to its uncomfortable state. It is important for the person with dementia to feel safe in their environment and verbalise their feelings. Being empathetic and having social skills impact on each other. They come hand in hand. When a HCW has social skills they can provide support from a person centred perspective. Having social skills give an insight into family dynamics as well as creating reassurance when a buy-in for new ways of doing things is required. Knowing how to approach situations can be particularly beneficial when defusing family conflicts relating to the person with dementia's choices/wishes. Family member frustrations regarding their lack of supports can be particularly difficult to deal with. Having social skills will allow the HCW the knowledge of knowing when it is appropriate to get involved and when to back off. A person with good social skills will have the skillset to persuade, lead, negotiate and settle disputes (Goleman, 1998b).

Synopsis of the HCW's feedback regarding social skills:

The HCW's discussed the importance of having social skills, describing how nearly every interaction with a person with dementia requires HCW's to be persuasive. People with dementia can be resistant of daily activities, particularly that of personal care as they tend to be afraid of water. Having the social skills to read an environment and the person with dementia helps. Singing is a great distraction for activities such as bathing or putting a person's teeth in. Social skills help to build trusting relationships but there is also a requirement for a HCW to have a good personality, otherwise it would be impossible to assist a person with dementia. By being attuned to another person's fears, anger, good spirits a person can take the necessary steps in the right direction (Goleman et al., 2002). The HCW's gave a detailed account of the importance of putting a person at ease, showing respect, getting down to their eye level and having the banter (conversation). By being socially skilled HCW's can observe when it is appropriate for touch, read the persons wants/needs, be engaging, give hugs or have an understanding that someone may just need the comfort of resting on a HCW's shoulder. Social skills allow a HCW to observe how a person is feeling on arrival, which is particularly important when maintaining effective relationships within family dynamics. A HCW needs to recognise the significance of putting the person with dementia first without jeopardising their relationship with the family. Sometimes social skills are required when a family member is too involved. A person with social skills can handle emotional relationships and situations well, ensuring that smooth interactions take place (Goleman, 1998b). HCW are often called upon to have challenging conversation e.g. suggesting to a family that they are there to support their parent and need privacy to do so. When a HCW is not socially skilled they may take a damaging approach with the potential to jeopardise relationships e.g. asking them to back off.

4.6.6 Emerging themes

The following figure gives an account of the comparative emerging themes of both focus groups and their interpretation of why each objectives was important for a person with dementia.

Objectives	Comparatives for the person with dementia
Objective 1: Self-awareness	- Self-awareness is an important aspect of proving care and support - Not being self-aware brings confusion to a person with dementia - The person feeds off the HCW's level of confidence to do the job - Laughter is very important and can lighten engagements
Objective 2: Self-regulation	- Providing care and support requires self-regulation - The absence of self-regulation effects the building of trusting relationships - Self-regulation puts the person with dementia first, always ensuring that they are treated with respect, particularly around their independence and making choices - Being self-regulated helps a HCW to be confident when approaching challenges within family dynamics
Objective 3: Motivation	- Money, titles etc. would never motivate a HCW - HCW are motivated emotionally, through rewards of gratitude - Seeing a person smile or their situation improve motivates HCW's - Motivation is required for building trusting relationships - A person with dementia can sense a person's intentions
Objective 4: Empathy	- Working with a person with dementia requires empathy not sympathy - It is important to acknowledge how a person is feeling - Emotions must be encouraged to allow the person to work through their frustrations and repetitive behaviours - Being empathetic can help with developing family relationships and when addressing struggling situations
Objective 5: Social skills	- A HCW requires social skills when working with someone with dementia, particularly for building trust - Social skills have a positive impact on people with dementia - Communication and how we communication to the person with dementia and their family is very important - Having social skills can create a buy-in and defuse potentially challenging situations when required

Figure 20: Comparative emerging themes from the focus groups

4.7 Findings with reference to literature

This research correlates highly with currently literature proposing that homecare lacks the supports required to meet the complex and ever-changing needs of Ireland's dementia community. This includes those living with dementia, their family, surrounding networks and the numerous healthcare professionals providing care and support to those with dementia. The findings in this piece of research supports previous research that proposed that a leading factor in this area is the lack of suitable dementia training.

In the absence of suitable dementia training HCW's find it difficult to support those with dementia because of their complex needs and their exhibited behaviours. According to Kitwood (1997b) people with dementia who are experiencing illbeing were often people who were exhibiting feelings of undermined personhood or whereby their living environments did not support personhood. It is important to note that, other than the "Understanding Dementia for Homecare Workers" training, personhood is not covered in any other dementia training currently provided to HCW's in Ireland.

This research suggests that understanding EI can have an impact on a person's personal and professional life. By understanding our emotion's, we better connect with others. People who are high in EI perform at higher standards and have better working relationships (Merkey, 2010). Emotionally intelligent people are more enthusiastic, show initiative and enjoy working in challenging situations (Zampetakis et al., 2009). It is important to note that EI can improve. When engaged in new learning a person's EI can mature over time (Mayer et al., 2004). EI is required from all levels of an organisation. Organisations strategic planning and development must captivate the importance of providing person-centred dementia care. This appears to be the case in Company A. The EI of health care providers affects client satisfaction, therefore it should be recognised as one of the quality indicators within health care services (Oyur, 2007).

By encouraging HCW's to attend dementia training Company A is addressing the increasing reports of sub-standard care provision. The vast educational deficits in dementia care must be acknowledged if providers are to move towards adequately providing person-centred care and supporting HCW's in their well-being. Research suggests that the lack of training is a major contributing factor of employee burn-out. HCW's by their nature give themselves readily to the everyday tasks required to support a person with dementia but fail to acknowledge their own psychological care (Kitwood, 1997b).

While there is much information available offering government intentions to address the presented challenges of staff deficits in dementia knowledge (training and skills), there is a lack of leadership towards the provision of same. As the largest non-for-profit on the north side of Dublin, Company A has only been in receipt of 5 IHCP referrals, which indicates a lack of such packages being financially supported by government. In an already underfunded sector of healthcare it is difficult to comprehend were funding initiatives will be generated from, despite the department of health identifying dementia as a national priority. These type of budget restrictions often result in the public sector shrugging off long-term responsibilities in the area of dementia care (Kitwood, 1997b).

The homecare industry has become a financially attractive industry over the last decade. Dementia care does not require any special inputs from nursing yet providers are charging higher fees for same (Bell and McGregor, 1995). The provision of dementia care does require a more person-centred approach which can require more time with the person from a humanist perspective. People with dementia often require higher ratios of personnel or longer hours allocated for the completion of tasks at the person with dementia's pace. This is not always catered for from a budgetary perspective therefore making the area of dementia care less attractive as a business (Kitwood, 1997b).

A story of success will only unfold when people with dementia can truly experience humanisation. While there is cause for encouragement, in current times, humanisation is occurring at a slow pace (Kitwood, 1997b). Better staff development and training to elevate the stigma connected to dementia is a step in the right direction. The term person-centred care goes beyond the individual with dementia, it requires an understanding and acceptance within society. People living with dementia prosper when they maintain connections and status within the family and community at large.

Chapter 5: Conclusion

5.1 Introduction

The aim of the research was to explore the importance of establishing a relationship between EI and dementia care, specifically for the provision of person-centred care by HCW's in the non-for-profit sector. The research was supported mainly by academic and government publications noting the significance of such an intervention. With a suspected 55,000 people currently living with dementia in Ireland, research established the vast educational deficit in dementia care. Such deficits were also acknowledged in HCW's low skills-set. While the lack of dementia skilled forces was readily reported as a public concern and national priority, government bodies showed little evidence of implementing the recommended community initiatives.

5.2 Applicability of the intervention

The study highlighted the need for dementia training to move beyond the traditional didactic models of training, with a particular requirement for training that captivates the importance of EI. The new training "Understanding Dementia for Homecare Workers" embodies the importance of the integration of EI into dementia training, therefore transforming learning and experience for both HCW's and the person living with dementia. It is important to note that people with dementia do not flourish under the typical restraints of homecare delivery. Working with someone with dementia requires a very different approach to that of someone of old age or disability. When there is little, or no short-term memory and the facts are misplaced in a person's mind, feelings are often the best place to focus when engaging in the provision of person-centred care. The "Understanding Dementia for Homecare Workers" training also focuses on this concept but not just for the person with dementia, it also includes the HCW.

5.3   Practical applications

The research methodology undertaken was underpinned by a mixed methods approach, conducted in a systematic sequence and order. Taking a mixed methods approach to research proved labour intensive. The mixed methods approach did however generated complimentary insights which has helped to enhance the validity of the study.

Three interventions were applied to this research 1) The delivery of Ireland's National Dementia Offices dementia training "Understanding Dementia for Homecare Workers" to 52 home care workers (HCW's) and 6 members of Company A's community management team (CMT), 2) The completion of three questionnaires regarding dementia, EI and training delivery; and 3) The facilitation of two focus groups. Group one consisted of 7 HCW's while group two consisted of 6 members of the CMT and their service manager.

5.4   Originality and value

It is important to note that, other than the "Understanding Dementia for Homecare Workers" training, personhood is not covered in any other dementia training currently provided to HCW's in Ireland. While there are no statistics or research currently available reporting training engagement outcomes, the majority of participants (94.8%) in the research rated the programme as very good in terms of content, presentation, handouts and reading material supplied. All 58 participants reported that they would recommend the dementia training to a colleague and that they now felt better equipped and confident to support a person with dementia. From a person-centred perspective the training could have a profound effect on service satisfaction levels for those with dementia.

5.5 Recommendations for further research

This work indicates that further research is required to captivate what impact adequately trained HCW's will have on people living with dementia, if such training develops the EI of HCW's and how to address the lack of specialisation and flexibility which is essential for the provision of dementia care.

5.6 Concluding point

Current dementia training does not focus on improving outcomes for both the person with the dementia and the HCW's. People with dementia have a right to a service that best meets their individual needs and respects their wishes. By addressing the vast educational deficit in dementia care we will be in a better position to address the challenges that arise in the provision of dementia care. Research suggests that conventional papers/ qualification mean nothing when they do not address the needs of the person with dementia. As direct providers of care and support, HCW's must be upskilled to manage the demands of supporting people with dementia.

This research highlights the importance of establishing a relationship between EI and dementia care for the provision of person-centred care by HCW's. Findings suggest that the "Understanding Dementia for Homecare Workers" training captivates the core knowledge required for the provision of person-centred care. All training participants suggested that they would recommend the training to a colleague, that engaging in the training gave them more confidence to do their job; and new skills and knowledge that can be applied when supporting a person with dementia.

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Appendix

Appendix 1: Participation in Research Information

Appendix 2: Facilitators Certificate

Appendix 3: Quantitative Research Methods

Appendix 4: Qualitative Research Methods: Focus Groups

Appendix 4: Qualitative Research Methods: Pilot Study

Appendix 1: Participation in research information

Appendix 1.1 Participants information sheet

Participants Information Sheet

Invitation: I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being completed and what it would involve for you. Please take time to read the following information carefully. Ask questions if anything you read is not clear or if you would like more information. Take time to decide whether or not to take part.

Who I am and what this research is about: My name is Deborah Rooney and I am a student at NCI college, Dublin. I am currently completing a Masters in Management and this piece of research is for my Dissertation.

The research: Through a change management project, can the incorporation of Dementia training sustain the viability of a homecare organisation and its staff into the future? On researching this topic literature suggested that:

- Dementia is the second largest cause of disability in people over the age of 70
- There is an estimated 35 million people living with Dementia worldwide, an estimated 55,000 living in Ireland
- People with Dementia, living in Ireland are at crisis point
- There is a lack of quality care being provided in both the acute and community setting
- Homecare is outdated and not capturing the intrinsic needs of people with Dementia
- Homecare is driven by a medical model and not suitable for the delivery of Dementia care
- There are training deficiencies amongst those who are required to provide care to people with Dementia
- There are reports of high staff turnover and burn-out
- There is a general requirement for change within the industry.

It is also important to note the projected figures for people with Dementia as outlined in the chart below:

Figure 3: Estimated and projected number of people with dementia in Ireland and living in the community, 2011-2046
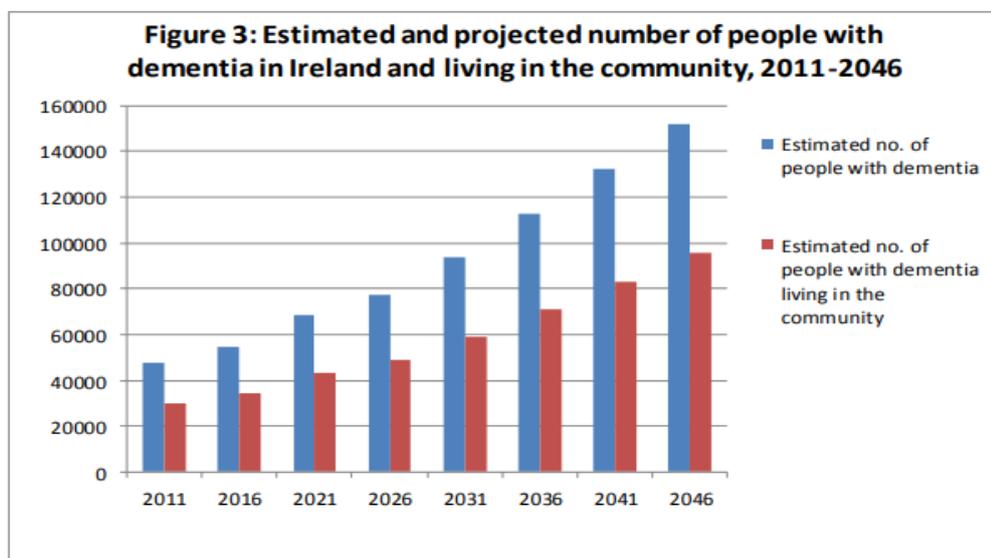
(Source: Pierce M, Cahill S, O'Shea E, 2014. Prevalence and Projections of Dementia in Ireland, 2011-2046. Genio. Mullingar).

The aim of this piece of research is to:

☐ Create an understanding of the current and future crisis in Ireland regarding the lack of appropriate Dementia training

☐ Identify the Dementia knowledge of the core group of Care Staff participating in this research

☐ Deliver the 2-day National Dementia Educational Programme to the core group

☐ Create a platform for learning that strengthens the knowledge base of Care Staff to meet the intrinsic needs of our Dementia community

☐ Capture the requirement for change for sustainment and viability of a homecare organisation (███████) and its staff into the future.

By engaging in this research you will: receive a training qualification in the newly developed 2-day National Dementia Educational Programme "Understanding Dementia for Homecare Workers", facilitated through Irelands National Dementia Office.

What will taking part involve? Taking place in this research will involve you completing a pre and post questionnaire (2 in total) regarding your knowledge of

Dementia. You will also be required to make yourself available for the two days and participate accordingly in the training provided.

Why have you been invited to take part? You have been invited to take part in this research as you are part of the Care and Support Team at ██████████, therefore have/or will have direct contact with our Dementia community.

Do you have to take part? Participation is completely voluntary, you have the right to refuse participation, refuse any question and withdraw at any time without any consequence whatsoever.

What are benefits to taking part? You will receive a new qualification in Dementia Care. This is only newly developed training therefore you will be a minority of qualified staff in this area. You will assist ██████████ in becoming a service that meets the intrinsic needs of our Dementia community as well as becoming sustainable into the future.

Will taking part be confidential? All information provided in this research will be treated confidentially. Participants will not be identified in any reporting segment of this research. If necessary, names will be changed disguising any details of your participation. In the event that the researcher is made aware that you or someone else is at risk of harm, the researcher may have to report this to the relevant authorities - they will discuss this with you first but there may be a requirement to report with or without your permission.

How will information you provide be recorded, stored and protected? Signed consent forms will be retained in the researcher's office in a locked cabinet. This information will only be retained until the exam board confirms the results of the researcher's Dissertation. Under freedom of information legalisation you are entitled to access the information provided at any time while it is in storage as specified. The participant can contact the researcher to seek further clarification if required.

What will happen to the results of the research? The results of the research are used as part of the final report for the researchers Dissertation. Disguised extracts from the completed questionnaires and/or group sessions may be quoted in the

researchers Dissertation, presentation's, published papers etc. and will be reported back to the board of management of ▮▮▮▮▮▮▮. However, no individual findings will be reported, therefore respecting the autonomy of participants.

Who should you contact for further information? Deborah Rooney: 087▮▮▮▮▮▮▮

Thank You!
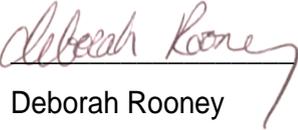
Deborah Rooney
Deborah Rooney

Appendix 1.2 Participants consent

Consent to Take Part in Research

I……………………………………… voluntarily agree to participate in this research study.

- I understand that even if I agree to participate now, that I can withdraw at any time or refuse to answer any question without any consequences of any kind.

- I understand that I can withdraw permission to use data from my questionnaires and/or group session's within two weeks after same has taken place, in which case the material will be deleted.

- I have had the purpose and nature of the study explained to me in writing and I have had the opportunity to ask questions about the study.

- I understand that participation involves participation in a pre and after training questionnaire and/or group sessions.

- I understand that I will not benefit directly from participating in this research.

- I understand that all information I provide for this study will be treated confidentially.

- I understand that in any report on the results of this research my identity will remain anonymous. This will be done by changing my name and disguising any details of my participation which may reveal my identity or the identity of people I speak about.

- I understand that disguised extracts from my completed questionnaires and/or group sessions may be quoted in the researchers dissertation, presentation's, published papers etc. and reported back to the Board of Management of ██████.

- I understand that if I inform the researcher that myself or someone else is at risk of harm that they may have to report this to the relevant authorities - they will discuss this with me first but may be required to report with or without my permission.

- I understand that signed consent forms will be retained in the researcher's office in a locked cabinet. This information will only be retained until the exam board confirms the results of the researchers dissertation.

- I understand that under freedom of information legalisation I am entitled to access the information I have provided at any time while it is in storage as specified above.

- I understand that I am free to contact the researcher to seek further clarification and information. Deborah Rooney: 0872653545.

--   ----------------
Signature of research participant   Date

I believe the participant is giving informed consent to participate in this study.

--   ----------------
Signature of researcher   Date

Appendix 1.3 Permission letter

█████████████████████████████████████
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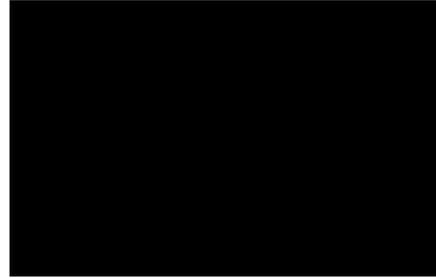
24th January 2019

Re: Permission to Conduct Research with the Employees at ████████████████████

Dear Deborah,

In response to your request to conduct research at ████████████████████, it is our pleasure to grant you permission to carry out the research. We are looking forward to your findings and how they could benefit the college and current peer learning curriculum.

Please contact the employees through ████████████████ who will handle all correspondence with employees. ████████ will distribute your letter of request to the employees'.

I wish you every success with your research.

Yours Sincerely,
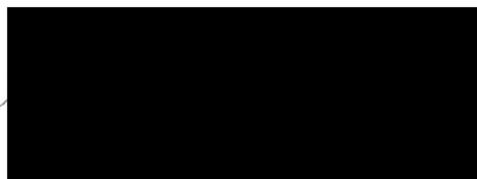
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Appendix 2: Facilitators certificate

CERTIFICATE OF ATTENDANCE

THIS IS TO CERTIFY THAT

Debbie Rooney

Has completed the

Facilitators course to deliver the

Understanding Dementia for Homecare Workers Programme

Venue: Dublin City University   Date: 7 & 8th February 2019

Professor Kate Irving

National **Dementia** Office

Appendix 3: Quantitative research methods

Appendix 3.1 DKAS questionnaire and scoring information

Scoring the validated 25-item Dementia Knowledge Assessment Scale (DKAS)

Q #	Statements about dementia	Response scale (Please tick one box ✓)					I don't know
		False	**Probably false**	**Probably true**	**True**		
A1	Dementia is a normal part of the ageing process. [FALSE]					**Remove TRUE/FALSE labels before use.**	
A2	Alzheimer's disease is the most common form of dementia. [TRUE]						
A3	People can recover from the most common forms of dementia. [FALSE]						
A4	Dementia does not result from physical changes in the brain. [FALSE]						
A5	Planning for end of life care is generally not necessary following a diagnosis of dementia. [FALSE]						
A6	Blood vessel disease (vascular dementia) is the most common form of dementia. [FALSE]						
A7	Most forms of dementia do not generally shorten a person's life. [FALSE]						
A8	Having high blood pressure increases a person's risk of developing dementia. [TRUE]						
A9	Maintaining a healthy lifestyle does not reduce the risk of developing the most common forms of dementia. [FALSE]						
A10	Symptoms of depression can be mistaken for symptoms of dementia. [TRUE]						
A11	Exercise is generally beneficial for people experiencing dementia. [TRUE]						
A12	Early diagnosis of dementia does not generally improve quality of life for people experiencing the condition. [FALSE]						
A13	The sudden onset of cognitive problems is characteristic of common forms of dementia. [FALSE]						
A14	It is impossible to communicate with a person who has advanced dementia. [FALSE]						
A15	A person experiencing advanced dementia will not generally respond to changes in their physical environment. [FALSE]						
A16	It is important to correct a person with dementia when they are confused. [FALSE]						
A17	People experiencing advanced dementia often communicate through body language. [TRUE]						
A18	Uncharacteristic behaviours in a person experiencing dementia are generally a response to unmet needs. [TRUE]						
A19	Medications are the most effective way of treating behavioural symptoms of dementia. [FALSE]						
A20	People experiencing dementia do not generally have problems making decisions. [FALSE]						
A21	Movement is generally affected in the later stages of dementia. [TRUE]						
A22	People with advanced dementia may have difficulty speaking. [TRUE]						
A23	People experiencing dementia often have difficulty learning new skills. [TRUE]						
A24	Difficulty eating and drinking generally occurs in the later stages of dementia. [TRUE]						
A25	Daily care for a person with advanced dementia is effective when it focuses on providing comfort. [TRUE]						

The primary approach to scoring the valid and reliable 25-item version DKAS involves recoding responses and the calculation of a total, subscale and item scores using SPSS (or similar data analysis software).

Verified DKAS subscales

Subscale A: *Causes and Characteristics* (7 items scored out of 14): A1 + A2 + A3 + A4 + A5 + A6 + A7
This subscale describes fundamental information relating to the pathology and terminal course of dementia.

Subscale B: *Communication and Behaviour* (6 items scored out of 12): A14 + A15 + A16 + A17 + A18 + A19
This subscale describes information about how a person with dementia engages with the world.

Subscale C: *Care Considerations* (6 items scored out of 12): A20 + A21 + A22 + A23 + A24 + A25
This subscale describes symptoms that are relevant to the provision of care.

Subscale D: *Risk Factors and Health Promotion* (6 items scored out of 12): A8 + A9 + A10 + A11 + A12 + A13
This subscale describes information about risk factors and conditions that are associated with or mistaken for dementia.

DKAS scoring

Step one: in your database, DKAS response categories should be labelled as follows:

False	1
Probably false	2
Probably true	3
True	4
I don't know	5

Step two: recode results to reflect whether responses are correct (True) or incorrect (False) and apply the scoring system. *Examples of recoding in SPSS syntax:*


```
RECODE [item_A1] (3,4,5=0) (1=2) (2=1)into [final_item_A1].
RECODE [item_A2] (1,2,5=0) (3=1) (4=2)into [final_item_A2].
```

The DKAS scoring system is as follows:
- Score 2 points for an answer of 'true' to a truthful (true) statement.
- Score 2 points for an answer of 'false' to an untrue (false) statement.
- Score 1 point for an answer of 'probably true' to a truthful (true) statement.
- Score 1 point for an answer of 'probably false' to an untrue (false) statement.
- Score 0 points for an answer of 'true' or 'probably true' to an untrue (false) statement.
- Score 0 points for an answer of 'false' or 'probably false' to a truthful (true) statement.
- Score 0 points for an answer of 'I don't know'.

Recoding of DKAS scores can be undertaken using the syntax function in SPSS. Note that the syntax below assumes that the order of items is the same as that presented in the scale.

Step four: sum items to provide a total score. The maximum total score on the DKAS is 50 points.

Step five: depict relative item scores and subscale scores. Subscales can be compared directly by creating a normalized score (that is – turning the score into a fractional score between 0 and 1).

Appendix 3.2 Assessing emotions scale questionnaire

Q#	Participants Name: _____	Response Scale				
		1. Strongly disagree	2. Some-what disagree	3. Neither agree nor disagree	4. Some-what agree	5. Strongly agree
A1	I know when to speak about my personal problems to others					
A2	When I am faced with obstacles, I remember times I faced similar obstacles and overcame them					
A3	I expect that I will do well on most things I try					
A4	Other people find it easy to confide in me					
A5	I find it hard to understand the non-verbal messages of other people					
A6	Some of the major events of my life have led me to re-evaluate what is important and not important					
A7	When my mood changes, I see new possibilities					
A8	Emotions are one of the things that make my life worth living					
A9	I am aware of my emotions as I experience them					
A10	I expect good things to happen					
A11	I like to share my emotions with others					
A12	When I experience a positive emotion, I know how to make it last					
A13	I arrange events others enjoy					
A14	I seek out activities that make me happy					
A15	I am aware of the non-verbal messages I send to others					
A16	I present myself in a way that makes a good impression on others					
A17	When I am in a positive mood, solving problems is easy for me					
A18	By looking at their facial expressions, I recognize the emotions people are experiencing					
A19	I know why my emotions change					
A20	When I am in a positive mood, I am able to come up with new ideas					
A21	I have control over my emotions					
A22	I easily recognize my emotions as I experience them					
A23	I motivate myself by imagining a good outcome to tasks I take on					

Q#		1. Strongly disagree	2. Some-what disagree	3. Neither agree nor disagree	4. Some-what agree	5. Strongly agree
A24	I compliment others when they have done something well					
A25	I am aware of the non-verbal messages other people send					
A26	When another person tells me about an important event in his or her life, I almost feel as though I experienced this event myself					
A27	When I feel a change in emotions, I tend to come up with new ideas					
A28	When I am faced with a challenge, I give up because I believe I will fail					
A29	I know what other people are feeling just by looking at them					
A30	I help other people feel better when they are down					
A31	I use good moods to help myself keep trying in the face of obstacles					
A32	I can tell how people are feeling by listening to the tone of their voice					
A33	It is difficult for me to understand why people feel the way they do					

Appendix 3.3 Training evaluation form

PROGRAMME EVALUATION FORM

Person-Centred Dementia Care

Did the programme content support your knowledge development on this subject?

Yes [   ]   No [   ]

Rate the programme overall (e.g. content & presentation, handouts, reading material).

Very Good   5   4   3   2   1   Poor

Would you recommend this programme to a colleague?

Yes [   ]   No [   ]

Can you suggest any changes that would enhance the programme to meet your learning needs?

1.

_____

2.

_____

3.

_____

4.

_____

Additional Comments:

Thank you for completing this evaluation form.

Appendix 4: Qualitative research methods: focus groups

- Appendix 4.1: Focus group statements and questions used

- Appendix 4.2: Script of the CMT focus group session

- Appendix 4.3: Script of the HCW focus group session

Appendix 4.1: Focus group statements and questions used

Using the Goleman's five identified basic emotional and social competencies to EI, there following topics were explored in the focus groups.

4.6.1 Objective 1: Self-awareness

In the training we looked at why it was important for a home care worker to be self-aware. Examples of being self-aware are:

- Having confidence about what we do
- Understanding that there are limits to the care and support that we provide to others
- And that we can laugh about not being perfect, bringing humour into what we do.

Question 1: Taking all of this into account, if we were not self-aware as home care workers, what impact would this have on a person with dementia?

4.6.2 Objective 2: Self-regulation

In the training we also looked at why it was important for a home care worker to be self-regulated. Examples of being self-regulated are:

- The importance of being trustworthy. Care can be a very tempting place particularly regarding money
- The importance of having integrity, always looking at doing the right thing
- How we offer comfort and staying open to the persons changing environment and all the family dynamics that go with that
- Being able to control our personal feelings and not making judgements of people's living wishes or circumstances.

Question 2: Taking all of this into account, if we were not self-regulated as home care workers, what impact would this have on a person with dementia?

4.6.3 Objective 3: Motivation

In the training we also looked at why it was important for a home care worker to be motivated. Examples of being motivated are:

- Having a passion for the work we do, that goes beyond money or status/titles

- The importance of striving to do the best that we can do, even if we are feeling unsupported by the organisation that we work for
- Staying optimistic (like being positive) even when we are faced with failure.

Question 3: Taking all of this into account, if we were not motivated as home care workers, what impact would this have on a person with dementia?

4.6.4 Objective 4: Empathy

In the training we also looked at why it was important for a home care worker to show empathy. Examples of being empathic are:

- Creating a genuine connection with a person with dementia
- Being able to focus on the person with dementia's emotions while providing care and support
- Understanding that it is the emotions that are important not the facts.

Question 4: Taking all of this into account, if we were not empathic as home care workers, what impact would this have on a person with dementia?

4.6.5 Objective 5: Social Skills

In the training we also looked at why it was important for a home care worker to have social skills. Examples of having social skills are:

- Being good communicators
- Building and managing effective relationships with the person with dementia and their surrounding networks
- Being particularly persuasive and skilled in the area of finding common ground for building relationships
- Asking ourselves "if the behaviour could talk, what would it be saying".

Question 5: Taking all of this into account, if we do not have social skills as home care workers, what impact would this have on a person with dementia?

Appendix 4.2: Script of the CMT focus group session

For the purpose of confidentiality, specific client references were removed from the script. The following details the discussions held in the CMT Focus Group:

4.6.1 Objective 1: Self Awareness

Facilitator: In the training we looked at why it was important for a home care worker to be self-aware. Examples of being self-aware are:

- Having confidence about what we do
- Understanding that there are limits to the care and support that we provide to others
- And that we can laugh about not being perfect, bringing humour into what we do.

Question 1: If we were not self-aware what impact would this have on a person with dementia?

Speaker 1: By not being self-aware you can cause more confusion to that person. Like at the start of the care call you have to go in and show them that you know what you're doing, being confident and that you have the skills and have come up with a plan before going in there.

Speaker 2: The person feeds off your confidence, giving them an understanding that your confident in completing what is needed in the call.

Speaker 3: And also as well yeah, you know, you're looking at him as a human being and not just looking at them as someone with an illness.

Speaker 4: Like, if I wasn't self-aware my mood might determine how that persons day goes and how I deal with my moods will impact on that person. Looking at the moods that you are having and how they impact on the person with dementia. Like if I'm having a bad day and I don't clear the desks before I go in, then my moods will have a negative impact of the person.

Speaker 1: Negativity can be brought in.

Speaker 2: It can be erratic. And if you are erratic this will have an impact on the persons moods. Can cause them to be erratic. Goes back to the confusion. The person would feel very confused.

Speaker 5: It's important to stay within the care plan. Self-awareness creates boundaries, making sure everything is okay for all parties involved.

Speaker 3: Keeping that routine familiar for the person every day, you may even have to be aware that they may need you to introduce yourself to them every day.

Speaker 6: It is important yes, that you are aware of the person having dementia. But the person must come before the dementia, the dementia is just the illness, not the person.

Speaker 4: Self-awareness is all about consistency for the person, you being aware of who you are as a person will bring consistency. Its key to what works.

Speaker 2: You might have to tame down your personality or make it more upbeat, it's important that you're at their level.

Speaker 5: If your aware of who you are its easier to adapt to your audience. You need to adapt to your audience.

Speaker 7: You need to always know exactly what you're trying to bring to the community as well. And to make sure that your emotions are like okay, before going into someone, like clearing the desks.

Speaker 2: And also, about bringing in humour, if they see you wrestling with something they then know it is okay to make mistakes and laugh about them.

Facilitator: What do you think this gives to the person with dementia?

Speaker 2: It gives them reassurance, that everyone messes up, its normal, and that it's okay to mess up. It doesn't have to be all doom and gloom, tears and more tears, laugher can help someone move on from this experience. It's about making it as normal as possible for them, like saying sure I don't even ever know what day it is. This helps the person, cause many things are very distorted for them. It's a positive experience when you can connect with someone through laugher. They are aware of their cognitive abilities going down and your just reassuring them that its ok.

Facilitator: Do you think that the ability to laugh at yourself is a positive thing?

All Speakers: Definitely.

Facilitator: Do you think we could be home care workers if we were not able to laugh at ourselves?

All Speakers: Definitely not, you have to bring humour into care, you would just keep beating yourself up over things, you wouldn't survive without it.

4.6.2 Objective 2: Self-regulation

Facilitator: In the training we also looked at why it was important for a home care worker to be self-regulated. Examples of being self-regulated are:

- The importance of being trustworthy. Care can be a very tempting place particularly regarding money

- The importance of having integrity, always looking at doing the right thing

- How we offer comfort and staying open to the persons changing environment and all the family dynamics that go with that

- Being able to control our personal feelings and not making judgements of people's living wishes or circumstances.

Question 2: Taking all of this into account, if we were not self-regulated as home care workers, what impact would this have on a person with dementia?

Speaker 1: If we can't be trustworthy, we are abusing them.

Speaker 3: We have to build up a trust, this comes with familiarity, if we don't have it they won't let us care for them.

Facilitator: So are you saying that the truth is important in the relationship? I mean, if we can't be trusted, what kind of impact would that have on somebody with dementia?

Speaker 3: The person wouldn't want to get close to you, they would be afraid.

Speaker 6: If we bring our own personal values and opinions into how we care for people, or in general how we are in our families, this may have an influence in the way that would automatically benefit you and not the person.

Facilitator: So what would that do if you were imposing your values on someone with dementia?

Speaker 5: It makes life a lot more difficult to live in a way. It can challenge how you do your job, makes it harder sometimes.

Speaker 6: In a way that they would probably prefer to live. But when they listen to people that's coming in constantly with different beliefs, they can be swayed.

Speaker 1: And that's not fair on them as you could be taking away their independence.

Speaker 4: Takes away their choices and power.

Speaker 5: It creates a situation where the person does not make decisions for themselves and they are then automatically looking for someone else to do it for them. So they're independent slowly goes, because they're looking for somebody else to make decisions. So they start to lose control of themselves, then about what way they actually did want to be.

Facilitator: Do you think that's common practice with home care workers?

Speaker 5: Yeah, because not everyone is self-regulated. Okay. It can be very hard to self-regulate, given scenario's that we come across, families often want differently to the person. And that familiarity can be good in one sense but it can also breath contempt.

Speaker 4: Another side to that is that the person may start showing anger, frustration and all other connected behaviours. And there is always the perception that families always knows what is best for that person and it's not always that way.

Speaker 1: Families can often be jealous of personalities and relationships.

Speaker 3: They often depersonalise the persons feelings.

Speaker 4: If we are in service to the person with dementia, it can only be about them. Their values, norms and wants.

Speaker 5: Not all home care workers are regulated and it is something that needs to be looked at. Because if we are not self-regulated it will create a whole different set of problems for the person that we are supposed to be looking after.

Speaker 2: By not being self-regulated we overlook the individuals wishes.

Speaker 4: It can be very frustrating for the person with dementia to have things being discussed around her and not with her. Also how people walk into their homes and pick up their home care files and start reading their private business.

Speaker 2: You would never reach over and pick someone's phone up and read its messages.

Speaker 4: It's a real violation of the person privacy.

Speaker 3: People want to get involved in the relationship or being part of making decisions for the person. But when they are deciding what is best for the person they sometimes miss the individual and act on what they think is best.

Speaker 2: We need to encourage people to speak openly about their wishes.

Facilitator: If I encourage somebody with dementia to speak openly about their wishes, how do you think that would and make them feel?

Speaker 2: It would make them feel good, relieved, happy.

Speaker 4: It could also make them feel sad but also empowered or liberated.

Speaker 2: Makes people feel like they are intitled to have a say.

4.6.3 Objective 3: Motivation

Facilitator: In the training we also looked at why it was important for a home care worker to be motivated. Examples of being motivated are:

- Having a passion for the work we do, that goes beyond money or status/titles
- The importance of striving to do the best that we can do, even if we are feeling unsupported by the organisation that we work for
- Staying optimistic (like being positive) even when we are faced with failure.

Question 3: Taking all of this into account, if we were not motivated as home care workers, what impact would this have on a person with dementia?

Speaker 2: Personally I think the person would just go into a bigger shell. It's not the type of job that you can do just for the money.

Facilitator: Why can you not do this job if you're not doing it for the money?

Speaker 2: Because you are not going to be meeting the needs of the person. Your just going to go in and do the job, no trust, connection or relationship.

Speaker 3: You have to have a heart to do this job. Anyone who is in this type of work for the money, just should not be in it.

Speaker 1: But you will still come across people who are in this work for the wrong reasons.

All Speakers: There definitely is people like this in care.

Facilitator: Do you think that these people have the skill sets required to stay in care just for the money?

Speaker 1: People can become clinical in the way that they look at situations.

Speaker 5: You can get accustomed to the feelings. You can also grow as a person, in a way that helps you to deal with these feelings. It doesn't have to be in your nature to care for someone, you can grow as a person to learn to care for people.

Speaker 2: Like I agree, I got into this line of work because it suited my lifestyle, drop the kids to school and work around them. I didn't think of being caring, it just worked in my situation.

Speaker 4: Whether someone has dementia or not, if there is a good relationship and engagement, you can support people. But you won't last in care if you can't do this.

Speaker 3: People like that can work in domestics and not get noticed.

Speaker 2: But vulnerable people can be taken advantage of.

Speaker 1: Homecare companies have a lot to answer to, leaving people like this out there and not addressing it.

Facilitator: Do you think that people who only provide home help, don't provide care and support to people?

Speaker 5: No I do think they do.

Speaker 1: You can stay optimistic till you are burnt to the ground but some people just should not be working in care. Some people may need more support, but some are over worked. But some are paid for 40 hours a week but only actually work 20 hours in comparison to someone who is committed to the job and only rostered for 20 hours a week. Whether you do 40 hours of 20 hours a week, you should give your best. But in some company's the persons availability to work 40 hours makes them more valuable just because of their availability and call needing to be covered. It has to be quality over quantity.

Facilitator: Everyone in this room has been a home care worker and worked their way up to management. So from a home care workers perspective, do you feel that it was ever the money or the status that made you do a good job?

All Speakers: No definitely not.

Facilitator: What was it that made you more caring?

All Speakers: The people, the passion, the caring, the personal rewards, the feeling you get from doing everything above and beyond.

Facilitator: What drives you to give above and beyond?

All Speakers: The smile on their face when you arrive and when your leaving, the impact you have on their lives, such a gratifying job to do.

Facilitator: Can everyone in this room say that they have worked way beyond their clock, when they are not getting paid?

All Speakers: Absolutely, no doubt, you have to be positive and make sure that all their needs are met.

Facilitator: What kind of impact would you have on somebody with dementia if you are going in with a negative attitude?

Speaker 6: You would have a very negative impact. People pick up on your vibes. Whether we like it or not we give off vibes and whether or not the person has dementia, they feed off the vibes we give. This can have either a positive or negative impact on how their day is going to go for them. It is all about making that connection with that person. You will never make a connection with a negative attitude. Your attitude can't just be about the job tasks, washing and dressing. It has to be about making a connection with the individual.

Speaker 5: Sometimes it's difficult to make a connection.

Speaker 4: Sometimes it takes longer for a connection to be built but it usually becomes a lasting one.

4.6.4 Objective 4: Empathy

Facilitator: In the training we also looked at why it was important for a home care worker to show empathy. Examples of being empathic are:

- Creating a genuine connection with a person with dementia
- Being able to focus on the person with dementia's emotions while providing care and support
- Understanding that it is the emotions that are important not the facts.

Question 4: Taking all of this into account, if we were not empathic as home care workers, what impact would this have on a person with dementia?

We have previously touched on empathy when we were taking about making connections and there was a mention of connections taking time. Why would this be the case?

Speaker 5: Sometime people with dementia fall into care and don't always know what it is. It takes time to trust the system. It can take time to get past that and develop the trust and to realise, that you know what you're doing, that you support their independence, because that it can be a big milestone for them.

Facilitator: Do you think that it is important that you support someone's independence?

All Speakers: Yes, massively. They don't like you going in babying them, they prefer to be supported. You can frustrate them if you don't work with them.

Speaker 3: It's about treating them with dignity and if you don't have empathy you're in the wrong job.

Speaker 6: It's important to let people hold onto what they have, even if what they have is so small, it will still be important to them. You nearly have to reverse what we normally would do and step back and observe what they can do before we understand what is needed from us.

Facilitator: Do you think that this observation is a skill that home care workers naturally have?

Speaker 6: No, most want to go in and mind the person, sometimes even take over. But it is important to allow the person to maintain their independence as much as possible.

Facilitator: Do you think there is a difference regarding the importance of promoting independence if the person has dementia?

Speaker 6: No, a person should be allowed to maintain their independence whether they have dementia or not. But it is more difficult for somebody with dementia to hold on to independence. Sometimes people see the dementia first and not the person which is part of the problem.

Facilitator: Do you think that's common, that the dementia is seen before the person?

All Speakers: Yes, definitely it is very common in dementia.

Speaker 2: A lot of people come with a sympathetic attitude and not an empathetic attitude which is kind of what we were thought in the past.

Speaker 4: Why should it be different for someone with dementia, when I am upset people show me empathy.

Speaker 2: But we were never thought this before we did the dementia training and we never knew why things weren't working.

Speaker 1: That's why it's very important that everyone gets to do the new training. Like before we used to get caught up with the frustrations of them being so repetitive. But now we now to look at the emotions and show empathy there.

Facilitator: What helps you to understand the person with dementia?

Speaker 1: It is the relationship and knowing the person.

Speaker 6: People need to move away from minding the individual to supporting them.

Speaker 2: It is about adapting and finding a way that suits them.

Speaker 3: Families can be problematic here.

Facilitator: Do you think you can be empathetic without the families?

Speaker 3: It's a bit of both, yes and no. You still have to listen to the family and still be empathetic to them too.

Speaker 6: This is where self-regulation comes into play, you can listen to the family but the individual with dementia still needs to come first.

Speaker 2: Sometimes I find the family more difficult in these situations.

Facilitator: Why is that?

Speaker 2: Sometimes they just don't understand that their parents are changing and can't do what they used to.

Speaker 1: Families have never been trained in dementia so therefore don't have an understanding of it.

Facilitator: Do you think that if we engaged with the family members and brought them through the training, that we would have a more cohesive working relationship?

All Speakers: Absolutely 100%, its totally needed. Everyone would benefit from that, including the person with dementia.

Facilitator: If we were to be very honest with ourselves, would we think that we were more sympathetic or empathetic before we had the new dementia training?

All Speakers: We would have definitely been sympathetic, but that's what we had been previously trained to be.

Speaker 6: We never understood that there was anything wrong with what we were doing.

Speaker 4: The training has made us more conscious of our interactions.

4.6.5 Objective 5: Social Skills

Facilitator: In the training we also looked at why it was important for a home care worker to have social skills. Examples of having social skills are:

- Being good communicators
- Building and managing effective relationships with the person with dementia and their surrounding networks
- Being particularly persuasive and skilled in the area of finding common ground for building relationships
- Asking ourselves "if the behaviour could talk, what would it be saying".

Question 5: Taking all of this into account, if we do not have social skills as home care workers, what impact would this have on a person with dementia?

Speaker 5: Communication is vital in any relationship, if you're not engaging, then that person can become more reclusive. If your self-regulation is in place where it's supposed to be you are going to be more positive, the clients will then feel more at ease, as well. And that also develops your relationships. And it gives a level of trust with their family, with the person with dementia and their surrounding networks. It's a real learning process for us all.

Speaker 6: We need to listen and observe more. When people with dementia are saying the same thing over and over we need to listen because they are trying to tell us something. Its' important to explore that further with them, staying with what they are trying to communicate instead of moving on or distracting them to something else.

Even if you cannot get the whole picture, overtime you may be able to help the person build a picture of what it is that they are trying to communicate with you.

Facilitator: Before you did the training would that have been the approach you took?

Speaker 6: No. I would have thought that they were just rambling and that there was no substance to what was been said.

All Speakers: Very different approach, would have being trying to make it better for them in the past, telling them not to be upset, distracting them, minding them, sympathising with them instead of empathising.

Speaker 6: We were trying to stop that emotion because we were uncomfortable with it. Now we understand the importance of acknowledging the person being upset and how important that is to them. That might be all they need to move on. Even knowing that somebody actually listens.

Speaker 3: Sometimes when your like that, your emotional, feeling sad and wanting to cry with the person.

All Speakers: We are now feeling what they are feeling, understanding it's importance.

Speaker 3: It's very important that they have a safe environment to verbalised what they are feeling.

Facilitator: Do you think there's a connection between having social skills and being empathetic?

Speaker 3: Yes, they impact on each other, almost roll into one another.

All Speakers: Yes, they come hand in hand.

Facilitator: Do people think that as a home care worker that you have to have social skills?

Speaker 5: We are supposed to be person centred, without social skills that isn't possible. How else could be grow?

Speaker 4: But if we're more empathetic towards people, then we are generally very considerate about how we communicate. This can be good news, bad news, difficult news, either way it's more considerate of the person.

Speaker 1: I can recall situations where I have been empathetic without even knowing I was being that way. I always thought I had good social skills. Even when I had dementia training it was never as indebt as this dementia training, so I wouldn't have known the difference. But I still found family dynamics very difficult particularly getting them on board.

Facilitator: That is kind of clicking onto persuasion and if a home care worker has the skills to persuade other relationships within their networks?

Speaker 2: Yes we can, but we would get a better by-in from families and their networks if they did the training and understood dementia more.

Speaker 5: When the family member gets the see and understand the skill set that we bring in, you know, they could benefit massively from it. It would help to defuse family conflict when more understanding is had.

Speaker 2: We still have to remember that some families might refuse training because they are in denial of what is actually going on for their parent.

Facilitator: Do you think that you have a persuasive nature as a home care worker?

All Speakers: Yes, definitely, we have to be persuasive all the time in what we do.

Speaker 3: Sometimes we even have to get buy-ins for what the person likes to eat. Like a family might leave out dinners but the person just wants a sandwich. Sometimes we spend time getting the family to buy-into the fact that their parent doesn't like the meals being left; and that can be difficult.

Facilitator: This is reminding me of the training, that the intention from someone is rarely coming from a bad place e.g. the family only want to give their parent a nutritious meal, they are not trying to take away their parents' choice. But that this requires real social skills to address this type of situation in a way that maintains the relationship into the future.

Speaker 3: Absolutely, it is so difficult to do, but I think we all do it well.

Speaker 5: Sometimes families are living in fear of what would go wrong if they didn't do X, Y & Z.

Speaker 6: Yes, but they are living in their fear, it's not the person with dementia's fear, and it's important to understand that.

Speaker 4: It does take a huge amount social skills to work with a family that is so distressed. Particularly when that family are probably living in fear, anxiety, and their parent means everything to them.

Speaker 6: But is important to remember that less than 10% of families come with the intention to do bad.

Speaker 5: And that most of these people within the 10% are usually dissatisfied that they've been totally unsupported by the system. And they've just become so stressed and so fed up with situation that they actually don't know how to let anyone reach out to them.

Speaker 2: There has been occasions were family members have said that the person that we are caring for was very different to them growing up, that the person was a horrible human being and that this had brought resent towards the person and how they cared for them.

All Speakers: It can be very difficult, particularly when people put their names down as next of kin's, they may not have the strength to pull away from their parent. And there is not enough information at the diagnosis stage of what is expected from family members, let alone dementia as a whole. But it is important that we have the social skills to know how and when to back off and not to get involved.

Facilitator: Has anyone else got anything that they would like to add before we bring this to a close?

All Speakers: No, happy with what has been said.

Facilitator: Thank you for your participation and contributions in today's focus group.

Appendix 4.3: Script of the HCW focus group session

For the purpose of confidentiality, specific client references were removed from the script. The following details the discussions held in the HCW Focus Group:

4.6.1 Objective 1: Self Awareness

Facilitator: In the training we looked at why it was important for a home care worker to be self-aware. Examples of being self-aware are:

- Having confidence about what we do
- Understanding that there are limits to the care and support that we provide to others
- And that we can laugh about not being perfect, bringing humour into what we do.

Question 1: If we were not self-aware what impact would this have on a person with dementia?

Speaker 1: They would be confused and frustrated if you don't have the confidence to deal with everything.

Speaker 2: You have to be confident, they wouldn't feel comfortable with you if you were not.

Speaker 3: If you're not confident they pick up on it.

Facilitator: Is this something you all would agree with?

All Speakers: Yes, absolutely you couldn't work in homecare if you had not got confidence, they expect us to know what and how to do things, it's how we build trust.

Facilitator: What about humour, do you all think that's important?

All Speakers: Absolutely, you couldn't work in homecare without humour, it breaks down barriers, makes people feel comfortable in uncomfortable situations e.g. personal care, washing, toileting.

Speaker 4: Humour makes it easier when you are dealing with the human side of providing care to someone. Sometimes you have to have very difficult conversations, a bit of laughter can lighten that.

Speaker 3: A bit of humour can take the tension out of what's going on for that person.

Speaker 7: It's a different type of industry to others, laughing is something that just makes the job easier and the person happier.

Speaker 5: It can set the mood for that person for the day, they can become more relaxed.

Speaker 1: Them being relaxed makes you more relaxed, which makes it easier to get the job done. In some cases you need a lot of confidence to bring out laughter, particularly in difficult cases. Sometimes dementia cases are beyond anything you have worked with before. Like one lady screams a lot. It takes a lot of work on yourself to work through that and almost ignore it to actually meet the needs of the person. The screaming is something that is just a behaviour but you can change the mood of that person with laughter.

Speaker 5: I have a woman that if you laugh when she is screaming she starts to laugh with you, she then feels happy, but it is hard to do. You have to be very confident about yourself, particularly when the family is around.

Speaker 4: I have a lady who loves singing and if you sing it can change her mood completely. She can walk up and down stairs when she is signing but not if she is not. Singing takes her mind off the task. At first people in the community would think it was a bit weird seeing us singing going down the road, but I think they get it now.

Speaker 5: Singing can create a connection with the person. Sometimes my lady just lies on my shoulder when I am singing. She could lie there for hours, all she wants is a cuddle.

Speaker 7: It is really down to you and how you are with them. Even how you greet them can have a huge impact of how the call is going to go. It's important to greet them in a kind way "good morning, how are you". And then listen to hear their mood. Like I have a lady who likes me to sit on the side of the bed with her and chat before she gets up. But I am not allowed to enter her room until she puts her teeth in. This is about her own dignity and me respecting that.

4.6.2 Objective 2: Self-regulation

Facilitator: In the training we also looked at why it was important for a home care worker to be self-regulated. Examples of being self-regulated are:

- The importance of being trustworthy. Care can be a very tempting place particularly regarding money

- The importance of having integrity, always looking at doing the right thing
- How we offer comfort and staying open to the persons changing environment and all the family dynamics that go with that
- Being able to control our personal feelings and not making judgements of people's living wishes or circumstances.

Question 2: Taking all of this into account, if we were not self-regulated as home care workers, what impact would this have on a person with dementia?

Speaker 7: It is all about being happy, even when you're not feeling happy. It's important that you do not bring anything personal into the call. You are only there for an hour so it is important that you make them feel good for the hour. You are probably the only person that they are going to see for that day.

Speaker 4: It's amazing how we can do that, I think it's a challenge sometimes.

Speaker 6: Going in somewhere else can help you get away from what's going on for you. It can be a break for you too. In some ways it helps you block what is going on for you too.

Speaker 5: It takes a certain type of person to work in care, certain clients can really get in on you. Like last week I was at a call and the woman just kept repeating herself over and over. I was using all the new training but she was stuck in an anxious emotion and I just could not get her out of it. She was afraid her daughter wasn't going to come back.

Speaker 7: We are only human, we still get upset and frustrated, but it's about being aware of that.

Speaker 1: Sometimes you have to dig deep to find yourself and stay professional. You have to have a certain personality to work in care, not everyone could do it. Everybody needs a break from that kind of environment, especially family carers, like we are only going in and out. They are living it. If we are finding it challenging can you image what it's like for them fulltime.

Speaker 3: When you just keep going and you're not aware of the impact that these environments are having on you, you will just burn out.

Speaker 4: It's hard to switch off, sometimes we can keep it under control at work but we can bring it home and everyone gets a lash of it.

Speaker 1: For me I don't because I often feel appreciated in work and not so much at home.

Speaker 3: Sometimes you have to really regulate yourself and stop yourself from saying things, particularly with family members. You have to choose what you say a lot. But you have to keep focussed on the person that you are there to care for not the others.

Speaker 2: If you don't click with the family it won't work with the person. The family are too involved to be ignored.

Speaker 6: Families often just want to be part of what's going on, know what's happening and to get help off you for how to deal with things.

Speaker 4: Sometimes you can become part of the family. Like if you get on well they well welcome you with open arms, making you a cup of tea when you come in. They can be so grateful for what you do.

Speaker 2: But there has to be a balance, you still have to put the person with dementia first. That sometimes means that a chat will have to be had with a family member, but it's how you have that chat that is important.

Speaker 6: Having a good relationship makes an easier environment to go in to.

Speaker 4: Working in care can be lovely. We make great connection and we form relationships quickly because of the nature of what we do. Like some of the discussion we have with people would never be accepted in any other industry. Like we are constantly laughing and joking about bowel movements and there are people in the other room, god knows what they are thinking.

Facilitator: Do you think it is easy to get someone to have personal care (pad changes, showers etc.) when they have dementia?

All Speakers: It can be very frustrating, difficult, takes great patience and social skills. Sometimes we have to use all the tricks of the trade.

Speaker 7: Even treachery. I know in the training we were thought that this was not right but that's not what we were told in the past.

Speaker 3: We were previously thought to do whatever it took.

Speaker 3: It's hard to be honest some of the time. Sometimes especially around the time we have for the call.

Speaker 6: The timescales can be very tight, sometimes you're watching the clock knowing that you still have a list of things to do.

Facilitator: What about peoples finances, do they pose a problem for people with dementia?

Speaker 4: Yes definitely, they are forever trying to give you money. Yesterday I got offered a fiver, but you don't want to insult them, you just have to find a way that they will understand that you can't take it.

Speaker 4: Sometimes they just want to show that they are grateful for everything you do.

Speaker 1: Like I am going on a week's holidays and I got flowers off one client and a box of chocolates off another. But I just log it with the office just in case.

4.6.3 Objective 3: Motivation

Facilitator: In the training we also looked at why it was important for a home care worker to be motivated. Examples of being motivated are:

- ☐ Having a passion for the work we do, that goes beyond money or status/titles
- ☐ The importance of striving to do the best that we can do, even if we are feeling unsupported by the organisation that we work for
- ☐ Staying optimistic (like being positive) even when we are faced with failure.

Question 3: Taking all of this into account, if we were not motivated as home care workers, what impact would this have on a person with dementia?

Speaker 3: You have to be motivated in order to motivate them.

Speaker 1: If you're not motivated you won't do the job right. If you don't wash someone properly, they will end up with sores. It just doesn't work that way, it would have a ripple effect. But it is hard to go into some houses sometimes, you have to sometimes take a deep breath and centre yourself.

Speaker 2: But it can be very rewarding, like seeing the slightest little changes in them can make you want to do more for them.

Speaker 7: When you see them with a smile that just means everything. You bond with them, they are very vulnerable and you get to know them inside out, it's just so rewarding to be in homecare.

Speaker 6: Like some of my clients say that we are just amazing and struggle to get the words out to show appreciation. That makes you feel so good. They go on about how we have our own kids, families and responsibilities and still come in to look after them 100%. They just appreciate you immensely.

Speaker 4: They are constantly saying what would I do without you. It just makes you feel great as a person.

Speaker 1: When you have clients that appreciate you so much it just makes you want to do so much more for them. Like I am going on holidays for a week and I spent the last week making sure everything was in (meds, gloves, shopping etc.) cause I wouldn't want them worrying about a thing when I'm gone. And they do be so anxious about who's covering and when you come back the usually enjoy the time they had with the person covering you.

Speaker 6: You do kind of take it home for a bit. It can take you a while to switch off. But it is great getting paid well. Like other companies don't pay what we get paid or get what we get. But it's not about the money.

Speaker 1: People often say it's a vocation. But there is a difference between the privates and the non-profits, we get paid more and even sick pay.

Speaker 4: Like these are our most vulnerable people, companies should be investing in their staff.

Speaker 1: Like we have more supports here and we get loads of different things like the chocolates for "just because" and the vouchers at Christmas. Like that means so much to us. It makes you feel so appreciated. Even the mentors, like new people working having people like them that they can turn to.

Speaker 4: I don't think you get all that in other companies.

Speaker 3: The mentors are great because they know exactly what has to be done and you can immediately relate to them. You will also be able to ask questions and not feel stupid. Its brilliant.

4.6.4 Objective 4: Empathy

Facilitator: In the training we also looked at why it was important for a home care worker to show empathy. Examples of being empathic are:

- Creating a genuine connection with a person with dementia
- Being able to focus on the person with dementia's emotions while providing care and support
- Understanding that it is the emotions that are important not the facts.

Question 4: Taking all of this into account, if we were not empathic as home care workers, what impact would this have on a person with dementia?

We have previously touched on empathy when we were taking about making connections and there was a mention of connections taking time. Why would this be the case?

Speaker 1: I have a client at the moment and I have been working with the family a lot because they are struggling with being honest with telling their mother that her husband is dead. The daughter in particular thinks it's best to be honest. But every day the client is experiencing the husband's death over again, not after remembering that he is dead when she wakes up. After a heart breaking couple of weeks the family agreed to not say he was dead and to instead explore their relationship e.g. how old were you when you got married etc. This has help immensely.

Speaker 2: It seems heartless to tell a person that over and over. But it's important not to lie, cause you need the connection.

Speaker 1: I am 20 years at this game, you just learn how to console people. Sometimes they are just miserable and it's your job to make them feel better.

Speaker 5: Sometimes it's good enough to just be there for them, being present and not saying anything, knowing what they want based on their ways even if they are childlike.

Facilitator: Do you mean their regression age?

Speaker 5: Yes, like this woman that I'm thinning of is very childlike and loves cuddles and tickles.

Speaker 4: I know the woman your talking about, she would be lost in a nursing home, she is very lucky, her family is so supportive of her.

Facilitator: Do you think you can be a home care worker and not have empathy for someone?

All Speakers: No, definitely not, it just wouldn't be fair on the clients. Their feelings are too important to ignore. As the training goes it's about the emotions not the facts.

4.6.5 Objective 5: Social Skills

Facilitator: In the training we also looked at why it was important for a home care worker to have social skills. Examples of having social skills are:

- Being good communicators
- Building and managing effective relationships with the person with dementia and their surrounding networks

- Being particularly persuasive and skilled in the area of finding common ground for building relationships
- Asking ourselves "if the behaviour could talk, what would it be saying".

Question 5: Taking all of this into account, if we do not have social skills as home care workers, what impact would this have on a person with dementia?

Speaker 3: Social skills are very important. Nearly everything that we do is around being persuasive with someone, especially when they have dementia. If you don't have the skills that will work for you and them, then you will be there half the day going around and around. They give every excuse especially around personal care, no I don't want to get a shower, my daughter will do that. For some reason people with dementia tend to be afraid of water.

Speaker 4: Like with the lady that loves to sing we have to sing with her to distract her to get her teeth in and out. If we didn't know this she would have mouth infections etc.

Speaker 3: Sometimes it's about building the relationship and making it fun and putting the person at ease. But you have to be able to read the person to do this and get them on board. You never forget that they are afraid though, you have to take it at their pace. Singing was very good when someone is afraid. It acts as a distraction. You have to have the social skills to build up a trusting relationship.

All Speakers: Very different approach to what we do with others, you have to have a good personality, it's important to show respect, getting down to their eye level when we are talking to them, like the lady I was talking about earlier about letting her put in her teeth before I come into the room. You have to have the banter, they love a good laugh.

Speaker 7: Also touch is extremely important, we are always reaching out and being emotional. But you read the person.

Speaker 1: We are more tactile than other professional's in our industry. They are often trained to be more distant.

Speaker 3: The very nature of what we do makes us more engaging with people, giving hugs and just letting them rest on our shoulders.

Speaker 6: Sometimes you can tell when you arrive how someone is feeling.

Speaker 1: It's important to go with that, letting them decide how they are feeling and that its okay. We can just listen, its hard to hear them upset but we can help them by listening.

Speaker 6: You have to get emotional with the person it's important to them. Sometimes it's good to have a good cry.

Speaker 7: If I see anyone upset I get upset too. They like that.

Facilitator: As home care workers how do you manage effective relationships?

Speaker 1: You can't have a relationship in care if you don't have social skills. It just doesn't happen for you.

Speaker 2: You have to have the confidence to do the job. If you are confident you can manage relationships.

Facilitator: What about the family members and their general dynamics, do you need social skills here?

All Speakers: Yes, it's very important. The family are an important part of providing care, you need to get them on board.

Speaker 3: I have a family member of a client that is well known for being difficult with us but you have to still put the person first. You can address how he is being but you have to address it in a way that allows you to work in a way that is best for his mother. You can't fall out with anyone. You don't ignore the woman's son but you don't give him the full attention he is looking for either. There's a fine line. I still provide care in the same way when he is there and when he is not. It is important to keep the consistency.

Speaker 2: It can be very hard to do it, sometimes you might have to ask them to leave the room, because you're not getting your job done properly. But you have to be very mindful of how you deliver that message e.g. I'm here to support you too but I need you to stand back for a minute.

All Speakers: Yes, it's very important. Social skills are everything in working with families. But you cannot let the family dynamics take over what's important for the person you are caring for.

Appendix 5: Qualitative research methods: pilot study

Appendix 5.1: Bios of participants

Age

87 years of age

Diagnoses

Dementia

Time of Diagnose

4 years plus

Living Situation

Alone

Accommodation Type

Semi-detached house

Location

Dublin 3

Supports

- Small network of family
- Home Care Package

Average Daily Descriptive of General Behaviours

- Dislikes:

Difficulties with completing tasks, the tasks can vary!

Can make situations very personal even when not related to the person in question

Meals being prepared by someone else

New people

Constant reoccurrence of moving objects and saying they are missing or have been stolen e.g. keys, handbag. Objects/items often later located in the garden

- Likes: But mainly requires prompting and supervising of most activates

To do her own personal care

Will make her bed and complete general domestics to her standard

Can prepare some meals and will consume meals

To show gratitude

To go out for dinner to the local pub or the hair dressers

Gardening

- Dangers:

Can be vulnerable, will open the front door to strangers

Can get confused, forgetful and with same comes aggression

Is prone to get lost

Installation of camera is used to decide on who to let in

Biggest Challenges

- Vulnerabilities associated with living alone
- No consistency in care and support delivery

Bio 2: HCW Mary (pseudonym)

Age

32 years of age

Sex

Female

Length of Service as HCW

8 years

Training

QQI Level 5 Major Award

Time Assigned to Susie

2   years

General Brief

- Mary enjoys being a HCW
- Provides support to variety of Service User' Older Persons, Disabilities, Family Support
- 2 years qualified as a HCW
- Previously worked as a Home Help
- Allocated a weekly schedule of 16 hours
- Works Monday to Friday and every second weekend

Bio 3: HCW Anne (pseudonym)

Age

53 years of age

Sex

Female

Length of Service as HCW

25 years

Training

QQI Level 5 Major Award

Time Assigned to Susie

4   years

General Brief

- Anne reports that she enjoys being a HCW
- Provides support to variety of Service User's Older Persons, Disabilities, Family Support
- 5 years qualified as a HCW
- Previously worked as a Home Help
- Allocated a weekly schedule of 28 hours
- Works Monday to Friday and every second weekend

Appendix 5.2: Consent form

The following is a consent form for a pilot research project carried out by Debbie Rooney who is a current student at NCI.

Consent for Participation

I volunteer to participate in this pilot research project conducted by Debbie Rooney, student at NCI. I understand that the project is designed to gather information regarding a change management project relating to Dementia care and training. I will be one of three people who Debbie Rooney has asked to participate. I understand that:

- My participation in this project is voluntary. I may withdraw and discontinue participation at any time

- If I feel uncomfortable in any way during the project that I have the right to decline participate or answer any questions

- My participation will involve being part of an observational study and the general gathering of related information

- I will not be identified by name in any manner including report

- I have read and understand the explanation provided to me. I have had all my questions answered to my satisfaction; and I voluntarily agree to participate in this project

- I have been given a copy of this consent form.

_____

Date

_____

Signature of participant

_____

Debbie Rooney, Signature of person completing the pilot research project

Appendix 5.3: Details of the approached used and the findings of the pilot group

With qualitative research in mind I:

• Completed a before and afterwards comparison of the similarities of behaviours and interactions between Susie and her two current main home care workers

• Completed a before and afterwards evaluation of the knowledge skillsets of Susie's two current main home care workers regarding the provision of care and support

• Engaged in an overall evaluation process

• Listened to and ensured that the voice of Susie was being heard.

Appendix 5.4: Before and afterwards evaluation of comparison of similarities

The observation sheets used looked at 5 main areas:

1. Interactions

2. Communication

3. Behaviours

4. Skills Demonstration

5. General Observation

Comparisons prior to receiving training and support

1. Interactions from both HCW's were poor and far from a person centred

2. Communications between both HCW's and Susie was minimal

3. Behaviours were dismissive of Susie's needs

4. Skills demonstrated did not reflect person centeredness, both HCW's were distant, judgemental and lacked personal touch

5. General observations were that both HCW's required training and further support in the area of person-centred care and that the lack of same was agitating Susie further.

Comparisons after receiving training and support

1. Interactions between both HCW's and Susie showed remarkable improvements

2. Communications were if higher quality and person centred in approach, giving Susie choices etc.

3.   Behaviours in general were more suitable for HCW's supporting someone with Dementia, touch and eye contact was observed

4.   Skills demonstration was far stronger, both HCW's were using their new skills while engaging with Susie

5.   General observations were that both HCW's appeared more confident in their approached to providing support to Susie and Susie appeared less agitated and content.

Appendix 5.5: Observation 1, HCW Mary

HCW: Mary   Interaction: 1 Service User: Susie

Observer: Debbie Rooney (Student)   Date and Time 27.11.2018 @9:00

Brief summary of observational call:

Susie is in receipt of a home care package funded by the HSE. She receives 3 calls a day, this observation was completed during the 1st call (morning time). Morning activities are generally to assist Susie with getting up, washing, dressing, preparing breakfast and supervising medication.

Review Section   Description/Comments

1.   Interactions   On arrival Susie was already up and appeared to have been out the back garden prior to our arrival. HCW Mary greeted Service User Susie with a hello. Mary did not introduce herself immediately and it was obvious that Susie was unsure as to who Mary was. It was clear that she knew her but not in what capacity. This change once Mary began to engage in the daily routine.

Mary did introduce me and explained to Susie that she had told her about me coming. I was unclear as to whether or not Susie totally understood what Mary had said so I again added to the conversation.

Throughout the call Mary interacted positively with Susie but Susie did not appear to want to engage back. At one stage Susie did say that she liked to be alone in her home and Mary did not acknowledge the comment.

2.   Communication   Throughout the duration of the call Mary communicated to Susie in a polite and warm manner. However the communication was not always consistent with the behaviours. For example when Susie was eating her breakfast and put the spoon down, Mary leaned over and said "finished" and took the bowl away without the breakfast been completed and without asking Susie if she was finished or waiting for Susie's response.

3.   Behaviours   Mary did not appear to be eager to engage, she almost looked uncomfortable when supporting Susie. She did not engage in any eye contact or make any effort to sit with Susie during any task e.g. personal care, eating etc.

Susie did not appear in her behaviours to be in any way angry but you could see that she was agitated. At one stage she left the house and again went back to the garden, appearing to want to isolate herself.

4.   Skills demonstration

Mary could be dismissive of Susie's need for person centeredness; she was keen to do things for Susie rather than supporting Susie to complete the tasks herself. An example of this was when Susie was dressing and instead of letting Susie dress herself, Mary appeared to be rushing the process by dressing Mary were she could. Another time was when Susie had lost her handbag. Mary did not demonstrate an understanding approach towards Susie instead she kept insisting that Susie done this all the time, despite Susie appearing frustrated with Susie's comments.

5.   General observation

While Mary's intentions appeared to be in the best place while supporting Susie she did not look to Susie to hear her voice. Instead Mary quickly rushed through the required morning activities, ensuring that all were completed. We were only present for an hour. It was clear that the further we neared the hour the more agitated Susie was becoming. Susie was not asked what she liked for breakfast, but Mary did demonstrate an understanding that due to prior experience of working with Susie, that she knew what her likes and dislikes were.

Appendix 5.6: Observation 1, HCW Anne

HCW: Anne   Interaction: 1 Service User: Susie

Observer: Debbie Rooney (Student)   Date and Time 28.11.2018 @ 09:00

Brief summary of observational call:

Susie is in receipt of a home care package funded by the HSE. She receives 3 calls a day, this observation was completed during the 1st call (morning time). Morning activities are generally to assist Susie with getting up, washing, dressing, preparing breakfast and supervising medication.

Review Section   Description/Comments

1.   Interactions From the minute I meet Anne she appears nervous and full of anxiety. On the way in the door of Susie's home Anne mentioned that you never know how this woman was going to be. Susie was in bed on arrival, Anne knocked three times on the door and when Susie didn't come to the door Anne let us in using the key-safe. Anne shouted up the stairs letting Susie know that we had arrived. Susie did not get out of bed, instead refusing to do so. Anne insisted that Susie had to get up, telling her that her daughter would be very annoyed and that if she didn't she wouldn't be able to go to the hairdressers. Susie was shouting back at Anne, appearing very agitated and telling Anne to get out of her house. Anne said to me that this was typical behaviour and that she was just going to leave her breakfast (porridge) on the table for her and go as her mood would be like this for the morning.

2.   Communication   Anne was very direct in her communication style towards Susie. It appeared that Anne was sure of what way Susie was going to be before we even entered Susie's home and therefore made little effort to change how each communicated to each other.

3.   Behaviours Anne's behaviours were far from person centred. There was minimal positive interactions between Anne and Susie. Susie appeared to be in a hurry to exit the call and gave across a message that Susie was just how she was and that there was nothing that could work with her when she was like this. It appeared like a mother and daughter relationship rather than a professional supporting someone with Dementia.

4.   Skills demonstration

Anne did not demonstrate any skills suitable to supporting someone with Dementia. I asked Anne if maybe Susie did not know who was in her house and that maybe this could be agitating her. Anne dismissed what I had said and instead insisted that she knew Susie well and she was just in bad form. When Anne prepared Susie's breakfast (not asking what Susie wanted) Anne shouted upstairs to Susie that we were off and that her breakfast was on the table. Anne did enter Susie's bedroom but only for Susie to shout at her to get out.

5.   General observation

While Anne believed that the best approach with Susie for this call was to leave her alone, I certainly did not agree. Anne could have approached the whole call very differently. While I understood the importance of alerting Susie of our presence in her home, how Anne did so could have been different which may of bought about a different outcome.

Appendix 5.7: Observation 2, HCW Mary

HCW: Mary   Interaction: 2 Service User: Susie

Observer: Debbie Rooney (Student)   Date and Time 07.12.2018 @ 09:00

Brief summary of observational call:

Susie is in receipt of a home care package funded by the HSE. She receives 3 calls a day, this observation was completed during the 1st call (morning time). Morning activities are generally to assist Susie with getting up, washing, dressing, preparing breakfast and supervising medication.

Review Section   Description/Comments

1.   Interactions   On arrival Mary greeted Susie by introducing who she was and what she was here for e.g. HCW from ████████. She then introduced me as the girl from the office that was here last week. I reminded Susie of the conversation I had with her daughter and while she didn't appear to recall it she seemed satisfied that I knew her daughter.

Throughout the call Mary interacted positively with Susie, encouraging Susie to participate in all activities.

2.   Communication   Throughout the duration of the call Mary communicated to Susie in a polite and warm manner, but this time it was different. Mary asked Susie what she wanted for breakfast and encouraged her to participate. Mary also made all three of us a cup of tea and we all sat together while Susie was eating her breakfast. Sometimes Susie can refuse to complete her personal care (shower) while someone was in the house but this time she agreed. Mary asked Susie what clothes she wanted to wear holding up green and pink jumper, giving Susie a choice. I was surprised at how much communication Mary was having with Susie and despite Susie not always responding to Mary, Mary continued to involved Susie in each process.

3.   Behaviours Mary was very consistent in her engagement with Susie, appearing very confident in how she approached her. Mary appeared happy and when Susie gave Mary a dirty look Mary inquired after Susie asking what was wrong. Susie did not respond but appeared to welcome the acknowledgement. There was a lot of eye contact in this call; I also observed Mary's gentle touch to Susie's arm when trying

to get her attention. While Susie did show signs of agitation it was minimal in comparison to the last observation.

4.   Skills demonstration

Mary was in no way dismissive of Susie's for person centeredness; appearing confident in her engagements with Susie. She appeared to be taking the person centred approach very seriously, encouraging Susie to participate in all activities. An example of this was as suggested above with the picking out of clothing and showering.

5.   General observation

Overall this was a far better engagement between Mary and Susie. At no stage did Susie suggest that she wanted to be alone which was very unusual, which the HCW's often report as making them feel awkward. While there was nothing too striking about the call, all appeared to go well but I could not help but wonder would this new person centred approach continue. It was at this stage that I realized that a Person Centred Care and Support Plan would be ideal here. I discussed this with Mary and she agreed to same.

Appendix 5.8: Observation 2, HCW Anne

HCW: Anne   Interaction: 2 Service User: Susie

Observer: Debbie Rooney (Student)   Date and Time 10.12.2018 @ 09:00

Brief summary of observational call:

Susie is in receipt of a home care package funded by the HSE. She receives 3 calls a day, this observation was completed during the 1st call (morning time). Morning activities are generally to assist Susie with getting up, washing, dressing, preparing breakfast and supervising medication.

Review Section   Description/Comments

1.   Interactions   On arrival to Susie's we were meet by Susie. She was pleasant and appeared to recognize Anne. When I mentioned this to Anne she advised that Susie doesn't necessarily recognize the person but will recognize the uniform. Anne engaged with Susie asking her what she wanted for breakfast, giving her the option of eggs/toast or porridge. Susie advised that she wanted eggs/toast and Anne asked Susie if she wanted to prepare the breakfast herself. Susie did not respond but immediately began to assist Anne in preparing her breakfast. During breakfast Anne sat with Susie but Susie did not engage in conversation despite Anne's encouragement to do so. Immediately after breakfast Susie left the table and went out to the garden.

2.   Communication   Anne's communication methods were very strong. She appeared to understand when to communicate with Susie; and when Susie was not in the humour of communicating with Anne. At one stage Susie said she wanted to be alone and Anne advised that this was fine but encouraged Anne to dress first. Susie would not have a shower but looked well presented. Anne advised Susie that it was cold and that she needed to wear a jumper giving Susie the option of a blue or pink jumper. Susie chose the pink jumper and sat back down at the table.

3.   Behaviours   Anne now appears to understand the concept of person centred care. She is continuously giving Susie options and listening to Susie despite her not always making sense of what she is saying. In this call Anne appeared a lot calmer and aware of Susie's needs.

4.   Skills demonstration

Anne's skills demonstrated were very strong. She engages well with Susie and sang as she was moving about. While Susie did not at any stage say that she was enjoying the singing, when I commended on how good of a singer Anne was Susie gave me eye contact. The singing and general calmness appeared to keep Anne calm too.

5.   General observation

While Susie did appear disorientated at times she never appeared agitated or aggressive. The call was a lot more person centred with a huge focus on meeting the individual needs of Susie. Even when Susie went out the back garden Anne followed Susie bringing her garden gloves suggesting to Susie that she might need these, helping her put them on. Anne had mentioned how cold it was to me and how she probably should have discouraged Susie going out the back garden, but then suggested that this was what Susie wanted and that she was warm and safe doing so. This call was no doubt far more person centred than the previous call.

Appendix 6: Submission of Thesis/ Dissertation to Norma Smurfit Library

Submission of Thesis to Norma Smurfit Library, National College of Ireland

Student name: Deborah Rooney   Student number: X16122224

School: School of Business   Course: MSc in Management

Degree to be awarded: Masters of Science in Management

Title of Thesis/Dissertation: 'A study of the importance of establishing a relationship between emotional intelligence and dementia care for the provision of person-centred care by home care workers in the non-for-profit sector'

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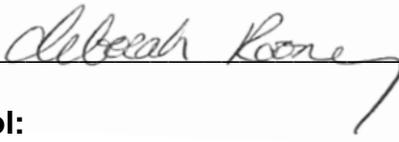
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