

# Dissertation Submission

LEARNER NUMBER	
	51668041
	21000011
NAME	
	Renata Aparecida de Assis
COURSE	
GOORGE	MAY BY A BY A W
	MA in Dispute Resolution
DISSERTATION TOPIC	
	The challenge of a caregiver in Ireland facing a patient with
	dementia: Negotiating a daily care process
SUPERVISOR	
SUPERVISOR	
SUPERVISOR	dementia: Negotiating a daily care process
	dementia: Negotiating a daily care process
SUPERVISOR  WORD COUNT	dementia: Negotiating a daily care process  Damien O'Shaughnessy
	dementia: Negotiating a daily care process
	dementia: Negotiating a daily care process  Damien O'Shaughnessy
WORD COUNT	dementia: Negotiating a daily care process  Damien O'Shaughnessy

I	certify	that
I	certify	that

• This dissertation	in is all my own work,	and no part of this dissertation has been copied from
another source:	Yes (X)	No ( )
• I consent to ha	ving my dissertation	be retained in the library for the purpose of future
research.	Yes (X)	No ( )
[Note that if no check submitted, and may be		this dissertation will be regarded as NOT propertssion penalty]
Signature:		Date:
<i>g</i>		
Notes:		

[insert dissertation here]

# **Table of Contents**

Declaration	i
Table of Contents	ii
Acknowledgements	iii
Abstract	iv
List of tables/Figures	v
Chapter 1 Introduction	9
Chapter 2 Aims and Objectives	11
Chapter 3 Literature Review	14
What is dementia?	14
Types and symptoms of dementia	15
Treatment and cure of dementia	16
Evolution of dementia	17
Professional health and family facing a patient with dementia	18
Negotiation and communication between caregiver and patient	21
Literature Conclusion	26
Chapter 4 Research Methodology and Methods	27
Research Design	29
Research philosophy	29

Research approach	29	
Research strategies	30	
Time horizon	32	
Selecting respondents	32	
Research ethics	33	
Research Questions and Hypotheses	33	
Chapter 4 Presentation of Data	34	
Data analysis procedures	35	
Chapter 5 Data Analysis/Findings	36	
Challenges in dementia care	42	
Communication skills in negotiating care	43	
Negotiating daily care: a challenge in dementia care	46	
Professional to professional: giving some advice to negotiate a daily care	50	
Limitation of Study	56	
Chapter 6 Discussion	57	
Chapter 7 Conclusion	57	
Reflection	58	
References	60	
Appendice 1	68	

# Acknowledgements

I would like to thank you everyone who was involved to help me to finish that work. My friends Liliane Pereira and Danielle Maia da Silva that were also working on their research however both of them always had time to answer my questions, doubts and also giving me advice. My supervisor Damien O'Shaughnessy that helped me to understand why I was doing this work and how to write a better research. Thank you Damien for your attention and time spend answering my doubts and listening to my laments.

Thank you God for making me strong enough to finish all work I start without doubts of giving up.

And finally for giving me bless to find time and willingness to get the end.

#### Abstract

Background: In the past few years dementia has been showing an increasing number of cases. Studies show that the numbers will have a significant increase because the population is in ascend. As a result, the necessity of professionals to work in this area will be very important. However, to work in dementia care is fundamental the professionals have any training because dementia is a disease that affects the brain causing innumerable different behaviors. These behaviors have been a challenge to health professionals who need to deal with patients who do not know what are doing or saying most of the time. Negotiating daily care and using communication are two topics that have importance on training a professional. This study aimed to find out what is the challenge facing by health professionals working for people with dementia and how to approach them and improve daily care.

Methods: A literature review of dementia was used to have some primary information about the topic. Followed of qualitative research done through a questionnaire with 16 questions answered by health professionals that have worked or still work in dementia care in Ireland. It was necessary use the computer to have the survey completed.

Results: The survey was answered by 100 health professionals working in Ireland. The questions were organized to collect information about how these professionals deal with dementia care. The result showed that most of the professionals are prepared to work in dementia care however that is not a sign that our professionals are totally satisfied and free of health problems such as stress, depression, and frustration doing this job. Many professionals agreed on how it is important communication to deal with patients who have dementia. Negotiate with these patients asks patients, time, knowledge and pleasure working on it.

Conclusion: This work showed how communication in dementia care is important followed by a professional well trained. Taking care of people who have dementia is not an easy job however the

professionals need also to be assisted in their difficulties to discover the challenges facing by them and have then possible to solve them.

# List of Tables/Figures

Figure 1	37
Figure 2	37
Figure 3	38
Figure 3.1	43
Figure 4	43
Figure 5	44
Figure 6	40
Figure 7	47
Figure 8	49

#### **Chapter 1 Introduction**

The world has been changing rapidly, with these changes government and humanity should discuss many important issues such as people are living more that is a good fact, however in this context it is crucial to note that having a longer life in a world where technology, inadequate diet, physical inactivity, and other factors are gaining more and more space in society there will also be consequences. One example of consequence is an increase of people with dementia, and that must be analyzed with care by the authorities in general. The cases of dementia in the world are worrying for many reasons but the first reason is the cost that countries must invest to support all people involved, patient, family, professionals who offer care for instance. According to the World Health Organization that wrote in a report about "The Global Impact of Dementia" (2015) dementia has a huge economic impact. Today, the total estimated worldwide cost of dementia is the US \$818 billion, and it will become a trillion-dollar disease by 2018. This means that if dementia care were a country, it would be the world's 18th largest economy, more than the market values of companies such as Apple (US\$ 742 billion), Google (US\$ 368 billion) and Exxon (US\$ 357 billion).

An article written in 2012 about the prevalence of dementia in Ireland did not show the exact number of people who suffer that disease because on that occasion there was only information based on estimative. According to Cahill et.al (2012), there is no population-based study on the prevalence of dementia in Ireland. Therefore, an estimate of the number of people with dementia was derived by applying age/gender dementia specific prevalence rates from the European Collaboration on Dementia to the most recent population estimates for Ireland. This gives an estimate of 41,740 people with dementia, of whom 3583 are aged less than 65.

In addition to that, an estimative of the cost of dementia in Ireland in the year of 2010 was given in the same article. It was written by Cahill et al (2012) estimated annual baseline cost of dementia in Ireland in 2010 was over E1.69 billion. Forty-eight percent of the total cost is accounted for by informal care provided by family and friends of those with dementia living in the community, while

43% is due to residential long-stay care. Formal health and social care costs comprise only 9% of the total cost of dementia. With an estimate of 41,740 people with dementia living in Ireland, the average annual cost per person with dementia is estimated to be  $\in$ 40,511.

In addition to the impact of dementia in the world be worrying, there is also the impact of scarcity of trained people to offer support to patients and families. Furthermore, the authorities must be attentive not only how many people are necessary and if they are trained but also be aware of these people may suffer health problems such as depression, stress when taking care of someone with dementia. The topic of this dissertation is about the challenges

The topic of this work is "The challenge of the caregiver in Ireland facing a patient with dementia: Negotiating a daily care process" that will present with literature using books, articles, and data collection through a questionnaire directed to the caregiver. The health professional when working with patients and dementia may suffer mixed feelings either positive or negative such as stress, fatigue, depression, contentment, satisfaction, happiness, and others. In other words, specialists that define the definition of dementia say that disease affects memory, thinking, behavior, and ability to perform everyday activities as a result professional who gives support to this patient may find many difficulties to engage its work. One study made with staff who works in the nursing home showed that behaviors that staff found most difficult to deal with were aggressiveness, unco-operativeness, and unpredictability. Many staff believed behaviors were deliberate rather than a consequence of dementia (Brodaty, Draper & Low, 2003).

Negotiation as word and action more known, used and taken more seriously when the objective is getting an agreement in a world of business, lawyers, politicians, and others. Fisher and Ury gave us with their book an idea about negotiation saying "every day, families, neighbors, couples, employees, bosses, businesses, consumers, salesmen, lawyers, and nations face this same dilemma of how to get to yes without going to war (2011). Fragale, Kim, and Pinkley (2005) said that power is widely acknowledged to affect negotiator performance. Yet few efforts have been made to

integrate the most prominent theories of power into a cohesive framework that can account for the results from a broad array of negotiation-relevant research.

Another way of explaining the definition of negotiation given by Anastakis (2002) was said that negotiation is defined as a strategy to resolve a divergence of interests, real or perceived, where common interests also exist. Negotiation requires effective communication of goals, needs, and wants. It occurs between individuals acting either for themselves or as representatives of organized groups of individuals.

Working with dementia may be considered war by several professional which is faced between them and patients. Looking in a dictionary where negotiate has more than one meaning for different situations. There is no specific meaning concerning health systems such as when dealing with a patient however each situation asks that professional has a minimum of knowledge of how to deal with an issue. Dementia is a disease that affects a person's behavior needs a professional who understands about it and how to move through, around, or over in a satisfactory manner (dictionary.com) a situation most of the time of stressful between 'them and patients'.

A phrase wrote by Spiers (2002) shows exactly how negotiation may be seen in the health field to negotiate implies readiness to risk and to use moment-by-moment communication skills within a context of broader strategies to guide the direction of the whole process. By accepting that negotiation for multiple simultaneous goals is a condition of interpersonal interaction, we can look at how meaning constructs and is constructed from the flow of events in the encounter.

# **Chapter 2 – (Aims and Objectives)**

This work will have as purpose two objectives to achieve. First, give to the readers especially those that do not know this subject a brief definition of dementia. Second and the most important topic in this work will present through health professionals (caregiver) the challenges and conflicts faced by

them with patients. Furthermore, three research questions will be used to get the main objective of this dissertation:

- What is the most challenge faced by a caregiver who supports a patient with dementia?
- What is the importance of training about dementia for a caregiver (professional)?
- How to use negotiation with a patient who suffers from dementia?

The World Health Organization reported in "Dementia: A Public Health Priority (2012) the importance of an action to support an increasing number of patients with dementia since the training of caregivers until actions from the authorities to increase the number of these professionals. Studies done relate that caregivers may have their emotional and physical health affected when offering care to the patient with dementia. The authors Given, Given & Sherwood (2008) pointed that most studies don't organize or classify interventions according to caregivers' tasks or the knowledge and skills they require, but this information is vital for planning and implementing interventions that will help them.

Coming back to the aims of this work, as it was quoted above the number of people who suffer from dementia is increasing, the authorities need to look after and listen to the professionals involved in the care with these patients. In other words, the researcher hopes to bring at the end of this dissertation what is happening with these professionals, what they have to say, their difficulties and challenges day a day. According to WHO (2012), the time to act is now by:

- promoting a dementia-friendly society globally;
- making dementia a national public health and social care priority worldwide;
- improving public and professional attitudes to, and understanding of, dementia;
- investing in health and social systems to improve care and services for people living with dementia and their caregivers;
- increasing the priority given to dementia in the public health research agenda.

The health professional always works under a lot of pressure coming by all sides such as managers, colleagues, patient's family, personal problems and the most important the 'patient'. This work has 'dementia' as the main subject because is a disease which has its numbers of cases increasing each year everywhere. In addition to that, it is possible to obtain results through studies over the years which show that caregivers are facing a difficult situation dealing with their patients who suffer from dementia.

At the end of this work, the important objective to be achieved will be a possibility to read what professionals have to say about their challenges, what could be changed by authorities about training for example. It will be constructed a questionnaire with the possibility of clarifying thoughts and ideas of these caregivers.

#### **Chapter 3 – (Literature Review)**

First of all, the literature review in this work tends to give to the reader general information about the topic. Such information is crucial to bring who is reading this paper to the real dementia world, the world that many people do not have knowledge consequently entailing episodes of racism.

Besides, to bring a brief definition of dementia, the main topic is talking through how nursing leads to challenges when having an elderly with dementia and how to negotiate a care day by day. Dementia presents a tremendous challenge to people living with the condition, their social partners, the care and medical sectors, and to societies in general. As life expectancy grows, the societal challenge can only increase worldwide (Howells et al., 2011).

#### What is Dementia?

The word dementia carries a stigma which makes people think that someone who has this disease is "crazy", however that is not true, many articles have been writing over the years giving clarify a definition of what is dementia. Alzheimer's disease creates anxiety; because people know very little about it, and as a result, they often attach a stigma to this illness. To foster early detection, more information needs to be provided about this illness to eradicate this stigma (Hesse, 2005).

The definition according to the World Health Organization and Alzheimer's Disease International (2012) is that: Dementia is a syndrome due to disease of the brain – usually of a chronic or progressive nature – in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded.

According to Alzheimer Disease International (2012) some tips to decrease the stigma of dementia are:

- ✓ Educate the public;
- ✓ Reduce isolation of people with dementia;
- ✓ Give people with dementia a voice;

- ✓ Recognize the rights of people with dementia and their carers; Involve people with dementia in their local communities;
- ✓ Support and educate informal and paid carers;
- ✓ Improve the quality of care at home and in care homes;
- ✓ Improve dementia training of primary healthcare physicians;
- ✓ Call on governments to create national Alzheimer's disease plans;
- ✓ Increase research into how to address stigma.

# Types and symptoms of dementia

Different types of dementia that may affect a person, Alzheimer's disease is the most common form of dementia and possibly contributes to 60–70% of cases. Other major contributors include vascular dementia, dementia with Lewy bodies, and a group of diseases that contribute to frontotemporal dementia.

Each patient who is diagnosed with dementia may present different symptoms a disease, some of these signs are known as neuropsychiatric symptoms and these include agitation, depression, apathy, delusions, hallucinations, and sleep impairment (Breitner et al., 2002).

Based on the Implementing Policy for dementia care in Ireland: the time for action is now written by O'Shea (2007) some changes in the individual that describe symptoms and behavioral of dementia:

- Memory loss
- Confusion
- Disorientation
- Language difficulties
- Wandering
- Failure to recognize people or objects

- Impaired comprehension, reasoning, and judgment
- Mood swings
- Night-time wakefulness
- Gradual failure to perform daily living tasks
- Hallucinations and delusions
- Challenging behaviors, such as verbal and physical aggression, suspicion, agitation, and repetitive acts, inappropriate sexual behavior, stealing and hiding things and the use of abusive or obscene language

One important notice that needs to be given is that every person that has dementia will be affected in different forms of symptoms and time. In other words, no one body is equal to each other then everyone will demonstrate symptoms in its period. Sometimes people may deteriorate more quickly, sometimes more slowly. It should be noted that not all persons with dementia will display all the symptoms, the World Health Organization (2012).

#### Treatment and cure of dementia

There are many diseases that there is no cure until the moment, one of them is dementia. According to the World Health Organization (2012), no treatments are currently available to cure or even alter the progressive course of dementia, although numerous new therapies are being investigated in various stages of clinical trials.

Despite dementia does not have a cure, other ways that may avoid a quick progression of the disease. Still described by a group of experts to the article "Dementia: a public health priority" by WHO (2012) much than can be offered to support and improve the lives of people with dementia and their caregivers and families, such as:

- early diagnosis;
- optimizing physical health, cognition, activity, and well-being;

- detecting and treating behavioral and psychological symptoms;
- providing information and long-term support to caregivers.

How there is no cure for dementia, the cost through the treatment and support are getting high for every country. According to Alzheimer's Disease International (ADI) that has a report written by (Ali *et al.*, 2015) the global costs of dementia have increased from US\$ 604 billion in 2010 to US\$ 818 billion in 2015, an increase of 35.4%. Our current estimate of US\$ 818 billion represents 1.09% of global GDP, an increase from our 2010 estimate of 1.01%. Excluding informal care costs, total direct costs account for 0.65% of global GDP.

#### **Evolution of dementia**

Over the years many studies have been showing that people are living more as a result it has been occurring an increase in population consequently there is another increasing that is, the number of elderly with dementia. The World Health Organization (2012) indicates a concern about this point that the number of people living with dementia will continue to grow, particularly among the oldest old, and countries in demographic transition will experience the greatest growth.

The World Health Organization (2015) has been on alert with the increase in the number of people with dementia which research shows that the number of people living with dementia worldwide is currently estimated at 35.6 million. This number will double by 2030 and more than triple by 2050. Dementia is overwhelming not only for the people who have it but also for their caregivers and families. There is a lack of awareness and understanding of dementia in most countries, resulting in stigmatization, barriers to diagnosis and care, and impacting caregivers, families, and societies physically, psychologically and economically.

The world has been affected by challenges that involve many changes however as it was said above by WHO the most important and worrying it is an increase of population and with this challenge is also coming diseases and other problems. The group of people aged >85 years is the most susceptible to disease and disability. The authors of an article written to show the challenges ahead

to the aging population pointed that the development of mortality, disease, and disability rates in elderly people will, therefore, have a fundamental effect on the sustainability of modern society (Christensen *et al.*, 2009).

Department of Health in Ireland had published in 2014 The Irish National Dementia Strategy which was created to deliver general information about dementia in the country and priority actions to be followed to help people with dementia and those who offer care to them. The strategy also seeks to progress the dual and overarching principles of personhood and citizenship by enabling people with dementia to maintain their identity, resilience, and dignity and by recognizing that they remain valued, independent citizens who, along with their carers, have the right to be fully included as active citizens in society.

As cited above one important point which was given by The Irish National Dementia Strategy (2014) is keep the focus on the Priority Actions that include:

- ✓ Better Awareness and Understanding;
- ✓ Timely Diagnosis and Intervention;
- ✓ Integrated Services, Supports and Care for People with Dementia and their Carers;
- ✓ Training and Education;
- ✓ Leadership.

#### Professional health and family facing a patient with dementia

Professional of health such as nursing, and caregivers may be considered one of the most important to a patient with dementia giving daily attention in each activity, however, this professional is also one of more can suffer during and after working with these patients.

Even though people might think the nursing care offer is similar most of the time, it is necessary to be conscious that each illness has protocols to be followed. Thus, patient who suffers from dementia need different attention from the others and this thesis had already been written a few years ago by Kahana and Young (1990, p.76) we are learning that caregiving to a demented elder differ in some

significant ways from giving care to an elder recovering from a heart attack or hip fracture. It is also becoming increasingly apparent that caregiving involves complex interactions with potentially positive or negative consequences for both care-recipients and caregivers.

In other words, to clarify what that point mean Breitner et al. (2002) say that neuropsychiatric symptoms have serious adverse consequences for patients and caregivers, such as greater impairment in activities of daily living, more rapid cognitive decline, worse quality of life, earlier institutionalization, and greater caregiver depression.

The Irish National Dementia Strategy (2014) also believes that caring for someone with dementia is challenging, both physically and emotionally. Staff in all relevant care settings needs the appropriate skills and competencies to effectively cater to people with dementia of all ages. However, available studies suggest that many staff employed to provide care to people with dementia often have little formal dementia-specific education. Physicians and nurse practitioners often focus their energies on the patients in front of them. Forgotten are the adult children and other caregivers to whom the responsibility falls. In dementia and Alzheimer's disease, outcomes are very closely linked with caregiver engagement and involvement (Jain and Pratty, 2015).

Following the quote above, the authorities should be more aware of the importance of giving training to professionals, family or whoever is offering to care to someone with dementia as a result, everyone involved in this situation could be satisfied at least doing the job in an appropriate form. Many family caregivers report they don't have the necessary skills and knowledge to provide sustained care for a person with a chronic illness, so they lack confidence and feel unprepared (Given, Given and Sherwood, 2008).

Training of either professionals or all those who are taking care of people with dementia is also significant in the function of this training be an important way to help in future diagnoses and caring of new patients with dementia. The authors Given, Given and Sherwood (2008) also point

the idea that caregivers also need to learn to monitor patients for new signs and symptoms, adverse events, and positive responses to treatment.

The care given to the patient with dementia may carry either simple or serious problems to a person who provides support day by day to this patient. Dementia care is difficult and requires time, energy and, often, physical exertion from the caregiver. As the disease progresses slowly, family members often provide care for many years and are under high levels of stress for long periods WHO (2012). Family and the professional that offers care for a patient have the responsibility that we called first care, it is important a good observation of the symptoms presenting by an elderly whose may be starting a process of dementia. As it was pointed that depression is one of the symptoms of dementia, whoever is closer that patient makes a first diagnose and after then talking to the medical professional who can make a final diagnose of dementia.

On the other hand, the difficult one of family, and professional in general accept that someone has dementia is the point to be discussed, and there it is where negotiation care enters as important factors to avoid a delayed diagnosis. The authors of an article that points primary care and dementia give us a great opinion about it saying that a specific problem with dementia is that some patients, families and primary care physicians are all reluctant to diagnose dementia, a serious and largely unmodifiable disease which carries a huge burden of stigma Ashley et al (2009).

According to Given, Given and Sherwood (2008) families want information about symptoms, disease progression, treatment, and possible adverse events. Caregivers seek information on skills they need to provide day-to-day care. Families expect to have concrete and complex information about their relative's disease that may help to deal with it. On the other side sometimes we find professionals who wantonly information on how to help these patients to keep a normal life.

According to WHO (2012), the provision of care to a person with dementia can result in significant strain for those who provide most of that care. The stressors are physical, emotional and economic.

A range of programs and services have been developed in high-income countries to assist family caregivers and to reduce strain.

Dementia needs special attention because according to specialists the progression of the disease is not always positive for both parties, patient and who is offering caring. The Irish National Dementia Strategy (2014) as other studies have informed that dementia is often accompanied by behavioral and psychological symptoms (BPSD), (sometimes known as behaviors that challenge) such as agitation, aggression, disinhibition, wandering and sleep disturbance and these can occur at any stage of the illness. These behaviors can pose significant challenges for staff and other patients and can be dangerous and distressing for the person with dementia. An individual well prepared to offer to care to people who suffer from dementia must be considered an important step to get an improvement in this area.

## Negotiation and communication between caregiver and patient

Working with health is not easy not only because the professional needs to lead with people suffering from some disease but also they have to fight with hard shifts, families and their questions, emotions, and many times how to negotiate care with their patients. In other words, giving attention to a patient especially one that suffers from dementia is a complicated task because of symptoms that this patient presents.

The author Spiers (2002) wrote an article about negotiating care in-home care and she said negotiating care is a complex process of negotiating issues of trust, legitimacy, authority, autonomy, competence, and vulnerability in their respective roles. Furthermore, she concludes that exploring processes of negotiation in nurse-patient interaction must encompass examining how inequality and power, threat, and challenge to another person and one's self are implicated through the actions of both nurse and patient (2002).

Negotiation in nursing care is not always easy to apply, it will depend not only on professional skills but also on patient's behavior and the situation at that moment. Health professionals must

respect the patient's space giving some time for both parties before creating a conflict between them. Accordingly, Spiers also include in her article (2002) understanding negotiation in interpersonal contexts of interaction has the potential to reconceptualize the notion of resistance in nursing care. Although models of nursing interactions that promote behavior change have become more sophisticated and patient-oriented with their focus on exploring and acknowledging patients' feelings and thinking, withdrawal from the conversation, hesitancy, and ambiguity are still framed as resistance.

Although a health professional has a training of caring before starting a job, each patient is different bringing with them different diseases, personalities, thoughts. In addition to that, a person with dementia may not be able to communicate clearly or to give an account of his or her history and preferences, and emotional responses may be unpredictable (Bailey et.al, 2010). In other words, the authors conclude that it is difficult for health care workers to treat patients with dementia, isolated from their normal environments and social circles, as individuals. Attention to basic physical needs may distract from the emotional dimension of caring, and impersonal routines may dominate the care process (2010).

The WHO points out that someone who gives support to the patient with dementia being family, caregiver, nurses, and other professional health need to improve skills for this kind of care. Dementia care training is especially needed for care workers who are responsible for the day-to-day physical care of this often highly care-dependent population (2012).

Over the years it is possible to be seen many studies writing from the importance of nursing in care. Besides, nurses and nursing scientists have been saying to the importance of communication and interaction between professionals and patients since Florence Nightingale in the 19th century and continuing until today (Behrens et al., 2009).

Allen et al. (2008) said that residents with dementia have particular difficulty understanding and responding appropriately to the requests of their caregivers, making their own needs understood by

their caregivers, and remembering what is communicated to them. In other words, professional who is taking care of the patient with dementia need to have an understanding of how to bring this person to reality with the comprehension that will not always be an easy task and helping him to keep life as normal as possible. Allen et al. (2008) also point out that these communication difficulties often result in inappropriate expressions of frustration and challenging situations for caregivers to handle. It is not surprising, therefore, that most training programs have a communication skills focus.

Being able to communicate with older people with dementia requires a high level of competence in the assessment of specific and individual communication challenges and needs of the person (de Vries, 2013). Nevertheless, having either communication or interaction with patients who have dementia it is always not easy work, everything has a connection with dementia's symptoms that it was clarified lines above in this paper. The symptoms usually influence the patient's behavior and this may bring difficulty in communication and interaction between nursing and patient.

Similarly, that dementia brings difficulty in keep interaction and communication, being an elderly this also has an impact on the care. Thus, the authors Caris-Verhallen, Kerkstra & Bensing (1997) point out that the generation gap makes effective communication between them difficult, for elderly people have different values and different expectations from the young. Training every professional or just a family who offer care to people with dementia is important to avoid wear and tear among all parties such as health professional, caregiver, family, and the patient. Ashley et al. (2011) said that being aware of and taking action to minimize or prevent burnout and stress; seeking appropriate support and continuing professional development opportunities and awareness of personal safety issues. These skills are likely to be neglected and under-emphasized in dementia training.

Communication skill to deal with elderly especially those with dementia has already been shown above in this work. However, it is important to complement one more quotation that includes types of communication. The author (de Vries, 2013) gave us three types of communication, she starts

saying that listening is an essential skill and involves close attention being paid, not only to words but to emotions of excitement, enthusiasm, interest, anger or fear, expressed by the speaker. De Vries (2013) also says about 'verbal communication' that becomes more difficult for a person with dementia to understand what is being said to them or to respond so that others can understand them, therefore the language used, tone and volume of words spoken. Furthermore, 'non-verbal' communication is the third type and becomes increasingly important. When people cannot understand language, non-verbal communication with caregivers whom they trust is of primary importance, and facial expression and touch should convey sincerity and kindness throughout the interaction wrote de Vries (2013).

Similarly was already told above about improving skills O'Shea (2007) wrote that there is, however, the scope for improving the communication skills of people caring for dementia patients at all levels. If health professionals are to develop the skills necessary for an empathic delivery of care, information and staff training is essential.

Although the importance of communication skills with their different types were showed through studies, a group of staff had participated in a project to study 'the emotional labor of health-care assistant in inpatient dementia care', this project illustrated that physical affection might also be important to the context 'patient and dementia'. Bailey et al. (2014) said in their article that physical affection was frequently observed between staff and patients. Many staff alluded to the potentially calming or therapeutic function of physical contact for patients. Physical affection was also seen by staff as an expression of humanity; an attempt to draw out a sense of the person beneath the impairment, and thus counter the sometimes de-humanizing effects of institutional care.

Similarly, those authors quoted above said through their works, how communication skills are really important in caring for people with dementia, many other authors also believe in that theory. As a conclusion of their work, the authors Eggenberger, Heimer, and Bennett (2012) said communication skills training in dementia care significantly improves the quality of life and

wellbeing of people with dementia and increases positive interactions in various care settings. In addition to that, they also complement that communication skills training shows a significant impact on professional and family caregivers' communication skills, competencies, and knowledge. Training in dementia care has been shown with such importance nowadays which is possible to see an increase in some studies about how to work in dementia care, what it is subjective to know about dementia and the care of patients who have some type of dementia. Many of the articles found are written to clarify the importance of communication between professional and patient.

According to the article called *Communication* wrote by Alzheimer's Society (2016) in England, there are some tips when talking to a person whit dementia:

- ✓ Speak clearly and calmly.
- Speak at a slightly slower pace, and allow time between sentences for the person to process the information and respond. This might seem like an uncomfortable pause to you, but it is important for helping the person to communicate.
- ✓ Avoid speaking sharply or raising your voice.
- ✓ *Use short, simple sentences.*
- ✓ Try to communicate with the person in a conversational way, not question after question (it can feel like an interrogation).
- ✓ Don't talk about the person as if they are not there or talk to them as you would to a young child be patient and have respect for them.
- ✓ Try to laugh together about misunderstandings and mistakes it can help. Humour can help to bring you closer together and may relieve the pressure. However, be sensitive to the person and don't laugh at them.
- ✓ Include the person in conversations with others. This may be easier if you adapt what you say slightly. Being included can help a person with dementia to keep their sense of

identity and feel they are valued. It can also help to reduce feelings of exclusion and isolation

#### **Literature Conclusion**

The brief literature review by works, articles, and especially the World Health Organization gives us an important point to start and consequently finish this thesis. All information found above may be the key to the final development of this work, being this crucial information to involve every participant that will be used in the data collection. At the end of this brief literature, the readers could have an idea over a topic which has been known as a stigma for years however the humanity needs to be conscious that it is important to have a minimum of knowledge of dementia because of a worrying number of cases every year.

The authors Eggenberger, Heimer, and Bennett believe that everyone who works for people with dementia should have better training about communication skills being this ability proved in many articles as total importance in caring with dementia. According to them, healthcare professionals and family caregivers usually receive very little training and support to enable them to meet the specific communicative needs of people with dementia. There is a lack of evidence regarding educational interventions to improve communication in the most important care settings in which people with dementia are cared for (2012).

Dementia has been discussed for years. The number of people with dementia is increasing as it has been showing in many studies. In other words, O' Shea (2007) wrote a phrase on his paper which describes the situation saying: The Action Plan for Dementia concluded with a simple statement as follows: the time for action is now. While that moment has passed, the time for renewal and enhancement of our initial commitment has arrived through making dementia a national health priority.

# **Chapter 4 Research Methodology and Methods**

First of all, to start research it is necessary to understand what it means. According to Creswell (2012, p.26) research is a process of steps used to collect and analyze information to increase our understanding of topic or issue. Concluding this explanation Walliman also quotes that a more academic interpretation is that research involves finding out about things that no-one else knew either. It is about advancing the frontiers of knowledge (2011, p.7).

Doing research may not be only a tedious work but also an activity whose people use their creativity. To conduct a study, we must organize and plan. We need to select research methods appropriate to a specific question. We must always treat the study participants in an ethically or morally way. Also, we need to communicate to others how we conducted a study and what we learned from it (Neuman, 2014). According to Gunaydin and McCusker (2014) research is the systematic and rigorous process of inquiry which aims to describe phenomena and to develop and test explanatory concepts and theories.

As it was said above research is done by step using topics. One of these topics is called methods that refer to techniques and procedures used to obtain and analyze data. This, therefore, includes questionnaires, observation, and interviews as well as both quantitative (statistical) and qualitative (non-statistical) analysis techniques and, as you have probably gathered from the title. In contrast, the term methodology refers to the theory of how research should be undertaken (Lewis, Saunders & Thornhill, 2009)

Al-Aboud (2011) says that a methodology encompasses concepts such as paradigm, theoretical model, phases and quantitative or qualitative techniques. A methodology does not set out to provide solutions it is, therefore, not the same as a method. Instead, a methodology offers the theoretical underpinning for understanding which method, set of methods, or best practices can be applied to a specific case, for example, to calculate a specific result.

The methodology according to studies may be divided into layers like an onion, in other words, it is worked following parts or topics to be exactly. To explain it better, in a research process a researcher should use the following components to write a methodology according to (Lewis, Saunders & Thornhill, 2009).

- Research Philosophy
- Research approach
- Research Strategies
- Time Horizon
- Data Collection and Data Analysis

This work was realized through an interpretivism approach bringing emphasis in inductive research, the use of qualitative method research may be the best way to provide a more complete comprehension of a problem given. Qualitative research can help researchers to access the thoughts and feelings of research participants, which can enable the development of an understanding of the meaning that people ascribe to their experience (ncbi.nlm.nih.gov, 2019).

Qualitative methods generally aim to understand the experiences and attitudes of patients, the community or healthcare workers. These methods aim to answer questions about the 'what', 'how' or 'why' of a phenomenon rather than 'how many' or 'how much', which are answered by quantitative methods (Gunaydin, McCusker, 2014). The developing during the process was based on an ethnography research strategy having as purpose to describe and explain research subjects just the way it would provide a description or explanation to the subjects.

Data collection methods were based on a survey with health professionals such as caregivers that faces patients with dementia who are mainly focused on the challenges facing day by day and how to negotiate in this situation. Every research may present limitations, and in special that because of researching topics about health is always considerate difficult to approach people who either work or use this area.

# **Research Design**

## Research philosophy

Doing research covers many different factors to get a result at the end. In addition to this, these factors help to obtain information, assumptions and new ideas or thoughts. Research philosophy is used to determine how your research is interpreted the research philosophy you adopt contains important assumptions about how you view the world. These assumptions will underpin your research strategy and the methods you choose as part of that strategy (Lewis, Saunders & Thornhill, 2009, p.108). This research has different types of philosophies such as positivism, realism, and interpretivism.

This current research will be written using "interpretivism" that is according to Walliman (2011, p.21) based on the philosophical doctrines of idealism and humanism. It maintains that the view of the world that we see around us is the creation of the mind. This does not mean that the world is not real, but rather that we can only experience it personally through our perceptions which are influenced by our preconceptions, beliefs, and values. Using this type of philosophy is important because of this topic that is, the research includes a known topic however somewhat stigmatized that there are different interpretations over the challenges faced by each professional.

The view of interpretivism given by Lewis, Saunders & Thornhill (2009, p.116) is similar that was said above that is, interpretivism advocates that the researcher must understand differences between humans in our role as social actors. This emphasizes the difference between researching people rather than objects such as trucks and computers.

# Research approach

Research may be done through two types of approaching being they "deductive or inductive". According to Lewis, Saunders & Thornhill (2009, p.124) deduction owes much to what we would think of as scientific research. It involves the development of a theory that is subjected to a rigorous test, an important characteristic of the deduction is that concepts need to be operationalized in a way

that enables facts to be measured quantitatively. In contrast to this, the same authors conclude the inductive approach has the purpose to get a feel of what was going on, to understand better the nature of the problem. Your task then would be to make sense of the interview data you had collected by analyzing those data. The result of this analysis would be the formulation of a theory (Lewis, Saunders & Thornhill, 2009, p.126).

According to Walliman (2011, p.71) numbers can be analyzed using the techniques of statistics. However, a lot of useful information cannot be reduced to numbers. People's judgments, feelings of comfort, emotions, ideas, beliefs, etc. can only be described in words. Words cannot be manipulated mathematically, so require quite different analytical techniques.

The dissertation done through the inductive approach may give a better understanding of some challenging faced by people that offer support to elderly with dementia as Lewis, Saunders & Thornhill said if you are particularly interested in understanding why something is happening, rather than being able to describe what is happening, it may be more appropriate to undertake your research inductively rather than deductively (2009, p.126). The inductive approach was used with influence in qualitative method data which was analyzed through a questionnaire to collect information where it will be possible to obtain the different challenges, what and why they are happening and consequently if there is something to do to change this situation.

# **Research Strategies**

The research strategy is used to obtain data which will give to the reader information about the dissertation such as, results through numbers, ideas, theories, definition or explanation of its history and researching books, etc. The research strategy includes these six types:

- Experiment
- Survey
- Case study

- Grounded theory
- Ethnography
- Action research
- Archival research

The author Bell (2005, p.8) gives us her point of view about research strategy saying that classifying an approach as quantitative or qualitative, ethnographic, survey, action research or whatever, does not mean that once an approach has been selected, the researcher may not move from the methods normally associated with that style. Each approach has its strengths and weaknesses and each is particularly suitable for a particular context.

The research strategy chosen to work in this dissertation was ethnography style which the study of people in naturally occurring settings or 'fields' by methods of data collection which capture their social meanings and ordinary activities, involving the researcher participating directly in the setting, if not also the activities, in order to collect data in a systematic manner but without meaning being imposed on them externally (Bell, 2005, p.16). The author Creswell (2012, p.21) complement with these words that the ethnographer also describes the group within its setting, explores themes or issues that develop over time as the group interacts, and details a portrait of the group. The choice of this strategy is important to understand the manner how dementia has influences in the behavior of health professionals. This is a research strategy that is very time consuming and takes place over an extended period of time as the researcher needs to immerse herself or himself in the social world being researched as completely as possible. The research process needs to be flexible and responsive to change since the researcher will constantly be developing new patterns of thought about what is being observed (Lewis, Saunders & Thornhill, 2009, p.149).

The exploratory research was used in this dissertation where the researcher through a search of literature and survey conducted with a specific group of professionals to get a final result which shows to the reader what the main objective of this work. According to Lewis, Saunders &

Thornhill (2009, p.139), exploratory research is particularly useful if you wish to clarify your understanding of a problem.

#### **Time Horizon**

Researchers when doing research may find two forms of time horizon that are cross-sectional studies and longitudinal studies. A study can be undertaken in which data are gathered just once, perhaps for days or weeks or months, to answer a research question that is known as a cross-sectional study. Lewis, Saunders & Thornhill (2009, p.155) complement that many case studies are based on interviews conducted over a short period time.

On the other hand, in longitudinal studies, the researcher might want to study people or phenomena at more than one point in time to answer the research question. The main strength of longitudinal research is the capacity that it has to study change and development (Lewis, Saunders & Thornhill, 2009, p.155). This dissertation will be written in the time cross-sectional using a short period time.

# **Selecting respondents**

The dissertation through ethnographic research used a questionnaire to conduct a survey using as participants a few professionals that offer support to the elderly with dementia. These professionals have included caregivers (nurses or not).

Participants were selected to answer the questionnaire based on the topic of this research. These participants are health professionals that include healthcare professionals and caregivers who work for people with dementia who could give to this paper some information about the terms negotiating and communication in their area of actuation. Data collection occurred in 48 hours using the questionnaire and a web page to receive the answers. The questionnaire was created through of computer's tool and redirected to participants also through the computer. The answers were collected through two groups of health professionals who work in Ireland, these groups are found in a web page. It was possible to collect 100 answers for every 14 questions in a total of 100

participants while 2 questions got less than 100 answers. As a sample of this research, the health professional who works for people with dementia in Ireland had a chance to show how they feel offering care to these patients.

#### **Research Ethics**

Ethics should be a primary consideration rather than an afterthought, and it should be at the forefront of the researcher's agenda (Creswell, 2012, p.23). Whatever someone is researching the use of methods ethics will be crucial to keep the integrity either of its work or participants. According to Walliman (2011, p.42) working with human participants in your research always raises ethical issues about how you treat them. People should be treated with respect, which has many implications for how exactly how you deal with them before, during and after the research. It is important to point out that each participant needs to have information about the research before it is done such as, why is being done? What is the objective? What will be done at the end? How can the result be used? And the researcher must be conscious that people have the right to give up or refuse to participate in the study.

#### **Research Questions and Hypotheses**

It is expected with findings to have answers to the question cited above. Professionals answering the questionnaire may give to the reader challenges, difficulties, and feelings facing patients with dementia. Importance of training and communication in dementia, how these topics have some influence in negotiation with patients daily.

- What is the most challenge faced by a caregiver who supports a patient with dementia?
- What is the importance of training about dementia for a caregiver (professional)?
- How to use negotiation with a patient who suffers from dementia?

#### **Chapter 4 Presentation of Data**

Data for this research was collected through a questionnaire consisted of 16 questions. These 16 questions, 14 are linked to the health field specifically in dementia which is an area where each professional should be attentive to the term 'negotiating with elderly people who suffer from dementia'. The questionnaire was elaborated to find out how the health professional feels approaching this kind of patient and how to behave facing the difficulties. The terms negotiation and communication were approached as a source in some questions to show to the readers that these terms are used not only in business transactions for example but also in a broad scale of professions such as nursing. The questions varied between personal ones such as age, nationality, and gender only to give some emphasis to collect data and as a result, the research could be able to show if occurs a significant difference in the samples. Other questions were elaborated to clarify feelings, advice and challenge those professionals who answered those questions facing day by day at work. The qualitative method was chosen to be used on this work in reason of having questions which present numbers with relevant significance such as, percentage of women and men having contact with dementia, their ages and nationality being the last one quoted as a topic that will be discussed in the findings of this research to bring information that how they answered about importance of communication between professional and patient with dementia. The strengths and weaknesses of qualitative and quantitative research are a perennial, hot debate, especially in the health sciences (Gunaydin and McCusker, 2014).

Mixed research, in its recent history in the social and behavioral or human sciences, started with researchers and methodologists who believed qualitative and quantitative viewpoints and methods were useful as they addressed their research questions (Johnson, Onwuegbuzie and Turner, 2007). Questions were done using method qualitative in terms of finding out feelings and advice of how to manage in dementia care. Qualitative work requires reflection on the part of researchers, both

before and during the research process, as a way of providing context and understanding for readers (ncbi.nlm.nih.gov, 2019).

Qualitative data collection is more than simply deciding on whether you will observe or interview people. Five steps comprise the process of collecting qualitative data. You need to identify your participants and sites, gain access, determine the types of data to collect, develop data collection forms, and administer the process in an ethical manner (Creswell, 2012, p.204). And to complete the research which is based on mixed methods, quantitative analysis deals with data in the form of numbers and uses mathematical operations to investigate their properties. The levels of measurement used in the collection of the data i.e. nominal, ordinal, interval and ratio, are an important factor in choosing the type of analysis that is applicable, as are the numbers of cases involved (Walliman, 2011).

#### **Data Analysis Procedures**

After you prepare and organize the data, you are ready to analyze it. You analyze the data to address each one of your research questions or hypotheses. Qualitative data analysis will represent this dissertation, according to Walliman (2011) this type of research is based on data expressed mostly in the form of words – descriptions, accounts, opinions, feelings, etc. – rather than on numbers. This type of data is common whenever people are the focus of the study, particularly in social groups or as individuals.

The authors Lewis, Saunders & Thornhill (2009, p.480) also have an idea of "qualitative" data analysis, to be useful these data need to be analyzed and the meanings understood, procedures assist this, allowing you to develop theory from your data. They include both deductive and inductive approaches and, like the process you use to construct a jigsaw, range from the simple categorization of responses to processes for identifying relationships between categories.

The qualitative method chosen to conduct this research was given after analyzing the research questions and the final purpose of this work. The questionnaire was elaborated through open and

closed questions which gave possibility the use of the qualitative method, as a result, the final of this work could clarify to readers the challenges facing by professionals who participated in this research and let them give some idea of understanding and help to others professionals. Quantitative studies are either descriptive or experimental. A descriptive study establishes associations between variables, while an experiment establishes probable causality (Magangi and Migiro, 2010).

Participants selected to answer this research were health professionals who work in dementia care that gave the possibility to work using the qualitative method in reason of these professionals conduct the answer of questions through feelings and advice to their colleagues or future health professionals. A qualitative approach to research aims to understand how individuals make meaning of their social world. The social world is not something independent of individual perceptions but is created through the social interactions of individuals with the world around them (Hesse-Biber, 2010).

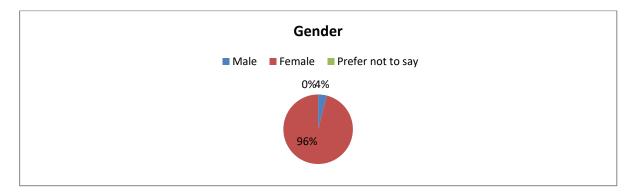
## **Chapter 5 Data Analysis/ Findings**

Analyzing findings collected using a questionnaire which was answered by health professionals who have already worked or are still working in dementia care in Ireland. The result of the research will show to the readers no one significant surprise in other words, the reader probably already knows how difficult and challenging to work in health service in general. In dementia care where professionals are facing a disease that affects the brain causing influence in memory, behaviors e.g. the challenging may be bigger than another area. Feelings such as stress, emotional tiredness are common however the reader will have the possibility to read how some professionals have the pleasure of working with dementia care.

Participants were not selected following any rule about ages, gender or nationality for example, they were chosen through their profession. However, they were asked to answer questions with personal

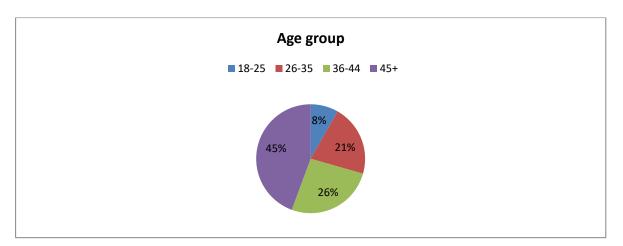
information as was cited above in intention to give to the research a way to discuss how communication that consequently helps with negotiating between professional and patient might be changed when having a diversity of people providing this service. See below three figures that indicate data of health professionals and their diversity.

Figure 1.



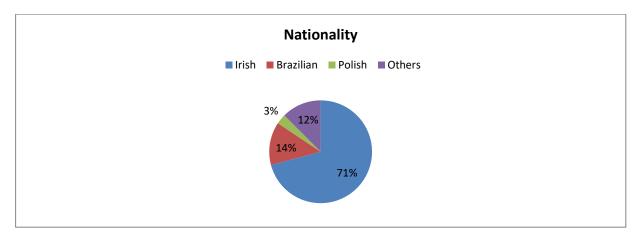
As the figure above shows the female gender prevalence is higher in comparison to males. The number of women working in the health area was always higher than men, there is no necessary to have a study or articles to prove that. If everyone goes to colleges, nursing homes, hospitals e.g. it is possible to see that the presence of women working as a health professional is higher than men. Working with dementia care that involves bad behaviors, sometimes may be seen as an easy job for women about women be more patient to convince and negotiate with someone, however, in a situation of attack from a patient with dementia men might feel more facility and safety to control it.

Figure 2.



Concerning the age group, the chart above showed an expressive number of 44% participants over 45 years old following professionals between 36-44 years old with 26%. It is known that a health professional with years of experience may have more to offer to their workplace and patients than a professional who is starting it. In fact of an high experience has is a crucial point however nowadays it is possible to have an idea how health professionals are getting sick for many reasons, frequent workplace stress can impact on the physical and mental wellbeing of health professionals and result in burnout and, in some cases, traumatic stress-like symptoms (Adamson et.al, 2013). Work in dementia care might bring feelings that might be noted as one cause of professional exhaustion. Being old or young health professional, having experience or not in dementia care, it does not matter because every person who suffers from dementia will show different behaviors, in other words, the health professional will never know what can happen, these professionals have to be ready to negotiate and communicate to control each situation.

Figure 3.



One of the important topics that were approached in this work is 'communication skill' and when speaking of negotiating anything it is crucial to know how to communicate. Normally, people who suffer from dementia present difficulties in communicating herself, as a result, a situation where a patient and health professional cannot understand each other the consequences may be frustrating and stressful for both parties. Communication is essential to everyday life and is at the core of

professional practice. How people communicate is unique and influences the quality of the relationships with those with whom they interact (Jootun and McGhee, 2010).

Residents in environments where effective communication is a priority will show greater independence, have less agitation and be more comfortable; this will allow residual strengths to surface and improve resident's effort, ability and desire to communicate (Todd, 2002).

The figure 3 above shows the number of different nationalities where Irish is on the top with 71% of professionals answering the questionnaire and 2 of them in featured Brazilian and Polish with 14% and 3% respectively whose country does not have English as a mother language.

Participants answered questions about the importance of communication in dementia care, although Ireland is a country where it is spoken the English language other nationalities have been having opportunity to work as care assistants or caregivers in the country from the moment they can communicate in English.

The findings were not a surprise when refers a few questions such as training in dementia care, agreement with the importance of communication skill and how to negotiate with a person who suffers from dementia may be stressful and tough most of the time. According to Innes and Kelly (2013) people with dementia, regardless of cognitive decline, continue to be to others and to strive towards inclusion. They continue to want a role, whether an old one or a new one, continue to experience hurt or pleasure, continue to need recognition to be seen and heard and continue to thrive in positive relationships.

Having trained in dementia care was discussed all over the work to show the importance of a course before starting work for people with dementia. Health professionals should know how to approach not only patients but also their families. Using all knowledge about how dementia affects a human brain its characteristics and consequences must be useful to all professionals and consequently to conclude a day of work with respect, attention, safety, and satisfaction. A significant percentage of 86% of participants answered that they have already had in their study life any training in dementia

care. According to a study done by Hope and Page (2013), they conclude that they remain optimistic that by making additional training and educational opportunities available, greater numbers of dementia care nurses can achieve effective practice at a higher level of competence and a 'new way of working' is possible.

Another expressive number was referent to a question asked them to know if all those who had participated in that questionnaire have already had any experience working with dementia. The result of this question was 72% of participants have ever worked with dementia followed by 23% of them are have still been working.

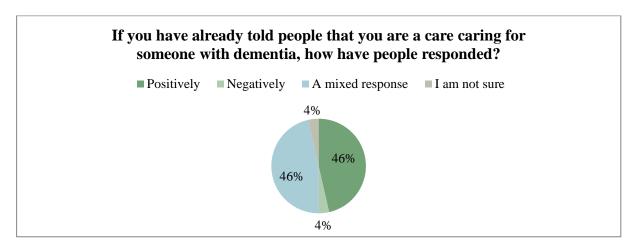
The challenge of working in dementia care was given by participants when asked to answer a question about the level of difficulty they observed in this area of actuation. It was given to participants a scale of 1 to 10 being 1 low level of difficulty and 10 high levels of difficulty. As a result, participants showed a diversity of opinions however a significant number of professionals answered that they felt from medium to high pressure of difficulty working with dementia. The significant result of numbers stayed between levels 5, 6, 7 and 8 being respectively 20%, 11,6%, 20%, and 16,8%. In addition to that 6,3% participants had to answer the level 10 of difficulty being this the highest on the scale.

That result takes the reader to understand how health professional feels facing a job in dementia care. The study about management of old people with dementia wrote by Borbasi et al. (2008) explain some of these difficulties faced by health professional saying care of the older person with dementia in an acute hospital setting, presents care staff with a special challenge, especially the need to care for the individual's personhood as well as management of their disruptive behaviours such as wandering and vocalization.

Even though dementia has still being stigmatized by part of the population in the world who do not have enough knowledge about the disease, something has been changing through public policy. Offering a piece of information to the population to break a fear of understanding, believing, dealing and especially helping someone who suffers from dementia is important to increase diagnose consequently a better treatment by part of professionals, family, and society to these patients. The World Health Organization (2017) said that a lack of awareness and understanding of dementia is often to blame, resulting in stigmatization and barriers to diagnosis and care.

As the reader can see below in figure 3.1 participants answered what type of reactions they receive from people in general when they let them know that they work with dementia care. People have been changing their thoughts about dementia and the result is there below. Much has still to be done by authorities to help to increase knowledge of population and professionals however through the numbers given by participants something is improving.

Figure 3.1



It might be seen as a good sign when according to professionals who participated in that questionnaire said only 4% of people respond negatively after listening to them say that work for people with dementia. A significant percentage was described by participants as being 40% positively responses coming from the population after participants refer they are working in dementia care.

Furthermore, 52% of people have been responding with mixed feelings that could mean different types of feelings such as fear, apprehension, doubts, e.g. so the authorities need to work given to a population more information to change its vision about dementia.

## Challenges in dementia care

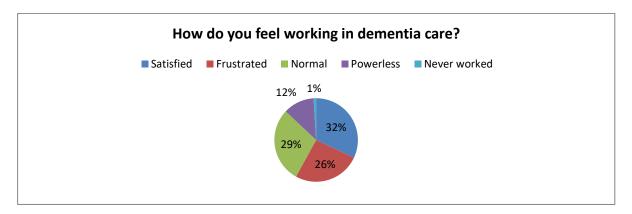
Professionals can face challenges every day, everywhere it does not matter where they work or live. Health professionals normally are facing more than challenges in their daily work, they may be changing their self inside and outside. Dementia care is an area where professional does not know what will happen next, in addition to that everyone who is offering service for people with dementia should be prepared for this job. By improving the capacity of health and social care professionals to provide evidence-based, multisectoral, gender and culturally appropriate interventions to the general population, educate about and proactively manage modifiable risk factors for dementia that are shared with other non-communicable diseases, the risk of developing dementia can be reduced or its progression delayed (World Health Organization, 2017).

However, it does not mean that if each professional has skills to work in dementia it means safety against problems, especially emotional ones. The caregiver is considered a very important element when caring for someone with high dependency, but all the stressors involved in the caring process make this role very different and it has been shown that focusing interventions or improving their skills and knowledge may well improve PwD "person with disabilities" comfort (Cabrera et al, 2014).

Besides most of the health professionals have the opportunity to improve their skills on day by day and also learning how to avoid mixing of feelings, it is important to point that the managers should take care of these professionals. Adamson et al (2013) said developing resilience-promoting environments within the health professions can be explored as a means to reduce negative and increase positive, outcomes of stress in health professionals.

Mixed feelings were perceptive in the research when participants were asked to answer a question about how they feel working in dementia care. The result may be seen as a challenge facing by health professionals since some feelings cited by them can bring difficulties to offer good care. See below in figure 4 how professionals are feeling working in dementia care

Figure 4.



As the figure shows, the number of participants who answered that they are feeling frustrated and powerless outperforms the number of feelings such as satisfied doing their job. It is worrying this kind of result because it shows how impotent a few professionals are feeling and consequently other types of problems may be facing by them for example (stress, anxiety, and depression e.g).

# Communication skills in negotiating care

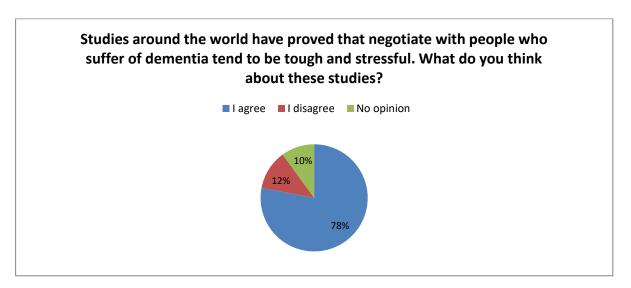
Jootun and McGhee (2010) said that communication is multidimensional. A spoken sentence may reflect more than a simple exchange of a message. It will reflect the relationship between individuals who are interacting. Some people must think that negotiate with someone should be easier if negotiator becomes tough and show expressions such as anger and power. However when talking of someone with dementia, the health professionals who need to negotiate most of the time with these patients may have changed their expressions to soft, patient and kindness.

According to authors Sinaceur and Tiedens (2006), although the effect of anger expressions on perceptions of toughness has not been demonstrated in the domain of negotiation, it seems likely that this effect would generalize, and that such perceptions could affect the outcome of the negotiation. In general, people concede more to negotiators they perceive as tough or dominant than to those they perceive as soft or submissive.

Professionals have to understand first which area they are working, who they are negotiating for so they will be able to find the best way to use negotiation. Negotiation is not just for making deals. People use, or should use, negotiation skills for resolving disputes and reaching decisions in teams and other multiparty environments (Brett, 2007).

The challenge of offering care for someone with dementia comes with the challenge of negotiating daily care and professionals were also asked if they agree with studies published over the years which show that negotiate care with someone who suffers from dementia may be tough and stressful. Following the same thoughts and opinion the others authors about training carers in dementia care, Benbow et al. (2011) point that people with dementia and their carers need to be supported and cared for by a trained workforce, with the right knowledge, skills and understanding of dementia to offer the best quality care and support. See below on figure 5 the result

Figure 5.



It is notable after this research that professional who offers to care for the patient with dementia agree that improving skills in negotiation is crucial to complete a job. In addition to that trying an approach to negotiate an agreement in the business area and use negotiation in dementia are different situations which demand from each professional some distinct skills. The strategic and diagnostic skills of negotiation will improve with each negotiation experience. The final outcome of each negotiation should be a balanced, mutually acceptable solution for all parties (Anastakis, 2002). Both areas work with different behaviors however in dementia, no one can predict what will happen each day or moment. Negotiators will be more likely to initiate power change tactics when

they perceive their potential power, relative to that of their counterparts, to be low rather than high (Fragale, Kim, and Pinkley, 2005).

Communication as an important part of negotiation has been discussed all over this research and each professional has conscious of improving their skills may bring advantages in work. When residents cannot articulate their needs or cannot understand others, behavioral problems, like agitation or depression, may arise. A key component of quality care is the ability of care providers to communicate with residents to understand their needs (Galimidi-Epstein et al, 2017).

As a health professional, some people have a hard process of work in dementia care and that does not only depend if they have years of experience, high skills or goodwill. Working for a patient with dementia bring every day a new surprise when speaking of its symptoms as a result all health professional are on the front lines facing challenges which may be a cause of health problems between these professionals. A caregiver is considered a very important element when caring for someone with high dependency, but all the stressors involved in the caring process make this role very difficult and it has been shown that focusing interventions or improving their skills and knowledge may well improve PwD "people with disabilities" comfort (Cabrera et al, 2014).

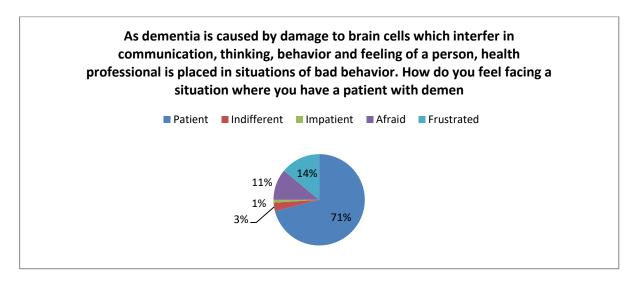
A question about the importance and benefits of communication in negotiation process were done to the participants and the result was not a surprise being 63% professionals who answered the questionnaire said they believe that good communication skill has a high benefit in negotiating in dementia care. To negotiate the complexities of their patients' needs, dispositions and communication abilities, while also delivering the practical aspects of good care, demands a high level of emotional output and superior skills in self-regulation, which are little-recognized characteristics of the role of HCAs (Bailey et al, 2013).

When working in a health area is not hard to find challenges and professionals tired. Every area of actuation presents different challenges. In dementia care may be seen as more stressful because is about behaviors especially in old people. This research was conducted to try to understand how

several health professionals feel and how their performance is seen in dementia care where to negotiate simple daily care may be transformed into a problem to the whole team.

Participants this research had a chance to describe how they feel facing a situation of stress, danger or a negative from a patient with dementia. Figure 6 below shows the result

Figure 6



When a health professional is facing a situation which asks from him feelings such as patience, attention or kindness it is not always possible to show this kind of posture. Dementia care is an area of health that needs those feelings cited above or that may become hard to be done consequently bringing frustration, indifference and other negative feelings that transform any profession into an unsatisfactory career.

As you can see in figure 6 above most of the health professionals 71 % of them show to be patient when offering a service to a person with dementia however a considerable number of health professionals total of 25% of them said to feel afraid and frustrated in the situation was cited in figure 6.

# Negotiating daily care a challenge in dementia care

Every job has situations that require professional a maximum of knowledge in dementia care it is no different. According to Bowers (2014) training should begin as soon as possible after someone is

hired, should be supervised by management, should be targeted to the trainees and should include continuing education in dementia care. We come back exploring the importance of having skills in negotiation specifically in communication to describe the next finding after health professionals answered the questionnaire. A situation where a professional has to deal with a patient with dementia trying to negotiate simple daily care such as have a shower, change clothes or just leave the bed. According to Lemieux-Charles (1994), the environment for health care is one of uncertainty and scarcity of resources. These conditions create mounting stress and increase conflict in any organization...Adequate time for negotiation is required; however, compromise is often the most expedient approach when time is limited.

Participants were asked answer what would be their attitudes facing that situation, having a memory that sometimes a situation like that may not means anything for who does not work in dementia care however for who are facing day by day this kind of behavior it is crucial to know what is the better form to manager attitudes cited. Figure 7 below demonstrates the answers of participants

Figure 7.

If the situation was simpler such as the patient is reductive of accepting daily care (e.g.	
shower, change clothes). What would you do in this situation? You can choose more than	
one option	
Being patient trying to convince 'he or	51%
she	
Ask a colleague for help	24%
Being impatient doing your job	0%
without permission	
Leaving 'he or she' alone and reporting	8%
to the manager	
Giving 'he or she' some time and	86%
coming back later	

Working under pressure is common in health work. Professional has to deal not only with the patient but also family, colleagues, and managers. All the jobs carry challenges and difficulties however when you have to deal with people and when these people who have mental problems or problems that affect the brain causing bad behaviors the professional suffer together with them. According to Adam et al. (2011), the use of anger and the use of threats are two common strategies in negotiation...Although anger and threats may both seem effective strategies in negotiation, it is not clear whether the more emotional strategy or the colder strategy is more effective.

Sometimes in some cases of negotiating be angry or make threats can bring positive results for who is presenting these attitudes however it is important to remember that in dementia care all professionals are dealing with human being who suffers from brain issues which present deterioration of cells which causes problems of memory, behaviour as a result being angry or try to make threats to convince these patients to accept anything can become the inverse situation such as stress or emotional tiredness for both parties.

As the reader can see in figure 7, 86% of participants answered that when a situation where the patient is not open to accepting a caring at that moment the best to do is give them some time and coming back later to try it again. People with dementia are persons with views, likes, and requirements that co-exist with their illness. It is for services to devise ways of actively listening to people with dementia on an individual basis and responding imaginatively to what they hear (Enderby, Reid and Ryan, 2001).

Day by day facing behaviors and trying to avoid conflicts with patients and that these patients do not get confronted with others. Negotiating with patients that do not understand what they are doing and in a few minutes or hours will not remember anything sometimes. This kind of situation brings to health professional especially those who work in dementia care some feelings that may affect their ability to work and/or personal life. Participants using the same situation discussed in figure 7

to let us know how they feel facing it but after the situation was finished being with negative or positive results.

See below in figure 8 what kind of feelings the participants answered had felt

Figure 8.

What is your feeling facing some situation as cited above? You can choose more than one option	
-	
Happy for helping	61%
Very patient	46%
Indifferent	2%
Very impatient	1%
Frustrated	7%
Stressed	18%
Emotionally tired	33%

Every profession has its different and what is relevant to conquer. Although for some professionals the challenges at work be to get a high position in the company or get a positive result in a transfer linked to money for example, on the other hand in health professions we usually have opportunity to find people working for passion of helping others in activities which a normal person can do for herself. Helping to have a shower, feeding someone, keeping a patient clean or interacting with them only, these are simple activities that may be significant challenges to a caregiver actuating in dementia care.

The figure above clearly demonstrates how a health professional feels satisfied being useful to someone through simple daily care. 61% of participants said to feel happy for helping a patient with dementia followed by 46% saying be very patient and understand the situation. However, how this research is trying to find what are the challenges facing by these professionals, the result also shows us negative feelings and such as 33% professionals said to feel emotionally tired and 18% of them finished the job stressed after working for people who suffer from dementia.

# Professional to professional: giving some advice to negotiate a daily care

The present study was also useful to ask participants if they as health professionals working in dementia care have any advice or know any method to approach a patient with dementia. The diversity of the dementia care workforce means those requiring workplace education may be at varying stages of proficiency about exposure to both clinical works with people with dementia and dementia education (Gates and Surr, 2017).

Sometimes some people present different abilities when offering their work. In dementia that it is no different, each professional may have a similar or different way to approach these patients. A few participants answered the question giving their advice on how to do a better job in dementia care. Read below some of the answers given to this research. All answers will not have names because the survey was done by anonymous professionals. I will use for each one nickname such as "participant 1, 2, 3..." In addition, all answers were taken from the survey with real words of professionals.

"Patience, kindness and put yourself in their places. We have to understand they are not in their normal judgment but we need to respect and understand their decisions."(Participant 1)

"Always being patient to patient and Always care for every patient with the individual approach because, even though Two patient might have the same mental disease diagnosis, they can have different behavior Which requires different caring." (Participant 2)

"Agree do not disagree, be patient, never raise your voice, kindness always." (Participant 3)

"Be trained to work with dementia, enjoying to work with elderly and mental health, be patient, don't get things personally, giving them time to do things, don't argue." (Participant 4)

As it is possible to read above, being patient and kind with the patient who suffers from dementia. This kind of feeling or approach according to them is the best method to work for these people. It was already shown above in figures 6, 7 and 8 that be patient and kind are the feelings demonstrated by the most professionals in this area of actuation.

According to Todd (2002) training caregivers to understand and implement the fundamentals of dementia care is the only way to establish a foundation for quality care...The focus of the fundamental training must encompass how to reduce confusion while enhancing the resident's ability to communicate, resident's safety needs and staff capabilities in managing behavioral.

Read below some of the answers from participants who said they agree with the importance of training staff.

"Training for health care professionals is sadly lacking, which would lead to a more confident carer and happier client." (Participant 5)

"Learn about different types of dementia, the effects, symptoms, and always remember it's the disease that talks, not the person." (Participant 6)

"Be trained to work with dementia, enjoying to work with elderly and mental health, be patient, don't get things personally, giving they time to do things, don't argue." (Participant 7)

"Be patient try to learn about the patient life and how they lived and what are their likes and dislikes are knowing all this in combination with training and good communication will help."

(Participant 8)

Participants also said that training in dementia is important because professionals need to know who they are taking care of and what they could be done to help them to manage each situation. Bowers (2014) said, "So if people with this disease are going to be in your facility, then you've got to have staff [who] know how to deal with it." Enjoying doing that job is also significant for some of them consequently the professionals could have a better result and less stress at the end of the day. Research shows that when staff members are trained how to care for residents who have Alzheimer's disease and related dementias, they find more satisfaction in their work, they are less likely to leave their positions and they deliver improved care, according to Randi Chapman, director of state affairs for the Alzheimer's Association (Bowers, 2014).

Not only participants who work in dementia care think of being patient and calm may be important to keep an approach of people with dementia. Todd (2002) said that administrators must emphasize to caregivers the importance of being patient and calm with confused residents. Caregivers must learn to explain care procedures to residents and encourage them to be as independent as possible. See below advice given by some participants that include the same thought of Todd.

"be calm and communicate decisively." (Participant 9)

"Listen to the person, go to their place rather than expecting them to come to yours." (Participant 10)

"When trying to give shower/change clothes talk to them that they think it's their idea. This works for me with a client with early dementia." (Participant 11)

"Communication and patience are very important." (Participant 12)

"Introduce yourself and ask them if they would like to have personal care done." (Participant 13)

"Communication is the key to it all." (Participant 14)

"Know how to communicate. Always agree with them and asuarance." (Participant 15)

Preparing students to be critical thinkers, and effective communicators are essential in today's complex health care environment. In addition to sound psychomotor skills, future healthcare providers must possess the ability to communicate confidently and effectively, not only to their patients but also to a wide range of constituents such as policymakers and payers, as well as other healthcare professionals (Hall, 2011). For some of the participants, the key to success working with dementia is communication. Communication skills have been discussed all over the research with quotes that prove that many authors also are saying how is important to know how to communicate in this area. You can avoid a lot of trouble if you try very hard to get inside the head of the person with dementia (Andrews, 2015).

Communication skills have been emphasized by many authors all over the years, your real importance in all area of actuation has been cited however the necessity of having a good

communication skill in healthcare shows us that keeping training is essential for all professionals. Jootun and McGhee (2010) pointed out that the process of communication can be complex in a care setting, especially when the nurse is interacting with a person who has dementia. Poor communication can compromise care, which can lead to undue anxiety and frustration on the part of the patient.

"Know them very well, what they like, and the history." (Participant 16)

"All Patients is different and all situations is different, dealing with each other." (Participant 17)

"I ll said important things to know a lot information about person with dementia espesially like and dislike previus hobby etc and use short sentense when you talking to them." (Participant 18)

"Know history about the person, gain their trust, patience & understanding is a must." (Participant 19)

"Just roll with them, talk about what they want to talk about or what they are interested in. Be mindful that they might become aggressive and frustrated. Treat every person with dementia as an individual and not stigmatize them because of dementia." (Participant 20)

Some interesting information given by participants was related to the knowledge of each patient. In other words, professional responsibility to help the patients with dementia should know what they enjoy to do, hobbies, type of clothes and food. Give some opportunity to the patients to help herself, ask them which clothes they would like to wear, which music to listen to. According to some participants of this research, the patient needs to be the center of attention as a result, the professional will be helping to put out memories and feelings of independence.

"Treat them as though you would like to be treated or how you would like your parents to be treated." (Participant 21)

"Just have a long patient and always think that you taking care your family member so you can work easily and happily." (Participant 22)

Working in health service is seen as hard and brave for some people concerning many different challenges which professionals have to face. In dementia care in general, patients need assistance in total or partial that is some people with dementia need help with shower, feed, personal hygiene however in dementia these activities may present the challenges that the research is talking about all over the paper. According to Todd (2002), residents respond most positively when they are treated with respect, therefore, a caregiver must not argue with, contradict or speak to them in a negative manner. Two answers had the attention of the research because they are linked to humanity and how these professionals think the patients need to be treated influenced by how these professionals would like to be treated if they or a family member need someday this kind of service. Have in mind when you are taking care of the patient with dementia that this person could be a relative and make this situation as happy and easy as possible. Caring for the frail elderly should never be about just amenities; rather, as the administrator must remind themselves every day, it's about humanity (Todd, 2002).

"Always follow lead never disagree and try to distract." (Participant 23)

"When trying to give shower/change clothes talk to them that they think it's their idea. This works for me with a client with early dementia." (Participant 24)

"To remember that those with dementia, are adults, who have the right to refuse the care u offer, eg shower, once they are not at risk, we as carers must respect their right to choose, and that they can maintain some control over their own lifes." (Participant 25)

"Never disagree with patient with dementia as it only frustrates them more." (Participant 26)

"Do not shout or demand. If a patient is refusing and is frustrated give them space." (Participant 27)

"Never argue be patient give them time in every day tasks and listen talk to them behaviour can be very challenging." (Participant 28)

"Take your time speak clearly and kindly dont rush or give to msny instrictions let them be involved as much as possible." (Participant 29)

Making patients feel that they have power is important according to a few participants. Give to patient power to decide if what they want, time for them to find what is going on and after that try an approach.

Working with dementia care asks from professionals to offer care in the person-centered that is professionals should show to the patient with dementia that they are the most important part of their daily activities. According to Brooker (2004), person-centered care encompasses four major elements, all of which have been defined as person-centered care in and of themselves by some writers.

These elements are:

- 1) Valuing people with dementia and those who care for them (V)
- 2) Treating people as individuals (I)
- 3) Looking at the world from the perspective of the person with dementia (P)
- 4) A positive social environment in which the person living with dementia can experience relative wellbeing (S)

Patient with dementia do not know if their attitudes are positive or negative sometimes, as a result, they do not have a sense of the problem, in other words, they think what they are doing is the correct. Despite that negative situations the professional should never disagree or treat the patient with angry and aggressiveness to get the job done.

Using distraction is also a way to negotiate and get an agreement with the patient with dementia according to a few participants. Professionals said that it is important to give to patients that the idea to do any activity came from them bringing them to reality.

"Take care of yourself first because it is emotionally draining." (Participant 30)

*Get tips from other carers." (Participant 31)* 

"Take your time." (Participant 32)

"If they're frustrated and cross they don't mean to be, it's the disease." (Participant 33)

"Not to take it personally which is not so easy if it the 3rd or 4th challenging behavior that morning." (Participant 34)

Understanding patients with dementia was given by most of the participants however professional needs to be assisted also. Working in dementia care as a few studies show is hard and stressful because health professionals are dealing with feelings and behaviors which most of the time are negatives or bad. Participants said their colleagues should not take some bad behaviors or situations as negative or personal being the majority influenced by the patient's brain which is not healthy.

Professionals should take time for herself when facing a stressful situation try to give some time to the patient and for itself. When the caregiver feels well, the patient benefits; when the patient is well cared for, the caregiver's health does not suffer (Hesse, 2005).

Having training about dementia will help to understand how the disease works and how to manage it. Frustration for both parties is common and understanding each party will bring more advantages than problems especially emotional ones. Asking for some advice and help from other professionals is also valuable and if each professional has the willingness to help his colleagues the work will flow as best as possible. According to World Health Organization (2017) 75% of countries will have developed or updated national policies, strategies, plans or frameworks for dementia, either stand-alone or integrated into other policies/plans, by 2025.

## **Limitation of study**

The present work presented a few limitations during its preparation that may have some influence on the final result. Limitations such as difficulty to find the best methodology to work on it resulted in a hard preparation of the questionnaire and a short time to obtain the answers with the necessity to use a computer and not face to face that will be more interesting for this work. Researching

health areas might be considerate a challenge and bring limitations about ethics problems, type of questions, time to participants answer the survey for example or only because work with feelings and frustration may bring a hard approach to these types of professionals.

## **Chapter 6 Discussion**

The purpose of this work was to identify challenges facing by health professionals working in dementia care and how to negotiate with a patient who suffers from dementia. It was found that difficulties are facing all the time by these professionals, especially in daily care. It was possible to get a conclusion of how health professionals are suffering working with dementia however the majority of the participants clarified that they can present frustration, stress during the job for example but most of the time feelings such as satisfaction to help, patience and respect are on the top of this type of work.

Communication skills were discussed all over the work as part important of working in health care especially with dementia. Negotiate with patients who have dementia asks a good skill from professionals to communicate with these patients. Keefer and Rider (2006) said that International medical organizations require competency in communication skills. These skills correlate with improved health care outcomes.

# **Chapter 7 Conclusion**

As this work has demonstrated, many health professionals have presented mixed feelings facing the challenges of working in dementia. As a result of the study, it is possible to have comprehension that work with a patient who suffers from dementia may also bring health problems to a professional who does not have training. Despite that, even each professional having any training or experience of working under stress, frustration might harm both parties either patient or professional.

A better conclusion of challenges facing by professionals in dementia care is letting people know that negotiate in an area where you are dealing with healthy people for example in the business company is different than people with dementia who do not have an understanding of what they are either doing or saying most of the times. Health professionals need to be in mind what to do in a few situations which ask training in behavior negatives coming from a person with some disorder on their brain that can be significative important in their daily care.

How would you feel if you could not convince someone to have a simple shower or get dressed? That is a big frustration for most of the professionals working in dementia care. Helping people with daily care for some of the health professionals can be more important and satisfactory that earns money. For this reason, this work was done to let non-health professionals know what happens in the daily life of those who offer services to the patient with dementia. The authorities and people, in general, should care more of who work in dementia care because if you have a healthy professional, trained and satisfied doing this kind of job, the positive points will outweigh negative ones and the consequences for all parties as professional, patient, family and others will only be gain.

## Reflection

Building this work was an experience that my knowledge was put in proof and it was not easy for many reasons.

First of all, choose a topic when you can find a big number of interesting subjects especially in my area of actuation that is health.

Second, having in mind how to link a subject from my area with Dispute Resolution. Many ideas came, however, one was perfect in the beginning to write about. It was the subject dementia that I have lots of experience working on. Using the term negotiate in dementia is important since the

professional work with elderly who have dementia. That is a challenge that only works can have any idea how it is hard and challenging to mind and body.

The topic is chosen, it was time to talk about what type of methodology that would be used. Difficult for someone who does not understand the subject. Through books, articles, websites it was possible to learn and find the best way to conduct the research.

Third, find a way to elaborate a survey was stressing because the necessity to create a questionnaire that did not take a long time to be answered by professionals was really important. Working in healthcare is exhausting, tiring and stressing sometimes so I would not ask professionals to answer a big and boring questionnaire.

Finally, the result was not surprised because I know how is to work in dementia care however it was important to know that most of the professionals have the same challenges facing by me daily and the readers of this work will have a chance to find out how professionals feel doing this job. Time to work in research is important I am proof that when someone is starting research it is crucial to have in mind how much time of your day you have, the topic is interesting enough and what do you want to achieve in the end.

## References

Adam, H.; Haag, C.; Kleef, G. A. V.; Neale, M. A. and Sinaceur, M. (2011) Hot or Cold: Is Communicating Anger or Threats More Effective in Negotiation? *Journal of Applied Psychology*, 96 (5), pp. 1018–1032.

Adamson, C.; Beddoe, E.; Huggard, J; Huggard, P; Kedge, S.; McCann, C. M. and McCormick, K. (2013) Resilience in the health professions: A review of recent literature. *International Journal of Wellbeing*, 3(1), 60-81.

Al-Aboud, F. N. (2011) Strategic Information Systems Planning: A Brief Review. *IJCSNS International Journal of Computer Science*, 11(5), pp.179-183.

Ali, G.; Guerchet, M.; Prina, M.; Prince, M. Wimo, A. and Wu, Y. T. (2015) World Alzheimer Report 2015: The Global Impact of Dementia an Analysis of Prevalence, Incidence, Cost and Trends, London, published by Alzheimer's Disease International (ADI).

Allen, R. S.; Burgio, L. D.; Dijkstra, K. and Bourglois, M. S. (2008) Communication Skills Training for Nursing Aids of residents with Dementia. Available at: <a href="https://www.researchgate.net/profile/Michelle Bourgeois/publication/230557065">https://www.researchgate.net/profile/Michelle Bourgeois/publication/230557065</a> Communication <a href="https://www.researchgate.net/profile/Michelle Bourgeois/publication/230557065">https://www.researchgate.net/profile/Michelle Bourgeois/publication/230557065</a> Communication <a href="https://www.researchgate.net/profile/Michelle Bourgeois/publication/230557065</a> Communication <a href="https://www.researchgate.net/profile/Michelle Bourgeois/publication/230557065">https://www.researchgate.net/profile/Michelle Bourgeois/publication/230557065</a> Communication <a href="https://www.researchgate.net/profile/Michelle Bourgeois/publication/230557065</a> Communication <a href="https://www.researchgate.net/profile/Michelle Bourgeois/publication/230557065</a> Communication <a href="https://www.researchgate.net/profile/Michelle Bourgeois/publication/230557065">https://www.researchgate.net/profile/Michelle Bourgeois/publication/230557065</a> Communication <a href="https://www.researchgate.net/profile/Michelle Bourgeois/publication/230557065</a> Communication <a href="https://www.researchgate.net/profile/Michelle Bourgeois/publication/230557065">https://www.researchgate.net/profile/Michelle Bourgeois/publication/230557065</a> Communication <a href="https://www.researchgate.net/profile/Michelle Bourgeois/publication/230557065</a> Communication <a href="https://www.researchgate.net/profile/Michelle Bourgeois/publication/230557065">https://www.researchgate.net/profile/Michelle Bourgeois/publication/230557065</a> Communication <a href="https://www.researchgate.net/profile/Michelle Bourgeois/publication/230557065">https://www.researchgate.net/profile/Michelle Bourgeois/publication/230557065</a> Communication <a href="https://www.researchgate.net/profile/Michelle Bourgeois/publicati

Allen-Burge, R.; Burgio, L. D. and Stevens, A. B. (1999) 'Effective Behavioral Interventions For Decreasing Dementia-Related Challenging Behavior In Nursing Homes', *International Journal of Geriatric Psychiatric*, 14, pp.213-232.

Alzheimer's Society: United Against Dementia (2016) Communicating. Available at: <a href="https://www.alzheimers.org.uk/about-dementia/symptoms-and-">https://www.alzheimers.org.uk/about-dementia/symptoms-and-</a>

<u>diagnosis/symptoms/communicating-and-language</u> (Accessed 19 August 2019)

Anastakis, D. J. (2003) Negotiation skills for physicians. *The American Journal of Surgery*, 185, pp. 74–78

Andrews, J. (2015) Dementia. The One-Stop Guide: Practical advice for families, professionals, and people living with dementia and Alzheimer's Disease. London, Profile Books LTD.

Ashley, M.; Benbow, S. M.; Kingston, P.; Morgan, K. and Tsaroucha, A. (2011) Patients' and carers' views on dementia workforce skills. *The Journal of Mental Health Training, Education and Practice*, 6 (4), pp.195-202.

Ashley, P.; Brayne, C.; Goodman, C.; Iliffe, S.; Manthorpe, J.; Rait, G.; Robinson, L. and the DENDRON Primary Care Clinical Studies Group (2009) 'Primary care and dementia: Diagnosis, screening and disclosure', *International Journal of Geriatric Psychiatric*, 24, pp.895-901.

Az Alzheimer's Disease International: The Global Voice on Dementia (2013) *Policy Brief for Heads of Government: The Global Impact of Dementia 2013-2050*. Available at: <a href="https://www.alz.co.uk/research/GlobalImpactDementia2013.pdf">https://www.alz.co.uk/research/GlobalImpactDementia2013.pdf</a> (Accessed: 15 November 2018).

Bailey, S.; Jones, R.; Lloyd, J.; Scale, K. and Schneider, J. (2014) The emotional labour of health-care assistants in inpatient dementia care. *Ageing and Society*, 1, pp 1 – 24.

Bailey, S.; Lloyd, J.; Scales, K. and Schneider, J. (2010) Challenging care: the role and experience of Health Care Assistants in dementia wards. Report for the National Institute for Health Research Service Delivery and Organisation Programme. Available at: <a href="http://www.netscc.ac.uk/netscc/hsdr/files/project/SDO\_FR\_08-1819-222\_V01.pdf">http://www.netscc.ac.uk/netscc/hsdr/files/project/SDO\_FR\_08-1819-222\_V01.pdf</a> (Accessed: 08 July 2019).

Behrens, J.; Berg, A.; Fleischer, S; Wüste, K. and Zimmermann, M. (2009) 'Nurse-patient interaction and communication: a systematic literature review', *Journal of Public Health*, 17(5), pp.339-353.

Bell, J. (2005) Doing your Research Project: A guide for first-time researchers in eduction, health and social science. 4<sup>th</sup> edn. England, Open University Press.

Benbow, S. M.; Kingston, P.; Mesurier, N. L. and Tsaroucha, T. (2011) Dementia skills for all: A core competency framework for the workforce in the United Kingdom. Available at: <a href="https://www.researchgate.net/profile/Anna\_Tsaroucha/publication/235428670\_Dementia\_skills\_for\_all\_A\_core\_competency\_framework\_for\_the\_workforce\_in\_the\_United\_Kingdom/links/565d9b3c\_08ae4988a7bc8bee/Dementia-skills-for-all-A-core-competency-framework-for-the-workforce-in\_the-United-Kingdom.pdf">https://www.researchgate.net/profile/Anna\_Tsaroucha/publication/235428670\_Dementia\_skills\_for\_all\_A\_core\_competency\_framework-for-the-workforce-in\_the-United-Kingdom.pdf</a> (Accessed: 18 August 2019).

Bensing, J. M.; Caris-Verhallen, W. M. C. M. and Kerkastra, A. (1997) 'The role of communication in nursing care for elderly people: a review of literature', *Journal of Advanced Nursing*, 25, pp.915-933

Breitner, J; Dekosky, S.; Fitzpatrick, A. L.; Jones, B.; Lopez, O. and Lyketsos, C. G. (2002) 'Prevalence of Neuropsychiatric Symptoms in Dementia and Mild Cognitive Impairment: Results from the Cardiovascular Health Study', *Journal American Medical Association*, 288(12), pp.1475-1483.

Brett, J. M. (2007) Negotiating Globally: How to Negotiate Deals, Resolve Disputes, and Make Decisions Across Cultural Boundaries. Available at: <a href="https://zodml.org/sites/default/files/Negotiating Globally How to Negotiate Deals%2C Resolve-">https://zodml.org/sites/default/files/Negotiating Globally How to Negotiate Deals%2C Resolve-</a>
<a href="mailto:Disputes%2C\_and\_Make\_Decisions\_Across\_Cultural\_Boundaries\_%28Jossey-">Disputes%2C\_and\_Make\_Decisions\_Across\_Cultural\_Boundaries\_%28Jossey-</a>

Bass\_Business %26\_Management%29.pdf (Accessed: 19 August 2019).

Brodarty, H.; Draper, B. and Low, L. (2003) 'Nursing home staff attitudes towards residents with dementia: strain and satisfaction with work', *Journal of Advanced Nursing*, 44(6), pp.583-590.

Brooker, D. (2004) What is person-centred care in dementia? Available at: <a href="https://pdfs.semanticscholar.org/8d36/dfd85dc5c7fedb836a0555ac3088c027a4b0.pdf">https://pdfs.semanticscholar.org/8d36/dfd85dc5c7fedb836a0555ac3088c027a4b0.pdf</a> (Accessed 18 August 2019).

Cabrera, E.; Hamers, J. P. H.; Karlsson, S.; Leino-Kilpi, H.; Renan-Guiteras, A.; Saks, K.; Soto, M.; Sutcliffe, C. and Zabalegui, A. (2014) Best practices interventions to improve quality of care of

people with dementia. Available at:

https://s3.amazonaws.com/academia.edu.documents/45898760/j.pec.2014.01.00920160523-25022-1sz53rp.pdf?response-content-

<u>disposition=inline%3B%20filename%3DBest\_practices\_interventions\_to\_improve.pdf&X-Amz-Algorithm=AWS4-HMAC-SHA256&X-Amz-</u>

Credential=AKIAIWOWYYGZ2Y53UL3A%2F20190816%2Fus-east-

1%2Fs3%2Faws4\_request&X-Amz-Date=20190816T143022Z&X-Amz-Expires=3600&X-Amz-SignedHeaders=host&X-Amz-

<u>Signature=0a3b1c01598196d74ef0c1c4530ed8639f6c4920a57bbac0327f2737a2bf83b1</u> (Accessed: 08 July 2019).

Cahill, S.; Connolly, S.; Gillespie, P; O'Shea, E. and Pierce, M. (2012) Estimating the economic and social costs of dementia in Ireland. Available at: <a href="https://www.researchgate.net/profile/Sheelah\_Connolly/publication/259530078\_Estimating\_the\_economic\_and\_social\_costs\_of\_dementia\_in\_Ireland/links/55dc6cac08aec156b9b176e7.pdf">https://www.researchgate.net/profile/Sheelah\_Connolly/publication/259530078\_Estimating\_the\_economic\_and\_social\_costs\_of\_dementia\_in\_Ireland/links/55dc6cac08aec156b9b176e7.pdf</a> (Accessed: 08 July 2019).

Christensen, K.; Doblhammer, G.; Rau, R. and Vaupel, J. W. (2009) 'Ageing populations: the challenges ahead'. Available at: <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2810546/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2810546/</a> (Accessed: 15 November 2018).

Creswell, J. W. (2012) Educational Research: Planning, Conducting and Evaluating Quantitative and Qualitative Research. 4<sup>th</sup> edn. Boston, Pearson Education Inc.

De Vries K. (2013) Communicating with older people with dementia. *Nursing Older People*, 25(4), pp.30-37.

Department of Health (2014) The Irish National Dementia Strategy. Available at: <a href="https://health.gov.ie/wp-content/uploads/2014/12/30115-National-Dementia-Strategy-Eng.pdf">https://health.gov.ie/wp-content/uploads/2014/12/30115-National-Dementia-Strategy-Eng.pdf</a> (Accessed: 08 July 2019).

Dictionary.com (2019). Available at: <a href="https://www.dictionary.com/browse/negotiate">https://www.dictionary.com/browse/negotiate</a> (Accessed: 08 July 2019).

Enderby, P.; Reid, D. and Ryan, T. (2001) What Does it Mean to Listen to People with Dementia? *Disability & Society*, 16 (3), pp. 377–392

Fisher, R.; Patton, B. and Ury, W. (2011) Getting to Yes: Negotiation an Agreement Without Giving In. 2<sup>nd</sup> edn. New York, NY, United States, <u>Penguin Putnam Inc</u>.

Fragale, A. R.; Kim, P. H. and Pinkley, R. L. (2005) Power Dynamics in Negotiation. *Academy of Management Review*, 30 (4), pp. 799–822.

Galimidi-Epstein, K. K.; McGilton, K. S.; Pichora-Fuller, M. K.; Rochon, E.; Saragosa, M.; Shaw, A. and Wilson, R. (2017) Can We Help Care Providers Communicate More Effectively With Persons Having Dementia Living in Long-Term Care Homes? *American Journal of Alzheimer's Disease & Other Dementias*, 32(1), pp.41-50.

Gates, C. and Surr, C. A. (2017) Effective Dementia Education and Training for the Health and Social Care Workforce: A Systematic Review of the Literature. *Review of Educational Research*, 87 (5), pp. 966–1002

Given, B.; Given, C. M. and Sherwood, P. R. (2008) 'What Knowledge and Skills do Caregivers Need?', *Journal of Social Work Education*, 44(3), pp.115-123.

Given, B.; Given, C. W. and Sherwood, P. R. (2008) What Knowledge and Skills do Caregiver need? *American Journal of Nursing* 108(9), pp. 28–34.

Gunaydin, S. and McCusker, J. (2014) Research using qualitative, quantitative or mixed methods and choice based on the research. Available at: <a href="http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.968.2338&rep=rep1&type=pdf">http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.968.2338&rep=rep1&type=pdf</a> (Accessed: 19 August 2019).

Hall, D. (2011) Debate: Innovative Teaching to Enhance Critical thinking and Communication

Skills in Healthcare Professionals. Available at:

https://nsuworks.nova.edu/cgi/viewcontent.cgi?referer=https://scholar.google.com/&httpsredir=1&a rticle=1361&context=ijahsp/ (Accessed 18 August 2019).

Hesse, E. (2005) Based Approach to Care for Dementia. Available at: openathens.net (Accessed 19 August 2019).

Hesse-Biber, S. (2010) Qualitative Approaches to Mixed Methods Practice. *Qualitative Inquiry*, 16(6), pp. 455-468

Hope, K. and Page, S. (2013) Towards new ways of working in dementia: perceptions of specialist dementia care nurses about their own level of knowledge, competence and unmet educational needs. *Journal of Psychiatric and Mental Health Nursing, doi: 10.1111/jpm.12029* 

Howells, D.; Manthorp, C.; Tullo, E. and Young, T. J. (2011) Developing a carer communication intervention to support personhood and quality of life in dementia. *Ageing & Society* 31, pp.1003–1025

Innes, A. and Kelly, F. (2013) Human rights, citizenship and dementia care nursing. *International Journal of Older People Nursing*, 8, pp. 61-70.

Jain, S. H. and Pratty, J. (2015) Two Ways to Better Care for Patients with Dementia. Available at: openathens.net (Accessed 19 August 2019).

Johnson, R. B.; Onwuegbuzie, A. J. and Turner, L. A. (2007) Toward a Definition of Mixed Methods Research. *Journal of Mixed Methods Research*, 1(2), pp. 112-133

Jootun, D. and McGhee, G. (2010) Effective communication with people who have dementia. Available at: academia.edu (Accessed 18 August 2019).

Kahana, E. and Young, R. (1990) Clarifying the caregiving paradigm: Challenges for the future.

Available

at:

https://www.researchgate.net/profile/Eva\_Kahana/publication/232485093\_Clarifying\_the\_caregiving\_paradigm\_Challenges\_for\_the\_future/links/0c96053568ee7c2250000000/Clarifying-the-caregiving-paradigm-Challenges-for-the-future.pdf (Accessed: 08 July 2019).

Keefer, C. H. and Rider, E. A. (2006) Communication skills competencies: definitions and a teaching toolbox. *Medical Education*, 40, pp. 624–629

Kothari, C. R. (2004) *Research Methodology: Methods and Techniques*. 2<sup>nd</sup> revised edn. New Delhi, NewAge International Publishers.

Lemieux-Charles, L. (1994) Physicians in health care management: 10. Managing conflict through negotiation. *Can Med Assoc* J, 151 (8)

Lewis, P.; Saunders, M. and Thornhill, A. (2009) *Research methods for business students*. 5<sup>th</sup> edn. England, Pearson Education Limited.

Magangi, B. A. and Migiro, S. O. (2010) Mixed Methods: A review of literature and the future of the new research paradigm. *African Journal of Business Management*, 5 (10), pp. 3757-3764

Neuman, W. L. (2014) *Social Research Methods: Qualitative and Quantitative Approaches*. 7<sup>th</sup> edn. Harlow-England, Pearson New International Edition.

O'Shea, E. (2007) Implementing policy for dementia care in Ireland: the time for action is now.

Available at:

https://www.lenus.ie/bitstream/handle/10147/196455/ImplementingDementiaCareFeb07.pdf?seque nce=1 (Accessed: 08 July 2019).

Sinaceur, M. and Tiedens, L. Z. (2006) Get mad and get more than even: When and why anger expression is effective in negotiations. *Journal of Experimental Social Psychology* 42, pp. 314-322.

Spiers, J. A. (2002) The Interpersonal Contexts of Negotiating Care in Home Care Nurse-Patient Interactions. *Qualitative Health Research*, 12(8), pp. 1033-1057.

Toddy, J. (2002) Maitaining Quality Alzheimer's Care. Available at: <u>openathens.net</u> (Accessed 19 August 2019).

Walliman, N. (2011) *Research Methods: the basics*. London and New York, Routledge Taylor & Francis Group.

World Alzheimer Report 2012 (2012) Alzheimer's Disease International. Available at: <a href="https://www.alz.co.uk/research">www.alz.co.uk/research</a> (Accessed 18 August 2019).

World Health Organization (2017) Global Action plan on the public health response to dementia 2017-2025. Available at: <a href="https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf">https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf</a> (Accessed 18 August 2019).

# Appendice 1

Link to open questionnaire of that research done using Google Forms

https://docs.google.com/forms/d/1\_2JkuziSDkVO4Mg\_hvae7yu85rhOeu5w2b9mpwAjZG0/edit