Dignity in Care Homes for Older People: A Qualitative Study

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Abstract

Dignity is a complex concept and according to research, dignity in care homes is a challenge. This study investigated the meaning of dignity for older people from their perspective as a resident in a care home. Therefore, the threats to residents' dignity were explored, as well as, how resident dignity can be promoted in a long-term care setting. A qualitative research design employing a non-experimental, exploratory-descriptive phenomenological approach was adopted for this study. The study was carried out at St. Vincent de Paul Residence. Participants needed to have been residing at the facility for more than one year. An initial screening process was conducted using the standardised mini-mental state examination and the 15-item geriatric depression scale, as assessment tools.

Fourteen cognitively and psychologically sound older adults from four different wards within the facility, between the ages of 68 to 91 years, were purposively selected using a maximum variation sampling technique. There were 9 women and 5 men of varied socio-economic backgrounds. Semi-structured interviews were carried out and all the participants were able to verbally communicate in Maltese. The data was collected during the month of March, 2016 and analysed using a thematic analysis approach.

The findings revealed that the older people at SVPR are more vulnerable to a loss of dignity, partly because of their health conditions together with staff attitudes and assumptions about older people and their capabilities. The findings also exposed the inadequacy in supporting the *National Minimum Standards for Care Homes for Older People* and the *10 Dignity Do's* proposed by the National Dignity Council (2016).

The core importance of this research study is to build awareness of dignity issues and to increase capacity among the care workforce within the healthcare system in dealing with these issues. Therefore, the study concludes that there is an urgent need to promote dignity-in-care and recommendations are being made to launch a dignity campaign across the board, in all local care homes. Educating staff on the meaning of dignity and what dignity means to older adults, and respect of the residents under the care of staff is deemed imperative.

Dedication

This work is dedicated to the residents in care homes, in Malta and to the ongoing research in geriatric care.

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Chapter 1

Introduction

1.1 Introduction

This thesis focuses on dignity and the quality of life of older adults residing in a long-term care facility in Malta. It explores the lived experience of this heterogeneous cohort in order to accurately capture and describe the phenomena of what dignity means to older men and women, the factors that threaten or promote their dignity, how such factors impact upon their quality of life on a daily basis, and their expectations of care whilst living in a residential care home.

This first chapter starts with the researcher's personal experience which provided the trigger for the study, as it highlights the perceptions of residents[1] in a care home whom she had come into contact with, while conducting different fieldwork placement studies as part of her first year compulsory academic studies of the Master of Gerontology and Geriatrics course.

The researcher had noted that although these older adults had not specifically mentioned the word 'dignity' *per se,* it is the observations and reflective analysis of the whole researcher's experience at the time, which elicited and raised questions about the meaning of dignity for this specific cohort, with similarities found in both public and private long-term care residential settings. For the purpose of this study, however, the main focus will be on older adults living in a state-run long-term care residential facility.

Employing Baillie's (2007) qualitative research study in the acute hospital setting as a backdrop for this study, the researcher explores the importance of dignity to residents living in a long-term care setting which establishes that residents' dignity should be respected. The chapter concludes with the aims and objectives of the research.

1.2 Inspiration for this research

The topic of dignity of older adults in a long-term care setting, specifically that of a care home, was inspired by certain incidents - scenarios of which are highlighted below, in Box 1.1 - while the researcher was on various fieldwork practice placements, as noted in the introductory part of this chapter. The nature of these practice placements was to

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[1] As the focus of this thesis is on older adults residing in a care home or residential care, the terms 'resident or older adult' are used throughout to refer to people living in this long-term care setting.

gain first-hand knowledge and understanding of older people, their concerns and issues, and the services and programmes that are available to them, through observation and interaction with both the older adults and the service providers.

Box 1.1: Scenarios of incidents derived from the researcher's direct observations

Scenario 1:

On one occasion, a gentleman in his late 70s, recently admitted to residential care, with a known history of Parkinson's disease, a year-old right hip hemi-arthroplasty and in the early stages of Dementia, besides other co-morbidities, had stated:

"I don't want to stay here; I want to go home … I'm invisible here".

Scenario 2:

Whilst another older person, with full cognitive capacity, a bilateral above knee amputation and wheelchair bound, had stated in Maltese:

"Qiegħed hawn nistenna li l-mewt teħodni".
[Translated: "I'm here just waiting to die".]

Scenario 3:

On yet another occasion, the researcher overheard a brief conversation (within earshot), whereby a local resident informed two staff carers that she needed to use the toilet. The reply was:

Carer 1 to Carer 2: "Erħila, dik bin-nappy"; Carer 2 to resident: "Għamel fin-nappy, issa niġu".
[Translated: Carer 1 to Carer 2: "Just leave her, she's got [wearing] a nappy";
Carer 2 to resident: "Do in your nappy, we'll soon come."]

These exclusive statements were by no means intended to reflect the overall or general feelings of all older adults who are in long-term residential care nor the standard of care provided by all frontline workers in the various local health care settings. Nonetheless, the researcher felt that it was important to validate and explore the meaning of such candid expression of feelings which were stated at the time. These events raised the question, even if for the minority, as to how residents perceived their quality of life and whether they felt valued as an individual – a person in his or her own right - a human being?

Corr and Corr in their *Textbook of Neurology for Physiotherapists* (1993) reinforce the premise that respecting the patient as a person, calls upon us to regard patients as unique individuals and to see them in the totality of their being, with physical, psychological, social, and spiritual dimensions alike. When considering the importance to value patients as persons and the basic goal of health care as a service provider, Corr and Corr reiterate that the personhood [2] of patients is to be valued because it is as persons that we are all fellow human beings, fellow members of the human community. Additionally, it is as a person that each of us possesses the capacity to be an agent of creativity, to bring into existence moral, spiritual, social and aesthetic value (*ibid.*).

Jacobson (2012) explains that personhood is damaged when people are made to feel that they are not human: that they are something less than human. Hence, in regards to the scenarios mentioned earlier (Box 1.1), it is plausible to state that, not only was the residents' personhood and self-worth that was being diminished – but alas, their dignity as human beings.

Admittedly, the researcher had mixed feelings on the subject. It is doubtful whether there is any literature to substantiate the following thoughts, still, drawing upon personal experience and the general discourse at work in the health care setting, then it is renowned for the Maltese people that when 'push comes to shove' – the Maltese people, even at large, will vehemently protest against any derogatory form of behaviour inflicted upon their loved ones, especially their parents. Comments such as, '*if that were my mother or my father … it would be a different story*' - could easily turn into a heated discussion with other various health care professionals (HCPs) entering the conversation, dictating what is ethically right and wrong in clinical practice. So much so, that one would wonder whether an allegiance to a cause was in its early formation, with followers initiating a campaign on human rights and the works. To one's amusement perhaps, this fervour may quickly dissipate, as the job, the environment and the institutionalisation of the self as a worker, takes over; where the mundane list of things-to-do escalates, the disdain towards the ever increasing workloads and shortages of staff seems a constant, the impersonal and alienation from a vocational duty resounds, thus leaving what could be the start of a social and cultural change, merely, a distant thought.

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[2] Personhood is described as: 1) 'the state or fact of being a person'; or, 2) 'the state or fact of being an individual or having human characteristics and feelings' (American Psychology Association (APA), 2015) and similarly, 'the condition of being a person who is an individual with inalienable rights' (Collins English Dictionary - Complete and Unabridged 10th Edition, 2012).

1.3 Defining Dignity

Further exploration was required in order to gain a deeper understanding. Reflecting on this experience, the researcher, realised that all too often, she too endorsed and talked about the importance for healthcare care professionals, in the role as service providers, to maintain the dignity of a patient, but what did it really mean? This led to further questioning on the subject matter at hand, namely - What is dignity?

Thus, in the same manner as Baillie (2007) and the questions posed in her study - Does dignity mean different things to different people? Are there different dimensions - maybe physical, emotional, and spiritual? Is dignity inextricably linked solely to independence? Is the word in itself used as an umbrella term to symbolise many other meanings and usages? If so, loss of dignity could be a central issue in long-term care settings where people, more often than not experience a substantial decline in their functional (and cognitive) abilities and furthermore, need help with even the most basic and personal activities of daily living, thus delineating furthermore their state of vulnerability.

Exploring dictionary definitions of dignity did not elicit the expected results, as listed in Box 1.2 and the researcher was not convinced that they rightly depicted the feelings articulated earlier by the older adults – the residents living in care homes (see Box 1.1).

Box 1.2: Dictionary definitions of dignity

1) A calm and serious manner that deserves respect: *She accepted the criticism with quiet dignity.*
2) The fact of being given honour and respect by people: *The dignity of work.*
3) A sense of your own importance and value: *It's difficult to preserve your dignity when you have no job and no home.*
4) A sense of pride in oneself; self-respect: *It was beneath his dignity to shout.*

(Oxford University Press, 2015).

1) The quality or state of being worthy of esteem or respect.
2) Inherent nobility and worth: *the dignity of honest labor.*
3) *a)* Poise and self-respect; *b)* Stateliness and formality in manner and appearance.
4) The respect and honor associated with an important position.
5) A high office or rank.
6) Dignities: The ceremonial symbols and observances attached to high office.
7) *Archaic* A dignitary.

(American Heritage Dictionary, 2011).

1) A formal, stately, or grave bearing: *he entered with dignity*.
2) The state or quality of being worthy of honour: *the dignity of manual labour*.
3) (Sociology) relative importance; rank: *he is next in dignity to the mayor*.
4) Sense of self-importance (often in the phrases stand (or be) on one's dignity, beneath one's dignity).
5) High rank, esp. in government or the church.
6) A person of high rank or such persons collectively.

(Collins English Dictionary – Complete and Unabridged, 2003).

All of the above cited dictionary definitions identify the origins of the word 'dignity' from the Latin *dignitãs*[3] meaning merit, and *dignus*[4] meaning worthy. The dictionary definitions infer that dignity is how one is regarded by others and that dignity is earned.

This experience revealed that although dignity is an important element in care homes, its definition, relevance and maintenance in clinical practice seems a hit-or-miss endeavour (Baillie, 2007).

The researcher's reflections led her to feel that in reality she knew little about dignity: the real meaning of dignity, whether residents were aware or felt that their dignity was lost and if so, what could prevent this from happening in a long-term care setting.

1.4 The importance of dignity to older people

It's not true that "sticks and stones may break my bones, but words will never hurt me". Words can hurt a lot and, used insensitively, can undermine people's dignity and self-respect. Even something as simple as whether a person is addressed by their first name or their title and surname can make a difference (Campbell, *et al.*, 2009).

It is increasingly evident that dignity matters to older people, and that dignity is a key factor in the delivery of good-quality health and social care. A plethora of literature reviews and concept analyses of 'dignity', 'care with dignity' and 'dignified care', have been published in recent years (Fenton and Mitchell, 2002); (Jacelon, Connelly, and Proulx, 2004); (Nordenfelt, 2004); (Coventry, 2006); (Jacobson, 2007); (Gallagher, Li, Wainwright, *et al.*, 2008); (Jacobson, 2009a); (Chadwick, 2012); (Oosterveld-Vlug, *et al.*, 2013); (Kinnear, Williams, and Victor, 2014).

Through these, dignity can be understood to be a fundamental right, subjectively experienced and rooted in a person's perception of being treated and regarded as important and valuable in relation to others.

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[3] Dignitãs means (1) a being worthy, worthiness, merit, desert, (2) dignity, greatness, grandeur, authority, rank, and (3) (of inanimate things) worth, value, excellence [as cited in Kass, 2008, p. 308].

[4] The noun dignitãs is cognate with the adjective dignus (from Greek and Sanskrit roots *DEIK* and *DIC*, meaning "to bring to light," "to show," "to point out"), literally, "pointed out" or "shown," and hence, "worthy" or "deserving" (of persons), and "suitable," "fitting," "becoming," or "proper" (of things) [as cited in Kass, 2008, p. 309].

A number of empirical studies have explored the salience of dignity from the perspective of older people (Woolhead, Calnan, Dieppe, *et al.*, 2004); (Bayer, Tadd, and Krajcik, 2005); (Levenson and Joule, 2005); (Calnan, Badcott, and Woolhead, 2006), from the perspective of health professionals (Arino-Blasco, Tadd, and Boix-Ferrer, 2005), as well as in a range of care settings, including hospitals (Jacelon, 2003); (Bridges, Flatley, and Meyer, 2009); (Webster and Bryan, 2009); (Tadd, *et al.*, 2011), nursing homes (Franklin, Ternestedt, and Nordenfelt, 2006); (Pleschberger, 2007); (Westin and Danielson, 2007) and more recently from the perspective of family caregivers (Lohne, *et al.*, 2014).

Tadd, *et al*., (2002) assert that dignity is central to interactions between health care professionals (HCPs) and patients but that staff often fail to appreciate the impact of patients and/or relatives experiencing or witnessing undignified care.

This body of evidence reinforces national and international policies and health standards such as highlighted in the *National Service Framework for Older People in Wales* (Welsh Assembly Government, 2006). Such evidence also underpins practice, with domains and indicators of dignity, such as, recognition and acknowledgement of autonomy, personal identity, participation and control, choice, effective communication, personal care, privacy and independence (Faulkner, 2006); (Matiti and Cotrel-Gibbons, 2006); (Picker Institute, 2008); (Clark, 2010), used in monitoring and assessing care and service delivery within a range of health and social care settings.

Alternatively, the Social Care Institute for Excellence (SCIE, 2010) indicates that there are eight main factors that promote dignity in care. Each of these Dignity Factors contributes to a person's sense of self-respect, and they should all be present in care. These are: choice and control, communication, eating and nutritional care, pain management, personal hygiene, practical assistance, privacy, and social inclusion.

1.5 Human Rights & Human Dignity in Healthcare

> "To be able to say what dignity is would be to describe the fundamental meaning of being human" (Meeks, 1984, ix).

Human rights principles may be used to realise a dignity-based health policy by suggesting interventions that target health and social care organization or systems (Jacobson, 2012). However, it is perhaps important to primarily define the term *human*, that is, “a member of the homo sapiens species; a man, woman or child; a person". Whereas, *rights* refer to the "things to which we are entitled or allowed; freedoms that are guaranteed". Thus, *human rights* are defined as "the rights you have simply because you are human" (Citizens Commission on Human Rights St. Louis, 2014).

In the United Kingdom, the Equality and Human Rights Group (2008) developed a framework for implementing the key human rights values of fairness, respect, equality, dignity, and autonomy *(FREDA)* (Mersey Care, NHS Trust, 2011) in health and social care. These are some key elements that organisations need to know about human rights; (Burns, 2014):

- Human rights are about our basic needs as human beings.
- Human rights are something that we all have simply because we are human, regardless of who we are, where we live or what we do.
- Human rights belong to everyone and should be at the centre of everything we do.
- Human rights represent all the things that are important to us as human beings, such as being able to choose how to live our life and being treated with dignity and respect and as an individual.

In essence, human rights are a set of universal minimum standards that must be met. They are not only about the protection of particular individuals and groups in society but are a practical framework to protect the rights of everyone (Mersey Care, NHS Trust, 2011).

Human Dignity has been a well-established legal concept since 1948, when it was enshrined under Article 1 of the United Nations Universal Declaration of Human Rights, which declares that, "human dignity is a basic human right for everyone in the world and it should not be taken away from a person" (Amnesty International, 1997), and since then, it has been regularly protected in constitutions around the world and in particular in Europe (Dupré, 2014). Seedhouse (2000) states that human dignity is important irrespective of the situations that people might find themselves in.

Going back to the incidents portrayed much earlier and under the circumstances, it was therefore very difficult to understand how the dignity of a person or a resident can prevail. Nor did it reflect the residents' right to autonomous decision-making or to the enhancement of living independently, besides other areas of concern that repel the *National Minimum Standards for Care Homes for Older People* (NMS) (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2015, p. 9).

To that end, in 2002, the United Nations Secretary General, Kofi Annan stated:

> "It is my aspiration that health will finally be seen not as a blessing to be wished for, but as a human right to be fought for." (World Health Organization, 2002, p. 4).

1.6 Code of Ethics for Health Care Professions

Dupré (2014, p. 113) states that, "the concept of human dignity is multi-layered, with deep roots in history and appears in disciplines such as philosophy, psychology", medical ethics, nursing and others where its importance in people's lives is emphasised.

The International Council of Nurses' Code of Ethics for Nurses (ICN, 2012) affirms that inherent in nursing is a respect for human rights, including cultural rights, the right to life and choice, to dignity and to be treated with respect. Nursing care is respectful of and unrestricted by considerations of age, colour, creed, culture, disability or illness, gender, sexual orientation, nationality, politics, race or social status.

In the UK, under the duties of a doctor registered with the General Medical Council [GMC], doctors are expected to treat patients as individuals and respect their dignity; to take prompt action in the event that patient safety, dignity or comfort is being compromised (GMC, 2014).

The General Pharmaceutical Council (GPC, 2012), which is the regulator for pharmacists, pharmacy technicians and registered pharmacy premises in England, Scotland and Wales, expects pharmacy professionals to respect and protect people's dignity and privacy.

The European Region of the World Confederation for Physical Therapy (WCPT, 2011) urges physiotherapists to respect the rights and dignity of all individuals and that everyone who seeks the services of a physical therapist has the right to service regardless of age, gender, race, nationality, religion, ethnic origin, creed, colour, sexual orientation, disability, health status or politics.

The Canadian Association of Occupational Therapists (CAOT, 2007) affirms the expectation that occupational therapists should value and respect clients' rights to be treated with respect and dignity within a safe and non-judgmental environment.

The American Speech-Language-Hearing Association (ASHA, 2014), in relation to the profession itself, declare that individuals shall uphold the dignity and autonomy of the professions, maintain harmonious inter-professional and intra-professional relationships, and accept the professions' self-imposed standards. In reference to patients, however, the word 'dignity' might be assumed as being mentioned implicitly, as it states that, individuals shall honour their responsibility to hold paramount the welfare of persons they serve professionally or who are participants in research and scholarly activities.

Interestingly, in their book on, *Counseling Skills for Speech-language Pathologists and Audiologists*, Flasher and Fogle (2004) support that respect for the person is most often communicated through daily interaction rather than through direct statements. In other words, the clinician's behaviours convey an implicit respect for the person's dignity, privacy, autonomy and vulnerability.

These global examples signify that different professions recognise the importance of patient or client dignity.

Nonetheless, Hicks (2013) emphasises that "Dignity is not the same as Respect. Dignity is our inherent value and worth as human beings; everyone is born with it. Respect, on the other hand, is earned through one's actions".

1.7 Aims of the Research

The aim of this study is to explore the lived experience of this heterogeneous cohort in order to accurately capture and describe the phenomena of what dignity means to older men and women residing in a long-term care facility in Malta, and their expectations of care. This research seeks to investigate the extent of which the right of dignity for residents in a long-term care facility in Malta is met and thus, to better understand the issues pertaining to the quality of life for residents in care homes.

To this end, the researcher will critically examine three key questions relating to dignity: What does it mean? What promotes and diminishes dignity? How should it be operationalised in relation to the care of older people? Objectives include:

1) To identify how residents, perceive dignity.
2) To investigate the extent to which resident dignity is currently being met or maintained.
3) To identify what factors, threaten residents' dignity.
4) To examine the implications of the findings of this study in order to create an awareness, propose further education for frontline staff and suggest development of policy on clinical practice in relation to the promotion of residents' dignity – [Dignity Campaign].

1.8 Chapter summary

This first chapter presented the trigger for the study based on the researcher's personal experience. A review of dictionary definitions in relation to dignity did not yield the expected results. The importance of dignity to older adults was indicated, and clearly, respect of patients' or clients' dignity is also important for the various healthcare professions as documented in their code of ethics. However, dignity is ascribed in being a fundamental human right and based solely on that, its significance is deemed far more complex and not merely interpreting it to mean respect. Therefore, dignity of older adults residing in a care home would appear to be a multifaceted issue and promoting residents' dignity is not necessarily straightforward. The aims of the research study were identified and in the next chapter, the meaning of dignity for older adults, including the factors which promote and diminish or threaten dignity in a long-term care setting are explored.

Chapter 2

Literature Review

PART I: DIGNITY

2.1. What is dignity?

While dignity is frequently referred to in the media and health policy, it is by no means a universally understood concept (Matiti and Baillie, 2011).

The French philosopher Gabriel Marcel believed that the "mysterious principle at the heart of human dignity" cannot be preserved unless its "sacred quality" is made precise (Marcel, 1963, p.128). Shotton and Seedhouse (1998) [cited in Matiti and Baillie, 2011] suggested that dignity is a vague and poorly defined concept, warning that unless dignity's meaning is clear, it can disappear beneath more tangible and measurable priorities. Whereas, the Social Care Institute for Excellence (SCIE, 2013b) pointed out that although defining dignity may be difficult, "people know when they have not been treated with dignity and respect".

Therefore, in order to be able to promote dignity in healthcare, the meaning of dignity ought to be firstly understood (Matiti and Baillie, 2011).

2.2 Theories of dignity

One of the earliest references to dignity is in Aristotle's *Eudemian Ethics* (1992) where it appears as one of fourteen virtues or mean states of character between an excess of unaccommodatingness and of deficiency or servility (Aristotle, 1992) [as cited in Gallagher, Li, Wainwright, *et al.*, 2008].

Gallagher, *et al.*, (2008) in their review works of theoretical and empirical literature subscribe to the notion that dignity for Aristotle is thus a quality, an excellence or moral virtue of the person, a quality that contributes to human flourishing or happiness and one in which one can err in terms of excess or deficiency. Beyleveld and Brownsword (2001) further discuss dignity and the conditions in which human rights can flourish, so that in relation to a person's autonomy, they argue that dignity can be a "two-edged sword", since it can either empower and support dignity or constrain it. Taking it from another perspective, therefore, if an individual has too little sense of her own worth, she may be servile and if too much, she may not accommodate others and may be guilty of the vice of arrogance (Gallagher, Li, Wainwright, *et al.*, 2008). Whereas Jacelon (2004) relates dignity to integrity whereby she describes personal integrity as "a dynamic intrinsic quality of the self, composed of health, autonomy and dignity."

The German philosopher Immanuel Kant who is regarded as the major theorist of dignity (Misztal, 2012) and his views on dignity have been widely referred to in discussions of the meaning of dignity (Matiti and Baillie, 2011). Kant defined dignity as an intrinsic value, "unconditional and incomparable worth" (Kant, Groundwork, 236, 4:447) or worthiness that should not be compared with things that have economic value because, unlike market value, a person’s value does not depend upon usefulness and cannot be replaced (Kant, 1948 as cited in Hill, 2014). He argued that dignity should be accorded on the basis of ability to reason and that since humans are able to reason, they possess dignity (Kant, 1909). He related rationality with autonomy: "Autonomy then is the basis of the dignity of human and of every rational nature" (Kant, 1909, p.54).

For both Aristotle and Kant, dignity thus seems to be contingent upon characteristics such as rationality and autonomy: it would be difficult for someone who lacked rationality to possess the Aristotelian moral virtues, while Kant's reference to "intrinsic value" seems nonetheless to rest on the possession of autonomy (Gallagher, Li, Wainwright, *et al.,* 2008).

However, Beauchamp (2001) asserted that Kant’s (1909) philosophy failed to acknowledge the dignity of those who lack the capacity for autonomy, which is particularly relevant in healthcare. Previously, Pullman (1999) [as cited in (Gallagher, Li, Wainwright, *et al.*, 2008)] distinguished between an ethic of dignity and an ethics (*sic*) of autonomy in relation to long-term care. He pointed out that autonomy "is crucial to certain aspects of dignity, but should not be confused with the whole of it" (*ibid.*). Pullman's view of an ethic of dignity does not, however, deny the importance of autonomy as a value and he states that:

> "Each autonomous citizen assumes some paternalistic responsibilities to protect the dignity of others who may never have the capacity, are not yet capable, or who are no longer able, to care for themselves – recognises and values our mutual interdependence. It is respect for the basic dignity of humanity that elicits our care and concern for the severely demented and frail older person. In responding to their dignity we express and enhance our dignity as well".

While Pullman recognises the importance of autonomy, he emphasises its limitations as a value: "it is a value, not the value", and suggests the importance of dignity, particularly where autonomy is lacking [as cited in Gallagher, Li, Wainwright, *et al.,* 2008).

A plethora of definitions found in the literature have been influenced by Kant's ideas about dignity. Spiegelberg (1970) [cited in Gallagher, Li, Wainwright, *et al.,* 2008] distinguishes between: the expression of dignity by inward and outward behaviour; dignity in general (a matter of degree); human dignity (minimum dignity which belongs to every human being qua human); intrinsic and extrinsic dignity; relational and absolute dignity; and dignity in itself (intrinsic worth) and ground for dignity and worthiness of respect.

Mann (1998) differentiates between internal (how I see myself) and external (how others see me) components of dignity. Here the common denominator is the fact of being seen and the perceived nature, or quality of this interaction. Mann asserts that, "for most people the interplay between internal and external elements seem constant, fluid and susceptible to rapid change" (p. 32). Whereas Sandman (2002), for instance, refers to human dignity and contingent dignity. Badcott (2003) writes of emotional dignity and distinguishes between intrinsic and extrinsic dignity: the former - something that everyone has, just because they are human and the latter - contingent or extrinsic.

Two theoretical accounts are particularly helpful in identifying features of indignity and dignity in relation to health and social care. Firstly, Mann (1998) [as cited in Gallagher, Li, Wainwright, *et al.,* 2008] developed a provisional taxonomy of dignity violations as follows:

- ***Not being seen*** – This occurs when someone feels that they are not acknowledged or recognised and where people feel unheard or disregarded. Mann suggests that an extreme example is where prison and concentration guards were instructed not to make eye contact with inmates and to 'look only at the centre of their forehead'. An example from nursing practice might be the patient or visitor who tries to attract the attention of a nurse, only to have the nurse avoid eye contact and to ignore the attempt at engagement.

- ***Being seen but only as a member of a group*** – In such situations people may be seen but only as a stereotypical member of a group, for example, as a woman, student, Italian, older person or a schizophrenic. As Mann (1998) points out, "group classification can be a source of pride" but here, as a type of dignity violation, being seen only as a group member is pejorative and depersonalising, diminishing the dignity of the individual.

- ***Injuries to dignity resulting from violations of personal space*** – There are differences in the way we perceive personal space and how we respond to people who enter our personal space. Responses will vary according to the nature of the relationship, whether permission has been gained and how dignified people feel when someone enters their personal space. There is much potential for dignity violations should permission not be sought and gained.

- ***Humiliation*** – This final type of dignity violation may occur if people are singled out, separated or distinguished from the group and subject to criticism. Mann gives the example of a child who is asked to stand in the corner at school. Although Mann refers to the conscious "singling out" of an individual, humiliation may equally follow from not being recognised as an individual, as in each of the previous three categories. Thus, although Mann calls this a dignity violation it might also be seen as the result of any other dignity violation. If we are not seen or seen only as a member of a group, or if our personal space is violated and we are thus treated as being of little worth, humiliation would describe our affective response to the experience and might also characterise how others would describe our situation.

Mann's provisional taxonomy was informed by discussions with students, anthropologists, sociologists and bioethicists. What becomes clear from the discussion of theoretical or philosophical perspectives on dignity is the necessary engagement of philosophy with empirical data about human experience and with the work of the social or human sciences (Gallagher, Li, Wainwright, *et al.*, 2008).

The second theoretical account, accommodating both intrinsic and extrinsic or contingent features, is that by Nordenfelt (2003) who developed a theoretical framework for dignity from reviewing the literature. His work was related to dignity in older people and he proposed four categories of dignity:

- ***The dignity of Menschenwürde*** refers to the intrinsic dignity that each individual has to the same degree just because he or she is human. Given our equal Menschenwürde, nobody may be treated with less respect than anybody else with regard to basic human rights. In particular, an elderly person has the same basic human rights as the young person.

- ***Dignity as merit*** includes rank in society, earned or inherited; this also entails a set of rights and honours installed in this position – for instance, a king, a cabinet minister, a bishop and a doctor have special dignities of merit that come with their positions in life, known also as *formal* dignities of merit. On the other hand, *informal* dignities of merit may be acknowledged for those people who have earned such merit through their deeds and in turn deserve respect, in view of artistic, scientific and athletic achievements. This definition closely relates to some of the dictionary definitions highlighted previously in Chapter 1, Box 1.2

- ***Dignity of moral stature*** includes respect of oneself as a moral human being and respect from others related to performances and attitudes, and may vary in relation to one's own acts.

- ***Dignity of personal identity*** focuses on human beings' self-respect, including notions of integrity and autonomy, and may be violated when a person is prevented from doing what they want to do or are entitled to do, or by physical assault and humiliation.

In a later paper, Nordenfelt and Edgar (2005) emphasised that while *Menschenwürde* (human dignity) cannot be diminished or lost while a person is alive, the presence and degree of the other three types of dignity varies in each individual. They acknowledged that *dignity of identity* is most relevant in the context of illness, as disability restricts autonomy and threatens personal identity.

Nordenfelt and Edgar (2005) presented a theoretical model of dignity created within the Dignity and Older Europeans Project (Tadd, Bayer, and Dieppe, 2002). By analysing older people's responses, descriptions and experience of dignity, they were able to develop a theoretical model (Figure 2.1). This model suggests that older people described or felt that there are four types of '*dignity*'. The dashed lines indicate that all types of dignity are interrelated and share equal importance. They built on Fenton and Mitchell's (2002) definition by presenting a model which could assist healthcare professionals to understand the relevance and importance attached to dignity by older people.

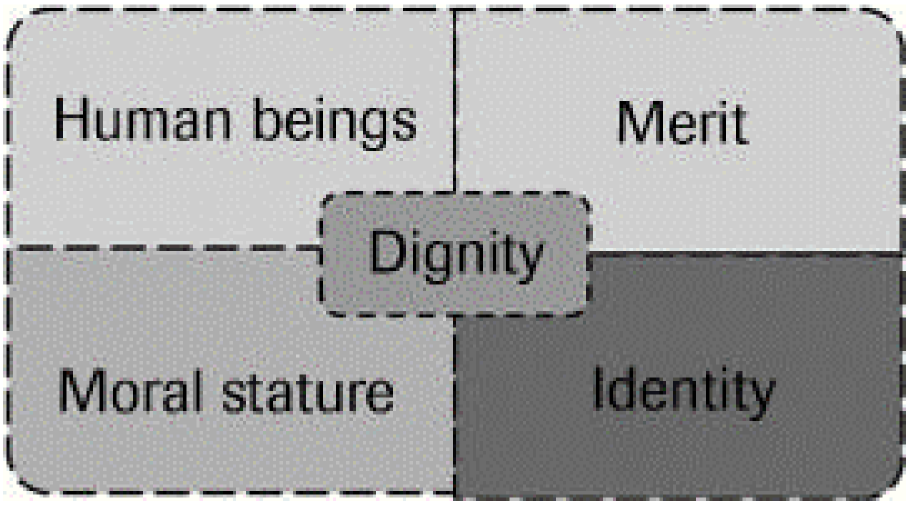

Figure 2.1: A theoretical model of dignity (Nordenfelt and Edgar, 2005).

In contrast, however, Baillie (2009) argued that two categories, namely: ‘dignity as merit’ and ‘dignity as moral stature’ have questionable relevance to healthcare because all patients should be treated with respect for dignity, regardless of perceived merit or moral status. Likewise, Wainwright and Gallagher (2008) have also critiqued Nordenfelt’s analysis.

Jacobson’s analysis in 2007, identified two distinct meanings of dignity: human dignity (a value that belongs to every human being because they are human) and social dignity. She explained that social dignity is experienced through interaction and, while human dignity cannot be removed, social dignity can be ‘lost or gained, threatened, violated, or promoted’ (p.295). She elaborated that social dignity always arises in a social context and comprises two linked elements: ‘dignity-of-self’ (includes self-confidence and self-respect), which is created through interaction, and ‘dignity-in-relation’, which concerns the conveyance of worth to others and is situated in time and place.

Jacobson (2007) declared that traditional definitions of dignity relating to status and merit (as in Nordenfelt’s model) are included in social dignity; thus, this broad category of social dignity encompasses various interpretations. Jacobson (2007) suggested that being clear about whether human or social dignity is being discussed may help to reduce some of the vagueness associated with dignity. She also asserted that the concept of human dignity can be used to argue for the right to health.

2.3 The concept of dignity

The notion of dignity is a concept with a long history, which stretches from antiquity to contemporary ethical and legal debates and documents (Misztal, 2012). In this light, therefore, the concept of human dignity is multi-layered, with deep roots in history and appears in disciplines such as philosophy, psychology, medical ethics, nursing and others where its importance in people's lives is emphasised (Dupré, 2014).

In fact, human dignity has been a well-established legal concept since 1948, when it was enshrined under Article 1 of the United Nations Universal Declaration of Human

Rights,[5] and since then, it has been regularly protected in constitutions around the world and in particular in Europe (Dupré, 2014).

Health care access and quality are widely considered to be determinants of health and institutions of health care are understood to replicate the social inequalities that are endemic in a given community or society. Attention to health equity is increasingly common in scholarly and policy-relevant examinations of health care systems (Centre for Research on Inner City Health, 2009); (Gardner, 2008); (Kilbourne, Switzer, Hyman, *et al.,* 2006).

The notion of dignity has been made explicit in some of these empirical explorations. In large international comparative studies conducted by the World Health Organization and the Commonwealth Fund, dignity has been conceptualized as a component of "health system responsiveness," an element of quality of care (Beach, *et al.,* 2005); (Blendon, *et al.,* 2002); (Valentine, Darby, and Bonsel 2008). These studies have found dignity to be a highly valued component of health care (Valentine, Darby, and Bonsel, 2008); when it is missing in service users' experience, their satisfaction with services, their adherence to provider recommendations, and the comprehensiveness of the care they receive, all suffer (Beach, *et al.,* 2005); (Blanchard and Lurie, 2004). Such findings suggest that dignity might be marshalled as a powerful indicator in the drive to assess and improve health equity in health care systems.

More recently, the definition of dignity was published by the Royal College of Nursing (RCN) in 2008 which closely relates to and perhaps encapsulates the meaning of social dignity as described by Jacobson (2007). The RCN's description of the definition follows overleaf, in Box 2.1:

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[5] 'All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood' (Geneva: United Nations, 1996).

Box 2.1: Royal College of Nursing's definition of dignity (2008)

Dignity is concerned with how people feel, think and behave in relation to the worth or value of themselves and others. To treat someone with dignity is to treat them as being of worth, in a way that is respectful of them as valued individuals.

In care situations, dignity may be promoted or diminished by:
- The physical environment
- Organizational culture
- The attitudes and behaviour of the nursing team and others
- The way in which care activities are carried out.

When dignity is present people feel in control, valued, confident, comfortable and able to make decisions for themselves. When dignity is absent people feel devalued, lacking control and comfort. They may lack confidence and be unable to make decisions for themselves. They may feel humiliated, embarrassed or ashamed.

Dignity applies equally to those who have capacity and to those who lack it. Everyone has equal worth as human beings and must be treated as if they are able to feel, think and behave in relation to their own worth or value.

The nursing team should, therefore, treat all people in all settings and of any health status with dignity, and dignified care should continue after death.

Researchers have often focused on experiences of dignity rather than the meaning of dignity; however, the following review studies have specifically explored what dignity means. Nearly all studies were qualitative, involving in-depth interviews with patients, healthcare professionals (mostly nurses) and occasionally relatives; a few used the observation-approach too.

Therefore, understanding the meaning of dignity in healthcare is clearly of universal concern, as researchers have explored the meaning of dignity in the US (Porkony, 1989); (Jacelon, 2003), the UK (Seedhouse and Gallagher, 2002); (Matiti, 2002); (Enes, 2003); (Reed, Smith, Fletcher, *et al.,* 2003); (Baillie, 2009), Sweden (Randers and Mattiasson, 2004), Canada (Chochinov, Hack, McClement, *et al.,* 2002) and Europe – the '*Dignity and Older Europeans*' project (Ariño-Blasco, Tadd, and Boix-Ferrer, 2005); (Bayer, Tadd, and Krajcik, 2005); (Stratton and Tadd, 2005), was based on Nordenfelt's (2003) theoretical framework which included members of the public as well as healthcare professionals. Furthermore, most studies were conducted with adult hospital patients but Enes' study was hospice based, the research of Chochinov, *et al.,*

(2002) was in a palliative care unit, while the study of Reed, *et al.*, (2003) was with children.

Matiti (2002) and Baillie (2007) conducted their own doctoral research into the meaning of dignity. Following a joint collaboration, Matiti and Baillie (2011), reviewed their findings and summarised the key themes as follows in Box 2.2:

Box 2.2: A Worldwide Meaning of Dignity in Healthcare (Matiti and Baillie, 2011)

1. ***Dignity is inherent in human beings*** (Matiti, 2002); (Nordenfelt, 2003); (Jacelon, 2003); (Reed, Smith, Fletcher, *et al.*, 2003); (Jacelon, Connelly, and Proulx, 2004); (Griffin-Heslin, 2005); (Marley, 2005); (Jacobson, 2007).

2. ***Dignity is dynamic***: patients adjust their perceptions of dignity during hospitalisation (Matiti, 2002); (Jacelon, 2003) and as illness progresses (Enes, 2003).

3. ***Dignity is an internal quality***: an aspect of self (Haddock, 1996), self-dignity (Jacelon, 2003), dignity-of-self (Jacobson, 2007), an attribute of the self (Jacelon, Connelly, and Proulx, 2004), a possession (Marley, 2005), and closely linked to each patient's individuality, their feelings and uniqueness as an individual (Mairis, 1994); (Fenton and Mitchell, 2002); (Marley, 2005).

4. ***Dignity relates to feelings***: self-esteem (Matiti, 2002; Chochinov, *et al.*, 2002; Enes, 2003), self-worth (Matiti, 2002; Enes, 2003), pride (Seedhouse and Gallagher, 2002; Chochinov, *et al.*, 2002; Matiti, 2002), confidence (Seedhouse and Gallagher, 2002; Baillie, 2007), self-respect (Seedhouse and Gallagher, 2002; Chochinov, *et al.*, 2002; Matiti, 2002; Baillie, 2007), feeling important and valuable (Baillie, 2007), being happy with self (Baillie, 2007), well-being (Chochinov, *et al.*, 2002; Baillie, 2007), hope (Chochinov, *et al.*, 2002) and feeling comfortable (Fenton and Mitchell, 2002; Baillie, 2007).

5. ***Dignity relates to behaviour***: behavioural dignity (Jacelon, *et al.*, 2004), dignity-in-relation (Jacobson, 2007), a gift (Marley, 2005). Examples are: behaving according to one's personal standards (Matiti, 2002; Jacelon, 2003; Baillie, 2007), courteousness (Matiti, 2002; Baillie, 2007), conveying respect (Seedhouse and Gallagher, 2002; Matiti, 2002; Enes, 2003; Jacelon, 2003), reciprocal respect (Jacelon, *et al.*, 2004; Baillie, 2007) and treating people as individuals (Enes, 2003; Baillie, 2007), as competent adults (Seedhouse and Gallagher, 2002) and as important and valuable (Haddock, 1996); Baillie, 2007).

6. ***Dignity and relationships***: interpersonal dignity (Jacelon, 2003) and relationships involving reciprocal behaviour (Enes, 2003; Jacelon, 2003; Reed, *et al.*, 2003; Baillie, 2007) *control as a component of dignity* (Matiti, 2002; Jacelon, 2003; Reed, *et al.*, 2003; Baillie, 2007). Related concepts are: autonomy (Chochinov, *et al.*, 2002; (Randers and Mattiasson, 2004) and independence (Pokorny, 1989; Seedhouse and Gallagher, 2002; Chochinov, *et al.*, 2002; Matiti, 2002; Enes, 2003; Baillie, 2007).

7. ***Presentation of self in public***: physical appearance (Seedhouse and Gallagher,2002; Chochinov, *et al.*, 2002; Matiti, 2002; Enes, 2003; Baillie, 2007) and modesty (Matiti, 2002; Baillie, 2007).

8. ***Privacy*** (Porkony, 1989; Seedhouse and Gallagher, 2002; Chochinov, *et al.*, 2002; Matiti, 2002; Enes, 2003; Reed, *et al.*, 2003; Jacelon, 2003; Randers and Mattiasson, 2004; Baillie, 2007). Other examples are: being private and able to keep one's boundaries (Haddock, 1996), protecting privacy to convey respect (Jacobs, 2000; Jacelon, 2003; Griffin-Heslin, 2005), being in control of one's own privacy (Marley, 2005).

Respect, including both respect from others and for oneself (Boisaubin, Chu, and Catalano, 2007), (Jacelon, Dixon, and Knafl, 2009), (Widang and Fridlund, 2003) and maintaining independence (Jacelon, 2003) are important for maintaining dignity in older people.

In Norway, a qualitative study using semi-structured interviews with 12 older people who had had strokes found that, being treated with dignity and respect was a core factor contributing to the patients' satisfaction with their rehabilitation (Mangset, Dahl, Forde, *et al.*, 2008). A previous study exploring dignity in hospital settings found privacy and communication to also be important (Webster and Bryan, 2009).

Additionally, qualitative studies have explored the views on dignity of older people in care homes. A German study showed that not being a burden was important to residents, and that their sense of dignity was threatened by illness and care needs (Pleschberger, 2007). A Swedish study described three main themes: (1) the unrecognizable body (loss of function and control); (2) fragility and dependency; and (3) inner strength and a sense of coherence (Franklin, Ternestedt, and Nordenfelt, 2006).

A study conducted in the UK (Hall, Longhurst, and Higginson, 2009) found support for three broad themes in Chochinov's dignity model (Chochinov, Hack, McClement, *et al.*, 2002), (1) illness-related concerns (level of independence and symptom distress); (2) dignity conserving repertoire (perspectives and practices); and (3) social aspects of the illness experience (social concerns or relationship dynamics which can erode or bolster a person's sense of dignity).

Although these studies give some insight into aspects of care that residents feel could help them maintain dignity, nonetheless, the views of health care providers are of vital importance in understanding which aspects of the care that residents receive, are more likely to impact on their sense of dignity, since loss of dignity remains a major issue in the lives of older people in many European countries (Tadd, 2004).

2.4 Threats to dignity

Dignity is an intangible characteristic, unique to each individual and manifested differently in different people. It includes feelings of pride, self-worth, and self-esteem, and much of it is internalized and some of it is visible to others in a person's bearings and actions (Jacobson, 2007).

Levine (2004, p. 2) terms an individual's dignity as:

> "His or her shield against the slings and arrows of the outside world. It allows him or her to exist within a predatory universe, inured to the insults and trauma of daily living, safeguarding his or her spirit. With our dignity gone, we face the universe as naked, primitive beings, powerless and fearful before the shifting currents of our environment".

Dignity scholars often have observed that dignity may be best understood in the breach (Jacobson, 2012) so much so that explorations of dignity violation and of indignity, teach us about dignity (Na°den, *et al.*, 2013).

This nascent attention to dignity is at odds with a decade or more of a worldwide trend for health care systems to emphasise the rationalisation of care in order to enhance its technical quality and to promote efficient cost containment. Critical examinations of this trend argue it may be antithetical to dignity. The structural contexts in which health care services are planned and delivered have features that may violate patients' dignity and constrain providers' ability to do their jobs in ways that promote dignity. Work in this area has pointed out the limitations of health care providers' training, the dynamics of unequal power inherent in health care settings and provider/patient relationships (as well as, in inter-professional relationships), the threats to dignity posed by various technocratic rationalisations of health care, and, especially, the many ways in which scarce resources affect the dignity of both patients and providers (Christakis, 2007); (Copp, 1997); (Iezzoni, 1999); (Jacobson, 2009b); (Malterud and Thesen, 2008); (Tarantola, 2000); (Tattersall, 2007)).

Dignity may be threatened by many of the policies and practices resulting from this structural context, including the implementation of clinical guidelines as a tool for structuring care practices (Christakis, 2007), the use of "medical necessity" as a criterion for determining the scope of services provided (Iezzoni, 1999). and the increasing influence of for-profit ("bottom-line") thinking in even public health care systems (Tattersall, 2007).

As highlighted previously, Jacobson (2007) delineates two basic categories of dignity: human dignity and social dignity. She explains that the objects of violation cluster around these categories, in that, personhood and humanity accord with the notion of human dignity, while social dignity may be seen in the body, the self, autonomy, moral agency, status, citizenship, and a people. Close examination of each object of violation helps to provide detail to either human or social dignity (Jacobson, 2012). Hence, an understanding of the object thus improves our apprehension of its category. Moreover, these objects can be marshalled as the target of practical efforts aimed at enhancing both human and social dignity.

On the other hand, Mann (1998) posited a psychosocial mechanism "in which dignity violations are understood to reduce resistance, or the capacity to respond adaptively to a wide range of environmental stresses". In fact, similar mechanisms have been proposed to explain, for instance, the associations between racism and health (Mays, Cochran, and Barnes, 2007); (Nazroo and Williams, 2006); (Paradies, 2006) and between lower socioeconomic status and health (Matthews, Gallo, and Taylor, 2010); (Shaw, Dorling, and Smith, 2006). Accordingly, these explanations are consistent with Wilkinson's descriptions of "the social patterning of psychological life" (2005, p. 61)

In Wilkinson's model, "social dominance systems that are about using power to gain preferential access to scarce resources" (2005, p.75) create status inequalities, subordination, isolation, and other injuries to dignity that through social comparison are internalised as inferiority, shame, and anxiety, and externalised as reduced social cohesion. Together, these internal and external responses - which describe something like "giving up" - create stress, which, when accumulated over a life span, affects the anatomy and physiology of the body.

The leading theory of how social environment induces ill health via the mechanism of psychosocial stress is that of "allostatic load"[6] (McEwen and Gianaros, 2010); (Seeman, Epel, Gruenewald, *et al.,* 2010); (Seeman, McEwen, Rowe, *et al.,* 2001),

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[6] Allostatic load is the 'wear and tear' of the body resulting from the repeated activation of compensatory physiological mechanisms in response to chronic stress. Allostatic load can significantly affect the ageing process and result in reduced longevity, accelerated ageing, and impaired health. Although low socioeconomic status is associated with high allostatic load during aging, the effects of status-related psychosocial stress on allostatic load are often confounded by lifestyle variables (Maestripieri and Hoffman, 2011).

which suggests that social conditions experienced as “stressful” - like the inequality-associated dignity violations of dismissal, contempt, intrusion, restriction, suspicion, exploitation, and bullying — trigger the brain to create hormonal responses that affect every physiological system in the body. When environmental stressors are constant and enduring, these physiological responses become maladaptive, leading to such somatic dysfunctions as chronic inflammation - manifested, for example, as cardiovascular disease, and metabolic disorders, such as diabetes.

Allostatic load, or “the cumulative physiological burden enacted on the body through attempts to adapt to life’s demands” (Seeman, *et al.*, 2001, p.4770), has been shown to follow a social gradient such that “lower SES [socioeconomic status, a marker for many of the dignity violations described by Wilkinson] is associated with more rapid aging of all major systems” (Seeman, *et al.*, 2010, p.223).

Cass, *et al.,* (2009) report that many of the threats to dignity take place at a small-scale, practical level. These can involve, for example as seen below in Box 2.3:

Box 2.3: Threats to dignity (Cass, Robbins, and Richardson, 2009).

- Treating adults ‘like babies’ because of actual or assumed incapacity – giving them mashed food, insisting on early bedtimes, using patronising tones of voice.
- Apparently small slights such as the imposition of leisure activities that imply a low intellectual level [*e.g.* playing bingo].
- Care which treats people as objects, or language which labels them as ‘conditions’ or problems.
- Poor environments and dirt.
- Never stopping for a conversation, or taking time to get to know service users as real people.
- Disregarding grief at bereavement among very old people, who see their circle of friends, relatives and companions shrink.

The public health theory thus posits a strong material and symbolic relationship between dignity and health: where dignity is lacking, there is a risk for ill health. Conversely, where dignity thrives, so too does the well-being and flourishing that constitutes good health (Jacobson, 2012).

Older people raised all of these with researchers as factors undermining dignity. Some of these certainly have their roots in the quality of management, training, supervision and leadership. Remedies have repeatedly been suggested which emphasise these factors. But some commentators (Macdonald, 2001 as cited in SCIE, 2013a) have seen the need for deeper analysis and more fundamental change. Increasingly, research and policy has begun to focus on the nature of society and on a series of interrelated factors which act as barriers to dignity in care (SCIE, 2013a); (Cass, Robbins, and Richardson, 2009).

In practice, however, there are many barriers to dignity in health and social care. Jacobson (2012) characterises these barriers as resulting from a series of tensions: the opposition between needs and resources, privacy and exposure, crisis and routine, care and production, autonomy and authority, experience and expertise, treatment and punishment, and rhetoric and reality. Together, these tensions describe an institution in which dignity is thwarted by the multiple scarcities (including those scarcities of time and empathy) provoked by enduring asymmetries of prestige and power, and by narrow technocratic definitions of quality and accountability that result in policies and procedures that are demeaning for both the users and the providers of care (Jacobson, 2009b).

2.5 Dignity promotion

So far, the literature has shown that there are so many ways to violate dignity, so many systems in place that perpetuate violation. Most of the conversations about dignity, in scholarship and in our daily lives, focus on how dignity may be threatened or lost. It would appear that explicit attention to dignity promotion is more of a novelty, however, it is important to recognize that dignity does not just claim victims of violation: it also has agents of promotion (Jacobson, 2012).

Jacobson’s (2012) exploration of dignity promotion aims to restore the constructive power of agency to dignity. She reiterates that the varieties of purposeful individual and collective action and interaction, can achieve both human and social dignity, as outlined below in Box 2.4, whereby she suggests a way forward toward a more dignified world.

Box 2.4: Promotion of Dignity (Jacobson, 2012)

1. Dignity is promoted when actors' encounters are characterized by ***courtesy*** – Similarly to Campbell, *et al.*, (2009), Jacobson points out that in health care settings, dignity is enhanced through small courtesies like polite address or greetings and mannerly (and timely) responses.

2. ***Recognition*** incorporates attention and validation – Therefore, through recognition, people see and acknowledge the humanity and the individuality of others, that which makes the other valuable. Furthermore, recognition is often twinned with *acceptance i.e.* non-judgmental attitudes and behaviours that demonstrate that differences are tolerated, even celebrated. Being accepted means feeling welcomed and feeling that you belong.

3. ***Empowerment*** promotes dignity by reframing people's understandings of the world and of themselves, changing their perspectives and raising their expectations. Empowerment also teaches, providing people with knowledge and tools, thus enhancing their capacities. It creates opportunities for new capabilities to be fulfilled.

4. Dignity is promoted by ***advocacy***, the practice of standing up for those who are struggling for their rights. Advocacy encompasses witnessing and testimony. Dignity promotion affects the same objects that are damaged by dignity violation, helping to create, maintain, protect, and maintain them. Social processes like advocacy and support can work to strengthen the body. The self is sustained and augmented by an array of processes, including courtesy, recognition, acceptance, discipline, enrichment, authenticity, love, concealment, and presence.

Therefore, Jacobson (2012) elucidates that autonomy is reinforced by empowerment and independence; moral agency is exercised through processes like discipline, perseverance, transcendence, preparation, avoidance, and resistance. Courtesy, recognition, and levelling, serve to enhance status; whilst citizenship is promoted by acceptance, contribution, advocacy, and support. Whereas, recognition, authenticity, love, and presence, bolster personhood. She concludes that directly and indirectly (via their effects on individuals or groups), a people and humanity as a whole may be dignified by any and all of these processes.

Any intervention must start with an assessment of the domain for which it is intended. Scholars and advocates have done much to describe the vicissitudes of dignity in the domains of health and social care. As noted earlier, qualitative research has been conducted in a variety of clinical settings - including palliative care, long-term care, acute care, rehabilitation, and paediatrics (Franklin, Ternestedt, and Nordenfelt, 2006); (Jacelon, 2003); (Lundqvist and Nilstun, 2007); (Mangset, Dahl, Forde, *et al.*, 2008); (Pleschberger, 2007); (Stabell and Naden, 2006); (Street and Kissane, 2001); (Woogara, 2005), and with a wide range of patient groups - comprising of the elderly, the dying, and persons living with HIV and other chronic illnesses or conditions

(Chochinov, Hack, McClement, *et al.,* 2002; Hughes, Davies, and Gudmundsdottir, 2008; Soderberg, Lundman, and Norberg, 1999; Werner and Malterud, 2003) [as cited in Jacobson, 2012].

Together, all of the above research has defined and modelled dignity and, especially, identified the intrapersonal and interpersonal pathways through which patients' dignity can be maintained while they are receiving care. Findings from these studies emphasise the importance to dignity of respect and recognition, of choice and control, of psychological and bodily integrity, of privacy, and of comfort and cleanliness.

The nursing profession has been particularly committed to researching dignity in practice. In article after article, nurse-researchers have reviewed what is known about dignity and explored the implications of this knowledge for care provision (*e.g.,* (Birrell, Thomas, and Jones, 2006; Coventry, 2006; Griffin-Heslin, 2005; Jacelon, *et al.,* 2004; Jacobs, 2000, 2001; Mairis, 1994; Matiti, Cotrel-Gibbons, and Teasdale 2007; Milton, 2008; Shotton and Seedhouse, 1998; Soderberg, Gilje, and Norberg, 1997). [as cited in Jacobson, 2012].

In their review on the theoretical, empirical, and practical work, *Gallagher, et al.,* (2008) concluded that nurses could best promote dignity for their patients by paying attention to four facets of care, namely:

1) **the physical environment** in which care is provided, including the cleanliness of the accommodations and the privacy available,

2) **the attitudes and behaviour of staff** who interact with patients, including the forms of address they use when speaking to patients,

3) **the culture of care**, including cultural competence among the staff and the existence of advocacy services in the institution; and, finally,

4) **the manner in which specific care activities are performed**, such as, feeding and toileting.

While a few authors have questioned the usefulness of dignity as a guiding concept in health care [for example, Wainwright and Gallagher (2008) have suggested that "an appeal to respect" might be more effective], the idea appears to have generated little controversy.

2.6 Dignity interventions

The rhetoric of dignity is pervasive in health and social care - witness the plethora of government white papers and organisational mission statements that wield the term - but, as it can be seen, the reality is something very different.

The literature contains descriptions of several interventions designed to address the dignity-related knowledge, attitudes, and behaviours of health and social care providers. These interventions tend to mix the defensive and the affirmative, seeking both to reduce providers' engagement in dignity violation and to increase their enactment of the social processes of dignity promotion (Jacobson, 2012).

Matiti, Cotrel-Gibbons, and Teasdale (2007) focus on "rais[ing] awareness of patient dignity by encouraging nurses to reflect on the concept and ensure they have the knowledge, skills and an appropriate attitude to support it". Their intervention asks nurses to explore what dignity means to them in their own lives, then to turn that raised consciousness to their practice, using techniques like SWOT [strengths, weaknesses, opportunities, and threats] analysis to assess their abilities to recognize and address the dignity needs of their patients.

Chochinov (2007) has published a similar set of self-reflective exercises for physicians; his intervention includes a primer on attitude and behaviour that is particularly concerned with heightening physician compassion and facilitating a dignity-promoting communication style. Parsons and Hooker (2010) have argued that providers should attain a "narrative competence" that allows them to elicit and respond to patients' stories, in this way reinforcing dignity-of-self.

The most recent edition of the bible of nursing care planning features a care plan for the nursing diagnosis of "risk for compromised dignity" (Ackley and Ladwig, 2008). It provides guidance to nurses in recognizing the risk factors for compromised patient dignity (things like "cultural incongruity" and "stigmatized label") and suggests steps nurses can take to maintain patients' dignity and increase their hope.

Educating for Dignity, a product of the Dignity and Older Europeans study (Calnan, Badcott, and Woolhead, 2006; Tadd and Calnan, 2009; Woolhead, *et al.,* 2006), focuses on the dignity of older people in health and social care, using the theoretical model of dignity developed by the study investigators to explore the social context of old age and the risks to dignity faced by elderly people who are using care services. This manual for educational intervention, designed for use in group or workshop settings, engages providers in discussions of the meaning of dignity and the practice of dignity-supporting care. Unlike the other provider-focused interventions, it seeks to get people to reflect on the social and cultural factors that affect dignity in old age, as well as the structural factors that underpin frontline workers' ability (or inability) to deliver dignity-promoting care.

The positions of client actors in health and social care also present a possible point of intervention. Care plans and many other published interventions help providers recognize particular vulnerabilities and act in the moment to mitigate them — for example, by using empathic language or by closing bed curtains. The literature contains other interventions designed to address the vulnerability of individuals who are experiencing particular health conditions or facing a period of institutional care. These interventions are largely affirmative in their approach, aiming to move people into positions of confidence.

Dignity therapy, a psychotherapeutic approach developed by Chochinov and his colleagues (Chochinov, 2002, 2007; Chochinov, 2007; Chochinov, *et al.*, 2002) seeks to help individuals who are terminally ill create their own legacies, in this way "bolstering their sense of meaning, purpose and dignity" (Chochinov, 2007, pg. 187).

A potential intervention is suggested by Matiti and Trorey's (2004) concept of *Perceptual Adjustment*: "A psychological preparation for the potential violation of dignity in a hospital situation" in which "a patient forecasts the potential indignities that he or she expects to suffer when in hospital, mentally analyses the situation and adjusts to a level that he or she feels comfortable enough to accept". Perceptual adjustment is sensitive to changing conditions. "Individual patients each have their own expectations with regard to their dignity and these perceptions may change in relation to the level of health" (Matiti and Trorey, 2008). That is, a very sick person may be less likely to perceive insults to her dignity, or more likely to accept such insults, than a person who is almost well.

In the model of dignity (Jacobson, 2012), positions, relationships, and settings are always mutually reinforcing. Due to this interdependence, dignity interventions at the person, organizational, and system levels must also be intertwined, if not practically, at least conceptually - that is, although a person-level intervention may not engage system-level conditions directly, it must be designed and implemented with knowledge of those conditions.

The “Dignity in Care” campaign in the United Kingdom (Dignity in Care Network, 2008) is an example of a dignity intervention whereby in its design and implementation attempts to integrate all three levels (Jacobson, 2012).

“Dignity in Care” focuses on the dignity of older people in systems of health and social care. Initiated in the late 1990s by a British advocacy group called Help the Aged, it has been taken up and elaborated by other non-governmental organizations and by various governmental advisory and oversight bodies in a campaign known as the “Dignity in Care Challenge” (Jacobson, 2012).

Campaign participants have undertaken empirical research and policy analysis, issuing a number of reports that vividly describe threats to the dignity of elderly people who are users of health and social care services. Using these findings, the campaign has provoked further government investigations and the funding and implementation of a multipronged strategy to address the problems identified. Among the components of this strategy are continued efforts at raising public awareness; educational programming for health and social care providers, including the production of instructional materials; network development; personnel deployment (“dignity champions” and the controversial “dignity nurses”); organisational and system-level guidelines, standards, and benchmarks; surveys and assessments; a series of specific policy recommendations; and tools for monitoring and evaluating the impact of these interventions (Bates, 2008; Birrell, Thomas, and Jones, 2006 ; Butler, 2006; Centre for Research on Inner City Health, 2009; Jones and Aranda, 2009; Levenson, 2007; Magee, Parsons, and Askham, 2008; Sandler, 2006).

The campaign has sought to engage a broad range of domains of action and interaction. Help the Aged has argued for a focus on matters of communication, privacy, self-determination and autonomy, direct payments, food and nutrition, pain and symptom control, personal hygiene, personal care and home help, death with dignity, and social inclusion (Bates, 2008; Levenson, 2007).

In their work, the Commission for Healthcare Audit and Inspection has looked at a number of Help the Aged domains, but also added assessments of patient involvement, dementia and confusion, workforce, leadership, complaints, and community partnerships (Healthcare Commission, 2007).

Other campaign participants have introduced the legal domains of abuse, complaint, and redress (Butler, 2006). “No standard working definition for dignity” has emerged from the campaign (Healthcare Commission, 2007, p.15). Thus, without a single definition, campaign participants have been free to proffer meanings that best serve their aims. Advocacy organisations have promoted a conceptualization of dignity that blends elements of both human and social dignity (Butler, 2006; Levenson, 2007), as reflected in Help the Aged dignity principles:

- Dignity in care is inseparable from the wider context of dignity as a whole.
- Dignity is about treating people as individuals.
- Dignity is not just about physical care.
- Dignity thrives in the context of equal power relationships.
- Dignity must be actively promoted.
- Dignity is more than the sum of its parts. (Levenson, 2007, p. 13)

Standard setting and measurement have also been used as proxies for definition. Thus, the Commission for Healthcare Audit and Inspection looks to social dignity phenomena like staff behaviour and the presence or absence of organisational “systems” for safeguarding dignity (Healthcare Commission, 2007). A set of indicators developed to assess "Help the Aged" dignity domains similarly focuses on broad themes of staff attitudes, facilities, choice, and control as these are manifested in each domain (Magee, Parsons, and Askham, 2008).

The breadth of domains claimed by the campaign and its definitional flexibility have allowed for the development of a similarly broad collection of interventions. Exhortatory and educational interventions have addressed frontline providers, administrators, and the general public, seeking to build awareness of dignity issues and increase capacity among the care workforce to deal with these issues. Specific tools have been designed to guide frontline providers’ behaviours in areas like privacy and to benchmark the dignity component of care quality in service provision (Jacobson, 2012).

These dignity-related best practices and standards also have aimed to change administrative and organisational procedures and practices, while the development of regulatory structures and the invocation of legal authority are designed to influence systemic policy.

Critics of the campaign as it is actually being implemented, however, fault its failure to move much beyond the individual level of provider knowledge, attitude, and behaviour (Jones and Aranda, 2009; Aranda and Jones, 2010). Pointing to the kinds of structural constraints described in health care settings, their critiques suggest the need for the campaign to promote a more politically sophisticated and socially situated understanding of dignity and to make organizations and systems, rather than individuals, the targets of change.

Lord Darzi’s review states:

> "Quality of care includes quality of *caring*. This means how personal care is the compassion, dignity and respect with which patients are treated. It can only be improved by analysing and understanding patient satisfaction with their own experiences" (DH, 2008, p.47).

2.7 The 'Dignity in Care' campaign

The "Dignity in Care" campaign (Dignity in Care Network, 2008) has sought to engage a broad range of domains of action and interaction, which include action to:

- Raise awareness of Dignity in Care,
- Inspire local people to take action,
- Share good practice and give impetus to positive innovation,
- Transform services by supporting people and organisations in providing dignified services,
- Reward and recognise those people who make a difference and go that extra mile.

Providers and commissioners of services, as well as, members of the public are invited to volunteer as 'Dignity in Care Champions' so as to *"take forward a dignity in care social movement*" and raise the profile of dignity in care, challenge bad practice, and share experiences and expertise (Dignity in Care Network, 2008; 2013).

2.8 The dignity challenge - *The 10 Dignity Do’s*

The Dignity Challenge (Box 2.5) helps staff ensure that residents are treated as unique individuals who are respected and valued just because they are human (Dignity in Care Network, 2013).

The "Dignity Challenge" (DH, 2006c) (SCIE, 2013b) is a ten-point plan known as the *10 Dignity Do's* (formerly, the 10-point dignity challenge) which describes values and actions that must be promoted so that high quality services are provided and maintained in order to respect people's dignity (National Dignity Council, 2016).

Box 2.5: The 10 Dignity Do’s (National Dignity Council, 2016, p. 4)

1. Do have a zero tolerance of all forms of abuse.
2. Do support people with the same respect you would want for yourself or a member of your family.
3. Do treat each person as an individual by offering a personalised service.
4. Do enable people to maintain the maximum possible level of independence, choice and control.
5. Do listen and support people to express their needs and wants.
6. Do respect people's right to privacy.
7. Do ensure people feel able to complain without fear of retribution.
8. Do engage with family members and carers as care partners.
9. Do assist people to maintain confidence and positive self-esteem.
10. Do act to alleviate people's loneliness and isolation.

Siviter (2013) emphasises that those working as professional carers must provide residents with non-judgmental care, promote their autonomy, as well as, ensure that the support they provide is respectful. In her article, the author adds that the Dignity Challenge "is there for all members of the care team" and insists that "any staff member who feels there is a failure in dignity must speak up, or they have added to the failure" (*ibid.*, pp. 682).

> "It is not a coincidence that the word ‘care’ means two things: the acts that people undertake for others (giving care); and doing things with kindness and consideration (being caring)" (Siviter, 2013, pp. 680-681).

It is easy to implement the dignity challenge in the care home (Dignity in Care Network, 2013) and it is an important step to ensuring an environment in which dignity can thrive (Siviter, 2013).

Part II: Holistic care in care homes for older people

2.9 Relocation and admission into long-term care

Relocation is defined as the change that occurs when people move their primary living space from one environment to another (Maas, Buckwalter, and Hardy, *et al.*, 2001). Relocation to long-term care is a major life event. The move to long-term care is often influenced by the older person's ill health (Svidén, Wikström, and Hjortsjö-Norberg, 2002) or his or her inability to keep up with household demands (Tracy and DeYoung, 2004). Other influences include carer burden, falls and lack of support (Pearson, Nay, and Taylor, 2004; Tracy and DeYoung. 2004; Cheek, Ballantyne, Gillham, *et al.*, 2006). The decision to relocate is often precipitated by confusion and crisis (Magilvy and Congdon, 2000) and invariably described in negative terms (Lundh and Sandberg, 2000). A pervasive theme is urgency to move older people from acute care (Cheek and Ballantyne, 2001), with individuals involved passively in decisions (Reed, *et al*., 2003, Coffey, 2006) and their choices restricted by poor information (Reed, *et al.,* 2003, Cheek, *et al.,* 2006). For those without advocates, navigating the system would be almost impossible - (After moving to long-term care, people can initially experience feelings of disbelief, loss and sadness) (Cook, 2006; Heliker and Scholler-Jaquish, 2006) [cited in Fraher and Coffey, 2011].

How well someone adapts to their new situation is influenced by the nature of the admission, for example, whether it was elective or not (Iwasiw, Goldenberg, Bol, *et al.,* 2003; Chao, Lan, Tso, *et al.,* 2008). In Ireland, as in the UK, national standards for care of older people highlight the importance of consultation about care decisions (Department of Health, 2003; Health Information and Quality Authority, 2008). However, few recent studies have focused on the older person's experience of this momentous decision (Cheek, *et al.,* 2006).

Admission to long-term care is a major life event and ought to be taken after a thorough and sensitive informed consent procedure. Older adults often have a different perspective in their decision of living in their community, despite the appreciation of potential risks and inconveniences. This often conflicts with the values and preferences of their family members or health care providers, creating a risk of infringing the individual’s autonomy through coercion, inadequate information of alternative community resources or not allowing for the person’s expressed wishes to be considered (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2013).

In the context of this thesis and extrapolating from the study conducted by Allen, Hogg, and Peace (1992), it tends to reinforce the evidence presented throughout this thesis, in that, people do not know about things until they need them, and even then, they may find it difficult to get information. Accordingly, there is not a widespread knowledge base among either older people or their carers about services for older adults, both in the community or in residential care. In their study, Allen, *et al.*, (1992), may have shed some light on the difficulties still faced by today’s older adults in residential care, in that, "it is very difficult to exercise choice if you know very little, and it is even more difficult to participate in decisions about your care if you are not aware of what is available".

Thus, even though their study was conducted more than twenty years ago, it is quite possible that the same feelings are relatable to our present time. Their explorative study in regards to ‘what elderly people and their carers felt about residential care’, is reminiscent and perhaps remains still valid till today, in the 21st century. The study portrayed a very strong undercurrent of fear of what might happen to ‘them’ in residential care and among many of the *elderly* people who were interviewed, there was a fear of losing autonomy and some saw no escape once a home had been entered, as described by an older adult lady in the northern area of the U.K.:

> "Put your faith in God. He’ll look after you. Old people don’t last long when they go into homes. You can’t make your own decisions ..."
>
> "Because then your independence has gone completely. You are watched over all day and fed when they want. You cannot lead a life as you want to ..."

Could these forms of expression be the general thoughts of older adults in residential care and is it representative of their loss of dignity? What remains a certainty however, is that, it is clearly wrong to assume that older people constitute a homogeneous group (Allen, Hogg, and Peace, 1992).

2.10 Long-term care [LTC]

Literature on long-term care policy, has tended to favour home- and community-based provision in recent decades, due to consumer preference and for cost-containment purposes. However, there remains a critical demand for institutional care, particularly among those who are oldest and/or experiencing the most severe impairments or co-morbidities (Scales, 2014). Furthermore, although two-thirds of LTC users receive services at home, according to OECD (2011) averages, spending on institutional care accounts for 62 per cent of total LTC expenditure; hence the importance of maintaining research attention on this sector [as cited in Scales, 2014].

In the UK, and in many other countries, older people are increasingly cared for in long-term care facilities such as care homes. These are collective institutional settings where care is provided for older people who live there, 24 hours a day, seven days a week, for an undefined period of time (Hall, Dodd, and Higginson, 2014).

The care provided includes on site provision of personal assistance with activities of daily living. Nursing and medical care may be provided by on-site nurses employed by the home (in nursing homes) and medical professionals working from an organization external to the setting (Froggatt and Reitinger, 2013). Residents are often heavily reliant on staff for their care, which can erode their sense of dignity (Hall, Dodd, and Higginson, 2014). Loss of dignity remains a major issue in the lives of older people in many countries (Tadd, 2004). Although dignity is an important aspect of quality of life for residents (Kane, 2003) and a strong predictor of residents' satisfaction with their care, (Burack, Weiner, Reinhardt, *et al.*, 2012), concerns have been raised about loss of dignity in care settings (Cass, Robins, and Richardson, 2009).

Hall, *et al.*, (2014) affirm that several qualitative studies have explored the construct of dignity from the perspective of care home residents, (Franklin, Ternestedt, and Nordenfelt, 2006); (Pleschberger, 2007); (Hall, Longhurst, and Higginson, 2009), and more recently, a survey study comparing nursing home residents' with family members' and HCPs (namely physicians and nurses) about the factors that influence (their) dignity using the MIDAM-LTC Tool (Oosterveld-Vlug, *et al.*, 2015).

Long-term care embodies a set of services delivered over a sustained period of time to people who lack some degree of functional capacity. Put alternatively, long-term care is the help needed to cope, and sometimes to survive, when physical and cognitive disabilities impair the ability to perform activities of daily living, such as eating, bathing, dressing, toileting, and walking. Long-term care services are needed by a diverse set of individuals who receive care from an equally wide array of providers. As the result of their diminishing abilities, older individuals especially the very old are more likely to be recipients of long-term care services; however, younger individuals with physical or mental limitations also require services in some instances (Grabowski, 2008).

Literature indicates that the primary providers of long-term care services are "informal" providers such as family members and friends (Grabowski, 2008); (Troisi and Formosa, 2004). On the other hand, formal providers include nursing homes, board and care homes, home health care agencies, assisted living facilities, adult foster and day care homes, and continuing care retirement communities (Grabowski, 2008).

Sinha (2012) elaborates further in saying that long-term care (LTC) requires specialised leaders and skilled staff to care for some of the most vulnerable people in our society. To this end, one area which is likely to be of great concern to residents of care homes, is preserving dignity (Pleschberger, 2007), and lack of dignity, results in many complaints and substantial media interest (Tadd, *et al.,* 2011). Albeit not the focus of this thesis, considering the geographical size of the Maltese Islands and its population, it must be highlighted that in the local scene, there too has been a relative increase in the number of reported incidents covered in the media, more so over the past few years, although it may be plausible to say that many other cases still remain unmentioned.

Formosa (2013, p. 95), revealed that, "presently there is no legislation on the setting up of nursing home services, with Church-run and private LTC being governed by residential requirements that are little more than health and safety legislations. He emphasised the, "urgent need for serious discussion, and subsequently legislation that establishes national quality standards that focus on objectives of nursing residential care, quality of care, education and training of staff, values, staff-client ratios, monitoring and evaluation processes, and physical environmental issues".

At the time of publication in April 2015, the National Audit Office, Malta, also reported that the National Standards of Services to be provided in LTC residences for the elderly were still in the process of compilation. Therefore, the absence of these published standards led to an administrative and operational vacuum, which in turn prohibited robust enforcement of services provided in residential homes by the Department for the Elderly [DfE] and other national competent authorities (NAO, Malta, 2015).

However, at the time of writing this thesis, the National Minimum Standards for Care Homes for Older People (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2015), was officially launched on the 30th September 2015 and implementation of the standards in the local scene, seems at best, in its early days. To this end, there remains a major concern, since many healthcare professionals hold stereotypical, negative attitudes towards older people (Lothian and Philp, 2001).

2.11 Life expectancy in residential and nursing care

"The figures around life expectancy of older people in residential and nursing care are contested; however, average life expectancy of an older person admitted to a care home that offers personal care is between 2-3 years and 1-2 years in a nursing home" (Goodman, 2011). Others refer to "a median life expectancy of approximately 15 months" (Forder and Fernandez, 2011; Horlick, 2013; British Geriatrics Society, 2012 as cited in The Older People's Commissioner for Wales, 2014, p. 4).

The majority of people institutionalised in nursing homes die within two years of their arrival, "whilst approximately 27% of older people live in care homes for more than three years" (Forder and Fernandez, 2011 as cited in The Older People's Commissioner for Wales, 2014, p. 4).

In 2008, the Royal College of Nursing (RCN) Scotland, ahead of a Scottish parliament debate on patients' rights, had urged the Scottish Government to place dignity in patient care at the heart of all its health policies. At the time, the associate director of RCN Scotland, Ellen Hudson, stated that all government decisions must be "dignity proofed" and that "all decisions, whether they concern staff numbers or the design of wards, must improve or at least maintain levels of dignity" (The Scotsman, 2008).

2.12 Person-centred care

Here, it is to be highlighted that the term “patient-centred” in medicine was first mentioned in 1970 by Balint and his colleagues, as an alternative approach to traditional medical practice which they portrayed as “illness-centred medicine”. In their view, a considerable proportion of patient complaints arose from emotional stress and not physical causes and they recommended that a thorough understanding of the patient’s complaints, based on patient-centred thinking, was important in promoting healing (*ibid.*).

There are several existing models in the literature and some of them attempt to delineate its predominant characteristics. The majority of these frameworks still focus mainly on the clinical experience of health care and are essentially variations of patient-centred care. Authors, academics and professional institutions such as Levenstein, the Picker Institute, the Institute of Healthcare Improvement [IHI] and the Institute of Medicine [IOM] have worked on the advancement on the concept of patient-centeredness and extending it to involve the patients’ families. The WHO has issued several studies and reports addressing the issues and challenges faced by today’s health care systems, particularly in relation to putting people at the centre of health care [as cited in Parliamentary Secretariat for Health Ministry for Energy and Health, 2014].

More recently, the Picker Institute Europe (2016) has published a new briefing; “*Person centred care in Europe: a cross-country comparison of health system performance, strategies and structures*.” The document provides an overview of the different approaches taken to providing quality healthcare across Europe by looking specifically at the person centred care interpretations and strategies taken in England, Italy, Spain, Germany and the Netherlands.

Highlighting the briefing’s core value, Giuseppe Paparella, Policy Officer at the Picker Institute (2016) said;

> “Despite the international prominence of the concept of person-centred care, the practice and policy of different nations is not always well publicised, and there have been few attempts to compare and contrast the way in which the principles of person-centred care are being adopted and advanced in different jurisdictions. In recent years, it has taken on heightened prominence, with many health services and providers explicitly aspiring to provide person-centred care”.

And yet, although many commentators profess that every service user has unique care co-ordination needs and concerns that can only be met by understanding their individual lifestyles and circumstances; unfortunately, older people remain particularly vulnerable to social isolation and loneliness, and there is much evidence of the negative impact this has on their general health (Nursey, 2015).

Reyna, *et al.,* (2007) state that prejudices against older adults have been shown to reduce effective care delivery which in turn impact upon long-term health outcomes for older adults. Thus, it is necessary to challenge these attitudes in order to enhance individualized, person-centred care and to ensure successful aging for older adults (Rubin, *et al.,* 2015). In fact, successful aging - defined by a low probability of disease, high cognitive and physical capabilities, and active engagement with life (Rowe and Kahn, 1997) - can be enhanced through interventions that promote productive and social engagement (Reichstadt, Sengupta, Deppet, *et al.,* 2010).

Bodner (2009) also remarks that in promoting successful aging, educators, researchers and practitioners often face the prejudice and stereotypes of ageism (fear of older people) and gerontophobia (fear of our own aging), as aging anxiety remains pervasive.

2.13 Ageism - dispelling myths

Independence and self-reliance are commonly acknowledged as cultural imperatives associated with the West (Rodgers and Neville, 2007) and yet ageism is apparent in many social structures and contexts and in diverse forms over the life cycle (Bodner, 2009). To address ageism and gerontophobia, it is important to raise awareness of how culture shapes attitudes about older adults and attitudes about our own aging (Gendron, Welleford, Pelco, *et al.,* 2014).

Butler (1969) first utilised the term ageism to describe the negative and stereotypic bias resulting in older people experiencing first hand, society's bigoted views about old age. He considered ageism to be:

> "a process of systematic stereotyping and discrimination against people because they are old, just as racism and sexism accomplish this for skin colour and gender. Older people are characterised as senile, rigid in thought and manner, and old-fashioned in morality and skills … Ageism allows the younger generation to see older people as different from themselves; thus they subtly cease to identify with their elders as human beings".

However, unlike sexism and racism, most people have not even heard of ageism or have only heard of it very recently; ageism affects everybody irrespective of race and gender, and that unlike the physical signs of race and gender, the signs of old age are gradual and subtle (Palmore, 1990 as cited in Formosa, 2000).

Butler (1980) extended his definition of ageism to include how institutional practices, guidelines and policies promulgate negative stereotypes about older people. He claims that ageism moves the focus of ageing away from it being a natural process to it being a social problem. Therefore, the problem of ageing often results in older people experiencing detrimental consequences, including social death as a result of paternalistic and infantilising practices and most specifically the loss of the right to autonomous behaviour.

Indeed, western society appears to promote old age as a time of decline, deterioration and the loss of aspects of functioning, and in doing so promotes dependency in this group of people (Minichiello, Somerville, McConaghy, *et al.*, 2005). As a result, older adults are marginalised through being placed in institutions such as residential care facilities. They are stigmatised, disempowered, treated like children and objectified. Objectification means that individuals are portrayed in terms of their functional status and as a set of health problems that need to be attended to, rather than as individuals with rights, needs and desires (Agich, 2004). Rodgers and Neville (2007), reaffirm that promoting dependency and infantilising of the older person are due to biased attitudes which in turn reinforce discriminatory practices.

Any ageist practices, such as those described above, reinforce the world view of old age as a time of physical decrepitude and dependency (Hockey and James, 2003). Ageism is therefore a direct threat to personal autonomy in older people (Rodgers and Neville, 2007).

Local research on ageism has tended to focus on four distinct areas of interest, namely: 1) *Societal images*; 2) *Employment and the Labour market*; 3) *Class*; and 4) *Gender relations* (Formosa, 2000) and Maltese research on ageism has been restricted to only the former and latter areas of inequality (Formosa, 2009). Nonetheless, in reference to the first area of interest, local studies found that later life and older persons tend to be represented in a negative manner. For instance, Baldacchino (2002) [as cited in Formosa, 2009] reported that Maltese society is consistently bombarded with stereotypical visual and audible information that highlights older persons' inevitable psychological and physical decline, as well as predestined dependence and need of institutionalisation.

Within some sections of society there seems to be a general lack of tolerance, sensitivity and disregard towards the needs of older people. Older people are often portrayed as a burden and demanding; healthcare is not immune to these negativities. There are many prejudices and myths that require dispelling, with regard to caring for older people (McSherry and Coleman, 2011). To ensure a reasonable place for older persons in society, Butler (1989) calls upon the need to review some of these contemporary myths, stereotypes, and distorted facts, which must be dispelled or reduced**.**

Accordingly, Traxler (1980), [as quoted in Woolf, 2000 and cited in Formosa, 2000], outlined four factors that have contributed to the origins and development of ageism.

1) **Fear of death in Western society** - death is felt and perceived as an offence to the self rather than a normal and foreseeable part of the life course.

2) **Emphasis on youth culture in society** - the media, place a high emphasis on early life, bodily attractiveness, and sexual characteristics.

3) **Economic capability** - economically, older adults are perceived as a financial liability, where upon retirement, the older adult is no longer viewed as economically productive and thus undervalued.

4) **Nature of how ageing was originally studied** - since most early Gerontological research focused upon older individuals with poor functional abilities.

Undoubtedly, as the ageing demographic grows, so will the demand for care home places increase, placing mounting strain on existing services (Forder and Fernandez, 2011). And yet, despite the fact that these figures are not new and have been in the public domain for a while, many countries are not putting in place policies and programmes to deal with the onset of what is being referred to as the "*grey tsunami*" (Ellen, 2012).

It must be highlighted that, ironically, even organisations that purportedly have the well-being of the aged high on their agenda may inadvertently use terms like '*tsunam*i' or other similes to make the point of the urgency in addressing the many challenges that society is facing associated with the ageing of the population, even when that ageing process is the result of all the wonderful advances that have been achieved in medical and other healthcare-related practices (Gordon, 2015).

In an article, titled "*Let the reader think of the burden: Old Age and the Crisis of Capacity*" published in Occasion: Interdisciplinary Studies in the Humanities in 2012, Charise takes on a comprehensive exploration on the use of such terms as tsunami and other categorisations of aging especially as expressed in the media and in literature. In it she notes, "… the language of ageism is promiscuous. Its terms are not confined by discipline. Yet the literary study of older age provides an opportunity to witness the ethical stakes of the metaphors we live by …"; a point she elaborates upon specifically for a medical and healthcare professional audience in her widely cited 2012 podcast for the Canadian Geriatrics Society — *Rising Tide, Grey Tsunami: Charting the History of a Dangerous Metaphor*. "Is the progressive aging of society really equivalent to the instantaneous devastation of cities?" Charise asks. "What is at stake when they're held up as equivalent?" Her answer should be a wake-up call for health professionals and media alike. "The grey tsunami metaphor has the potential to endanger the validity of caring for elderly: if the elderly (people) are like a dangerous tsunami, then why would we work to prolong or improve quality of life for this threatening population?" (Charise, 2012 as cited in Gordon, 2015).

With reference to the introductory part of the research study and the scope of this thesis on dignity and expectations of care, Gordon (2015) accentuates that:

> "it is important that all of us, especially healthcare professionals committed to eldercare in all the various domains, stay attuned to the use of language, often in subtle forms to diminish the intrinsic, human and societal value of our aged population: they who are our mothers and fathers, and grandparents, and us in the years to come. It is 'they' that have built the world we live in and carry the narrative of our world with them for all of us to enjoy, bemoan, but most of all learn from, recognise, and, in most instances, admire."

2.14 Elder abuse

Elder abuse is a term used to describe certain types of harm to older adults. Unfortunately, it is a common problem with serious consequences for older people’s health and well-being (McBride, 2011).

Thus, in view of the above section, perhaps the most insidious form of abuse against the elderly lies in the negative attitudes towards, and stereotypes of, older people and the process of ageing itself, attitudes that are reflected in the frequent glorification of youth. Therefore, as long as older people are devalued and marginalised by society, they will suffer from loss of self-identity and remain highly susceptible to discrimination and all forms of abuse (World Health Organization, 2002).

According to the Department of Health (2000, para. 2.5), "abuse is a violation of an individual's human and civil rights by any other person or persons".

By far, elder abuse is not a new phenomenon with literature dating back as far as 1975, and since then, many terms have been used over the years to describe this problem, such as, ‘elder mistreatment’, ‘abuse in later life’ and ‘abuse of older adults’. Despite McBride’s (2011) affirmation that there is no clear consensus regarding its definition, it is generally agreed that abuse of older people is either an act of commission or of omission (in which case it is usually described as "neglect"), and that it may be either intentional or unintentional. The abuse may be of a physical nature, it may be psychological (involving emotional or verbal aggression), or it may involve financial or other material maltreatment. Regardless of the type of abuse, it will certainly result in unnecessary suffering, injury or pain, the loss or violation of human rights, and a decreased quality of life for the older person (Hudson, 1991).

Whether the behaviour is termed abusive, neglectful or exploitative will probably depend on how frequently the mistreatment occurs, its duration, severity and consequences, and above all, the cultural context (World Health Organization, 2002). Conceivably, the most commonly accepted definition was devised by the UK Charity Action on Elder Abuse (AEA) (1995); (2004) and subsequently, this definition was adopted by the International Network for the Prevention of Elder Abuse (INPEA) and the World Health Organization (WHO) (McBride, 2011), which states that:

> "Elder abuse is a single or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person" (1995, p.11).

Such abuse is generally divided into the following categories (World Health Organization, 2002):

- **Physical abuse** – the infliction of pain or injury, physical coercion, or physical or drug induced restraint;
- **Psychological or emotional abuse** – the infliction of mental anguish;
- **Financial or material abuse** – the illegal or improper exploitation or use of funds or resources of the older person;
- **Sexual abuse** – non-consensual sexual contact of any kind with the older person; and
- **Neglect** – the refusal or failure to fulfil a caregiving obligation. This may or may not involve a conscious and intentional attempt to inflict physical or emotional distress on the older person.

This definition of elder abuse has been heavily influenced by the work done in Canada, the United Kingdom and the United States. Studies conducted in China (Hong Kong SAR), Finland, Greece, India, Ireland, Israel, Norway, Poland and South Africa have approached the topic in distinctly different ways (Kosberg and Garcia, 1995). Norwegian researchers, for instance, identified abuse with a "triangle of violence" that includes a victim, a perpetrator and others, who - directly or indirectly - observe the principal players. In countries such as China, that emphasize harmony and respect within society, neglecting the care of an older person is considered an act of elder abuse. If family members fail to fulfil their kinship obligations to provide food and housing, this also constitutes neglect (World Health Organization, 2002).

Mistreatment of older people has been identified in facilities for continuing care (such as nursing homes, residential care, hospitals and day care facilities) in almost every country where such institutions exist. Various people may be responsible for the abuse: a paid member of the staff, another resident, a voluntary visitor, or relatives or friends. An abusive or neglectful relationship between the older person and their caregiver at home may not necessarily end once the older person has entered institutional care; the abuse may sometimes continue in a new setting.

Hence, a distinction must be made between individual acts of abuse or neglect in institutional settings and institutionalized abuse – where the prevailing regime of the institution itself is abusive or negligent. In practice, though, it is often difficult to say whether the reasons for abuse or neglect found in an institutional setting have been caused by individual acts or through institutional failings, since the two are frequently found together (*ibid.*).

Bennett, *et al.*, (1997) argue that the spectrum of abuse and neglect within institutions spans a considerable range, and may be related to any of the following:

- **The provision of care** – for example, resistance to changes in geriatric medicine, erosion of individuality in the care, inadequate nutrition and deficient nursing care (such as lack of attention to pressure sores).
- **Problems with staffing** – for example, work related stress and staff burnout, poor physical working conditions, insufficient training and psychological problems among staff.
- **Difficulties in staff–resident interactions** – for example, poor communication, aggressiveness on the part of residents and cultural differences.
- **Environment** – for example, a lack of basic privacy, dilapidated facilities, the use of restraints, inadequate sensory stimulation, and a proneness to accidents within the institution.
- **Organizational policies** – for example, those that operate for the benefit of the institution, giving residents few choices over daily living; bureaucratic or unsympathetic attitudes towards residents; staff shortages or high staff turnover; fraud involving residents' possessions or money; and lack of a residents' council or residents' family council.

On the other hand, McBride (2011) warns that abuse can occur in the setting of a badly run establishment and it is more likely to take place when members of staff are: inadequately trained, under-supervised, poorly supported by management or working in isolation.

WHO (2002) advises that much can be done to prevent abuse of the elderly in institutional settings and measures that may be useful include: 1) the development and implementation of comprehensive care plans, 2) training for staff, 3) policies and programmes to address work related stress among staff, and 4) the development of policies and programmes to improve the physical and social environment of the institution.

2.15 The long-term care workforce

In a recent doctoral thesis study conducted by Scales (2014), she highlights that most (Knowledge Translation - KT) research has focused on professional groups of practitioners working in acute health-care settings, including doctors, nurses, and allied health professionals, leaving LTC settings and support workers in the shadows.

In the United Kingdom, this setting is home to a resident population of approximately 414,000; this represents less than one per cent of adults between the ages of 65 and 74 but almost 16 per cent of those aged 85 and above (Age UK, 2013).

The vast majority of care for these residents is provided by care assistants, whose role includes assisting residents with activities of daily living (ADLs) such as eating, dressing, bathing, and using the toilet; performing a range of clinical tasks such as recording vital signs and collecting specimens; assisting with range-of-motion and other mobility measures; engaging residents in activities; and, least measurably, providing social interaction and emotional support. For the reason that they have the most sustained contact with residents, care assistants also play a critical role in monitoring their health and reporting any changes or potential problems. These staff, therefore, have significant influence over residents' day-to-day quality of life, especially for those residents with the most severe physical and/or mental impairments and thus the highest level of dependence.

Efforts to improve the quality of LTC – which has been recognised as falling behind the evidence-based curve (Farkas, *et al.,* 2003; Levenson and Morley, 2007) – must therefore, take into account care assistants' knowledge and practice. However, with little formal training and limited autonomy in their role, these staff certainly do not fit the profile – already problematized within KT studies – of the sovereign practitioner who reads the relevant reviews, analyses the findings in light of their professional expertise, discusses the matter with colleagues, and makes reasoned choices about implementation. Given the lack of evidence about how these staff *do* learn about, develop, and change their practice, most interventions default to standard in-service training approaches, with little attention to how the training content will be transferred to and sustained in practice.

This issue is particularly salient for the purpose of this study on *dignity in care* and the perceptions of (formal) carers working directly with older adults in residential care.

2.16 Chapter summary

This chapter was divided into two parts. Part I, highlighted that dignity has a range of meanings and that the term is used in varying contexts. From a healthcare perspective, the literature review indicated that dignity is experienced through feelings (internalised), expressed through physical appearance and personal behaviour (externalised), and all of which are influenced by the attitude and behaviour of others. Feeling in control is a major attribute which relates both to personal feelings and the behaviour of others. The literature also provided descriptions of the several interventions designed to address the dignity-related knowledge, attitudes, and behaviours of health and social care providers. Of particular interest was the dignity intervention in relation to the *10 Dignity Do's*, especially as it was used as a benchmark during the analysis of the findings for this study, as discussed in Chapter 5.

Meanwhile, Part II, dealt with the holistic care in care homes for older people, unveiling aspects in relation to the effects that relocation and admission to a long-term care facility may have on older adults. Differences in life expectancy for older adults in a care home seem to vary depending on the quality of care and service delivery together with a positive approach towards validation of person-centeredness.

The stereotypical and ageist attitudes of today's society were presented along with another very pertinent issue, that is, elder abuse, especially since these elements are major contributing factors which negatively impact upon older people's health and well-being. The final section of this chapter was dedicated to what the literature identifies as gaps in the long-term care workforce in terms of service delivery for older adults and the lack of skilled training in the Gerontological field, predominantly, from the bottom-up, *i.e.* specialised training for carers, especially since they form an integral part of the nursing team and their presence in the life of older adults in care homes is a constant. Therefore, the role of a carer must not be underrated and provisions for the betterment in practice for this large workforce is a requirement.

The next chapter highlights the significance of global population ageing and the Maltese context; and finally, the location of this study is also addressed.

Chapter 3

The empirical universe

3.1 Global Trends in Population Ageing

> "Let's remember: people getting older is not a crisis; it's a blessing"
> (Poo and Conrad, 2015).

While global aging represents a triumph of medical, social, and economic advances over disease, it also presents tremendous challenges. Population aging strains social insurance and pension systems and challenges existing models of social support. It affects economic growth, trade, migration, disease patterns and prevalence, and fundamental assumptions about growing older (National Institute on Aging, 2011a).

At the international level, population ageing has come to dominate the demographic scenarios of all continents (Formosa, 2015a). This crossover is the consequence of the long term reductions in fertility and mortality that are leading to the steady ageing of the world population (United Nations, 2007).

This process leads to a relative reduction in the proportion of children and to an increase in the share of people in the main working ages and of older persons in the population (United Nations, DESA, 2013). The global share of older people (aged 60 years or over) increased from 9.2 per cent in 1990 to 11.7 per cent in 2013 and will continue to grow as a proportion of the world population, reaching 21.1 per cent by 2050 (*ibid.*). Not only is the world ageing, but it is also ageing differently (IFSW, 2012). Globally, the number of older persons (aged 60 years or over) is expected to more than double, from 841 million people in 2013 to more than 2 billion in 2050 (United Nations, DESA, 2013).

An important feature of population aging is the progressive aging of the older population itself. The fastest-growing age group is the over-80s (McSherry and Coleman, 2011). Globally, the share of older persons aged 80 years or over (the "oldest old") within the older population was 14 per cent in 2013 and is projected to reach 19 per cent in 2050. Accordingly, if this projection is realised, there will be 392 million persons aged 80 years or over by 2050, more than three times the present (United Nations, DESA, 2013).

Statistics show that the older population is predominantly female. As women tend to live longer than men, older women outnumber older men and comprise the larger segment of the older adult population in many countries (IFSW, 2012). In 2013, globally, there were 85 men per 100 women in the age group 60 years or over and 61 men per 100 women in the age group 80 years or over. These sex ratios are expected to increase moderately during the next several decades, reflecting a slightly faster projected improvement in old-age mortality among males than among females (United Nations, DESA, 2013).

Population ageing has major social and economic consequences. The old-age support ratios (number of working-age adults per older person in the population) are already low in the more developed regions and in some developing countries, and are expected to continue to fall in the coming decades with resultant financial pressures on support systems for older persons. In a number of developing countries, poverty is high among older persons, sometimes higher than that of the population as a whole, especially in countries with limited coverage of social security systems (United Nations, DESA, 2013).

Presently, about two thirds of the world’s older persons live in developing countries. As the older population in less developed regions is growing faster than in the more developed regions, the projections show that older persons will be increasingly concentrated in the less developed regions of the world. Therefore, by 2050, nearly 8 in 10 of the world’s older population will live in the less developed regions (*ibid.*) Simultaneously, besides the low fertility rates, overall population is also declining in many countries due HIV/AIDS and international migration (National Institute on Aging, 2011b).

The United Nations estimates that the number of adults 60 years and older will outnumber children under the age of 15 - a historical first - by 2045 (IFSW, 2012); (United Nations, 2007).

3.1.1 The Gerontological transition

Without a doubt, the last century witnessed unprecedented demographic changes to the extent that the final three decades have been termed as the “age of ageing” (Formosa, 2009). As a result, the world is in the midst of a unique and irreversible process of demographic transition that will result in older populations everywhere (United Nations, 2015).

Since, older adults comprise a growing proportion of the global population; this population shift has far-reaching socioeconomic and political implications for people of all ages. Older adults make valuable contributions to society, both material and immaterial, and younger generations benefit from their experience (IFSW, 2012).

Increased longevity and the growing presence of older adults create new opportunities for both individual and societal development. At the same time, social and economic policies, services, and research are needed to enhance the well-being of older adults and to eliminate the ageism that prevents older people from living with dignity, realising their full potential, and accessing resources (National Association of Social Workers, U.S., 2006).

3.2 The Maltese Context

3.2.1 Population Ageing & Ageing Policy

The three main islands, Malta, Gozo and Comino, form an archipelago in the Mediterranean Sea that has the highest average population density in Europe (1325 persons per km^2) (Parliamentary Secretariat for Health, 2014).

As with the rest of the world, Malta’s Gerontological transition has also seen a change (The National Commission for Active Ageing, 2013). The Census of Population and Housing is a nationwide exercise which is generally carried out approximately every ten years. Official censuses in Malta date back to 1842, with the 2011 Census being the 17th in the series. Over a century, the population of Malta has nearly doubled, from 211,564 in 1911 to 417,432 in 2011, while it increased more than three-and-a-half times since the first census in 1842, totalling at 114,499 persons (National Statistics Office, 2012); (Parliamentary Secretariat for Health, 2014).

However, the Maltese population is ageing with a steady decrease in the percentage of persons under 15 years whom in 2011 accounted for 14.8% of the population, and an increase in the number of persons 65 years and over whom accounted for 16.3% of the population; the percentage of persons aged 80 years and over is also steadily increasing, standing at 3.6% of the total population in 2011 (Parliamentary Secretariat for Health, 2014).

Whereas the old-age *dependency ratio*[7] in 2011 registered at 23.7%, which was lower than the EU average, reportedly at 26.8% (National Statistics Office, 2012).

In contrast to the global population ageing phenomenon, it is worthwhile to note that the development of the ageing population in Malta was experienced in a slower fashion. In fact, it was only in the twentieth century that marked changes in the age composition of the Maltese population started to emerge. This is in sharp contrast to what happened in other countries which were already in the process of their demographic transition (Formosa, 2015a, p. 46). While in the year 1901, the 0-14 and 65-plus age groups consisted of 34.1 and 5.4 per cent, in 2012 these age groups reached 14.5 and 17.2 per cent respectively (Formosa, 2013b). The Maltese median age in the year 2011 stood at 40.5 years, up from 38.5 years in 2005 (Formosa, 2015a, p. 46).

Consequently, during the course of the 20th Century, the Maltese population has evolved out of a traditional pyramidal shape – characteristic of low income developed countries - to an even-shaped block distribution of equal numbers at each cohort except at the top, where older women out-number older males (Formosa, 2015a). From a policy perspective, the population pyramid helps to envision cohorts that will be entering pensionable age in twenty years' time.

Likewise, as in other international circles, such fluctuations in Malta's Gerontological transition were largely the result of a declining birth rate together with an increasing life expectancy for both men and women (*ibid. p.47*). Although there was a slight increase of 0.4 per cent in births compared to 2008, the fertility rate remained unchanged at 1.4 in 2011, down from 1.7 in 2001.

Life expectancy in Malta has steadily increased over the past 20 years and compares well with the EU average. In parallel, while at the beginning of the 20th Century life expectancy in Malta was around 43 years for men and 46 years for females, in 2013 these figures reached 79.6 and 84.0 years respectively (EU-28 average: 77.8 and 83.3

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[7] "The dependency ratio is misunderstood. Not everything is given to the elderly. It is true that there is an increasing number of retirees compared to non-retirees. But if one looks at the total dependency ratio, that is, including both people under 18 and people 64 and above, there has been a steady decline in the total dependency-support ratio since the year 1900, and this decline will continue to the year 2050 and the reason is the low birth-rate - just below zero population growth" (Butler, 1989, p. 143).

years for men and women, respectively) (Eurostat, 2015); (National Statistics Office, 2014a).

The National Statistics Office is Malta’s official national statistical agency and conducts a number of surveys, in line with EU harmonised standards and methodologies (National Statistics Office, 2014a; 2014b).

Accordingly, Malta registers excellent results in Health Life Expectancy. At the age of 50, Maltese women and men are both expected to live an additional 23 healthy life years, second only to Sweden amongst EU-27 Member States where male and female citizens can expect 26 and 25 additional healthy life years respectively (Formosa, 2013b).

Formosa (2009) concedes that similarly to other countries, even the traditional caring role of the Maltese family is being subjected to considerable strain. This is due to the fall in the average Maltese family size which has resulted in a reduction of the number of available carers for older persons. Moreover, the ever increasing participation of females in the labour force continues to diminish their availability as carers. The consequence is a higher dependence on residential and nursing homes to care for semi-dependent and frail older persons. When older persons reach high levels of dependency, so that their needs cannot be met neither by family nor community services, they tend to enter residential or nursing care.

3.2.2 National ageing policy

As longevity is one of the universal pursuits of humankind, population ageing should be seen as an achievement rather than a threat (Leung, Woo, and Kofler, 2013). Brundtland (1999), the former Director-General of the World Health Organization, on the subject of ageing, declared that:

> "Population ageing is first and foremost a success story for public health policies as well as social and economic development."

Notably, Malta holds a key place in the history of international ageing policy. In fact, population ageing was first raised as an issue of world concern by the Government of Malta back in 1969, when it appealed for its inclusion as a supplementary item on the agenda of the 24th session of the United Nations General Assembly (Formosa, 2009). As a result, in 1982, when the first United Nations World Assembly on Ageing was held in Vienna (United Nations, New York, 1983, as cited in Formosa, 2009), it adopted a resolution in support of the implementations of age friendly policies.

This conference focused on the specific needs of older persons and the socio-economic implications of ageing, thus producing a 62-point *Vienna International Plan of Action on Ageing* [VIPAA], whereby it called for specific action on such issues as health and nutrition; protecting elderly consumers; housing and environment; family; social welfare; income security and employment; education; and the collection and analysis of research data.

With specific reference to the section on Social Welfare in the VIPAA (United Nations, New York, 1983), the 34th recommendation states:

> "Whenever institutionalization is necessary or inevitable for elderly persons, the utmost effort must be made to ensure a quality of institutional life corresponding to normal conditions in their communities, with full respect for their dignity, beliefs, needs, interests and privacy; States should be encouraged to define minimum standards to ensure higher quality of institutional care".

To this effect, some years later, in 1987, the Maltese government created the post of Parliamentary Secretary for the Care of the Elderly within the Ministry of Social Policy which served as a catalyst for the development of a spectrum of services catering for the needs of older persons (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2015). Nonetheless, it would take the Maltese state more than two decades to officially implement the National Minimum Standards for Care Homes for Older People (*ibid.*).

In December 1990, the United Nations General Assembly proclaimed October 1st as the *Day of the Older Persons* and in 1991, adopted the *United Nations' Principles for Older Persons* enumerating 18 entitlements for older persons — relating to independence, participation, care, self-fulfilment and dignity (United Nations General Assembly, 1991).

The following year, the International Conference on Ageing met to follow-up on the Plan of Action, adopting a Proclamation on Ageing. Following the Conference's recommendation, the UN General Assembly declared 1999 as the *International Year of Older Persons* and action on behalf of the ageing continued in 2002, when the United Nations' Second World Assembly on Ageing was held in Madrid. Aiming to design international policy on ageing for the 21st century, it adopted a Political Declaration and the *Madrid International Plan of Action on Ageing*. The Plan of Action called for changes in attitudes, policies and practices at all levels to fulfil the enormous potential of ageing in the twenty-first century. Its specific recommendations for action give priority to older persons and development, advancing health and well-being into old age, and ensuring enabling and supportive environments (Second World Assembly on Ageing, Madrid, Spain, 2002).

The United Nations (2015) advocate that older persons are increasingly seen as contributors to development, whose abilities to act for the betterment of themselves and their societies should be woven into policies and programmes at all levels.

3.2.3 Non-communicable diseases (NCDs)

In truth, while people are living longer lives almost everywhere, the prevalence of non-communicable diseases and disability increase as populations age (United Nations, DESA, 2013).

Globally, more people are dying from non-communicable diseases and chronic, degenerative conditions than from infectious and parasitic diseases, a trend expected to grow in the next couple of decades – and whether increased life expectancy will be associated with increases or decreases in disability status remains an open question (IFSW, 2012). At the same time, communicable diseases - especially HIV/AIDS - remain prevalent, particularly in low- and middle-income countries (Lopez, Mathers, Ezzati, *et al.*, 2006).

In considering the benefits and consequences of population ageing, therefore, it is essential to consider not only longevity but also healthy life expectancy, or expected years of life free of illness, disease, and disability (IFSW, 2012).

Although elderly persons, in general, enjoy good health and live independent lives, there exists a high proportion of disabled persons amongst those aged 75 and over who tend to frequent outpatient clinics and hospitals, residential homes, and are users of community services (National Commission Persons with Disability 2003, 2000).

In Malta, health patterns are not solely dependent on age but are also gender-related as seen in the 70-plus age group with age-specific mortality rates consistently higher for males when compared to females (Directorate for Health Information and Research [DHIR], 2013).

Reportedly, the 80-84 and 85-89-year age groups account for the largest number of deaths in both sexes (35.5 per cent of all deaths). That is to say, that whilst the 80-84-year age group reflect the largest number of deaths in males (17.1 per cent of all male deaths), the 85-89-year age group mirror the largest number of deaths in females (21.4 per cent of female deaths) (*ibid.*). Yet, males, albeit holding a lower life expectancy, are generally healthier than females, since the latter record a higher incidence of morbidity.

Statistics for Mortality during the year 2013 (DHIR) reveal that non-communicable diseases (NCDs) such as diseases of the circulatory system, mainly ischaemic heart disease, heart failure and cerebrovascular disease system (39.6 per cent) followed by neoplasms (32.1 per cent) dominate the 65-84 age group as the commonest causes of death with the average age at death from neoplasms being 7.7 years less than that from circulatory diseases.

It is worthwhile noting that diseases of the circulatory system are also deemed responsible for a similar amount of disability in the form of pain and suffering, reduced mobility and loss of independence (Cordina and Borg, 2012). With reference to neoplasms - lung, colorectal, pancreas and prostate are the leading causes of death in males; whereas breast, colorectal and pancreas are the leading causes of death in females.

Circulatory diseases again prevail in the 85-plus age group. However, other conditions including dementia, respiratory infections, renal failure and urinary tract infections are inclusively important causes of mortality in older persons. Due consideration must be given for the fact that deciding on the underlying cause of death in this age group is challenging, given that several co-morbidities are often present. Interestingly, as stated in the document, "malignancies tend to be a less important cause of death in this age group" (Directorate for Health Information and Research [DHIR], 2013).

Diabetes mellitus which is associated as an important risk factor for circulatory diseases accounts for 3.2 per cent of all deaths or 105 deaths. Reportedly, there was a decrease in the age-standardised mortality rate between 2009 and 2012 which may be attributed to changes in coding practices whereby diabetes is considered as a contributory condition to the cause of death rather than being the underlying cause of death. Even so, the overall trend shows that mortality from diabetes in both males and females in

Malta is consistently higher than that of the EU average. Additionally, the vast majority of deaths (85 per cent) occurred in hospitals or in residential homes with St. Vincent De Paul Residence accounting for 11 per cent of deaths between 2012 and 2013.

3.3: The Location

3.3.1 St. Vincent De Paul Residence - The myriads of change

St. Vincent De Paul Residence [SVPR] is situated in the southern part of Malta on lands called "ta’ l’Imghieret" covering an area of about 27½ acres. Architectural plans were completed back in 1862 by T.H. Wyatt and Hon. F.V. Inglott and at the time, these plans were seen and commented favourably on by Florence Nightingale, Dr. J. Sutherland and Captain D. Galton (Savona-Ventura, 2015).

Originally, an asylum for the *Aged and Incurables* commonly known as the "poor house", the building was opened on May 23, 1892 (Medical Staff Officers of the Malta Garrison-1892, 2015); (Cassar, 1994). This new hospice was initially intended to house 930 elderly persons and consisted of several detached wards, one or two storeys high with administration blocks, quarters for staff, and the necessary annexes. Then, in 1910, when a proposal to change the edifice into a general hospital was being contemplated, several other wards were added (Savona-Ventura, 2015). It is interesting to note that this hospice also served as a leprosy asylum (Savona-Ventura, 2006), until St. Bartholomew’s Hospital for lepers situated in the vicinity of the "poor house" and housing 120 patients was built in 1911.

Over time, other persons besides the elderly started to be admitted to SVPR. These included cases of malignancy, paralysis, mental deficiency, medical conditions including Tinea, trachoma, medical and surgical convalescence, brucellosis, and tuberculosis. Some social conditions also merited admission to St. Vincent de Paul Residence [as it was written back then]. These included children who had been abandoned (prior to 1937) and orphaned children (prior to 1939), reformed prostitutes, and women prisoners (prior to 1895) (Savona-Ventura, 2015).

The building was evacuated during the Second World War after it suffered extensive damage through enemy action and was re-opened after repairs were completed in 1944. In the post-War period it continued to serve other purposes besides the care for elderly, including the provision of isolation wards. For instance, in 1957, the hospital catered for 986 inmates including four wards devoted to chronic sick cases. The hospital also dealt with "indigent and infirm, and mentally defective children" whilst four further wards were devoted to the treatment of tuberculosis. Meanwhile, a new block consisting of three floors accommodating a further 150 inmates was being reconstructed. The medical staff included a resident Medical Superintendent, two resident medical officers, and four other medical officers responsible for the management of tuberculosis patients. The nursing duties were in charge of members of the religious order Sisters of Charity; one sister to two wards of 50-60 beds each assisted by eight hospital attendants (Savona-Ventura, 2015).

Modernization of the hospital started in 1957 and continued throughout the 1970s, 1980s, 1990s and 2000s in line with the increasing demands of care of the elderly (Savona-Ventura, 2015).

It is during these later years that a number of local authors commented on the multiplicity of roles of SVPR, describing it as a hospital and a chronic institutional care facility (Tonna, 1992), a nursing home (Gauci, 1993) and as a provider for sheltered accommodation to older persons who are independent (Cachia, 1985), [as cited in Fenech, 2001].

Then in 1994, Dimech and Fiorini [as cited in Fenech, 2001], termed SVPR as a chronic institution providing a spectrum of care, including:

1) Residential accommodation for independent older persons.
2) Multidisciplinary care for older persons with chronic medical and functional problems.
3) Psychogeriatric services for older persons with mental health problems.
4) A respite service for carers in the community.

During this same year, Fenech and Troisi (1994) [as cited in Fenech, 2001] investigated whether the long-term care at SVPR met the true needs as perceived by the older persons themselves. A list of assumed needs was correlated with Maslow’s Pyramidal Level and presented to a sample of the residents within SVPR.

Priority comparison by gender and age of the different needs was then undertaken, whereby the need to be respected for past accomplishments; the need to be able to take decisions; the need for privacy and for freedom, as well as the need to feel protected were considered to be of prime importance by these older persons.

Subsequently, Tanti in 1996, motivated by the belief that staff members with the lowest levels of training and least disposition for the job were providing round the clock care for older persons at SVPR, employed a descriptive study amongst doctors, nurses and health assistants. The study was aimed primarily at examining whether the older persons were given due respect and if the staff members were hindered in any manner from upholding the rights of the older persons. Results were indicative that most of the staff members duly gave importance to the value of life in old age and respected the older persons. Nonetheless, they appeared to be encountering considerable difficulties in the course of their work which was not conducive towards maintaining older person's rights. The staff members in the study highlighted increased staff shortages which consequently undermined their caring roles.

There is evidence that older people – especially the very elderly – may not be aware of these rights (Allen, Hogg, and Peace, 1992); (Harding, 2005); advocacy may have an important part to play here (Wright, 2006). Many care staff also remain unaware of them (Woogara, 2005). But inspection and research have also found that the framework of rights is gradually having some impact on standards of care, and next and subsequent generations of older people may increasingly demand them (Woolhead, Calnan, Dieppe, *et al.,* 2004); (Stratton and Tadd, 2005); (Cass, Robbins, and Richardson, 2009).

3.3.2 A contemporary St. Vincent De Paul Residence

To reiterate on previous discourse, St. Vincent De Paul Residence has been defined by the state as a hybrid between a nursing home and a hospital, whereby the population exceeds just over 1,100 residents and the multidisciplinary health care professional and non-caring staff manning the residence accounts to a population of 1,090 employees (Parlimentary Secretartiat for Rights of Persons with Disability and Active Ageing, 2012). This is the largest residential facility catering for older adults to be found in Malta.

The residence is a Public funded entity, with the residents' contributing 80% of their retirement pension and 60% of other income (Parlimentary Secretartiat for Rights of

Persons with Disability and Active Ageing, 2012). The government's website states that at SVPR:

> "Emphasis is made to support the activities of daily living of all residents, giving particular attention to nutrition, mobility, personal hygiene and social and spiritual activities. The holistic care approach applied caters to the well-being of every resident from a physical, psychological, social and spiritual point of view. The health and social care services at SVPR are of high standards and are provided by a myriad of health care professionals and employees that ensure the quality of life of residents."

SVPR offers a 24-hour medical service through the resident medical officers under the guidance of their respective consultants. A Comprehensive Geriatric Assessment [CGA] on admission, as well as, routine medical assessments and interventions are carried out at SVPR and most medical problems are normally dealt with in-house. Surgical, orthopaedic and complicated medical problems are referred to the main public hospital of Mater Dei. In addition to the inclusive nursing care, this majestic facility offers services such as dental, pharmaceutical, physiotherapy, occupational therapy, speech-language therapy, podiatry and ophthalmic care (Parlimentary Secretartiat for Rights of Persons with Disability and Active Ageing, 2012); (Formosa, 2009), Day Clinic, Infection Control and Social Work services. SVPR also caters for couples, especially those who are mobile or semi-mobile, and enables them to share a flat let accommodation. Respite care service is also provided as a means of offering temporary relief for informal carers in the community (Formosa, 2009). The premises also provide for two Churches, an Active Ageing Unit, a Day Centre in Dementia Care and common areas such as yards and gardens (Parlimentary Secretartiat for Rights of Persons with Disability and Active Ageing, 2012).

3.3.3 Extended-care models – the environment at SVPR

As declared by Koff (1997), perhaps the worst model has been viewing the hospital as the appropriate design for long-term care facility. For instance, in the United States, as a result of the impact of Medicare, the extended care facility became a significant health service resource, usually as an adjunct to the hospital. The assumption was then made that the extended-care facility should be like the hospital. Consequently, the trend has been to build facilities which look like hospitals, with nursing care units and bedrooms that approximate those in hospitals.

In response to the changing needs resulting from these trends, institutions known by many names have entered the long-term care continuum and the extended-care facility has adopted many models over the history of its development. Moreover, it must be recognized that designs which are appropriate or legitimate for the hospital may not necessarily be appropriate for any other facility. A long-term care facility does not merely provide a room with a bed accompanied by some nursing services; rather, it should provide a total environment that will be responsive to the totality of needs found in the population that the facility will serve (Koff, 1977).

Such is not the intent or design of the hospital. The nursing station as conceived for the hospital is not appropriate for the long-term care facility. The bedroom designed for the hospital is not necessarily the bedroom that any of us would like to live in for weeks or years. In other words, spaces that may be tolerable for a short period of time create tensions when people are continually confined there without any of the accoutrements that make it more like home.

Nearly 50 years ago, back in the late 70s, Koff had argued that the name of a facility can be damaging to the environment of its residents, - we still hear people talk of "rest homes" - which is synonymous with quiet and dark - a place of rest – with many restrictions. In contrast, his interpretation on the matter was ‘the hope of building opportunities for people to continue to live in a productive way: based on older adults’ existing resources, a sensitivity to their losses and an awareness of their capabilities’. With this statement, it is plausible to say that Koff was ahead of his time and that his insightful understanding for the future of older adults was perhaps a foundation for what is renowned today’s definition of Active Ageing (WHO, 2001), which states:

> "Active ageing is the process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age".

The British Geriatrics Society (1997) defines geriatric medicine as "that branch of general medicine concerned with the clinical, preventive, remedial and social aspects of illness of older people. Their high morbidity rates, different patterns of disease presentation, slower response to treatment and requirements for social support, call for special medical skills. Accordingly, the purpose is to restore an ill and ‘disabled’ person to a level of maximum ability and whenever possible return the person to an independent life at home". Despite the fact that geriatric medicine has been recognised as a specialty in the United Kingdom since 1948 (Brocklehurst, 1997), it was not until

1991 that Malta witnessed a remarkable turning point in the history of health services for the older adult population.

And yet, in 1998, Fiorini reported that the specialty of geriatric medicine in Malta was still at crossroads and in this regard, he retorted, "it is imperative (that geriatric medicine) is allowed to follow the correct path and practise as it should, in its own right and as recommended by international bodies and experts in the field. Otherwise, doctors and other health professionals would, not surprisingly, be reluctant to enter or remain in a field that is reverting to becoming a second class specialty" (Fiorini, 1998).

The general parlance of today's local HCPs seems to infer that SVPR has become a geriatric hospital for highly dependent older adult individuals. However, the Maltese government has not concurred to this idea, and although Formosa (2009) concedes that SVPR is a long-term care facility for older persons where the majority of the residents are in need of medical and nursing care, he also underlines that SVPR is not a geriatric hospital as it functions as a residential nursing home and provides sheltered accommodation for older persons. Therefore, in reference to Fiorini, Malta's first leading pioneer in geriatric medicine and rehabilitation, and the concerns which he addressed in 1998 may have regrettably materialised, in that, the geriatric field "is reverting to becoming a second class specialty" (Fiorini, 1998, p. 4) for many of HCPs in the local settings.

3.4 Chapter summary

Chapter 3 focused on the implications of ageing, from both a global perspective, as well as, locally. As the world embraces its medical, social, and economic advances over disease, and longevity prevails, it is deemed a must for agency and policy makers to establish a constructive and productive strategy, in line with both healthy and active ageing for our esteemed older population. This unprecedented exponential growth of this cohort is to be embraced rather than admonished and with the advent of the baby-boomers entering into what is considered older age, measures have to be put in place and choices need to be made in relation to ageing in place which must not necessarily imply long-term care in a care home facility. Non-communicable diseases have taken over, leading to chronic diseases and ill health whilst debilitating further more one's functional impairment. Our health policy needs to be revisited and health promotion must be encouraged from an early age.

In the meantime, this chapter also discussed aspects of the location, that is, St. Vincent De Paul Residence, where the study was conducted. The history of SVPR was presented and linked to the concept of extended-care models as described in the literature. The design of care homes ought to be just that – a welcoming home, rather than the sterile and cold appearance of a hospital, whereby one is inclined to perceive sickness as a norm; repetitive and never-ending. The term patient is more therefore, befitting of a hospital environment. In contrast, a care home caters for residents, paying clients and alas, service users. Quality in care and quality of care must therefore prevail for the betterment of our older generation whom out of no choice of their own are increasingly becoming in need of such long-term care facilities. As discussed earlier in chapter 2, quality of life is also a marker for promotion or loss of dignity.

In the following chapter, the methodology and research methods of this qualitative phenomenological research study are next addressed and thoroughly explained.

Chapter 4

Methodology and Research Methods

4.1 Introduction

The following chapter provides an overview of the methods and methodology applied in this study and how such methods are the most appropriate, given the aims and the nature of the research.

Methodology refers to "the theoretical, political and philosophical backgrounds to social research and their implications for research practice and for the use of particular research methods" (Robson, 2011 p. 528). Methodology is thus, a strategy of enquiry that guides a set of procedures. Methods, on the other hand, refer to the techniques used to acquire and analyse data to create knowledge (Denzin and Lincoln, 2000); (Creswell, 2009) [cited in Petty*, et al.,* 2012].

Additionally, this chapter offers a description and discussion of the procedures followed; including sampling and population; the rigour established during and after data collection; ethical considerations and data analysis.

4.2 Aim of the Research

The aim of this study was to explore the lived experience of this heterogeneous cohort in order to accurately capture and describe the phenomena of what dignity means to older men and women residing in a long-term care facility of St. Vincent De Paul Residence in Malta, and their expectations of care.

Given the importance of preserving dignity in older age, it was deemed necessary to investigate the extent to which resident dignity is currently being met or maintained, and to identify what factors may be threatening residents' dignity. Thus, by examining the implications of the findings of this study, in regards to the perceptions of older adults on dignity, it is hoped that this research sheds light on understanding the issues pertaining to quality of life for this population and on how to adequately address quality of life so as to better the service for residents in a care home.

In addition, it could possibly instil the necessary ‘dignity-in-care’ awareness which can ultimately lead to the creation of a ‘dignity campaign’ in the local healthcare setting, reinforce the obligation that the national minimum standards for older adults in care homes be in fact upheld, as well as, promote front-line staff education through the provision of intensive training programmes for healthcare providers, and the development of policy both within the establishment and across the board.

To summarise, the objectives of this research are:

1) To identify how residents, perceive dignity.
2) To investigate the extent to which resident dignity is currently being met or maintained.
3) To identify which factors, threaten residents' dignity.
4) To examine the implications of the findings of this study in order to create an awareness, propose further education for frontline staff and suggest development of policy on clinical practice in relation to the promotion of residents' dignity – Dignity Campaign.

4.3 Research Design

A qualitative research design employing a non-experimental, exploratory-descriptive phenomenological approach using a selective purposive sampling technique was adopted for this study.

According to Polit, *et al.,* (2001, p. 178), non-experimental research is used in studies in which its purpose is description and where it is unethical to manipulate the independent variable. For the purpose of this research, non-experimental research was by far more suitable for the study of people in nursing homes for several reasons. Firstly, due to ethical considerations, manipulation of the human variable is not acceptable because of the potential for physical or mental harm to the participants. Secondly, human characteristics are inherently not subject to experimental manipulation such as health beliefs and opinions. Thirdly, research constraints such as time, personnel and the type of participants, make non-experimental research more feasible. Lastly, qualitative studies do not interfere with the natural behaviour of participants being studied, since the type of research question would not be appropriate for an experimental research (*ibid.*). As a result, in this study, data was collected without introducing any treatment and no inducement was offered.

Burns and Grove (2003, p. 195) define a research design as "a blueprint for conducting a study with maximum control over factors that may interfere with the validity of the findings". Parahoo (1997, p. 142) refers to it as "a plan that describes how, when and where data are to be collected and analysed". Whereas, Polit, *et al.*, (2001, p. 167) define a research design as "the researcher's overall for answering the research question".

The reason for choosing qualitative research for this study was due to the possibility of having "numerous approaches to exploring human experience, perceptions, motivations and behaviour" (Parahoo, 2006). In fairness, it ought to be highlighted that by its very nature, qualitative research can be emotionally taxing and extraordinarily time consuming. Yet, at the same time, it can yield rich information not obtainable through statistical sampling techniques (Hoepfl, 1997). Porter (2000a; 2000b) reinforces the premise that qualitative research "is concerned with the collection and analysis of words, usually speech or writing" and therefore, the design itself "needs to remain sufficiently open and flexible to permit exploration of whatever the phenomenon under study offers for inquiry" (Lincoln and Guba, 1985).

In this respect, by using this approach, it was possible to "adopt a person-centred holistic and humanistic perspective to understand human lived experiences without focusing on the specific concepts" (Field and Morse, 1996, p. 8). Furthermore, this research focuses on "exploring how human beings make sense of the experience and transform experience into consciousness, both individually and as shared meaning" (Patton, 2002).

A number of research methods have been developed to answer questions within the realm of nursing and the health sciences (Penner and McClement, 2008). Hence, after reflecting on the aim and objectives of the study, a phenomenological approach was considered to be the next logical progression; pertinent in the design of the research method so as to elicit relevant and in-depth information from the target population. In fact, phenomenology has been defined as "an approach to thinking about people's life experiences" (Polit and Beck, 2006) and "is concerned with the way in which the individual interprets his or her experiences" (Clissett, 2008). Again, to further substantiate this process of the chosen methodology, Penner and McClement (2008) add that, "a phenomenological analysis does not aim to explain or discover causes", it is "to clarify the meanings of phenomena from lived experiences". Lived experiences involve the immediate consciousness of life's events prior to reflection and without interpretation, and are influenced by those things that are internal or external to them. It is the lived experience that gives meaning to each individual’s perception of a particular phenomenon and thus presents to the individual what is true or real in his or her life (Giorgi, 1997).

Consequently, in addition to philosophy, phenomenology as a research method is used in psychology, education, and in health care (Connelly, 2010) which relates well to this study, given the subject matter being dealt with.

As such, phenomenology offers an important shift from a positivist cause-effect focus to one of human subjectivity and discovering the meaning of actions (Giorgi, 2005). Moreover, phenomenology practiced within a human science perspective can thus result in valuable knowledge about individuals’ experiences (Penner and McClement, 2008).

Literature shows that phenomenology supports the re-examination of a taken-for-granted experience and, through examining the qualities of the experience, it allows the researcher to identify its essence. Therefore, the goal of phenomenological research is not to describe a grand theory or develop a model but to describe accurately a person’s ‘lived’ experience in relation to what is being studied.

Yet, it must be highlighted that phenomenological research is not so straightforward. In the nursing literature the two main phenomenological frameworks are descriptive (Husserlian) and interpretive (Heideggerian) phenomenology (Lopez and Willis, 2004) [as cited in Penner and McClement, 2008], where the latter is also known as the hermeneutic tradition.

Commentators agree that if researchers are not clear about which approach they are using from the start so that they collect data to suit that method; the value of that research is significantly reduced (Annells, 2007; Dowling, 2004; Crist and Tanner, 2003). Therefore, further elaboration on these two different approaches will be dealt with next.

Each of these approaches favour knowledge that reflects insights into the meaning of the phenomena under study; however, they differ in their aim. In both the interpretive and descriptive methods, the researcher assumes a readiness to listen to the descriptions of the lived experiences as described by the participants (Penner and McClement, 2008).

As Kleiman (2004) points out, in the interpretive method, the researcher uses his or her prior knowledge and insights to interpret and uncover hidden meanings with the goal of producing a vivid textual representation of the phenomenon described. In so doing, interpretive frameworks are used to search out the relationships and meanings that knowledge and context have for each other. Principally, interpretative phenomenologists believe it is impossible to rid the mind of preconceptions and approach something in a completely blank or neutral way.

In contrast, in the descriptive method the researcher makes no interpretations. Rather, he or she analyses the descriptions given by participants and divides them into meaning-laden statements, gathering those meanings that are essential to the construct of the phenomenon being studied. Consequently, the researcher is able to bring to written description the structure of the phenomenon of interest. Additionally, a descriptive phenomenological approach is used when little is known about an issue and the aim of the study is to make clear and understand the most essential meaning of a phenomenon of interest from the perspective of those directly involved in it (Giorgi, 1997).

In view of the aims underlying each of the major phenomenological approaches, the use of a descriptive phenomenological approach was deemed better suited to examining the experiences of this particular cohort and far more appropriate considering the paucity of research examining dignity of older adults residing in care homes in Malta.

Undeniably, this approach could enable the researcher to focus on the experiences and feelings from the participants’ perspective, by "stressing [on the] uniqueness of the individual" Parahoo (1997, p. 59), and by emphasising on the understanding of these elements.

Through exploration of the phenomenon at hand, the researcher wanted to remain as authentic and loyal towards the experiences of the older persons under inquiry. This is in contrast to the belief held by interpretative phenomenologists, who assert that "we use our own experiences to interpret those of others" (Balls, 2009 cited in Connelly, 2010).

However, the researcher strongly discounts this argument for the simple fact that there is no experience to be interpreted in the first place. In the sense that, her research seeks to explore the perceptions on dignity, from older adults above the age of 65 who are living in a long-term residential care facility. It is the researcher's belief that due to the obvious age gap between her and the participants, the environment itself and the socio-cultural generational differences; thus, one can merely make assumptions. In truth, the researcher trusts that in this case, attempting to interpret an experience which has never been lived nor shared would by far have a potential risk of failing this target population in terms of dignity. Besides the fact that any lived experience is different for any person, the researcher agrees with Munhall (2007) who adds that, "phenomenologists want to know what the experience was like to *live it*, not just the person's reaction to the experience." Thus, it is fair to state that it is indeed the older adults themselves, presently in LTC, who can truly tell their 'story' how it really is and what its significance may be.

In reference to the paternalistic approach, discussed in Chapter 2, which in the researcher's opinion still echoes and remains rather predominant within the healthcare field in Malta; then, the interpretative approach would quite possibly only reinforce the former.

Considering all of the above, the researcher was challenged with the notion of putting aside any biases and preconceived knowledge to induce a pure description of the older adults' perceptions on dignity and alas, their experiences.

In view of the researcher's own personal experience described in the introductory section in Chapter 1 and having carried out a thorough literature review on the topic under study, it was pertinent to utilise bracketing, which is part of a framework used in descriptive phenomenology, prior to the starting the study. Bracketing involves putting aside what the researcher already knows about the experience being investigated and approaching the data with no preconceptions about the phenomenon (Polit and Beck, 2006); (Dowling, 2004; Lopez and Willis, 2004). This will now be further discussed in the following section.

4.3.1 Attributes Affecting Bracketing

Parahoo (2006) states that "our knowledge hinders our ability to research the topic thoroughly when we unconsciously bring assumptions about the topic into the research process." Whilst Chan, *et al.,* (2013) indicate that "our foreknowledge and suppositions limit our understanding of the participants' perspectives because we already know a great deal about the phenomenon."

Aside from personal biases inherent in the human experience (Penner and McClement, 2008), this aspect became an inherent issue for the researcher attempting to conduct this phenomenological study to explore the lived experiences of older adults mainly owed to her professional role as a physiotherapist, having a special interest in the field of geriatric physiotherapy, professional knowledge in long-term care settings and previous clinical working experience at St. Vincent de Paul Residence. More importantly, prior to the commencement of this dissertation, the researcher had also undergone a fieldwork placement at SVPR which was a compulsory credit during her first year master's course. These factors alone could inevitably introduce bias into the research due to presumptions of the researcher related to caring for these residents which could in turn affect her ability to discover the pure essence or meaning of dignity for older adults.

Therefore, the researcher identified any pre-existing perceptions, prejudices and beliefs she held about the topic of dignity of older adults in care homes being explored, through the process of 'bracketing' (Parahoo, 2006). Bracketing is a specific technique proposed by descriptive phenomenologists (Dowling, 2007) and involves the researcher's setting aside preconceptions and personal knowledge when listening to and reflecting on the lived experiences of those being studied.

Categorically, in order to address the key issues in achieving bracketing, there was a strong need to develop strategies to acknowledge and tackle the influence of the researcher throughout the research process.

Wall, *et al.,* (2004) devised a reflective framework to guide the research process and demonstrated how using a reflective diary and field notes can be an effective tool for developing bracketing skills so as not to influence the researcher's description of the participant's experience (Clissett, 2008). Visual imagery, practicing neutral non-verbal behaviour, and honing active listening skills facilitate bracketing in preparation for research (Wall, Glenn, Mitchinson, *et al.*, 2004). Throughout data collection and analysis, the researcher acknowledged and set aside biases during the process and about the process through the use of a reflective diary and conversations with mentors (*ibid.*). As such, bracketing was a continuous process, used to facilitate the clear emergence of the phenomenon under investigation.

4.3.2 Sampling Technique

According to Patton (1990, p. 169), the "logic and power of purposeful sampling lies in selecting information-rich cases for study in depth … those from which one can learn a great deal about issues of central importance to the purpose of the research, thus the term purposeful sampling" [as cited in Coyne, 1997].

Defined as "the most useful strategy for the naturalistic approach**[8]**" (Lincoln and Guba, 1985), the researcher made use of a method of study described as "*Maximum Variation Sampling*", in which fourteen cognitively and psychologically sound older adults over the age of 65 years, residing at St. Vincent De Paul Residence, were purposively selected.

This process of purposive (purposeful) sampling (also called *judgmental sampling),* is a non-probability sampling method in which the researcher selects participants based on personal judgement about who will be most representative or informative (Polit and Beck, 2006, p. 507) so as to ensure that "certain types of individuals or persons displaying certain attributes are included in the study" (Berg, 1989, p. 179).

Accordingly, for small samples a great deal of heterogeneity can be a problem because individual cases are so different from each other, but this is where the maximum variation sampling strategy turns that apparent weakness into a strength, since it can yield detailed descriptions of each case. Patton (1990, p. 172) argues that, "any common patterns that emerge from great variation are of particular interest and value in capturing the core experiences and central, shared aspects or impacts of a program" [as cited in Hoepfl, 1997].

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[8] Naturalistic inquiry refers to a paradigm of inquiry with two major features: a low degree of manipulation or control of the variables prior to the inquiry and a low degree of constraints imposed on the outcomes of the inquiry (Jacobs, 1985).

4.4 Recruitment of participants

The target population, and thus the main focus of this research were older adults living in a long-term care setting in Malta. The research was based on a qualitative design employing a descriptive phenomenological approach to explore the lived experience of older adults aged 65 years and over, who had been residing at St. Vincent de Paul Residence for more than 1 year. In order not to exclude the views of the oldest residents, there was no upper age limit set in the eligibility criteria.

The recruitment of participants[9] for this study was grounded on a combination of purposeful sampling and criterion, whereby the chosen subjects, a total of 5 men and 9 women from 4 different wards within SVPR, were recruited using a method of study described as “Maximum Variation Sampling", as previously discussed in section 4.3.2. Criterion sampling allowed for easier and more effective participant selection (Patton, 2002, p. 46). Therefore, through the use of purposive-convenience samples drawn from the population, the inclusion and exclusion criteria was based upon the following, as illustrated next, in Box 4.1:

Box 4.1: Selection Criteria at a glance

Inclusion Criteria: (must fulfil all of these) The resident:

1. Has been a resident at SVPR for more than one year.
2. Is 65 years of age and over - in order not to exclude the views of the oldest residents, no upper age limit was set in the eligibility criteria.
3. Is willing to participate in the study.
4. Is able to provide informed consent
5. Is able to communicate verbally in either Maltese or English.
6. Is of sound cognitive and psychological capacity, medically stable, as well as, oriented to time, place and person.
7. Frail elderly residents who might potentially contribute towards the conduct of the research and could inform ways to improve the care they receive
8. Is not taking part in another research study.

Exclusion criteria: (any of these excludes) The resident:

1. Has been a resident at SVPR for less than one year.
2. Has Dementia, Alzheimer’s disease, severe mental health problems or learning disabilities.
3. Is unable to communicate verbally in either Maltese or English.
4. Is unable to give informed consent (*e.g.* if confused).
5. Is too ill or distressed.
6. Is already taking part in another research study.

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[9] The term 'participant' is used throughout this thesis when referring generally to those residents who participated in the research. Where discussion is specific to one group of participants only (*e.g.* older adults, residents, elderly population), the participants are then referred to, as per their specific group identity in the text.

The recruited participants needed to have autonomous decision-making capacity; fully apt at exercising their own rights and free will. This approach was to systematically ensure that potential participants were knowingly participating by their own volition and they could opt to take part in this study upon giving their informed consent; which was warranted in written and/or verbal format. Another criterion for eligibility included a stipulation that participants had to be able to speak Maltese or English and able to communicate verbally. More importantly, the subjects needed to be willing to participate in a one-time, individual meeting whereby an in-depth, semi-structured face-to-face interview (lasting between 45 to 90 minutes) would be carried out, led by the researcher.

As part of the debriefing process, an additional appointment was offered to all participants upon completion of the interview, so as to follow-up on their well-being and to provide them with closure from the study. None of the participants taking part in this study were subjected to any harm. No treatment was introduced during the data collection or at any time during the study, and no inducement was offered for this study.

It stands to reason that neither minors were included in this study, nor the mentally infirm, or otherwise those who were not legally competent. In this regard, it should be noted that, older people having Dementia, Alzheimer’s disease, severe mental health problems or learning disabilities were also excluded from the study, due to the fact that in the researcher’s opinion, "they would be better served by separate research projects specifically designed to sensitively explore their needs" (Reeve, 2008).

The researcher also deemed it would be inappropriate to approach residents - with less than 1-year residency at SVPR - early on during their transitionary period; especially since leaving their home and families to move into a care home could induce feelings of grief and loss. An adjustment period may be necessary and it was possible that this particular study, related to dignity, could provoke unwanted distress to these people. Consequently, residents of St. Vincent de Paul Residence from the Psychogeriatric Wards and Admission’s Ward were immediately excluded from this study. Similarly, subjects from the Respite Ward, which serves as a short-term placement for community dwelling older adults so as to relieve family care-givers, were not included in this study.

Nonetheless, frail elderly residents, able to potentially contribute towards the conduct of this research and inform on ways to improve the care being received, were not excluded from such research.

As a physiotherapist, the researcher adhered to the requirements of her Code of Professional Conduct (WCPT, 2011), which holds physiotherapists responsible for their professional conduct as researchers as well as clinicians to "respect the rights and dignity of all individuals" (*ibid.*).

The World Confederation for Physical Therapy (WCPT) (2011) declares that physiotherapists "engaged in research shall ensure that they abide by all current rules and policies applying to the conduct of research on human subjects." These were addressed by ensuring consent, protecting confidentiality and protecting subjects' safety and well-being (*ibid.,* ethical principle 5). Each of these will now be discussed in the next sections.

4.4.1 Screening Process

During the first phase of the sampling process, the respective ward's nurse-in-charge together with a supervising faculty member assisted the researcher to exclude subjects with known cognitive impairment and/or who were distressed.

As a next step and so as to ensure transparency, the Nurse-in-charge of each respective ward made the initial approach at introducing the research study to the eligible participants. This was because "it was anticipated that residents could decline more easily than if the researcher approached the residents directly" (Baillie, 2007). For this reason, the researcher met and briefed each nurse-in-charge individually and asked them to emphasise (to the eligible participants) that there was no obligation to take part and that care would not be affected should residents not wish to participate.

Eligible Participants were invited to participate in the study through the provision of a written *Recruitment Letter* in either English or Maltese (Appendix 2), which explained the research goals and what the study involved. Participants were also invited to contact the researcher so as to express their interest and to confirm their acceptance to taking part in the study.

The research protocol included that if a resident was unable to read because of illiteracy or a visual impairment but wished to participate in the study, then the nurse-in-charge of each respective ward would be appointed to act on behalf of the participant, in order to:

a) read the *Recruitment and Consent Form(s)* to the eligible participants;
b) ensure the participant's understanding of the written terms and conditions; and
c) sign the *Consent Form* on behalf of the participant, solely upon the willingness and acceptance of the participant.

This criterion ensured that residents would be able to understand the scope of the study together with their rights, and accordingly decide whether they wished to take part, thus promoting informed consent. This was necessary for 6 participants who were illiterate and for another two residents: with moderate to severe visual impairment. Whilst another female participant, albeit able to read, had severe arthritis in both of her hands and was unable to write. In this instance, the nurse-in-charge was called in to assist on behalf of the willing participant and to sign on her behalf.

4.4.2 Ensuring participant consent and confidentiality

Once confirmation and initial contact was made by the participants, a first meeting was held so that the researcher could go through the Recruitment Letter again and explain further in regards to the research process, as well as, answer to any necessary queries. The researcher informed each participant of the research goals, processes and benefits. Ensuring confidentiality of personal information is essential towards conducting research ethically (Baillie, 2007) and the research design detailed plans for ensuring confidentiality.

During the first encounter with the researcher and again prior to the commencement of the interview, the participants were assured that their identity would be safeguarded and maintained at all times and that the information they provided to the researcher or their participation, would not be used against them and that it would be treated confidentially.

Participants were informed of their right to withdraw from participation in the study, at any time without penalty, and that they could, if they so wished to, refuse to answer any questions without comment. Participants were informed that a decision to withdraw at any time, or a decision not to take part, would not affect their medical care or legal rights being received at present or in the future.

Informed consent to participate was indicated following written and/or verbal consent from residents (Appendix 3). Informed consent was also sought from the participants agreeing to be audio-recorded (Appendix 4). These consent forms had to be signed by each participant (or the appointed nurse-in-charge, if indicated) so as to specify that s/he had understood the scope of this study and agreed to take part in the study through their own volition. Both the participant and the researcher kept signed copies of the Consent Form(s) for their own records.

The researcher-participant relationship was not exploited. No names or personal details of anyone taking part in the research were recorded. Each participant was assured of complete anonymity by using a *Participant Identification Code* (*e.g.* 'M01' or 'F13') which was used throughout the data collection and final report in order to protect their identity. Codes were used for all participants in data records (assessment tools – SSMSE and GDS, interview transcripts, field notes and notes made from residents' hospital files).

All transcriptions were anonymised: so that any real names or places mentioned were substituted in the transcript with a letter (*e.g.* 'X'). Each assessment tool and interview was given the same numerical code per participant in order to identify it for the data collection, for example, M01 or F08 (Male 01 or Female 08). Each participant had three sets of documentation, namely the *SMMSE*, the *GDS* and the *Participant Profile/Interview Schedule*. Whereas, hard data (tapes, printed transcripts and field notes) were stored in a locked filing cabinet so as to maintain security of data.

The researcher notified each participant that all information collected [audio tapes and written transcripts of audio tapes] would be kept in a locked filing cabinet at her home for the duration of the research study, after which the audio tapes of the interviews would be erased upon completion of her Master degree qualification [November 2016].

4.4.3 Screening Tools

Once participants were tested for inclusion and exclusion criteria and informed consent was received, the second phase ensued. To be able to take part in this study, it was a pre-requisite that participants have the mental capacity to make this decision and be of sound psychological capacity to take on the interview. Therefore, prior to starting the interview, a cognitive and psychological assessment/test of the selected participants had to be carried out through the use of the Standardised Mini Mental State Examination - SMMSE (Appendix 5) and the 15-item Geriatric Depression Scale – GDS (Appendix 6).

Participants who scored above a certain cut-off point on these two brief tests – termed as mental ability (SMMSE) and psychological well-being (mood stability) (GDS) - were able to take part in the study. Since residents' interviews were a crucial source of evidence within the study design and their quality relied on the ability to communicate experiences and feelings; this criterion also ensured that residents would be able to understand the information and decide whether they wished to take part, thus promoting informed consent.

The following tests were carried out in order to ensure participants' eligibility for this study.

A) **The Standardised Mini-Mental State Examination (SMMSE**) was used in order to assess cognitive functioning.

The SMMSE was administered by Dr. Christian Borg Xuereb, a warranted health psychologist and faculty member of the Department of Gerontology at the University of Malta, as well as, in-charge of students' practice placements during the first academic year of Master of Gerontology and Geriatrics course**.**

It is worthwhile noting the reason in choosing the Standardised Mini-Mental State Examination (SMMSE) over the Mini-Mental State Examination (MMSE). Although, the MMSE is a valid and reliable instrument widely used to screen for cognitive impairment in older adults (Folstein, Folstein, and McHugh, 1975); the reliability of this original instrument was improved by adding explicit guidelines for administration and scoring, as seen in the SMMSE (Vertesi*, et al.,* 2001, p. 2019).

Additionally, the SMMSE is used for comprehensive assessments of older adults. The tool is a standardised approach to scoring and interpreting older people's cognitive function as it provides a global score of cognitive ability that correlates with function in activities of daily living (*ibid*.).

More specifically, the test measures various domains of cognitive function including orientation to time and place; registration; attention (and calculation); short-term (word) recall; naming familiar items; repeating a common expression; and the ability to read and follow written instructions, write a sentence, construct a diagram (visuospatial ability), and follow a three step verbal command (*ibid*.).

As a tool, the SMMSE requires little time to complete, taking approximately 10 minutes to administer, and is a key component of a comprehensive dementia workup since it provides a baseline score of cognitive function, and pinpoints specific deficits that can aid in forming a diagnosis (Vertesi, *et al.,* 2001). In all, this tool allows a rapid analysis of a patient's [resident's] current cognitive ability.

The eligibility criteria for study participation was > 24 [*i.e.* a cut-off point of 24 or more] (Appendix 5).

B) **The Short Form 15-Item Geriatric Depression Scale (GDS-15)** was used in order to assess psychological well-being.

The Geriatric Depression Scale[10] (GDS) has been tested and used extensively with the older population. Modified from the original 30-item assessment tool which was first created by Yesavage, *et al.,* (1983), the 15-item GDS is a short form which was developed to decrease fatigue or lack of focus seen in the elderly (Sheikh and Yesavage, 1986) and is used to focus on items with the highest correlation to depressive symptoms in validation studies (Greenberg, 2012). It is a reliable and valid self-rating depression screening scale for elderly populations which takes five to seven minutes to complete and can be filled out by the '*patient*' or administered by a provider with minimal training in its use (Greenberg, 2007, p. 61).

Although there is a growing number of screening measures available to measure geriatric depression (Heiser, 2004), data on their clinical utility, specifically in residential care settings, is mixed. However, a number of studies reported that the GDS-15 is valid for use in residential care facilities (Watson, Zimmerman, Cohen, *et al.,* 2009); (McCabe, *et al.,* 2006); (Sutcliffe, *et al.,* 2000) [as cited in Azulai and Walsh, 2015, p. 29]. Literature also shows that the GDS-15 seems to have an overall usefulness

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[10] **Note:** Although the GDS-12R, (R = residential) is the only scale that has been designed specifically for residential care, and is promising since it has shown excellent performance in English-speaking older adults living in residential care facilities; yet, it requires further testing in the United States and Canada (Azulai & Walsh, 2015). Hence, the reason that the GDS-SF (15 item) was the preferred choice for this research study, more so, due to the fact that the scale was administered in Maltese in order to suit the sample population, and thus, it was necessary to ensure that a more reliable tool was used.

to assess depressive symptoms among very old people with an MMSE score of 10 or more (Conradsson, *et al.*, 2013). [To be noted that although the SMMSE tool was used in this study instead of the MMSE, nonetheless, the cut-off point was at 24 so as to ensure cognitive viability].

Therefore, for the purpose of this study, the GDS-15 screening tool (Greenberg, 2012) was administered by the researcher via interview. It consists of 15 items; each answered “yes” or “no” depending on which response is most appropriate at the time of measurement, with 0 or 1 point for each answer. The total score is calculated by summing responses that endorse depression. Negatively endorsing items 1, 5, 7, 11, and 13 indicates depression, while positively endorsing the remaining 10 items indicates depression (Smarr and Keefer, 2011).

There is a scoring guide accompanying the screening tool that determines the value of each answer. The total score is then compiled and the person is rated dependent upon their score. Higher scores indicate a higher level of depression with a maximum score of 15, that is, scores >5 (more than) are suggestive of depression and those >10 (more than 10) highly likely indicate depression (Greenberg, 2012); (Smarr and Keefer, 2011); (ACRC, 2016).

Consistent with the work of Sheikh and Yesavage (1986), Greenberg (2012) and ACRC (2016) support that a positive score of 5 or greater on the GDS-15 is indicative of the need for an in-depth psychiatric assessment. This is more so important, since undetected depression can result in limited access to mental health services (Bern-Klug, Kramer, and Sharr, 2010); (Morrow-Howell, *et al.*, 2008), increased physical and cognitive health deterioration (Sutcliffe, *et al.*, 2000), increased medical care utilization (Koopmans, Zuidema, Leontjevas, *et al.*, 2010); (Raj, 2004), poor quality of life (Heisel, Duberstein, Lyness, *et al.*, 2010), and premature death (Harris and Cooper, 2006); (Wagenaar, *et al.*, 2003) [as cited in Azulai and Walsh, 2015, p. 21].

To further provide a breakdown of the scoring system, literature explains that scores of: 0–4 correspond to a normal condition; 5–8 indicate mild depression; 9–11 indicate moderate depression; and 12–15 indicate severe depression (Azulai and Walsh, 2015), in which case, sensitivity and specificity have been reported as 60% to 79% and 75% to 67% in the GDS-15 using cut points of 4 or 5, respectively (Sutcliffe, *et al.*, 2000;

Watson, *et al.*, 2009). Whereas, using cut points of 6 or 7 increased sensitivity and specificity to 92% and 89%, respectively (Watson, Zimmerman, Cohen, *et al.*, 2009).

Conversely, studies involving medical patients propose cutoffs ranging from 5–7 (Marc, Raue and Bruce, 2008); (Cullum, Tucker, Todd, *et al.*, 2006); (Bijl, van Marwijk, Ader, *et al.*, 2006); (Weintraub, Oehlberg, Katz, *et al.*, 2006); (Friedman, Heisel and Delavan, 2005) [as cited in Smarr and Keefer, 2011].

Azulai and Walsh (2015, p. 29) conclude that the GDS-15 is a better tool for identifying depression in nursing home residents, so much so, that it has performed better than other screening measures for geriatric depression, with sensitivity of 86% and specificity of 83% albeit with the cut-off point set at 7.

To be noted that the GDS is in the public domain (Smarr and Keefer, 2011) and available from the original article by Yesavage and colleagues (1983) which can be accessed online through the Stanford / VA / NIA Aging Clinical Research Center (ACRC) Website, and it includes the Maltese long version (30-item GDS) by Gerada and Ferry (ACRC, 2016) at http://www.stanford.edu/~yesavage/GDS.html. For the purpose of this study, the researcher modified the 30-item Maltese to create the GDS-15 Maltese version due to its unavailability, albeit based on the previous work proposed by Gerada and Ferry.

For the purpose of this study, the inclusion criteria allowed scores of: 0 to 4, No Depression and 5 to 10, suggestive of Mild to Moderate Depression. The eligibility criteria for study participation was GDS < 10 [*i.e.* a cut-off point of 10 or less] (Appendix 6).

4.4.3.1 Considerations

In the event that a participant failed the SMMSE or the 15-item GDS Short Form, it was established that the researcher was to inform the participant's named doctor. As part of this methodology design and for sound ethical reasoning – the researcher would then:

1. Inform the participant that he/she did not meet the eligibility criteria necessary for participating in the study.
2. Apologise to the participant for any inconvenience caused and thank the participant for his/her time thus far, and for having shown interest to participate in the study.

3. Provide the participant with an *Information Sheet on Concerns about Loss of Memory* (Appendix 7) and/or *Information Sheet on Depression* (Appendix 8), written in either English or Maltese, as required.

However, if eligible participants scored in the cognitively and psychological intact range, then, informed consent would be collected and participants would be able to move on to the next phase, that is the interview process (see section 4.6).

4.4.3.2 Subjective Health Status and Activities of Daily Living (ADLs)

Normal aging changes and health problems frequently appear as deteriorations in the functional status of older adults and this decline may place the older adult on a spiral of iatrogenesis[11] leading to further health problems.

In view of the fact that all GDS-15 questions relate to mood, rather than the physical symptoms frequently reported by older adults (Smarr and Keefer, 2011), it was essential to obtain more background information about the participants physical and functional well-being. Thus, the interview process was divided into three parts and included two brief assessments (shown hereunder in **bold** *italics*) which were carried out by the researcher (see Appendix 10), namely:

A) Participant's profile:
   - Socio-demographic information
   - ***Subjective health status***
   - Self-reported or diagnosed chronic illness(es)

B) ***ADLs*** - assessment of the participant's ability to perform activities of daily living independently

C) Interview schedule for participants

Therefore, with reference to their *Subjective Health Status*, the participants were asked to rate their current health status as either being *Good*, *Fair*, or *Poor*. In order to determine the value of each answer, a scoring guide was used as follows: Good = 3; Fair = 2; Poor = 1.

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[11] Iatrogenesis is defined as the "inadvertent and preventable induction of disease or complications by the medical treatment or procedures of a physician or surgeon" (Merriam-Webster.com), and "drugs may cause side effects which can lead to iatrogenic disease" (Oxford University Press, 2016).

In addition, one of the best ways to evaluate the health status of older adults is through a functional assessment, known as the Katz Index of Independence in Activities of Daily Living (Katz, Down, Cash, *et al.*, 1970), commonly referred to as the Katz ADL (see Appendix 11). This tool is most effectively used among older adults in a variety of care settings as it provides objective data that may indicate future decline or improvement in health status (Shelkey and Wallace, 2012). The Katz index summarizes an individual's overall adequacy and performance in the six functions of bathing, dressing, toileting, transferring, continence, and feeding. The participants were scored '1 point' for independence or '0 points' for dependence, in each of the six functions, whereby, a score of 6 indicates full function (*i.e.* independent), 4 indicates moderate impairment (*i.e.* semi-independent), and 2 or less indicates severe functional impairment (*i.e.* dependent) (*ibid.*).

4.4.4 Exception to Confidentiality Arrangement

The exception to the confidentiality arrangement would precede if cause for concern about a participant's health or safety was raised over the course of the interview. Therefore, if as a result of the interview, participants were to ask the researcher to take up with the facility (SVPR) an aspect of their care that they felt unhappy about - the researcher would in that instance only use a participant's name, if permission had been given by the participant. In this event, the Nurse-in-Charge of the ward would be informed, and then the Medical Superintendent of St. Vincent de Paul Residence, if necessary.

4.4.5 Disclosure of Abuse

The researcher pre-empted that if during an interview, abuse was disclosed by a participant, the researcher would discuss with the participant whether he/she wanted to take this up with the facility (SVPR). Should the participant wish to do so, the researcher would then discuss with the participant how to go about this in terms of advocacy, mediation, complaint-investigation and resolution. In such a case, however, the researcher would not take any action on a participant's behalf without his/her consent. Alternatively, and as a safeguard, the researcher would provide the participant with an *Information Sheet on Abuse* (Appendix 9) written in either English or Maltese, as required.

4.5 Research Site

The chosen research site for the study was the facility of St. Vincent De Paul Residence in Malta. During the initial preparatory stages, a letter of presentation about the proposed study was sent to Chief Executive Officer (CEO) of SVPR, after which a formal meeting was scheduled with the Medical Superintendent of SVPR whereby ethical considerations and operational approvals were addressed. In reference to the inclusion criteria, the available wards were discussed; and the venue, were the interviews would be held, was also identified in advance.

Permission was granted from the ‘gatekeepers’ at SVPR and it was established that the office of the nurse-in-charge of each respective ward, would be used as the venue in which to conduct the interviews. This was to ensure that participants’ privacy during the interview process could be maintained and to avoid any external interruptions.

4.6 Research Instrument

In order to uncover and explore the meaning of dignity that underpins the lived experience and perceptions of older adults in long-term residential care, the use of an interview method was required. The interviews which served as the main instrument for data gathering in this research, took the form of an in-depth, face-to-face, semi-structured interview, and these were all carried out individually, led by the researcher.

This interview format is used most frequently in healthcare, as it provides participants with some guidance on what to talk about, which many find helpful. The flexibility of this approach, particularly compared to structured interviews, also allows for the discovery or elaboration of information that is important to participants but may not have previously been thought of as pertinent by the research team (Gill, Stewart, Treasure, *et al.,* 2008). Additionally, semi-structured in-depth interviews are often the sole data source for qualitative research projects, as opposed to unstructured interviews, which are usually conducted alongside other methods such as observation (University of Oregon, 2014). When sampling for semi-structured interviews "[you] concentrate on people who have direct experience with the practice that is problematic, and people who are knowledgeable about it" (Hardon, Hodgkin and Fresle, 2004); (Hardon, *et al.,* 2001). Semi-structured interviews consist of several key questions that help to define the areas to be explored, but also allows the interviewer or interviewee to diverge in order to pursue an idea or response in more detail (Britten, 1999) [as cited in Gill, Stewart, Treasure, *et al.,* 2008].

The predetermined, open-ended questions served as a guide during the course of each interview so as to create a standardized methodology and to ensure consistency. Nonetheless, although questions were "asked in a systematic and consistent order" (University of Oregon, 2014), it is important to remember that "in-depth, semi-structured interviews usually unfold in a conversational manner offering participants the chance to pursue issues they feel are important" (Longhurst, 2009). In such instances, the researcher had "the flexibility to digress and forgo certain questions, while also asking probing questions for the purpose of clarification that were not initially planned" (University of Oregon, 2014). Further questions were also introduced, as necessary, in response to comments made by the participants.

Another advantage was that the individual in-depth interview allowed the researcher "to delve deeply into social and personal matters" (University of Oregon, 2014), which in turn enabled the researcher to investigate "complex behaviours, opinions, and emotions and for collecting information on a diverse range of experiences" (Longhurst, 2009) from this selected sample population.

The main issues probed during the interviews concerned residents' perceptions towards dignity, the extent to which resident dignity is currently being maintained at SVPR and the factors that threaten residents' dignity. Secondary issues included the participants' expectations of care within the care home and asking for their suggestions on how to provide them with a better service.

It is essential to highlight that both the work presented by Matiti (2002) in her unpublished doctoral thesis on "*Patient Dignity in Nursing: A Phenomenological Study*" and that of Baillie (2007) in her doctoral thesis on, *"A Case Study of Patient Dignity in an Acute Hospital Setting*" subsequently published in the International Journal of Nursing Studies (Baillie, 2009), served as a background for this research instrument. The framework of the semi-structured interview questions utilised in this research, mirror in part, the work carried out by Matiti (2002, p. 251) and Baillie (2007, p. 312). However, the questions were slightly adapted to better suit the parameters of the study (see Appendix 10).

The semi-structured interview questions sheet for the participants, referred to as the *Interview Schedule for Participant*, were written in both English and Maltese and had an initial section which deals with the *Participant Profile*, including the functional performance in activities of daily living – ADLs (Appendix 10).

Through the use of these semi-structured interview questions, the researcher attempted to elicit autobiographical reflections and short narratives of participants' experiences related to their dignity in the selected care home - SVPR. The duration of the interviews lasted between 45 minutes to 90 minutes, and none of the participants had any objections to their interview being audio-recorded. No proxy interviews took place and the subjects were interviewed once at their convenience.

4.7 Pilot Study

Prior to commencing the data collection, a pilot study was carried out for the purpose of this research. Two semi-structured pilot interviews were conducted with two older persons - a male and a female resident from two separate wards respectively, within SVPR - whom met the criteria established for this research.

The pilot studies were carried out mainly to refine the research instrument, namely, the interview schedule in order to determine whether the questions were appropriate for the collection of the data required, or if revisions needed to be made. In fact, during the pilot interviews, it soon became apparent that certain questions were not clearly understood by the participants. This was particularly evident when using the Maltese interview schedule, thus these questions were carefully modified, clarified and strengthened.

Overall, the results of this pilot study contributed towards reinforcing the research design and data collection process in a number of ways. To begin with, it enhanced the researcher's confidence, effectiveness in interviewing techniques and time management skills. For instance, it provided the researcher an opportunity to practice and to experience at first hand the differences in how an interview is conducted, be it in English or Maltese, in short, how the words 'roll off the tongue', the tone and how to quickly switch to the use of a more familiar word, if necessary. Another issue, was to verify the actual timeframe of the whole process – starting from administration of the two assessment tools: SMMSE and GDS; going through the Consent Form; and the interview schedule itself – and whether, inclusively, all could be managed between 45 to 90 minutes as anticipated by the researcher during the initial stages of the project or to consider whether a separate appointment was needed in case the process was deemed lengthy or tiring for the older person.

Additionally, this was an opportunity to test the unpredictability of the participants' verbal and emotional responses and how the questions posed on dignity, could affect them. This was especially necessary, since speaking about the experiences in regards to threats or maintaining dignity from the perspective of an older person living in long-term residential care, might evoke feelings and emotions in participants. Penner and McClement (2008) point out that "individuals might express various emotions overtly during the course of recounting their experiences" and "this reaction might cause discomfort for researchers or render them uncertain as to how to proceed".

This factor reinforced the importance of being prepared to stop an interview, in the event that an older person becomes upset during an interview, and provide emotional support to the person, and pursue psychosocial follow-up as necessary. The researcher pre-empted that should such a situation take place, that the participant would be given the option of stopping the interview and rescheduling for another time.

Yet, on a more positive note, it is important to highlight that although the emotional aspect of speaking about the older person's experience of dignity might be challenging to researchers and participants alike, older people are also frequently appreciative of having the opportunity to share their stories, with someone who is genuinely interested in what they have to say. As such, face-to-face in-depth semi-structured interviews within the context of a phenomenological approach facilitate the opportunity for such discourse.

Ultimately, the pilot interviews facilitated "in highlighting gaps and wastage in data collection" and in discovering "broader and highly significant issues such as research validity, ethics (and) representation" (Sampson, as cited in Marshall and Rossman, 2010 and in Haber, 2011).

4.8 Data Collection

In accordance with qualitative research methods and given the focus of this methodology, data collection involved individual interviews. The main form of data collection was the in-depth interview, through which the researcher attempted to gain an insight into the world of the participant. The researcher's role as an allied healthcare professional, previous knowledge and experience were subordinated as a "hidden agenda" (Oppenheim, 2000) to avoid influencing the process of exploring the participants' own perceptions of the issues.

Data was collected through semi-structured, in-depth interviews held during the month of March, 2016 (see List of Tables: Tables 2A to 2D). During the main data collection period, the wards were visited on a regular basis and on every occasion, the nurse-in-charge identified and approached patients meeting the criteria for selection in the study (see Box 4.1).

Participants then met individually with the researcher and the supervising faculty member at their respective ward. The researcher greeted the participant in a polite and friendly manner and introduced herself as a university student researcher. It was important for the researcher to initially engage in small talk so as to build a rapport with the participants and to help them feel relaxed, for instance, by offering to escort them to their room, when this was their preferred choice of venue, asking after the participant's general well-being and making friendly conversation such as admiring family photographs on their bedside cabinet or craftworks they had done.

The first researcher explained the research purpose and participants’ rights. Written consent to conduct and audio-record the interview was obtained from all participants (see Consent Forms, Appendix 3 and 4), who were advised that they could terminate the interview at any time and need only answer questions they wished to. All participants appeared comfortable to answer the questions and none asked for the interview to be stopped.

Interviews were initiated by: 1) taking a brief participant’s profile which included socio-demographic information, subjective health status and self-reported or diagnosed chronic illness(es); 2) establishing their level of independence using the Katz’s six Activities of Daily Living – ADLs (Katz, Down, Cash, *et al.,* 1970); (Shelkey and

Wallace, 2012); and, 3) describing their views on dignity and quality of life by carrying out the semi-structured interview schedule (see Appendix 10).

On average, the interviews lasted approximately forty minutes; the shortest was twelve minutes and the longest was 75 minutes. As advocated by Gray (2004) and cited in Baillie (2007) at the end of the interview, participants were thanked warmly for their contributions.

Immediately after each interview, the researcher used field notes and a reflective diary to record observations, impressions and participants’ behaviour during the interviews and ideas about coding. The audio-recordings were then transcribed immediately so that participants' non-verbal communication (for example, gestures) could be recalled and included in the transcripts. These details were useful when data analysis commenced as they helped to indicate meanings. If parts of a tape were difficult to hear, the researcher could remember what had been said because of the immediacy of the transcribing (Baillie, 2007). The researcher continued to interview residents until data saturation was reached.

Although permission was granted and it was pre-established that the interviews would be held in the nurse-in-charge’s office at each respective ward, it must be noted that most of the participants preferred that the interview be either conducted by their bedside in the resident’s room or in a secluded area in the corridor of the same ward. The room occupancy varied between 3 to 6 residents and interviews were conducted in privacy whenever possible. Depending on the time of day, it was observed that in the mornings, rooms would be vacant since most of the other residents would be either in the atrium of the ward or at the chapel located within the facility, listening to mass. On the other hand, if the appointment was held during the mid-afternoon or in the evening, this meant that most of the residents would already be in their bed, asleep (further information about the residents’ routine at the facility are discussed as part of the limitations to the research in section 4.11). However, it is considered that privacy was somewhat ensured; except for the occasional room occupant walking in to use the bathroom or staff entering the room to attend to toileting duties for those who were bedridden or other matters.

Nevertheless, residents were duly informed about the provision of the office for their privacy prior to commencing each interview. However, this invitation was commonly declined, with the residents preferring to remain in ‘their familiar surroundings’. Only one interview was held in complete privacy at the nurse-in-charge’s office, eight interviews were held in residents’ rooms by the bedside, four interviews were held at the far end of the corridor on the various wards (with no other residents, staff or relatives present) and another interview was held in the Atrium during the hours of the afternoon (only a staff member was present – a carer, who was at the very far end - watching TV).

Some residents were not mobile enough to leave the bedside. Others could have gone to a more private area (some were able to walk moderate distances with the use of a mobility aid, whist others were using a wheelchair) but for reasons already mentioned, they preferred to stay at their bedside (or at least, not too ‘far away’ from their room). The researcher offered on each occasion to draw the curtains round for those participants who opted to stay by their bedside, and all agreed. Even though two of the participants were wearing hearing aids, none of the residents interviewed had any significant hearing impairment, so it was possible to conduct the interviews in a discreet manner albeit maintaining a moderate voice. None of the residents appeared uncomfortable with these arrangements.

Research participants were recruited from both genders, varied ages and social backgrounds. All were Maltese Nationals, although two participants were from the neighbouring island of Gozo. Most of the residents approached by the nurse-in-charge were initially interested in taking part in the study, bar two eligible candidates who immediately refused. Another five eligible candidates were excluded from the study during the initial screening process since they were uncertain or unable to understand the topic of dignity. Two other residents that met the eligibility criteria (one female and one male) were not recruited for the study. The reason being that, during conversation with the nurse-in-charge of the respective ward, it emerged that these two residents had a previous history of abuse, namely, sexual abuse (internal: within the institution) and financial (external: from family members), respectively.

Although it is possible that salient information could have been retrieved during the interview process with these residents, the researcher felt that it would be categorically unethical to even attempt to invite these residents for study participation since a) the scope of the study could potentially invoke unnecessary harm to them, b) the researcher deemed that the study would exploit their vulnerability, and c) irrespective of whether these residents could have accepted to participant in the study, from a professional standpoint, the researcher felt unequipped to handle such delicate issues, and accordingly, informed the nurse-in-charge of their respective wards that both persons would not be approached for the study.

The researcher always checked with the nurse-in-charge about a resident’s condition to consent on the day of the schedule interview appointment. In fact, a male resident declined to participate when consent was checked on the day, saying that he "had a lot on his mind", due to "family matters", whilst another participant changed her mind the day before the scheduled appointment stating, "I don’t have anything to say on the subject". On both occasions, the researcher reassured these persons that their decision was fine. These events indicated that patients did feel able to decline if they changed their minds about participating. Staff information gave similar assurance that they could withdraw consent at any stage (Baillie, 2007).

In another instance, one elderly female participant had to be excluded from the study due to a low score in the SMMSE. In this case, the researcher followed the protocol as discussed earlier in section 4.4.1. Whilst another participant had to be excluded from the study since she has been a resident at SVPR for the past 50 years; and was deemed an outlier due to the vast length of time already spent in institutional care. Whereas, another male participant, despite accepting the *Recruitment Letter* (by the nurse-in-charge) and having a preliminary meeting with the researcher – did not make contact with the researcher for a follow-up interview appointment. This resident was not pursued further since his implicit silence was deemed a form of polite refusal.

Resident interviews were a crucial source of evidence within the study design and their quality relied on the ability to communicate experiences and feelings. The participants’ right to privacy was protected during the data collection phase.

4.9 Data Analysis

The raw data obtained from the participants' profile and the semi-structured interview questions (Appendix 10) were analysed during the transcription of the data collected. The transcription was double checked by re-listening to the recordings to ensure that the information was correct. This strategy was adopted so as to overcome transcription errors and to maintain a high degree of accuracy during the transcription process (Patton, 2002 as cited in Haber, 2011).

Data analysis can be challenging in qualitative research. No rules are universally accepted for analysing and summarising the data (Polit and Beck, 2006). At its simplest, it involves clustering together related types of narrative into a coherent scheme. This process can be facilitated with the use of computer programmes (Silverman, 2013). Although, such programmes assist in the analysis rather than doing it for the researcher; nonetheless, in this study, a computer programme was not used for the qualitative analysis due to the small number of participants in the study and because the researcher wanted to remain fully immersed in the whole process.

Once the transcribing was completed, the next stage of the process was to extract meaning out of the data collected through a process of 'open-coding'. This method necessitated the identification of independent themes emerging from the data collected, whilst results were compared. This was conducted by reviewing the field notes and by listening to the interview recordings several times. The data extracted was then revised and categorised into different sections. Once completed, the interview was analysed for themes, patterns or trends that facilitate a logical summary of the perspective of the individual. These themes were then put together with those from other participants to produce an outline of the 'essence' of the phenomenon.

Indeed, analysis can be complex, since words and phrases have different meanings to different people even when they speak the same language. The researcher questioned whether she or the participants might be making assumptions that they were unaware that they were making. For this reason, data collection and analysis were conducted simultaneously allowing for ideas generated following analysis of data collection to be explored with the same or other participants if necessary, in order to create a more detailed understanding of the issue.

From the descriptive data, further analysis enabled the researcher to uncover a description of the ‘essence’ of the phenomenon of dignity and the universal meaning for the individuals involved in the study. To derive the essence, the researcher placed to one side her own views of the phenomenon, through the technique of bracketing, in order to deepen her understanding. Petty, *et al.*, (2012) posit the assumption that if the researcher can separate (herself) in this way; it has echoes of objectivity within post-positivism.

The post-positivist stance asserts the value of values, passion and politics in research. Research in this mode requires an ability to see the whole picture, to take a distanced view or an overview. But this kind of objectivity is different from ‘just the facts’, devoid of context – it does not mean judging from nowhere (Eagleton, 2003, p. 135). On the contrary, it requires a fair degree of passion (Eagleton, 2003, p. 134) – especially passion for justice and the ability to subject one’s own assumptions to scrutiny. This requires patience, honesty, courage, persistence, imagination, sympathy and self-discipline alongside dialogue and debate (Ryan, 2006).

The post-positivist social researcher assumes a learning role rather than a testing one (Agar, 1988, p. 12). In parallel, one of the opportunities and challenges posed by this approach is that the researcher recognises the common humanity that connects researchers and the people who participate in research: "we regard ourselves as people who conduct research among other people, learning with them, rather than conducting research on them" (Wolcott, 1990, p. 19).

One last point for this section is in regards to qualitative studies, which are often guided by the principle of data saturation, whereby data collection ceases when nothing new is being uncovered (Rodwell, 1998) [as cited in Clissett, 2008], which was also the case for this study.

In summary, qualitative studies tend to be flexible, involving the collection and analysis of words and actions with a view to gaining an insight into the differing perspectives and understandings that people hold (Clissett, 2008).

4.10 Ethical Considerations

Employing a phenomenological approach to inquiry requires attention to ethical considerations. Therefore, while planning the research, ethical and operational approvals to conduct the study were granted from the ‘gatekeepers’ at St. Vincent De Paul Residence and approval to conduct the research was sought from the same institutional review board of St. Vincent De Paul Residence. As per data protection of the residents, permissions are inclusive through these gate-keepers (Appendix 1B).

Additionally, ethical issues were addressed to fulfil requirements of the University Research Ethics Committee (UREC) at the University of Malta (Appendix 1A). Therefore, the study was registered with the Department of Gerontology, Faculty of Social Wellbeing at the University of Malta and following submission of the completed research ethics proposal form in December 2015, the study was approved by the Faculty Research Ethics Committee [FREC] and successively, the university ethical approval was confirmed by the University Research Ethics Committee (Appendix 1A) following amendments.

Therefore, due to specific prerequisites set by UREC, it was requested that the researcher be accompanied by another professional for each interview. Accordingly, "researchers who conduct the interviews need to be skilful interviewers who can elicit the detail needed to answer the research question … for novices, this takes training and supervision by an experienced researcher" (Connelly, 2010, p. 127). Therefore, provisions were made to meet this requirement and the researcher was assigned a faculty member of the Department of Gerontology at the University of Malta – inclusively, a warranted Health Psychologist and in-charge of students’ practice placements during the first year academic course programme.

Another condition set by UREC was in reference to the Standardised Mini Mental State Examination (SMMSE) whereby the committee queried that the tool could only be administered by a doctor and thus, the researcher would not be able to carry out the examinations, herself. Hence, the assigned faculty member was also endorsed with the task of conducting the SMMSE for each participant during the screening process. Additionally, a separate consent form for audio-recording was also requested (see Appendix 4).

All participants received both oral and written information about the purpose, content, and extent of the study, and written consent was obtained. To be noted that all relevant documentation and paperwork used for the participants was presented in a large font to ensure ease of reading through the information. Participation in the study was voluntary, and the anonymity of the participants and the duty of confidentiality was respected during the research process and publishing of the study results.

4.11 Limitations to the research study

This study aims to seek in-depth information regarding how older adults understand their world and how this understanding shapes their dignity.

In the literature there is debate about the inherent human factors and the ability to be aware of the researcher's pre-conceptions since, in terms of this study's methodology as discussed in section 4.3, these are the key attributes that can affect bracketing (Chan, Fung and Chien, 2013). The researcher is the primary instrument for data collection and analysis in qualitative research and the findings are mediated through this human instrument (*ibid.*).

Crotty (1996) pointed out that it is not humanly possible for qualitative researchers to be totally objective and emphasizes that if the researchers are unaware of their own preconceptions and beliefs, it is impossible for them to put these issues aside. Therefore, the ability to be aware of one's own values, interests, perceptions and thoughts becomes a pre-requisite before one can set aside the things that influence the research process. Therefore, as already discussed in section 4.3.1, the researcher adopted the technique of bracketing which was pursued all throughout the study process; fundamentally, to ensure the correct execution of the research and to exclude personal biases.

In spite of the apparent flexibility in purposeful sampling, Patton (1990) warns that researchers must be aware of three types of sampling error that can arise in qualitative research. The first relates to distortions caused by insufficient breadth in sampling; the second from distortions introduced by changes over time; and the third from distortions caused by lack of depth in data collection at each site [as cited in Hoepfl, 1997].

In view of the above, it should be noted that although the interviews carried out with older adults were limited to only one selected care home, that is, SVPR – yet, one needs to consider that SVPR is the largest long-term facility on the Maltese islands and caters for a population exceeding over 1,100 residents (Parlimentary Secretartiat for Rights of Persons with Disability and Active Ageing, 2012). It is fair to state that among this population there are also those older adults who fell below the inclusion criteria, that is to say, the age group between 60 and 64 years as well for the small percentage of adults who are below the age of 60 years. Nonetheless, the older population above 65 years does prevail. Therefore, in terms of sufficient breath in sampling, this was deemed to have been achieved.

With regards to distortions introduced over time, this was not applicable in terms of this study, since the interviews were on the basis of a one-time meeting. In addition, the data collection was conducted over a period of one month. Therefore, the time-frame between first contact from the nurse-in-charge to the participant to the researcher was relatively, so much so. that the scheduled appointments and data collection commenced within a day or two from first contact.

As suggested by Hoepfl (1997), in reference to the distortions caused by lack of depth in data collection at each site, the researcher trusts that the measures taken to avoid such an issue were put in place, such as, selecting the sample population (participants) from different age groups and from various wards within SVPR. In particular, there were two wards whereby the participants informed the researcher that they had been transferred from other wards (to newly refurbished ones) due to restoration being carried out in their original wards of residence. These participants were still accepted for the study since they met all of the criteria (including residence at SVPR for more than one year) and the information gathered from these participants was beneficial for this study, as they were able to provide comparisons ranging from staff practices, behaviour and ward environment.

During the pilot study, a few issues were encountered. A major draw-back was that the English interview schedule (Appendix 10A) was not tested and nor was it used during the data collection process at SVPR. To counterbalance this problem, the researcher trialled the English version with community dwelling older adults (two females and one male), whereby English was either their first language or otherwise they were proficient in its use. For the record, feedback received was that the questions appeared rather straightforward, with an easy flow to the language and syntax. Unfortunately, for obvious reasons, none of this data could be used in the results for this study.

One needs to bear in mind that the majority of the population sample for the study were born between the late-1920s to the mid-1940s, except for one male participant who was born in 1924. Fundamentally, there was a language barrier. Indeed, the language of choice for this cohort used during the interview was therefore, Maltese, their mother-tongue.

The level of education was another prominent feature in this study. Besides a few exceptions, most of the participants born in the 1940s had completed their educational schooling years by the age of 14. Whereas, those born pre-war, had either not gone to school (reportedly, at that time, it was normal practice for children to help their parents in the fields and work the land) or they had attended to a few hours of study classes per week.

In fact, going back in history, one needs to appreciate that during World War I, the interwar years and World War II, there was widespread poverty in Malta which prevented the children of the lower classes from pursuing basic education in favour of staying home to assist parents with agricultural work and other income earning activities. To counteract this phenomenon, education was declared compulsory in 1946. In 1988, the age at which education became compulsory was lowered to five years.

This singularity helps to shed light on the reason as to why nearly half of the participants in the study were illiterate; albeit not by choice but perhaps circumstantial. Further explanation and review of the demographics will be discussed in the next section, Chapter 5, which deals with the results and discussion.

This brings us to the use of the Maltese interview schedule (Appendix 10B). During the pilot study, it appeared that some questions were not being clearly understood, either because the content of a sentence was too wordy or it needed to be simplified.

One needs to appreciate that when switching from one language to another (*i.e.* English to Maltese), the conveyance of a meaning or what one really wants to say may be easily ‘lost in translation’. Sentence constructions inherently vary from one language to another, and certain phrases do not carry the same meaning across multiple languages (NHANES, 2006).

Since the researcher is bilingual and also qualified in languages (besides her science-based profession), it was imperative for her that the Maltese interview schedule, likewise, "accurately (captured) and relayed the full meaning and spirit" of what was written in the English interview schedule, "rather than a literal interpretation per se, which conveys all of the words but not always all of the meaning" (NHANES, 2006) especially since "most people incorrectly assume that a bilingual person can interpret effectively by virtue of being bilingual" (*ibid.*). This was a concern for the researcher and such errors needed to be avoided.

It is worthwhile noting that the terms "interpret" and "translate" have similar definitions and are often used interchangeably (*ibid.*):

- Interpret – To explain the meaning of; to conceive the significance of; to translate orally;
- Translate – To render in another language; to put in simpler terms; to explain.

NHANES (2006) elucidate that the major difference between the two terms is that an interpreter relays a message orally, whereas a translator works with the written word. Consequently, interpreters and translators develop different skill sets. Interpreters must have the capacity to work "on the spot" and convey spoken words from one language to another, in both directions. In contrast, translators require strong writing abilities and will typically convert written text from a second language into their native language, in one direction (*ibid.*).

The researcher felt capable to take on these dual tasks, however skilful preparation was a must which further grounded the rationale for having semi-structured interview questions prepared beforehand. The researcher initially worked diligently on the Maltese translation of the interview schedule and the completed work was then submitted to a professional for proof-reading, orthographical corrections, and organization of syntax and meaning. Minor corrections were in fact deemed necessary. Thus, it was established that the Maltese interview schedule would be presented in its entirety since further modification or simplification would detract from the essence of the interview questions and scope of the study. In the event, that queries or uncertainties in comprehension by the selected participants occurred, then substitute words could be used to assist with meaning; albeit maintaining the same format throughout, with all participants, so as to ensure consistency in the approach.

Other limitations involved the actual timing for when to conduct the screening process (using the assessment tools) and actual interviews with the residents at SVPR. The researcher discussed with the nurse-in-charge of each ward in regards to appropriate timings to conduct the interviews so as to ensure minimal interference with, for instance, the nursing duties, ward rounds, residents’ meal times, activities, sleeping patterns and relatives’ visiting hours – not to mention the need to liaise with the faculty member so as to conduct the SMMSE. Overall, the afternoon and evening times were more suitable, whereas, at the weekends it was far better since there was less activity from staffing duties (*i.e.* wards rounds, external medical appointments, etc.).

Lastly, the original design was to have a total of 20 participants – 10 males and 10 females - from 4 different wards within SVPR. However, due to either refusals or cancelations from participants, the requirement to liaise with an outside professional (needed to conduct the SMMSE) time constraints and above all, data saturation - the number was reduced to 14 participants.

4.12 Reliability and Validity

Qualitative research methodologies are valuable for understanding subjective experience (Carey, Laws, and Ferrie, 2013). The inductive thematic analysis approach used in this study was consistent with this research approach, providing narrative as opposed to numerical/statistical results.

Qualitative data is validated using four key criteria: credibility/truth value, transferability/applicability, dependability/consistency, and neutrality (Guba, 1981).

Credibility of the results was ensured by purposeful sampling of participants by gender, age, different levels of education (as much as possible), varied previous occupations, and residing in long-term care for more than 1 year, so that a wide range of participant experience were represented in the results. Credibility of the results is also supported by the use of an appropriate rapport prior to interview and withholding the researcher's own agenda from the interview structure. Nonetheless, a second independent coder was not availed of for the purpose of this study.

Transferability was optimized by interviewing a range of subjects with a variety of years residing at SVPR and consistency was enhanced by careful recording of sources of variability in the data. Then again, it needs to be stated that triangulation and the use of a second independent coder would have substantially strengthened transferability.

Neutrality or freedom from bias was ensured by using a semi-structured interview format (so that there was no implication of a ‘correct’ response); by withholding the researcher's own agenda from the interview structure; and by transcribing all interviews in the participants' own words.

4.13 Chapter summary

This chapter provided a detailed account of the research design and methodology according to the manner in which this research was conducted.

To summarise, the method of inquiry provided a qualitative collection of data. The study relied on three methods of enquiry namely: 1) a research of the literature available, 2) a preliminary pilot study to refine the research instrument, and 3) an in-depth phenomenological semi-structured interview.

While the literature review, as described earlier in chapter 2, provided the foundation, the pilot study provided the groundwork for the phenomenological interview, which in turn supplied a rich and detailed description of how ‘dignity’ is experienced by this qualitative sample of Maltese older adults living in long-term residential care at St. Vincent De Paul Residence.

An explicit benefit of using a phenomenological approach to examine the experience of Dignity in Care Homes is that the experience is captured from the older person’s perspective. As a result, clinicians are better able to support older adults and deliver interventions that are most meaningful to these individuals. In light of ideologies around patient-centred care, it seems logical that interventions geared toward supporting older adults living in long-term residential care would be free of paternalism and grounded in knowledge emerging from the older adults themselves.

A phenomenological approach is well suited to examining the experiences of older persons in regards to dignity. More specifically, the use of descriptive phenomenology allows the researcher to directly explore and analyse this particular phenomenon to arrive at a description of the lived, or subjective experiences (Speziale and Carpenter, 2007) of the older persons. Examining this particular cohort of individuals using a phenomenological perspective has inherent challenges for the researcher, albeit an appropriate methodological fit with explicit benefits. Eliciting a thorough understanding of the method and philosophical underpinnings of phenomenology, as well as gaining an awareness of and addressing its potential challenges and benefits is essential. In so doing, a rigorous process of inquiry can ensue, resulting in sound empirical findings that will guide staff in supporting older adults in care homes (Penner and McClement, 2008).

The next chapter presents both the results and the discussion of the research study. For ease of reference, following the introduction, Chapter 5 is divided into Part I which deals with the analysis of the data and Part II, which deals with the results of the interview process.

Chapter 5

Results and Discussion

5.1 Introduction

While, Chapter 4 explained the rationale behind the qualitative research design, the setting for the research, data collection methods and analysis, this chapter is divided into two parts.

Part I deals with the analysis of the results and starts by introducing the main protagonists of this research study: the participants. To ensure confidentiality and anonymity, a system of coding and pseudonyms have been used respectively, as previously described in Chapter 4. A brief descriptive overview of each participant is presented in 'a case format' and includes gender, age, length of stay and functional mobility of each individual. Next, the results of the screening tools used (SSMSE and GDS-15), and other independent variables, such as, the socio-demographic characteristics of the sample group, as well as, other pertinent details relating to the participants' health status and background information are also presented, all of which help to set the tone of the phenomenon under study.

Part II presents the findings of the interviews in relation to the meaning of dignity for residents in the long-term care home setting of SVPR and follows on how residents' dignity is threatened. Threats to dignity relate to the environment within the facility, staff behaviour and resident factors. Results of this qualitative study revealed several themes that emerged from the thematic analysis. For ease of reference, these were organised and grouped into sub-categories; each of these aspects is examined and discussed in relation to previous research. Quotations from the data are included throughout this chapter to support the findings and coded to preserve residents' anonymity[12].

The chapter ends with a summary, which indicates areas of new knowledge, and links forward to the conclusion in Chapter 6, which explains how residents' dignity can be promoted in care homes and further suggestions in regards to promoting the need and enhancing a skilled workforce in the local geriatric field.

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[12] Resident participants were referred to by a number, prefixed by Mr. (if male); Mrs. (if female), both for the married or widowed women participants; or Ms. (if female) for single women. Observational data was coded 'FN' (field notes of observation episodes).

Part I: Analysis of the results

5.2 Profile of Respondents

Box 5.2 below, provides a brief descriptive overview of each participant and includes (1) the participant’s code, used by the researcher; (2) the pseudonym used for the purpose of preserving the humanity of each participant, and on this note it helps the reader establish a sense of connectedness, as he or she can relate better to the findings described by these people; and (3) gender, age, length of stay of each individual and functional performance as per the results of the Katz Index assessment.

Box 5.2: Profile of respondents

Case 1: ***Mr. M01 - Alan***

Alan is a 79-year-old single man. He has now been a resident at SVPR for 2 years; and is visited frequently by his surviving siblings and on occasion, by some friends.

The gentleman is semi-independent in his ADLs and able to walk medium to long distances using a Zimmer frame. He is partially incontinent of urine and wears a nappy.

Case 2: ***Mr. M02 - Bert***

Bert is an 84-year-old man, a widower for the past 24 years and has been living at SVPR for the past 1½ years. He has 7 children of whom 4 live in Malta, 2 live overseas and one passed away 27 years ago.

The gentleman is dependent in most of his ADLs and is able to walk short to medium distances using a Gutter frame. He has partial double incontinence and wears a nappy.

Case 3: ***Mr. M03 - Charles***

Charles is a 91-year-old single gentleman and has been a resident at SVPR for 1 year. His older sister, who is also single, resides in an another care home and is the only other surviving member of his family. His extended family rarely visit him.

The gentleman is dependent in most of his ADLs and is able to walk short to medium distances using a Rollator frame. He has partial double incontinence and wears a nappy.

Case 4: ***Mr. M04 - David***

David is an 80-year-old married man and has 2 sons. He has been residing at SVPR for 2½ years. He is in contact with his wife via phone on a daily basis and the family visit him at the weekends.

The gentleman is semi-independent in his ADLs and is able to walk short to medium distances using a walking stick. He has partial double incontinence and wears a nappy.

Case 5: ***Mr. M05 - Eric***

Eric is an 81-year-old widower since 8 years and has been at SVPR for 4 years. His social and family network remains strong as his two children visit him daily.

The gentleman is fully independent in all his ADLs and walks unaided. However, of late, he has become restricted to his surroundings due to frequency of urination and needs to be in the vicinity of a toilet.

Case 6: ***Mrs. F06 - Fiona***

Fiona is 81 years old, a widow since 6 years and has 7 children (and 4 miscarriages). She has been residing at SVPR for the past 1 year and her children visit her regularly during the week, including her grandchildren.

The lady is semi-independent in her ADLs and walks independently with a Rollator frame. She has a colostomy bag and a permanent indwelling urinary catheter. She wears neither a nappy nor underwear.

Case 7: ***Mrs. F07 - Grace***

Grace is a 76-year-old lady and has recently become widowed (1 month ago, from the time of the interview). She has been a resident at SVPR for 1 year.

The lady is dependent in most of her ADLs and needs to be transferred in/out of bed with a hoister onto a wheelchair. Accordingly, she is continent but wears a nappy.

Case 8: ***Mrs. F08 - Helen***

Helen is 78 years old and has 4 children (of whom a son passed away 14 years ago at the age of 42). She was widowed 2 years and 3 months ago which is the same amount of time that she has been a resident at SVPR.

The lady is semi-independent in her ADLs and able to walk independently with a Gutter frame, albeit with minimum assistance of one person from sitting to standing. She has partial double incontinence and wears a nappy.

Case 9: ***Ms. F09 – Isabel***

Isabel is a 68-year-old single lady. She has been at SVPR for the past 8 years and has no immediate family.

The lady is dependent in most of her ADLs and needs to be transferred in/out of bed with a hoist lifter onto a wheelchair. However, she is independent in wheelchair management. She is partially incontinent of urine and wears a nappy.

Case 10: ***Mrs. F10 - Janice***

Janice is 87 years of age, a widow since 7 years and has 6 children. She has been a resident at SVPR for 1 year. Her children and grandchildren visit her quite regularly.

The lady is mostly dependent in her ADLs and able to walk short to medium distances with a Rollator frame. She has partial urinary incontinence and wears pull-ups.

Case 11: ***Ms. F11 - Kelly***

Kelly is an 81-year-old single lady and is Liz's sister. She has been a resident at SVPR for 10 years. Her surviving siblings visit her as often as they can.

The lady is fully independent in all her ADLs and walks unaided. She wears underwear but feels safer doubling up with a pull-up nappy if she has to leave the ward for an unspecified length of time.

Case 12: ***Ms. F12 - Liz***

Liz is a 79-year old single lady and is Kelly's sister. She too has been a resident at SVPR for 10 years and has always shared her room with her sister.

The lady is dependent is most of her ADLs and is able to walk short to medium distances using a Rollator frame. She has partial double incontinence and wears pull-ups.

Case 13: ***Mrs. F13 - Mary***

Mary is 73 years old, a widow since 2 years and has one son. She has been a resident at SVPR for 2½ years.

Albeit having a bilateral above knee amputation, the lady is fully independent in all her ADLs and is independent in wheelchair management. She does not wear any underwear out of choice as it is more practical and safer for her when transferring to/from the toilet.

Case 14: ***Mrs. F14 - Nora***

Nora is a 76-year old lady who is married and has 3 children - 2 are married, one is single and lives in the family home. Her husband visits her daily and spends his time with her for most of the day (approx. 8 hours). Her children also visit her very regularly throughout the week. She has been a resident at SVPR for 1 year and 3 months.

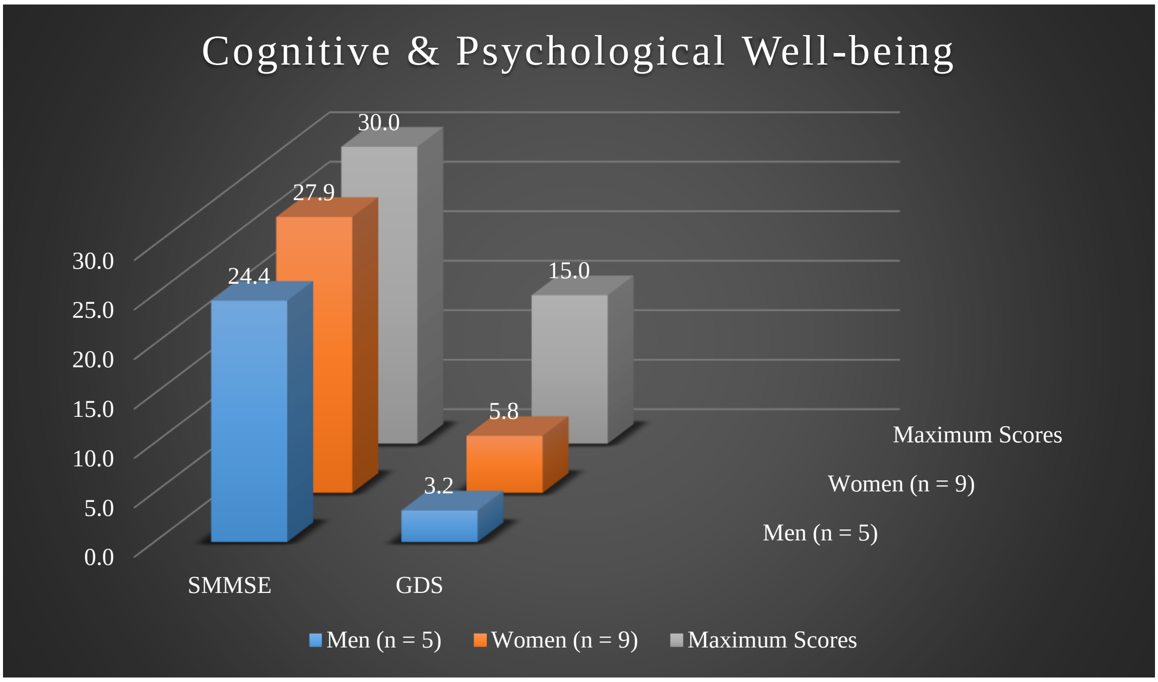
The lady is dependent is most of her ADLs and needs to be transferred in/out of bed with a hoist lifter onto a wheelchair. She has a permanent indwelling urinary catheter and wears a nappy.

5.2.1 Participants' cognitive and psychological well-being

At the time of the interviews, all of the fourteen participants had relatively good cognitive functioning and psychological well-being.

For ease of reference, Chart 1 below, illustrates the average scores of the SMMSE and the GDS-15, for both male and female participants. The term *Maximum Scores* in the chart below, represents the totals for each test performed (see List of Tables: Table 1, for a detailed account of these results for the individual participant) followed by a description and significance of these results.

Chart 1 - Results of Participants' Cognitive & Psychological Well-being (n = 14)



5.2.1.1 Standardised Mini Mental State Examination (SMMSE)

The figures in Chart 1, show that with regards to cognitive functioning, the female participants scored higher in the Standardised Mini Mental Scale Examination than the males (see List of Tables – Table 1).

However, it must be noted that with particular reference to Question 2b of the SMMSE, '*What province are we in?*', all the participants bar one exception, were unable to answer this question (see Appendix 5: Standardised Mini-Mental State Examination). What is worthwhile to note is that, in the Maltese version of the SMMSE, *province* is translated to signify *district*, and for the majority of the population on the Maltese islands, the numerical code of a district is mostly used during the country's national general elections (held every five years) and therefore, a district is closely associated to one's locality for voting purposes. Since, SVPR is in Luqa, the electoral division corresponds to District 6 (Electoral Commission Malta, 2012). The only participant (male) who knew the answer to this question is originally from Zurrieq, which corresponds to District 5.

Bearing this is mind, it is plausible to state that had the sample group been asked to answer in reference to their own locality, then perhaps, they might have been able to provide a correct answer, since voting is bound to one's original district as per the address stated on the person’s identity card, and every attempt is made to ensure that the right to vote is upheld for those older adults residing in care homes.

Hence, this particular question (Q.2b) could potentially be a flaw for the local older adult population under examination. That is, unless the tool is modified in such a manner that it allows further explanation, especially when it is evident that a person is not familiar with the relevance of the question being asked. On a more positive note, with regards to participants being oriented to place, this was more than evident in the subsequent questions. Nonetheless, one point was deducted for all of the thirteen participants who were unable to respond to Question 2b, hence, lowering the overall Mean Score.

Additionally, it needs to highlighted that with regards to Question 4 in the SMMSE, the serial sevens task was presented to participants who were illiterate, as an alternative to spelling ‘world’ backwards. (see Appendix 5A: Scoring Guidelines).

5.2.1.2 Geriatric Depression Scale (GDS-15)

Meanwhile, as for the psychological well-being of the sample group, scores ranged from 1 to 10 and overall, the male participants appear to have fared much better in the Geriatric Depression Scale, obtaining lower scores to the female participants (see List of Tables – Table 1 for individual results). For the record, it ought to be noted that, the wording in Question 9 (see Appendix 6) was slightly modified and the first part of the sentence ‘*Do you prefer to stay at home, …*’ was changed to reflect ‘*Do you prefer to stay in your room, …*’.

For ease of interpretation of the data and respecting the scoring classification proposed by Sheikh and Yesavage (1986), and Greenberg’s (2012) as used in this study (see section 4.4.3), the findings show that five participants scored below 4 (*i.e.* no depression) and the remaining ten participants scored between 5 and 10; suggesting that that these participants were experiencing some form of depression (see List of Tables – Table 1).

Used as a screening tool, the GDS-15 may facilitate assessment of depression in older adults and be used to monitor depression over time in all clinical settings especially when baseline measurements are compared to subsequent scores. However, the GDS is not a substitute for a diagnostic interview by mental health professionals and it does not assess for suicidality (Greenberg, 2012). In fact, *Standard 7 – Health Care* of the NMS also emphasises that:

> "The resident's mental health shall be monitored regularly during quarterly assessments or earlier if necessary, and both preventative and therapeutic action taken in a timely manner" (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2015, p. 15: 7.7).

However, in agreement with Sutcliffe (2000) "some items in the GDS-15 appear(ed) irrelevant in the context of institutional living". It is a fact that the researcher is neither a psychologist nor a psychiatrist. However, from a humanistic standpoint, the researcher considers that some questions in the GDS-15 were somewhat harsh. Given the participants' medical conditions and various levels of dependency, the researcher further believes that the wording in this particular test may need to be revisited since it can etch away at one's personhood.

5.3 Independent Variables

The age of the fourteen participants (total of nine females and five males) ranged from 68 to 91 years, with the youngest participant in the sample group being female and the oldest, being a male participant. All were born in Malta except for two participants, born in Gozo. Box 5.3 below, provides an overview of the sample population and the socio-demographic characteristics for these participants (see List of Tables: Tables 2A to 2D for a comprehensive and detailed account of each individual participant).

Box 5.3: Socio-demographic characteristics of the sample (n = 14)

Variables		Women	Men
Age	65-75 years	2	0
	76-85 years	6	4
	86-95 years	1	1
Marital Status	Married	1	1
	Single	3	2
	Widowed	5	2
	Separated	0	0
Educational Level	Unable to read and/or write*	4	1
	Able to read and/or write**	5	4
	Primary education completed	5	4
Date of Admission	1 to 5 years ago	7	5
	6 to 10 years ago	2	0
	Over 10 years ago	0	0

Note:

1) * denotes that Questions 4, 9 and 10 were omitted from the test due to participants' self-reported illiteracy. Subsequently, the SMMSE scores were modified accordingly (see Appendix 5 – Scoring Guidelines). To be noted that out of the 5 participants who stated they were unable to read or write, only 2 participants were unable to write their own name (Fiona and Bert).

2) ** denotes that Questions 4, 9, 10 and 11 were omitted from the SMMSE test due to physical inabilities, *i.e.:* one female participant was unable to write due to severe OA in both hands. Subsequently, the SMMSE scores were modified accordingly (see Appendix 5A – Sections: Directions for Administration of the SMMSE and Scoring Guidelines).

5.3.1 Widowhood

As described in Box 5.3, seven participants within the sample group were widowed (5 females and 2 males). In terms of a given timeframe, widowhood varied between 6 to 8 years for three of the participants and just over 2 years for another two participants. Notably, the extremes were: 24 years (Bert) and the more recent time-frame of one month (Grace), (see List of Tables - Tables 2A to 2D).

5.3.2 Level of Education

In reference to the participants' level of education, a few of them said: '*ilħaqt l-iskola ta' bil-fors*', which means that they started attending primary school when primary schooling became compulsory in 1946, (whereas, secondary education up to the age of sixteen, in Malta, was made compulsory in 1971) (Euro Consulta International, 2016).

This information was useful when analysing the data, since it helped to put the participants' comments into perspective. However, it was not so straightforward when it came to selecting a category for the participants' completed level of education, since different ages where provided which do not fit into the cut-off points of today's educational system (see List of Tables: Tables 2A to 2D). In order to avoid confusion in the interpretation of the results, further explanation is deemed necessary.

A few participants attended '*after hour classes*', (Eric, Isabel, Kelly and Nora), which were held a couple of times a week and accordingly, classes were mixed, catering for both girls and boys of different ages.

Throughout the interviews with the female participants, it emerged that, depending on the birth order and gender, children were assigned to different tasks within the household, as was described by Kelly, who said,

> "I didn't do much schooling, it wasn't something for me … we *had* to help our parents, … I don't know how to sew; I *wish* I had learnt but that was my older sister's job … I did the house chores and the cooking … I looked after my brothers and sisters … we were a family of eight". **(Kelly)**

Similarly, Grace made reference to her strict upbringing and the lack of opportunity to enter the workforce, as illustrated below:

> "My sister and I, *were the ruffians of the family*, working with our father (in reference to farming and tending to the animals) … and sometimes he would give us some money. We were still young ladies and not married … he didn't allow us to go to work". **(Grace)**

In contrast, Kelly's younger sister, Liz completed her school education and went on to become a nurse. Both these sisters never married and lived together at home with their parents. Kelly never worked (*i.e.* paid work) and would later become the sole carer (informal) for both her parents, whereas, Liz's job provided financial security, especially after their parents had passed away.

Nora said that she "had to go school when it was made compulsory". In her case, schooling years ranged between the ages of 8 and 12. When she was 12 years old, her father passed away, which necessitated her to stay home to help her mother and "look after [her] older brothers";

> "We had no money. I don’t know how my mother managed to raise us all. Times were tough (becomes emotional)". **(Nora)**

On the other hand, Fiona never went to school. By the time primary schooling had become compulsory, she was 11 years of age and reportedly, she also used to help her parents with agricultural work. Fiona was the only female participant unable to sign her name. In fact, her consent form was signed by one of her sons who was present (visitation hours) during the researcher’s first meeting (to further discuss the purpose of the research study). Likewise, out of the male participants, only one male stated that he was ‘*illiterate*’ (Bert), thus, the consent form was signed on his behalf by the nurse-in-charge, as per the protocol discussed in Section 4.1.1.

Overall, most of the participants said that they had completed Standard 4 or 5, or otherwise that they were either 12 or 14 years of age when they left school. Nonetheless, it is important to note that lack of formal education does not imply lack of intelligence.

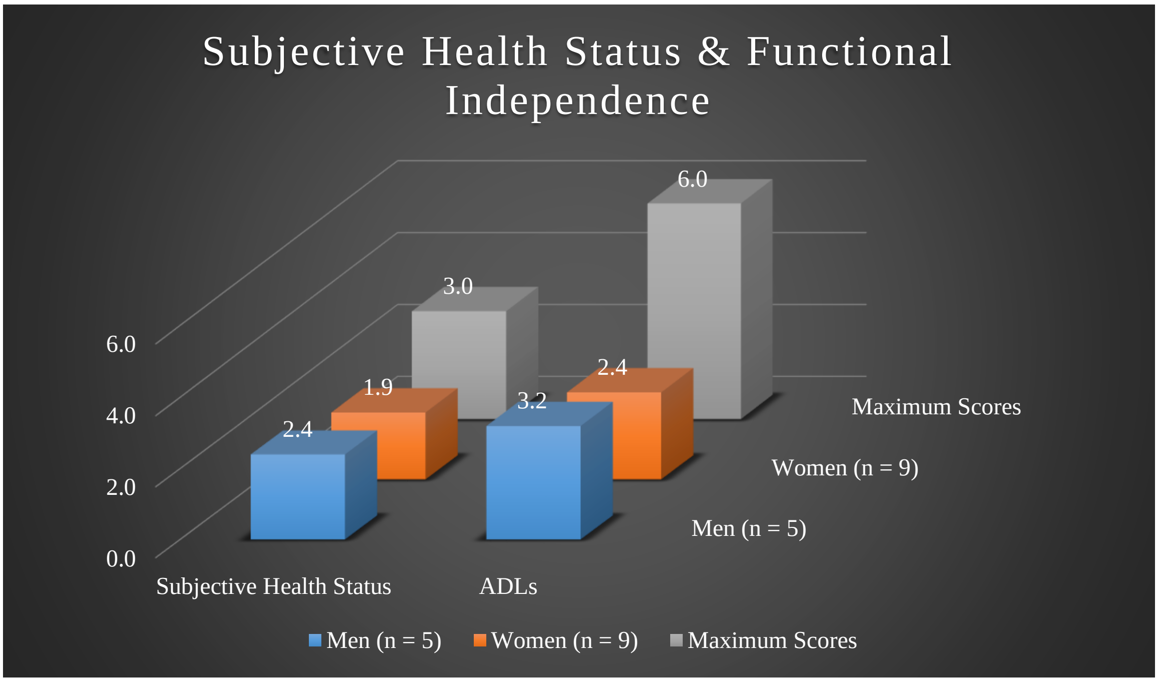
5.3.3 Self-reported or diagnosed chronic illness(es)

As per the self-reported or diagnosed chronic illnesses, each participant had more than one co-morbidity. However, Diabetes Mellitus (DM) and Hypertension (HT) were found to be the most common chronic illnesses, affecting eleven and nine participants, respectively, from a total of fourteen. Osteoarthritis (OA) affected three participants, whilst one female reported having a history of two episodes of stroke (Cerebral Vascular Accident - CVA), and another had had a Transient Ischaemic attack (TIA). Chronic low back pain (LBP) with occasional acute exacerbations was another common complaint amongst quite a number of participants. From observation, one participant appeared to have kypho-scoliosis and another participant mentioned that she had leg-length discrepancy in her left lower limb. Reportedly, this latter participant had also suffered from a life long history of back pain and it appears that adaptive footwear was introduced at a later stage in her life. Meanwhile, although three female participants were wheelchair bound; Isabel and Mary were both independent in wheelchair management, which bolstered their sense of dignity since they were able to leave their ward unattended and at will, thus enhancing their autonomy and sense of "*freedom*". On the other hand, Nora felt that her medical condition was the cause of her being confined in bed and in her case, the fact that she needed staff to hoist her out of bed, injured her 'self-esteem' and 'self-worth' which added to her sense of "*powerlessness*".

5.3.4 Participants' health status and functional independence

For ease of reference, Chart 2 below, illustrates the average results of the Subjective Health Status and the Activities of Daily Living (ADLs), for both male and female participants. The term *Maximum Scores* in the chart below, represents the totals for each test performed (see List of Tables – Table 1, for a detailed account of these results for the individual participant).

Chart 2 - Results of Participants' Subjective Health Status & Functional Independence (n = 14)



Part II: Results of the interview process

5.4 The meaning of residents’ dignity at SVPR

All participants interviewed were asked an open question inviting their views about dignity. The meaning of dignity emerged from both these responses and during the interview process, through their descriptions of how dignity was threatened or promoted, supported by observational data. Box 5.4 below, presents all of the participants’ illustrative quotations with regards to their interpretation on the meaning of dignity.

Box 5.4: Participants’ interpretations on the meaning of dignity
"Dignity? … (laughs) … How do you explain it?". **(Bert)** "Dignity, for me? Well, at times it’s good and at other times, it’s not that perfect". **(Fiona)**
"There’s nothing more beautiful than Dignity … that you’re not made to feel bad (laughs) … to do what your heart desires … not to be ordered around by staff". **(Alan)**
"Dignity? - It’s related to how you behave. It’s about one’s behaviour: tell me who you hang out with and I’ll tell you who you are ... and the members of the family - the respect that they show you". **(David)** "Dignity means a lot of things; that you’re healthy, that you’re good to people … how you behave". **(Eric)** "That you’re healthy and that you’re able to do the same things that you were able to do before ... not needing to ask people to come and help you all the time". **(Nora)**
"Respect … but not everyone sees it the same". **(Isabel)** "I don't even know what it is … I suppose it’s got to do with respect". **(Kelly)**
"Being a good woman … a woman of good conduct". **(Grace)**
"That everyone values that you are a woman or that you are a human being (laughs)". **(Helen)**
"For me, it means that if possible, I don’t want a man to come in and change me [*i.e.* a male member of staff to attend to her personal care *e.g.* changing her nappy]". **(Liz)**
"Dignity is being allowed to eat in an appropriate manner, comfortably at your own pace, and not being rushed so that they can come and take your plate away". **(Mary)**
"I don’t know … you get thrown here and there … the fact of the matter is, now you have it and now you don’t, that’s what it’s like here. No, they don’t uphold your dignity … no, nothing is maintained for you here". **(Charles)**
"Nothing! Dignity is worth nothing to me. What? - To have power (control) over something? Why – what do I need that for? Respect? And so what!? - what’s the point? … Nah! Never mind. I’ve lost my dignity! Of course I’ve lost it! … What am I worth right now? What’s it (dignity) worth, being here?". **(Janice)**

Despite some of the participants' initial difficulties with articulating their view, all offered suggestions. Essentially, the findings were consistent with the literature as described by the Social Care Institute for Excellence (2013b) [see Chapter 2, 2.1], in that, these residents were able to pin-point instances and provide both insightful and meaningful examples which clearly depicted a loss or threat to their dignity whilst in the care home of SVPR.

This next section presents the environment of SVPR in terms of its organisation and how it appears to be operationalised in relation to the care of older adults, which serves as a backdrop to the views of the sample group of participants in relation to episodes or situations which they felt threatened their dignity, discussed in Section 5.5.

5.4.1 Facility Systems

In reference to St. Vincent De Paul Residence being described as a hybrid between a nursing home and a hospital (see Chapter 3, 3.3), a few points need to be raised and clarified.

By definition, *a residence* is "the place, especially the house, in which a person lives or resides; a dwelling place; a home" (Dictionary.com, LLC., 2016), and similarly, *a house* is "a building in which people live; a residence for human beings" or "a building for human habitation, especially one that consists of a ground floor and one or more upper storeys" (Dictionary.com, LLC., 2016).

So, in this case, a home can be defined as (1) a house, apartment, or other shelter that is the usual residence of a person, family, or household; (2) the place in which one's domestic affections are centered; and (3) an institution for the homeless, sick, etc.: *a nursing home* (Dictionary.com, LLC., 2016).

Whereas, a residential care home offers personalized service to small groups of adults and is also known with other industry terms, such as: a "care home", or an "adult family home", "board and care home", "residential care or personal care home". In any case, a residential home provides lodging, meal services and assistance with daily living activities (A Place for Mom, Inc., 2016).

Given the above dictionary definitions and in view of the findings in this study, combined with the participants’ reasons for admission to SVPR and linked to their vivid narratives throughout the course of each interview, then it is fair to conclude that this large facility is not representative of an ideal residence at all, *but merely an institution for the homeless and the sick*; indeed, a hospital based nursing home, in its true form.

First of all, the running of this majestic institution is synonymous with numerous large hospital wards. Similarly, residents' quarters are referred to as 'wards'; furnished and equipped accordingly. In exchange of beds lined-up in corridors (suggestive of busy and overloaded hospitals), instead, one finds that it is the residents themselves who are neatly lined-up, adjacent to one another, all throughout the length of the corridors. Concurrently, although renovations have been carried out in various wings within SVPR, however, the wards have not been converted to reflect a smaller, intimate home (FN). To date, the same concept of what SVPR was used for in the past, remains, that is, a hospital (as described in Chapter 2, 2.2), (see safety and protection).

Secondly, reference is made to "*homeless*", because this is the manner in which nine out of the fourteen participants described themselves as being; since it was not their choice to enter into this long-term care institution, nor any other for that matter.

> "My daughter and daughter-in-law brought me here – not because I wanted to! They knew I didn't want to come here, in fact, I kicked up a storm and gave them hell!" **(Janice)**

Therefore, the majority of these participants stressed on the fact that their autonomy and control was stripped away from them. Being away from their own home and domestic affections negatively impacted on their sense of belonging and personal identity which categorically, was a violation and loss of their human dignity, as illustrated below:

> "Towards the end of my old age, I feel like they (family) *threw me in here, as though I were a ruffian*". **(Janice)**

Thirdly, linking back to the literature, where Mann (1998) differentiates between internal and external components of dignity (see Chapter 2, 2.2), reference is made to "*sick*" because only four participants deemed that their health was good, whereas, eight participants judged their health status as being fair and another two females depicted themselves as having (very) poor health.

Participants' views and perceptions about themselves (internal component) were more likely to be affected on the basis of whether they were functionally viable or not. Therefore, even though their level of dependence was a direct result of their chronic conditions, they did not associate their subjective health status to their medical conditions, but directly to whether they were independent in their basic activities of daily living or not. And the higher the level of dependency was for participants, the greater were the negative terms attributed to them. Inclusively, their perceptions were grounded on the basis of how ward staff '*saw them'* (external component), that is, "old"; "frail"; "weak"; "needy and in need"; and "useless", to name a few.

From observation and field notes (FN), residents were labelled as patients by members of staff on the wards. Therefore, if healthcare staff truly regard the older adults living at SVPR, as merely being patients; then linking to what Mann described in 1998, these residents are "being seen" as one homogenous group, basically, "sick patients" who are *in need* of skilled nursing care.

Matiti (2002) also explained dignity as being dynamic so that patients adjust their perceptions of dignity during hospitalisation. So essentially, this factor further reinforces the premise which was suggested by Matiti and Trorey (2008), so that, if indeed, the residents *see themselves* as patients who are "very sick", then they may be more likely to accept insults to their dignity, than a person who is almost well.

In fact, this was consistent with the findings related to the participants' level of functional independence, whereby the Katz's Index was utilised to assess the six Activities of Daily Living (ADLs) (Shelkey and Wallace, 2012 - slightly adapted from Katz, Down, Cash, *et al.,* 1970) – (see List of Tables – Table 1).

Only three participants (Eric, Kelly and Mary) were fully independent, reportedly, being able to perform all of the six activities of daily living, whilst two participants (Alan and David) fell within the *moderate impairment* category (*i.e.* semi-independent in ADLs). The remaining nine participants (seven females and two males), fell within the *severe functional impairment* category, meaning that they were mostly dependent and required the ward staff to assist them with most of their basic activities of daily living (except feeding), (see Section 5.5.2 – Respect - Authoritarianism).

Interestingly, when topics arose which could have been attributed to a loss or threat to their dignity – it was observed that some of the participants from within the *severe functional impairment* category seemed to justify a given situation or were more forgiving and accepting towards the negative behaviours of certain staff.

The researcher perceived a sense of submissiveness on their part and quite possibly they had a lack of awareness in terms of their own human rights but this could in part be attributed to the fact that were already *institutionalised*, well ahead of their admission to SVPR. For ease of reference, Box 5.4.1a below, outlines the participants' successive location/s leading to their admission to SVPR and their reported length of stay at SVPR.

It should also be noted that when summing up the length of stay at both MDH and RHKG (*i.e.* excluding the five participants who were admitted to SVPR directly from their own home), it emerged that these participants had also spent many months or even more than a year away from their own home.

Box 5.4.1a: Participants' successive location/s prior to their admission at SVPR and Participants' reported length of stay at SVPR

Participants	MDH	RHKG	Own Home	Length of stay at SVPR
Alan			✓	2 years
Bert	✓	✓	✓	1 year, 6 months
Charles	✓			1 year
David			✓	2 years, 6 months
***Eric**	✓	✓		4 years
**Fiona	✓			1 year
Grace	✓	✓		1 year
Helen	✓	✓	✓	2 years, 3 months
Isabel			✓	8 years
Janice	✓	✓		1 year
Kelly			✓	10 years
Liz			✓	10 years
Mary	✓			2 years, 6 months
**Nora	✓	✓		1 year, 3 months

Note:

1) * denotes that following his discharge from RHKG, Eric spent 1 month and 3 days at Roseville – a private care home, after which he was admitted to SVPR

2) ** denotes that participants also spent a length of time in ITU at MDH

As highlighted by Iwasiw, *et al.*, 2003 and Chao, *et al.*, 2008, in relation to whether admission into a care home was elective or not – the findings show that, for most of the participants, lack of choice and control were the contributing factors which had initially led to their admission at SVPR, and at ward level, these were closely linked to difficulty in adapting to their environment which contributed to their loss of dignity.

For the record, none of the participants' reported having an unplanned admission to SVPR and findings revealed that had there been support and assistance from family members and/or effective services within their local community, then the chances are that they would have remained living in their own home rather than,

> "waiting for the inevitable in a nursing home". **(Janice)**

Clearly, if the residents are induced to believe that they have no hope in achieving their maximum functional potential because they are trapped within, what the researcher terms as *the bubble of the patient syndrome*, then, by living as a patient there is no motivation towards improvement or self-help because as Enes (2003) highlighted, their illness may well progress.

Hence, in reference to Mann's (1998) psychosocial mechanism, and the allostatic load presented by McEwen and Gianaros 2010; Seeman, *et al.,* 2010; Seeman, *et al.,* 2001, then those residents who incessantly suffer dignity violations on a day-to-day basis will eventually end up disarmed, void of their physiological reserve and unable to cope with stressful situations within their social environment due to chronic stress which can magnify and/or otherwise, induce further ill health.

Drawing upon the 5 stages of Maslow's hierarchy of needs (McLeod, 2014), as listed in Box 5.4.1b below, (see also List of Tables – Table 3), the participants overall agreed that the facility of SVPR met their basic needs described in Stage 1, albeit restricted to lodging, meal services and assistance with daily living activities.

Box 5.4.1b - The original hierarchy of needs five-stage model includes:

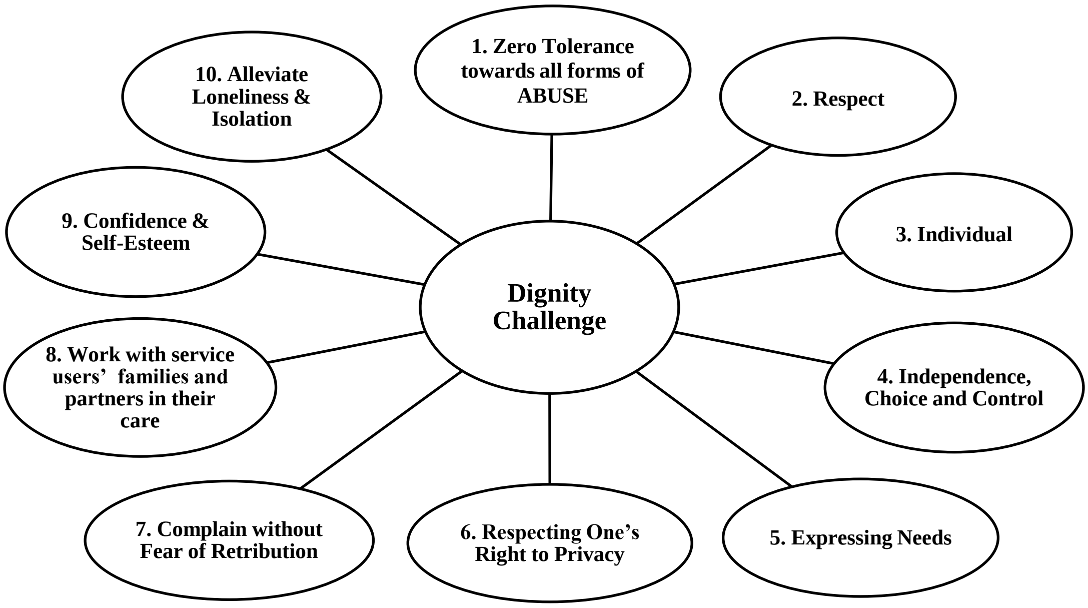
1. Biological and Physiological needs - air, food, drink, shelter, warmth, sex, sleep.
2. Safety needs - protection from elements, security, order, law, stability, freedom from fear.
3. Love and belongingness needs - friendship, intimacy, affection and love, - from work group, family, friends, romantic relationships.
4. Esteem needs - achievement, mastery, independence, status, dominance, prestige, self-respect, respect from others.
5. Self-Actualization needs - realizing personal potential, self-fulfillment, seeking personal growth and peak experiences.

However, with regards to the staff or the environment meeting the other needs, as listed in Maslow's hierarchy of needs or otherwise, in reference to providing a personalised service, participants' views were mixed and varied.

5.5 Threats to residents' dignity at SVPR

This next section compares the findings of the research study against the National Minimum Standards for Care Homes for Older People (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2015), (see Appendix 12) and the *10 Dignity Do's* proposed by the National Dignity Council (2016) as highlighted earlier in Chapter 2 (see Section 2.8) and as summarised in Box 5.5 below;

Box 5.5: The 10 Dignity Do's (National Dignity Council, 2016)



5.5.1 Zero tolerance of all forms of abuse

In relation to the different categories of elder abuse described by WHO (2002) (see Section 2.14), participants described incidents and certain staff behaviours which could be attributed to ‘physical abuse’, ‘psychological or emotional abuse’ and ‘neglect’.

For example, Liz, explained that she had been recently transferred to a renovated ward, since renovation in her original ward of residence was to commence. She pointed out that although this ‘new’ ward was not for people with dementia, nonetheless, she was sharing her room with three other ladies; one of whom has dementia. In reference to personal hygiene duties, Liz stated to have witnessed, on two separate occasions, the differences in behaviour and approaches of two carers when carrying out personal care duties for the lady with dementia. Accordingly, Carer A was gregarious, kind, compassionate and caring towards the lady. Whilst, Carer B, as she was about to change the lady’s nappy, said in a loud voice:

> "Jesus! … Pfffft … *You stink*!".

Liz confirmed that indeed there was a smell in the room but concluded that the cause of it was because the lady must have been lying in her bed with a soiled nappy for quite some time, adding that "it must have been stuck to her". Liz stressed that she was appalled at such rude behaviour and expected that the staff ought to speak properly and respectfully to the lady in question. Consequently, her only consolation was knowing that the lady, "in a way, she could not have been hurt by the carer’s comments because the lady is unable to understand", in view of her poor cognitive function. In relation to her new ward environment, Liz reinforced the fact that there is a distinct difference in the way staff speak to residents, implying “us, - the ones with a sound mind", as opposed to the other ladies and explained:

> "They are *rough* when they speak to patients! The women here are much older and have many ailments and some have dementia … but as for *us, the ones with a sound mind* – they’d never get away with it". **(Liz)**

In contrast, Janice, who is also in the same ward as Liz, was of the opinion that the residents with dementia should be:

> "put in a separate place … closed off in a room for themselves". **(Janice)**

Her reasoning for this was that Janice was annoyed by the "incessant shouting" of these residents with dementia and gave other examples such as,

> "There's one who keeps calling out for 'X', another one keeps blaspheming against Our Lady and another one is completely nuts. They shouldn't be here with us! You can't stop them! They don't know what they're doing! … And I'm *going to end up going mad just like them*". **(Janice)**

In this instance, Janice was expressing her frustration owing to the circumstances that she was in, in relation to her ward environment. During the course of the interview, it became clearer as to why she may have come across as negative in regards to the ladies in her ward with dementia because she further elaborated on the staff behaviour towards these ladies, as clarified below:

> "I wish they were *more patient* with them. They [the residents] tell them: *You've hurt me.* But *they don't apologise* to them … or sometimes they tell them [in a condescending voice]: *Oh no sweetheart … Oh come on doll …* You know? - Sort of, like trying to dampen the situation". **(Janice)**

Even though the focus of the study is not on dementia care, the fact that it was highlighted by the participants has shed light on the way that people, in this case, certain staff members, perceive the body of someone with dementia (*e.g.* an empty shell, prison, etc.) and the manner in which staff relate to them can be detrimental to the recognition and maintenance of their personhood.

Another example in the findings which link to abusive behaviours by certain staff members was brought to light when Grace commented on the manner in which ward staff behave towards another female resident sharing her room (a 6-bedded occupancy room). Grace illustrated her comments as follows:

> "The staff are *always quarrelling* with her because *she doesn't do as she's told*. She gets itchy and scratches *down there* … she'll be *tearing away at her nappy* … then when the nurses come to change her, they see that her nappy is a mess and *they get angry at her* and *start shouting at her* …. They tell her that if she does it again, they'll *leave her in her own piss* … that they *won't change her nappy* … now, isn't that worse? No patience!" **(Grace)**

Regarding the quality of care and the length of time taken to have a nappy changed, similar comments were noted from other participants, such as:

> 'The staff get along with you, they see what you need, but that's it. There's not much more to say'. **(Charles)**

And:

> "Not all of them keep you waiting. Some do, some don't. Some work hard and look after you, others just don't care … but what can you do? You stay with it on (soiled nappy) … You put up with it, no?". **(Isabel)**

For instance, Isabel was able to ignore personal criticism from other residents or staff alike, by developing a ‘thick skin’, during her years of residence at SVPR.

> "I’ve learnt to toughen up and not take things to heart … now, I don’t pay much notice to what they say". **(Isabel)**

Even though, she was wheelchair bound due to a physical disability in her lower limbs, she was nonetheless independent in wheelchair management and this sense of liberty was what allowed her to remove herself away from any given unpleasant situations. In reference to maintaining self-preservation and self-identity, she was able "*to escape"* from her ward environment and get her "*ration of outdoor fresh air"*, when she deemed it was necessary. Hence, Isabel described what appears to be coping skills and strategies that she has developed. Isabel did state that in many instances she felt truly hurt by the manner in which other people on her ward behaved towards her, but she quickly brushed it off by saying:

> "People like that, I don’t give two hoots about them and there are those ones who are *nice*, which makes it easier. Anyway, I have my pets to look after [in reference to stray cats], they are my true friends, they comfort me". **(Isabel)**

5.5.2 Respect

Respect was the most commonly used expression relating to social behaviour and interactions with others, which in turn, was associated with either promoting or threatening one’s dignity. The participants believe that dignity entails reciprocity, that is, mutually respectful behaviour. Respect as a term, seemed to serve as an ‘umbrella’ linking to other types of behaviour, be it derogatory use of words or disparaging comments. Other aspects that were commented upon included staff taking on an authoritarian approach, that is, being controlling and ordering the older adults around, as well as, not offering choices or respecting requests, all of which were identified as a threat to dignity. Interestingly, this type of behaviour was more likely to be associated with the carers rather than the nurses.

> "Not so much the nurses though … it’s the carers who have the power … they walk around with their nose stuck up in the air". **(Mary)**

All of the participants interviewed described a situation where a staff member (mostly carers rather than nurses) behaved in a curt manner which either threatened their own dignity or the dignity of another resident. The behaviours described were related to staff showing lack of courtesy and kindness towards the residents or a lack of interest in them, giving the impression that the staff member did not care about them or otherwise, respect them as a person.

Dismissal was another type of behaviour that participants brought up during the interviews, implying that staff would either ignore them, when trying to get their attention or walk right past them, "pretending not to hear" them. Again, the lack of eye contact from staff members is evocative of what Mann (1998) describes as 'not being seen'.

Most of the female participants also pointed out differences observed between the carers working on their ward. For instance, in reference to the hot beverages service on the wards, participants' praised some of the members of staff for their prompt service, offering personalised care. This sort of attention to detail and graciousness made the participants feel valued as it met their expectations of care. Helen provided an example to illustrate these differences, as seen below:

> "When [male carer 1] is on duty, we praise the Lord because we don't need to tell him anything, *he's so efficient and polite* - he gives me half a cup of hot tea – just the way I like it … but the other one [male carer 2], he's too slow and takes for ever with the service … once I told him how I like to take my tea … he *rolled his eyes, was abrupt and started shouting at me* for wasting his time … so it's better not to say anything then". **(Helen)**

In reference to bathing routines, participants stressed on the fact that it depends on the staff who are working the morning shift and described how some of them work systematically: keeping areas of the body covered with a towel, while washing another area, and that they ensure the "water is warm enough, at the correct temperature".

> "Sometimes you find *those ones* (staff) who are like *Saints*, they understand how you like things to be done … they are good and kind-hearted". **(Grace)**

Nonetheless, participants also mentioned that some other ward staff, '*just don't care*', alluding to the fact of being fully exposed in bed during bed bathing.

Below is an excerpt of the another female participant's comments in regards:

> "... sometimes you find another one who *snaps* at you and *wants* you to do everything on your own, *but you can't, because you're not feeling well* [in reference to medical health issues], so I tell her: now if it were your own mother, would you be happy if someone did that to her? … but it's no use … in the end, *isn't it them who win*? ". **(Grace)**

Fiona praised the staff on her ward for the manner in which they help her, especially in relation to personal hygiene,

> "They're very nice here; gentle and helpful. I do my best but areas that I cannot reach, you know … like my back or my feet, they *gently* tell me, don't worry, let me do that for you". **(Fiona)**

However, the views of some of the participants in the other wards differed:

> "Here, (on the ward) there are things that can't be fixed because it depends on the nurse you get … what mood she's in … and you have to put up with her". **(Grace)**

5.5.3 Treated as an Individual

Mary, who has a bilateral above knee amputation, explained that following her first operation, she had spent 6 months at MDH where she received amputee rehabilitation and very proudly stated:

> "I was able to walk again with the use of a prosthetic leg and a mobility aid … they (staff) were surprised at how well I had recovered from my operation … I told my physio to teach me everything … I wanted to know how to transfer myself from the wheelchair to the toilet, on my own. I wanted to be independent … I worked hard and I succeeded". **(Mary)**

After one year, she had the second operation, but the experience was far different. She stated that she had spent only two days at MDH, after which, she was discharged back to SVPR,

> "… and here, you're considered only as being old". **(Mary)**

In this instance, Mary expressed her disappointment because she stated to have not received rehabilitation, and this evoked her sense of helplessness given the situation, as she explained:

> "Here [at SVPR], I don't know, it's like they don't bother. Here, you know? - It's like there's no one to push you [in reference to the intensive rehabilitation she had received following her first operation] … I might have been able to walk again; I don't know. I guess I'll never know if I would have been able to … but at least I could have tried, I wanted to … but instead, I'm using a wheelchair … but I do my own thing, I'm independent [in reference to her ADLs], so I don't need their help [in reference to staff] and I don't bother them with anything either". **(Mary)**

Mary's vivid example sheds light on the fact that due to her age and physical presentation following her surgeries, she was labelled as incapable of achieving further independence in her mobility (see Section 5.5.4). Furthermore, besides the fact that her individual needs and wants (see Section 5.5.5) were dismissed, the concept of ageism (see Chapter 2, 2.13) prevailed since she was deemed to be "only good enough for a wheelchair".

Another factor which emerged from the findings of this study is that, participants, mostly female, regarded the foreign staff as being better than "some of the Maltese staff" working on their ward. These comparisons between 'the foreigners' and the 'local staff' were in reference to the differences in attitude and behaviour, which link to what Jacobson (2012) described as *Dignity Promotion* (see Chapter 2, 2.5).

This aspect is significant since there are various nationalities complementing the wards' local direct care workforce at SVPR (reference is made here to include registered nurses, carers and domestics); with nationalities ranging from European to Central or Southern Asians. Through observation and field notes, it was noted that the foreign staff members communicate with the residents primarily in English, albeit maintaining a strong cadence of their own mother tongue.

To link to the official document of the NMS for Care Homes for Older People in regards to employing staff to work with the geriatric population, accordingly, fluency in both the English and Maltese spoken language is not a pre-requisite, as evidenced below, where it states that:

> "All nurses and carers shall be able to speak in English or Maltese" and that the "management shall ensure that there are no language barriers for the clients" (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2015, pp. 32, 27.9).

In reference to the above, only one participant, who requires assistance with most of her activities of daily living, stated as follows:

> "The only thing, is that they don't understand you properly … you know … it's like, when they're searching in the cabinet for your clothes … for instance, you tell them something in Maltese and they don't understand you; well that's bad too.' **(Grace)**

However, participants expressed the fact that foreign staff made them feel welcome and that they spoke to them in a gentle manner. In fact, on this note, Grace quickly pointed out that:

> "The foreigners are better than the Maltese (staff) … yes, they (foreign staff) are not bad at all actually …". **(Grace)**

Whereas, in reference to the non-verbal communication, the foreign staff were described as:

> "The foreigners are much nicer than the Maltese". **(Liz)**
>
> "They're courteous and kind. I'm not saying that the Maltese aren't but there are a few of them, especially the carers, well, they have their nose stuck up in the air". **(Mary)**

Whilst with reference to the Maltese carers, the following was mentioned:

> "You'd think you would have to *pay them to talk to you*". **(Charles)**

None of the other participants expressed having any issues with foreign staff due to a language barrier and therefore, it was not identified as a threat to residents' dignity. If anything, it was noted that the occasional usage of very basic Maltese phrases or expressions were very much welcomed by the residents, who appreciated the effort made by the foreign staff, as it made the participants feel valued and recognised as an individual in their own rights. Moreover, it emerged that residents seemed able to cope well enough in between pointing at objects and gesticulating or sharing a laugh with the foreign staff. Feeling acknowledged contributed to their feeling of importance which was linked to a sense of empowerment in that the participants were not regarded as being just one of many others on the ward.

In view of the above comments, perhaps the expression, 'actions speak louder than words', would therefore seem quite appropriate.

5.5.4 Independence, choice and control

For most of the participants, lack of choice and lack of control were the contributing factors which had initially led to their admission at SVPR. If an individual has no control over the choices he or she makes, then this can directly affect one's sense of autonomy and at ward level, these factors were closely linked to participants' loss of dignity.

5.5.4.1 In relation to activities of daily living

Apart from the three participants who were fully independent in their ADLs, other participants actually reported being able to do far more for themselves than was actually 'permitted' by the ward staff, but seemingly, bed bathing was the preferred choice for staff as it was considered to be '*quicker*' and '*more practical*'.

> "They told me that they have to wash me. I'm 91 years old, I suppose I would have learnt by now how to wash myself, don't you think? But here, they win. What am I supposed to do? Sometimes it's best to just keep your mouth shut and go along with things". **(Charles)**

> "They (the staff) wash me in my bed … but you know, it's more of a wipe down than a proper bath … I like to wash my own face … I like to splash water on my face, to feel clean … yes, I ask them if I can have some clean water in the basin, not with soap … yes, most of them oblige". **(Grace)**

> "No, they wash me. They even change my nappy … (clears his throat) … they help me get dressed too … yes, it's always with their help … it's quicker for them, you know, they have a lot of work to do … I'm used to it now". **(Alan)**

A few other participants described that they were provided with a basin for self-bathing; albeit to be used at their bed side rather than in the bathroom. The findings showed that given the chance, for those participants who were able to walk and required minimal supervision or assistance, would have preferred to use the bathroom, 'to take a proper shower', but accordingly this was not possible, due to the tediousness of the task for the staff and because it was time consuming.

What is interesting to note is that the illustrative quotations from the participants are in contrast to the standards listed in the section on *Health Care* (*Standard 7*) of the NMS, which states:

> "Care staff shall ensure that residents' personal and oral hygiene are properly maintained. Residents shall be encouraged to execute the basic activities of daily living and independent activities of daily living providing their health enables them to do so" (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2015, p. 15; 7.2).

5.5.4.2 In relation to promotion of continence

In reference to promotion of continence, the NMS describes the following:

> "The licensee shall ensure that professional advice about the promotion of continence is sought and acted upon, and aids and equipment needed are provided" (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2015, p. 15; 7.6)

Most of the participants were either wearing adult diapers (*i.e.* nappies) or pull-ups. Reportedly, not all participants were experiencing partial or complete, urinary or dual (faecal) incontinence.

A case in point was Grace's vivid narrative. Accordingly, she had sustained a left sided hemiplegia and part of her care plan at RHKG was to be able to transfer onto a commode with minimal assistance. She stated that she had achieved her goals following a lengthy and intensive rehabilitation period with both a physiotherapist and an occupational therapist at RHKG. However, she highlighted that all of her efforts went to waste following her admission to SVPR.

> "I told them that *I was able to* … but they didn't allow me to use the commode here or alternatively, to bring me a bedpan … No, they didn't want to – they told me, *from now on you need to use the nappy*". **(Grace)**

Upon further probing, it emerged that Grace is dually continent but still has to use her nappy because she requires staff's assistance to help her ambulate and, if she is in bed, staff then use a lifter to hoist her out of bed.

> "They have a lot of work to do and they're always in a big rush … sometimes they'll be short of staff, and how do you say it, they would be crucified … I feel sorry for them because to put me in sitting, it's a lot of trouble for them".

Grace described her coping strategies and the manner in which she deals with the situation under these given circumstances, as illustrated below:

> "So, when I need to dirty my nappy, I make sure l do it before they come for the evening nappy change – like that, I don't have to wait too long – otherwise, it's not pleasant. On the other hand, if I pass urine in my nappy during the day, I don't mind it as much, I mean, let's say that I can put up with it – because I know the timings when they're coming to change me, so I wait". **(Grace)**

Clearly, the policies and standards set in the NMS (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2015) are not being met, so much so, that rather than moving forward towards a preventative model of care, the healthcare system remains steadfast in its curative approach; and as for social care systems, it would appear that although attempts are being made to promote rehabilitation and independence, yet, the mainstream of supporting dependency seems to remain a predominant factor.

Not only was Grace negated from maintaining her previously attained maximum functional potential and independence but to date, the lady remains subjected in having to endure this undignified process of bodily functions; a violation to her dignity which is constant and repetitive on a daily basis.

Moreover, "both the regulations and the standards highlight the importance of consulting residents about their health and personal care, interests and preferences" (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2015, p. 34). The findings distinctly show that Grace was neither consulted nor were her preferences, wishes or needs taken into consideration.

5.5.4.3 In relation to quality of food

Residents regard the food they are given as one of the most important factors determining the quality of their lives and since "individuals' food preferences, both personal and cultural, are part of their identity, they must always be observed"

(Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2015, p. 20). In fact, as per the official information on the government's website in relation to the section on '*St. Vincent De Paul Residence Rebranding*', it states that:

> "Complaints on food has been noted, and thus there is ongoing monitoring of food" (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2012).

Interestingly, the above citation dates back to 2012. Four years on, and one of the major complaints amongst all of the fourteen participants within the sample group was in regards to the quality of food and service. Participants commented on the inferior quality and taste of the food served on their ward at SVPR and that overall, they were unhappy with the provision of service provided by the outside caterer. Participants' comments are illustrated below in Box 5.5.4.3.

Box 5.5.4.3: Participants' illustrative quotations in relation to quality and choice of food

Eric	"Repetitive"
Charles	"You take what you're given" – associated with lack of variety: *e.g.* the participant wanted *a hot cup of Bovril* or another selection of breakfast cereal.
Janice & Mary	"Staff take your menu order but *give you something else* on the day or they tell you that *your food choice was given to someone else* or that *it's finished*"; "Pizza is served raw" – in relation to the pastry
Grace	"Too salty or too sweet"
Isabel	"Not like the old days"
Mostly all of the participants	"The broth tastes awful" or "Looks more like a thick soup" "Not the same as home-cooked meals"; "Unavailability of typical Maltese food". "Too regimented and lack of choice" – because meals are provided by an external caterer "Food is re-heated" (observations made by the female participants)

Mary pointed out that some of these residents have no teeth (and no dentures), so that even if the staff cut the food into small pieces, the residents still need time to eat their food:

> "How are they supposed to chew the meat? Should they swallow their food or wait until it melts in their mouth? Bless them, at best they end up eating just the mashed potatoes, if anything … Oh, and let's not talk about the pizza, it's disgusting! They bring them in, blast frozen from the supplier (refers to caterer) and they heat them up again here … they serve the food and the pastry is practically raw … yeuk … and you see these ladies … slowly trying to eat this thing but they can't … how on earth could they possibly eat that stuff? - You know what? They say you have a right to choose but here they don't give you that choice … this makes my blood boil!" **(Mary)**

For those participants residing long enough at SVPR, they linked the quality of the food being served at present to the time when the "kitchen was open" on the premises and commented on how they missed having fresh produce, "the smell of fresh vegetables" or the idea of a fresh piece of meat, "just cooked and placed on your plate".

Isabel related how much she used to look forward to the festive seasons and special events, "like Christmas or Easter" since *the kitchen* would prepare,

> "little surprises for the residents … the typical sweets like for example, cakes or a small *figolla* [a typical Maltese sweet prepared at Easter time] ... nowadays, if you want a *figolla,* you have to buy it!" **(Isabel)**

Food could be prepared in real time, so that if a resident,

> "preferred something else or was unwell, a warm bowl of clear soup would be immediately prepared and delivered". **(Isabel)**

However, with the advent of the outside caterer, this was no longer possible, since everything is pre-cooked, and:

> "you can't choose *to not have* sauce added to your pasta … the staff tell you, well that's what we have today … but for me, the tomato sauce gives me *acid* in my stomach … and if I prefer to have *white pasta*, then why can't I have it?" **(Grace)**

Participants from two different wards (*i.e.* a total of eight participants) described that they felt deprived of certain food items, such that,

> "you take what is given to you". **(Charles)**

Helen, described an episode where she was unable to eat anything, presumably, following an episode of gastritis and wanted to have a slice of toast without butter, but this was denied to her by the staff, reportedly because there was no toaster or oven available on the ward; she added:

> "You know; they really take the piss here … Do they think we're stupid or something? … The smell of toast on the ward, it's so obvious - but it's for the consumption of the nurses and carers, it's not for us … so now, even the carers are better than us?" **(Helen)**

Perhaps, Grace's comment captured the essence of how the concept of food links to one's sense of dignity, as she said:

> "When you're in pain, *all that's left to alleviate your pain is your food*". **(Grace)**

The food provided for residents is also important for maintaining their health and well-being. Failure to eat – through physical inability, depression, cognitive dysfunction, or because the food is inadequate or unappetizing – can lead to malnutrition with debilitating consequences for health.

> "Care staff should monitor each resident's food intake in an as discrete and unregimented way as possible, and should also provide assistance when required in a patient and timely fashion to ensure adequate amounts of food and drinks are consumed" (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2015, p. 20).

5.5.4.4 In relation to personal belongings

Perhaps what seems to have hurt Nora the most, was an incident which took place the week prior to the interview. Accordingly, the nurse-in-charge passed disparaging comments in reference to her personal items; a small picture frame and keepsakes of her craftworks that she had displayed and placed on top of the cabinet. The episode was still fresh in her memory and the comments are illustrated below:

> "Last week the N.O. (nursing officer) took my things away. She told me, - remove that rubbish from there. I don't want to see any rubbish. - I had Christmas cards, but she said she was going to give them to the old people … something about craftwork, I don't know … What could I say? – I didn't have time to say anything because she just grabbed them and took them away". **(Nora)**

To be noted that another word for *rubbish* could be *clutter*, which perhaps might sound more acceptable. Yet, the point being made here is that there has been no mistake in translating what the participant said, from Maltese to English. The fact of the matter is that, Nora felt offended in having her personal items which were of sentimental value, referred to as *rubbish* and worse still, because they were removed.

Perhaps it is due the newness of this ward that any form of clutter on top of the residents' cabinets was nowhere in sight. And by the word clutter, the researcher intends, at least, a large bottle of water, some small bottles of soft drinks and a box of tissues; items of which were all observed on top of cabinets of the other participants in the other wards and if anything, there were many more items. However, the room on this ward could be described as impeccably neat and orderly, so much so, that it appeared rather sterile. Except for the furniture, there was nothing to indicate that the room was homely.

Considering that this participant was not physically able to get out of her bed, then the most logical thing would be to have needful items within reach, rather than hidden inside a cabinet. More importantly, is the aspect of being surrounded by familiar items which enhance one's emotional well-being but on this point, Nora said:

> "… all I have is some items of clothes-wear for everyday use… the rest (of the items) are just nappies". **(Nora)**

Similar stories emerged during the interviews which were directly related to those participants who had been temporarily transferred from their ward to another due to renovations, as already described earlier. These participants also explained that they had to have many of their items returned to their own home or stored away at a relative's house.

In fairness, it needs to be pointed out that it would be impossible for each resident to keep a large number of items in their room, especially since they are sharing with many others. The researcher also appreciates that too many items or knick-knacks call for more cleaning duties since dust can otherwise accumulate, breading germs. So from a hygienic point of view, this would not be appropriate.

However, it is the approach that is inappropriate and degrading for the older adults. In Nora's case, if perhaps the nurse-in-charge had calmly explained the reason behind not being able to keep 'so many items' then it would have given Nora the opportunity to rationalise the situation and understand. Perhaps, it would have been nicer had the nurse-in-charge apologised for the inconvenience caused and followed-up by offering options, such as going through Nora's items to see what she really wanted to keep and what she could have done without. By involving Nora in the process, it would have made her feel that she had a choice, that she was being allowed to express her wishes and wants (which is linked to the next section) and in turn, that she was being listened to and validated for what she had to say.

5.5.4.5 In relation to safety and protection

Nora, who is dependent in bed mobility, commented on aspects which appeared to have compromised her safety and sense of emotional well-being which in turn, had a negative impact on her sense of dignity. The participant narrated that two months earlier she had been transferred to a newly renovated ward but there was no call bell available at her bedside (*i.e.* to call a nurse in case of emergency). Eventually, it was organised. However, in reference to the ward staff, she declared that more often than not:

> "at night, they forget to place the call bell close to me". **(Nora)**

In relation to the furnishings and equipment of this newly renovated ward, Nora remarked:

> "I call it half a bed because it's not a bed (laughs). The remote control doesn't work and you have to use the main console at the edge of the bed … it's not as if I can reach it". **(Nora)**

With regards to the call bell at each resident's bedside, similarly Mary (also a resident on the same ward as Nora), mentioned the same point in passing conversation and confirmed that '*they didn't take that long to install them*'. Mary did not relate this delay to her feeling unsafe. This was due to the fact that although she has a bilateral above knee amputation, she is still independent in bed mobility, in transfers to/from her wheelchair, as well as, in all of her ADLs, as she clearly stated:

> "I *don't need help from the staff* and as much as possible, I try *not to ask them for anything* either". **(Mary)**

Mary did however, mention that the bed rails are placed in the locked position when she goes to sleep in the evening and in her case, this was something that enhanced her safety because it meant that there was '*no chance of (her) falling out of bed'*.

On the other hand, Charles (who has been residing in one of the recently renovated wards – the same ward where Eric resides), expressed concern with the window curtains above his corner bed. His first issue was that the actual curtains had fallen to the floor,

> "with a thud which gave me a fright … had I been standing by my (clothes) cabinet; they would have surely fallen on top of me … thank goodness I was sitting at the edge of my bed". **(Charles)**

His second issue was that he had asked the staff on the ward in regards to when it would be repaired, however, he was met with:

> "look it's not us, I already told you, we're waiting for the maintenance people … maybe tomorrow ok?" **(Charles)**

His third issue was that he felt exposed owing to the fact that the window did not have a curtain. In fairness, Charles did point out to the fact that the window was rather high so it was not as if people could look in and see him, but that was 'beside the point' he said. The gentleman felt annoyed that if he wanted to rest in the afternoon, the sunlight shone in over his eyes and especially at night, he felt that the curtain protected him from the draught as the cold air swept in, thus, making him feel uncomfortably cold. He stated that he had 'a cold' because of this and on observation, it was duly noted that the gentleman did have a runny nose and was discretely trying to wipe it off with his hand as he was talking, to which the researcher reached into her handbag and offered him a tissue – the conversation carried on as normal, with no consequence.

Charles felt that had he been younger (91 years old), he would have:

> "got a ladder and fixed the curtain (himself), as it's no big deal … but at my age, my legs are not as strong as they once were". **(Charles)**

This issue made Charles feel powerless in view of his manhood, and amplified his sense of dependency on the staff due to the fact that he had to wait for others in order to get things done. An aspect which he felt was a threat to his dignity in terms of self-worth and value of self. Additionally, as per the researcher's observations, the curtains were as described by the participant and accordingly two weeks had already passed and no maintenance personnel had yet fixed the curtains.

5.5.5 Expression of needs and wants

Participants commented on instances when they would have asked a staff member for something, termed as "a small favour", in relation to providing them with a cup of tea or accompanying them to the toilet. Reportedly, staff would tell them that they were not working in their section. What was worse for the participants is that there was no follow-up, therefore, they would have to wait until some other staff member passed by their area in the corridor.

Expressing needs, wants and desires, is something so basic, rather trivial and quite ordinary. Yet, it is not so obvious; rather, such limitations become a painful reality especially when people need to rely on others for their basic needs.

Liz described how her declining health has put her in a position of needing assistance, which makes her feel that she has 'no control'. Due to severe arthritis in her hands and restricted shoulder mobility, Liz needs help when getting dressed:

> "Sometimes you wake up in the morning and put on some clothes, only to change your mind because you do not feel comfortable with the clothes you have on, so you get undressed and wear something else. You get to choose what you want to wear, isn't that right? Well, I could do that before, but now, it's not as if I can ask the staff to wait on me until I make up my mind (laughs) … Oh they're so busy with all the washings (bathing of residents), and that's the last thing they'd want to hear … besides, I wouldn't feel comfortable asking them either". **(Liz)**

5.5.6 Respecting one’s right to privacy

Locally, promoting dignity in care has been endorsed in the National Minimum Standards for Care Homes for Older People (2015). However, it would appear that a proportion of the staff working in this residential care home do not endorse the concept of respecting the residents’ dignity at all times.

If bedroom doors were slightly ajar or closed over, it did not deter staff from walking in the room unannounced, as was observed on many occasions during the interviews. Even when a curtain was drawn around the bedside, it did not seem to trigger or hint to the need to announce oneself; to the contrary, staff merely peaked through the curtain and continued about their business.

During the interviews, there were a few occasions when some of the staff members (nurses) needed to speak to a participant and politely excused themselves for their intrusion. However, there were other occasions, when a conversation would ensue, initiated by a staff member (a carer) towards the resident, as if it were of no consequence. The latter occurrences were more often than not observed to take place in the male ward rather than the female wards. Then again, on the female wards, lack of privacy or intrusion was associated with a specific time of the day, that is, when personal care duties had to be carried out. In this case, there was no need for staff members to announce themselves, since they could already be heard from half way down the corridor, calling out "*come on, it’s time to do the nappies"*.

Nonetheless, while conducting the interview with David, there was one incident which particularly stood out, whereby a male carer peaked through the closed curtain and walked straight in, unannounced. After mumbling something to the participant, this male carer calmly rummaged through David’s personal belongings, took a sweet out of a white paper bag and walked straight out again. Besides the carer’s behaviour and action, which can be interpreted as reprehensible; it was the look on the participant’s face which stuck in the researcher’s mind. The researcher gently asked the participant if this was a usual occurrence, if it had happened before - to which the gentleman, with his eyes lowered towards the floor and a slight smile from the corner of his mouth replied, "*well ... yes*", then continued, "but I have many (sweets) … you see, my wife brings them for me"; and now, with a stiff smile and looking up at the researcher, he continued, "*nah, it’s ok, ... it’s ok, I have many*".

In fact, the findings revealed, that none of the participants within sample group reported having a key to lock the door of their room – "it’s not common practice". Hence, the reason, that curtains were deemed to have a crucial role in providing participants with privacy within their rooms, especially since, the running of different wards, appear to operate on more of an open door policy system and further still, room occupancy at ward level may vary from anything between a 2-bedded to a 6-bedded. The participants regarded that it was essential that curtains could be closed fully, especially in reference to the provision of their personal care.

In contrast, this was not an issue for Eric who shares his room with five other male residents. For him, being fully independent in all of his ADLs meant that there was no direct risk of having any invasion of privacy occurring during personal care routines carried out by the ward staff. Since this issue did not directly affect him, it was therefore, of no consequence to him. In fact, he rationalised that if he needed his privacy and personal space, all he had to do was "go out for a walk" or draw the curtains around his bed, because in this manner he was able to shut himself off to the "outside world", as he stated:

> "… with the curtains closed, I don’t bother anyone and no one bothers me either, it’s as simple as that". **(Eric)**

On this note, *Standard 9 - Privacy and Dignity* of the NMS (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2015, p. 18: 9.8) states that:

> "Where residents share a room, adequate screening or partitioning shall always be provided to ensure that their privacy is not compromised when personal care is being given or at any other time".

However, most of the participants pointed out that although the curtains at their bedside provided a form of visual privacy when closed, they felt that there was a lack of auditory privacy, so much so, that everyone in the room knew ‘*each other’s business*’, be it both the residents and their relatives during visitation hours.

Grace was the only participant who linked loss of dignity to what can be termed as olfactory privacy and this is in reference to the personal hygiene routines carried out by staff within the residents’ rooms. She described that one of the ladies in her room must have had "*her tummy upset*" and as a result had soiled herself, as related overleaf:

> "The *smell was everywhere*. Bless her, it's not her fault … and I feel bad saying it but the smell *was sickening*. I mean, I understand that they [the staff] couldn't open the balcony door for some fresh air because they were washing us, but you know, *some air freshener might have helped; not nothing, they left us like that!* … Then again, everyone's smells eh?! … But *I felt dreadful for her* … it's awful when something like that happens to you … *it's so embarrassing*". **(Grace)**

In effect, residents have no control over who enters their ward or room environment and staff behaviour is highly influential in relation to residents' dignity, especially as it plays a crucial part in whether residents feel that their dignity is being promoted or not.

Therefore, in relation to bodily exposure, participants remarked that they do not appreciate the fact that, for instance, "the cleaner" walks in the room while personal care and hygiene routines are ongoing, or that "staff peak through the curtains to talk to their colleagues". In regards to personal hygiene or the insertion of a catheter, participants were able to rationalise the fact that their personal space was being invaded out of pure necessity but they could not understand the purpose of what one participant described as,

> "… having a crowd of people, just standing there and do nothing, but watch". **(Nora)**

It is unclear whether the reference was being made to qualified staff or if perhaps, it could have been students or new staff members learning on the job. Nevertheless, this issue raises a very important point, in that staff need to be aware of their body language. Then again, if it is a matter of learning certain skill sets on the job, perhaps it would be more appropriate and dignified for the older person, if a staff member stood to the side of the bed, instead of directly in front of the person. Given the vulnerable position that a person would already be in, at least, such uneasiness or embarrassment could be avoided. Apart from the provision of care, it is vital for staff to display sensitivity and empathy; and to understand that having many people huddled in around a bed, albeit with the curtains closed, may still make a person feel overwhelmed, if not frightened by the whole situation. This also reinforces the fact that not only older people but truly, people in general, like to be informed beforehand about certain routines or procedures, especially when it concerns private matters.

Consistent with Marley (2005), the findings also showed that female participants needed to feel in control of their own privacy and this was especially so for Liz. In reference to her interpretation on the meaning of dignity (see Section 5.4), the lady made reference to an incident, occurring a couple of years earlier while she was on a different ward. She vividly explained that it was during a time when she was very unwell and was experiencing frequency in urination which necessitated that she starts using a nappy at night time. Liz described a series of mixed feelings when recounting the event, ranging from humiliation and anger at the time when the incident took place; to feeling deeply hurt and even embarrassed due to her own outburst, and lastly, disappointed at how the whole situation had been dealt with by the regulator at the time. Her comments are illustrated below:

> "So at about 11 p.m. they would come to change you … you would have just about drifted off to sleep, but anyway … they'd be doing the rounds, you know, with the torch … so they'd come in to change my nappy. Anyway, the nurse (female) came in flashing her torch light and there was this man with her, … whom I can only describe as a *fool* … and *he came over, to have a look*! At that moment, *I roared at him: What the f**k are you doing over there?* … He was a nursing aide! And do you know what? - She didn't even say anything! To tell you the truth, she started laughing!". **(Liz)**

The researcher believes that Liz's candid depiction of the event, sheds light on so many different areas which the literature describes as violations to one's dignity. Linking this to Nordenfelt's (2003) theoretical framework for dignity, then it becomes clear that, Liz's dignity was violated on all four counts, firstly on a level of her own intrinsic humanity.

The second aspect which needs to be taken into consideration is that Liz worked all throughout her life up until her retirement[13] age of 60 years; boasting a nursing career with over 40 years of service whereby she had spent a large part of her career working at SVPR. Therefore, taking her social standing and ex-profession into account, then her dignity in relation to merit was diminished.

Thirdly, her dignity of moral stature was violated. With reference to Agich (2004), Liz was objectified, in terms of her functional status since was seen by staff as a set of health problems that need to be attended to, rather than as an individual with rights, needs and desires.

The fourth and last component described by Nordenfelt (2003) refers to personal identity and in this instance it is related to the fact that Liz was humiliated by both the staff members, on the basis of bodily exposure and laughter.

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[13] In relevance to this cohort, one needs to consider that retirement age from the workforce for these participants was that of 60 years for females and 61 years for men.

Liz had reported the incident to the ward's nurse-in-charge, who in turn reported it to higher management at SVPR. The participant recalled the manner in which the situation was handled and felt greatly disappointed. Accordingly, higher management had spoken individually to the three people concerned (*i.e.* the two members of staff and Liz) and in Liz's opinion, she felt that the situation should have been addressed in a manner where, "we should have met, *all together*". In reference to the female being transferred to another ward whilst the male nursing-aide had remained working on her ward, albeit never to speak to Liz again, the participant said;

> "You see, they (*i.e.* staff) have the ones in power who are on their side and act on their behalf". **(Liz)**

5.5.6.1 In relation to the physical environment

The three participants who were fully independent in their ADLs and another two participants who were semi-independent (see Section 5.4.3), reported that having an ensuite bathroom promoted their privacy, irrespective of whether their room was shared with other room occupants.

Most of the participants commented favourably about the aesthetics of their ward, and all of them highly praised the level of cleanliness. In fact, participants who have been residents for a number of years at SVPR were able to draw comparisons between the previous layout and décor of their ward and the changes made on a given ward due to the recent renovations, as highlighted by Eric, who pointed out:

> "I've always been on this ward but let me tell you, before it was really ugly here, but now they've brought it looking like a hotel … a 4-star". **(Eric)**

Whilst, one female participant (Mary) commented that she was pleased that the rooms had been widened as it enabled her more space for wheelchair manoeuvrability, which promoted her independence.

Yet, for all the renovations being carried out, the fact remains that the wards are still unconverted, with room occupancy ranging from the few 2-bedded to a commoner layout of the 6-bedded rooms. Three participants even highlighted the fact about being in a supposedly 4-bedded room, only to have another fifth bed squeezed in beside them.

The female participants identified individual staff members whose behaviour had threatened their dignity or, they perceived that of other residents. They highlighted the potential of staff behaviour to threaten dignity and the female participants vividly remembered these experiences. In situations concerning other residents, witnessing such interactions left the female participants feeling vulnerable and disempowered. Staff behaviour that threatened dignity was curtness (otherwise described as 'off-hand', 'stand-offish', 'abrupt', 'ignoring', ‘dismissal’), authoritarianism and breaching privacy. Each of these is next discussed.

Overall, the residents interviewed, considered that lack of privacy threatened their dignity on their respective ward. However, this was more likely to relate to the impact of bodily exposure than the physical environment of the ward. Different views were offered by all participants and observational data supported lack of privacy as a major theme threatening residents' dignity. Bodily exposure is discussed next.

5.5.6.2 Bodily exposure

Residents' views about dignity and bodily exposure varied, however a common denominator amongst the participants was that they all mentioned that when staff members were gracious in their approach towards them, it made them feel like they were seen as individuals, and accepted for having personal preferences, so that, in terms of dignity their personal identity was restored.

For instance, four of the male participants, did not associate or comment about loss or threat of dignity in relation to their bodies being exposed during personal care and hygiene duties. Whereas, Charles was "very embarrassed" for the fact that at the age of 91 he was wearing a nappy due to urinary incontinence. This factor, left him feeling "disempowered" and without dignity, as described below:

> "I don’t know … you get thrown here and there … the fact of the matter is, now you have it and now you don’t [in reference to his dignity], that’s what it’s like here. No, they don’t uphold your dignity … no, nothing is maintained for you here". (**Charles**)

Bodily exposure was a major concern amongst the female participants, especially during personal care (*i.e.,* bathing or dressing) and hygiene routines (*i.e.,* nappy changing or insertion of a urinary catheter or cleaning of a colostomy bag), all of which echo the barriers between privacy and exposure, described by Jacobson (2012).

The female participants were far more descriptive and offered more detail on the subject. Overall, they described the process as making them "*feel uncomfortable*" because the task itself was "*too personal*". Since they had become dependent in many of their ADLs due to their chronic illnesses, which had left them with debilitating physical limitations, they therefore had "*no choice*", so the fact that they were "*not used to it*" became "*irrelevant*" and irrespective of whether it made them feel "*vulnerable*" and "*exposed*", they had to "*let* go" and "*accept the situation for what it is*", as explained by Helen:

> "Before I was able to wash myself … *on my own*, but because of my arthritis, well … now *I must bare myself to them* [staff] ...". **(Helen)**

Other female participants stressed that they felt '*more vulnerable*' if they were subject to exposure, especially if a male staff was assisting a female member of staff, or if for instance, a staff member walked in on them during personal care and hygiene routines, to talk to the nurse who was washing them.

Liz stated that due to shortage of staff, there have been times when male staff have been sent to work the shift (in reference to her new ward of residence). The lady complained that it was not appropriate for the female staff to ask for male staff assistance during personal hygiene duties. She stressed that the male staff do not assist with the execution of such duties "with us, who are still in our senses" but was concerned at the fact that they possibly did help "with the others", in relation to residents who were more dependent in their ADLs or who had diminished cognitive functioning.

However, Liz felt sorry for Nora (sharing the same room), since on many occasions she heard staff referring to her as a '*dead weight*'. In view of the fact that Nora has to be hoisted out of bed and transferred onto a wheelchair, Liz confirmed that the staff do not position her properly in sitting or that they do not take the trouble of re-positioning her with the hoist, instead, the message relayed to Nora is,

> "I'm not going to stay breaking my back over you". **(Liz)**

However, Liz added that:

> "… you can see that she is sitting to one side but they tell her that she's fine as she is, or: *look, you're like the queen*". **(Liz)**

Grace commented that not all staff were respectful during bathing routines as she explained that some staff members kept areas of her body covered with a towel while washing another area; and some other staff, '*just don't care*', alluding to the fact of being fully exposed in bed.

Participants' comments also highlighted how seemingly minor details are crucial in relation to dignity in a care home. For example, Helen described the many times she would have to wait for a staff member, who would be "washing" her, to 'get off' the mobile phone, as illustrated below:

> "Yes of course they (staff) take the call … they'd be on their mobile arguing either with their boyfriend or their husband … you hear all the ins-and-outs … who's getting married, who's cheating on who … ". **(Helen)**

In reference to what happens next, Helen continued:

> "Well you know, they still try to wash you … they'd be holding their mobile (phone) between one shoulder and their ear, whilst trying to kind of reach out with the one hand, then they might start shouting down the phone again ... well, yes, I'd be stark naked but what can you do?". **(Helen)**

Remaining on the same topic of bathing, Grace stressed on the fact that it depends on the staff who are working the morning shift and who is allocated to her room. She described how some of the ward staff, work systematically by uncovering only one area at a time during bathing routines and that they ensure that the water is warm; whilst other staff members '*do not seem to care at all*'. Below is an excerpt of the lady's comments in regards:

> "Sometimes you find that *one* (staff member) who's *a Saint* … now, *those* are the good and kind-hearted ones … and then sometimes you find another one who *snaps* at you and *wants* you to do everything on your own, *but you can't*, because you're not feeling well, so I tell her: now if it were your own mother, would you be happy if someone did this to her? … but it's no use … in the end, *isn't it them who win*? ". **(Grace)**

5.5.7 Fear of retribution

> "All residents and their relatives, friends and representatives are confident that their complaints will be listened to, taken seriously and acted upon and that they will be treated confidentially if so requested". (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2015, p. 24)

Chapter 4 in the NMS, has two pages dedicated to *Complaints and Protection* and there are three standards in place, namely, *Standard 16 – Complaints, Standard 17 – Rights, and Standard 18 – Protection* (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2015, pp. 24-25). For instance, Standard 16 elaborates on the importance to acknowledge the fact "that many older people do not like to complain – whether due to difficulty in communicating effectively, embarrassment, fear of being victimised or other valid reasons" (*ibid*.).

For the sake of argument, it was observed that there is no '*quiet room*' physically available on any of the wards at SVPR, for the exclusive use of the residents (and their relatives or for any private interchange with HCPs). In fact, for the purpose of this research study, alternate venues had to be sought in order to conduct the interviews and this factor in itself already indicates a lack towards maintaining confidentiality, anonymity or privacy for the residents at ward level.

The participants, with the exception of one, did not want to have their interview held within the confinement of the nurse-in-charge's office and this was because they felt it would have put them '*on the spot*' and they too wanted to ensure that their anonymity was safeguarded '*from the eyes and ears of staff*'. In fact, some participants even posed the question to the researcher, as to whether the ward staff knew that they were being interviewed on the day. Although participants wanted to share their experiences with the researcher, this factors links to Levine (2004) on the premise that participants did not want to feel 'bare'. Hence their choice, of being interviewed at their bedside or at the most, in a secluded area of the corridor, "*away from the scrutiny of the ward staff*".

For instance, Helen, appreciated that the curtain was drawn around her bed as it gave her a sense of '*protection*' during the interview as she felt it safeguarded her anonymity. However, on the other hand, she was also concerned that the closed curtains might attract unnecessary attention from the staff, leading them to think that she was

> "using [her] mobile phone to call customer care and complain about the staff". **(Helen)**

Her worry stemmed from the fact that in the recent past, Helen had made a formal complaint to *Customer Care Services* at SVPR in regards to an incident with occurred with one of the carers working on her ward. Helen described that the carer had been rude to her and had even used foul language against her (*i.e.* consistent with verbal abuse). Accordingly, the issue was investigated but in the meantime, the participant had to endure running comments from other ward staff members, such as:

> "Oh, you better watch out from this one because she'll report you". **(Helen)**

The participant then described the fact that at a later date, she was approached by the carer in question who '*calmly*' told her:

> "So Helen, you were going to nail me? You were going to get me fired? – And where would I work eh?". **(Helen)**

Helen’s comments here indicate that although she exercised her right to complain, not only were her rights to confidentiality violated, but that she was also put in a more vulnerable position, as she was later harassed by the perpetrator. Additionally, the fact that the carer was left to work on her same ward augmented her feelings of powerlessness and this was a direct loss to her dignity as she felt that she was now at the mercy of those who are presumably supposed to protect her and safeguard her well-being.

Therefore, the findings described above, show that the concept of the whistle-blower serves no purpose to older adults in care homes, unless once they are encouraged to take action, a person is actually given back-up, supported and protected from the added insults and violations of others in a care home.

On the other hand, Mary related that on many occasions she has forwarded her suggestions or complaints to ‘Customer Care’ at SVPR but accordingly, it all fell on ‘deaf ears’, as she added:

> "There are many things here which need to be addressed, changed and improved … I’ve said my peace many times, but nobody listens … they just don’t care". **(Mary)**

5.5.8 Family members and carers as care partners

Considering that the purpose of this research study focused on interviews with the older adults at SVPR and since, half of the participants within the sample group had limited or no contact with their family, the findings were deemed askew. Thus, point 8 of the *10 Dignity Do’s* will not be discussed in view of the limited data.

5.5.9 Confidence and positive self-esteem

Most of the residents associated dignity with appearance, that is, being dressed appropriately, and additionally for the female participants, not having their bodies exposed.

The male participants were noted to be smartly dressed and most of the female participants seemed to be wearing more comfortable, practical attire. This could be linked to the fact that, overall, the males were by far more independent in their mobility than their female counterparts. One participant (Nora) was wearing a night dress and this gave the impression that she was unwell or in a hospital.

Helen stressed the importance that she does not leave her room in the morning until she is fit to be seen in public. Her physical presentation was important towards maintaining her dignity:

> "Even if I'm unwell and it just means going out into *that corridor*, I have to be properly dressed, I like wearing my necklaces and having nail varnish … Oh Lord, I'm so vain (laughs) … but I wouldn't feel complete otherwise … this is who I am … I like to look presentable … besides, I would hate to stay in my nightie all day … (laughs) … what the hell, I don't even wear them here … I have so many of them and they're all beautiful … my daughter begs me all the time … nah, I tell her to take them away … see this T-shirt? This is what I sleep in … it's more comfortable (laughs)". **(Helen)**

Therefore, physical presentation was closely linked with feelings, influencing how comfortable and confident residents felt about themselves in regards to their self-image. Moreover, having a sense of control over their physical presentation could potentially enhance or diminish their self-esteem.

A common factor which was observed amongst the female participants is that none of them wore a bra. This topic was brought up in conversation with Helen who confirmed that in fact she does usually wear a bra, but prefers to remove it when she is in bed and coincidentally, the participant was in her bed at the time of the interview.

However, Helen then volunteered information on one of the other ladies in her room who had suffered a stroke. Likewise, it emerged that this lady cares very much about her appearance and that it is important to her that she looks 'proper' especially if she has medical appointments to attend to, outside of SVPR or when her children take her out over the weekends. Accordingly, this lady is not allowed by the staff to wear her bra because "she is too heavy, and it's a hassle to stay moving her around", when staff have to get her dressed.

Helen stated that she had seen this lady in tears because the staff had asked her children to slit the dresses all the way down the back as it would be easier and more practical for them to get her dressed. The participant further elaborated that this lady has complained many a time because she feels chilled with her back exposed and more so, the lady confided to Helen that she feels very embarrassed going out with her children because of what people might say about her clothes. Accordingly, Helen also witnessed a few arguments between staff and the lady's children, since the latter did not want to keep spoiling the lovely new dresses that they buy for their mother by splitting them at the back. Seemingly, this was not helpful either, because as the participant stated, the staff have even ripped a few dresses themselves from the back, saying then, that it was a necessity; to be able to get her dressed.

5.5.10 Alleviating loneliness and isolation

In agreement with Nursey (2015), loneliness is pervasive. It varies with age and poses a particular threat to the very old, quickening the rate at which their faculties decline and cutting their lives shorter.

In an acute hospital setting, threats to a person's dignity can be somewhat seen as being restricted to a particular time-frame since patients are eventually discharged and are able to return to their own home. In the case of a long-term care environment, there seems to be no concept amongst residents of this, nor the possibility of returning to one's own home, since admission to a care home is associated with '*reaching the end of the line'.* The essence of this thought process was best captured in what Janice had to say in reference to her hometown and her state of being in a care home (SVPR), as she stated:

> "I won't die in Zejtun. *I'm going to die here!* … Oh, how much I love my hometown"
> **(Janice)**

Overall, the findings showed that loneliness and isolation for residents at ward level were components that greatly affected those who were either highly dependent in their ADLs or who were unable to accept or adjust to their 'new' environment, as they felt it had jeopardised their freedom and choice to return to their own home.

> "They hardly even bother to talk to you, let alone help you. You have to be here to understand what I mean". **(Nora)**

In relation to Charles who felt 'trapped', he related that both himself and his older sister (91 and 97 years, respectively) where placed in separate care homes a year earlier. He was very upset due his current situation and there was a sense of nostalgia in his voice; resigned to the fact that towards the end of his life he would:

> "… never be able to return to my own home, nor be together with my sister again … but what can you do?". **(Charles)**

One school of thought insists that loneliness is a failure of social networks. The lonely get sicker than the non-lonely, because they do not have people to take care of them; they do not have social support. Not surprisingly, Fromm-Reichmann defined 'loneliness' as the want of intimacy (Shulevitz, 2013).

On the other hand, Bert, commented that although he had '*nothing to complain about*' in regards to his present ward; yet, he was looking forward to returning to his original ward (in reference to ongoing renovation) because he '*was used to being there*' and wanted to be re-united with his three friends (residents) with whom he spends most of his time. This implies that for Bert it was not the aesthetic value of a place which promoted his dignity but rather the familiarity and sense of belonging that he had, in view of the ward environment itself and of his social network of friends. These were the aspects that mattered most to him.

Psycho-biologists can now show that loneliness sends misleading hormonal signals, rejiggers the molecules on genes that govern behaviour, and wrenches a slew of other systems out of whack. They have proved that long-lasting loneliness not only makes a person sick; it can kill a person. Emotional isolation is ranked as high a risk factor for mortality as smoking. A partial list of the physical diseases thought to be caused or exacerbated by loneliness would include Alzheimer's, obesity, diabetes, high blood pressure, heart disease, neurodegenerative diseases, and even cancer - tumours can metastasize faster in lonely people (Shulevitz, 2013).

With regards to her medical health status and loss of function, Nora made reference to her life space[14] where she stated:

> "This corner is my life; I find myself crying at what my life has become". **(Nora)**

5.5.11 Loss of Advocacy

Dignity is promoted by *advocacy*, the practice of standing up for those who are struggling for their rights and advocacy encompasses witnessing and testimony (Jacobson, 2012).

Only two participants, Janice and Mary, brought up the subject on the promotion of advocacy. They felt strongly about the need '*to speak up for those who can't*'.

Mary had previously contacted customer care services at SVPR to enquire on whether there was a resident's committee that she could join. Mary explained that she was

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[14] Life space, a measure of spatial mobility, is defined as the size of the spatial area people purposely move through in their daily life as well as the frequency of travel within a specific time frame (Baker, Bodner, and Allman, 2003); (May, Nayak, and Isaacs, 1985).

informed by the staff at customer care that there '*used to be a committee but they no longer meet*'. Upon probing for further information about the residents' committee, Mary was met with; '*I don't know*'.

Mary expressed her wish to be able to act as a representative on behalf of the ladies in her ward and suggested that,

> "Each ward at SVPR should have a resident nominated as a representative – we need to have meetings, to tell each other what's going on in other wards too and to take our complaints or suggestions for improvement, to the management … our voice needs to be heard". **(Mary)**

As for Janice, she pointed out that:

> "They (the staff) tell me: Janice … don't be a CID". **(Janice)**

It should be noted that all of the above statements, made by the two female participants, concur with the NMS as highlighted below:

> "Feedback shall be regularly sought from individual residents and through group discussion, and at least yearly through user satisfaction questionnaires. Residents shall be encouraged to form an association" (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2015, p. 36: 33.5) .

5.6 Conclusion to discussion

The findings show that older people at SVPR are more vulnerable to a loss of dignity, partly because of their health conditions together with staff attitudes and assumptions about older people and their capabilities.

To summarise the findings; there were aspects of care which were considered important to residents. In fact, all of the participants associated dignity being maintained, in relation to their overall level of medical care being received on their ward at SVPR. However, the findings show that it was the quality in delivery, the demonstration of emotional care and approaches in the various interactions with residents (intrinsic factors associated with physical frailty and psycho-social factors), as well as, staff attitudes or behaviour and the facility's culture (extrinsic factors) that either compromised or maintained their sense of dignity.

The male participants were all interviewed from the same ward and overall, they were far more independent in their mobility when compared to the other nine female participants. From the results of the interviews, it appears that the men necessitated more of a custodial environment than strictly nursing care and most of them commented that they were '*appreciative*' and '*grateful*' for the fact that staff provided them with assistance in their basic activities of daily living, including: bathing, dressing, personal care and hygiene (*i.e.* bathing and having their nappy changed), provision of meals and distribution of medication in a timely manner. For the four male participants who required some degree of assistance in their ADLs, irrespective of whether they were able to do far more for themselves or not, mentioned that they were used to the staff doing everything for them or as David pointed out, "they do their duty".

The fact that Bert stated that he did not feel abandoned might be in reference to the sense of abandonment that he had experienced when his daughter returned to work which led to his admission to SVPR. It is also possible that the ward environment and round-the-clock medical care made him feel protected since his basic life needs and safety needs were being fulfilled.

> "No, I'm good. I can't say that I feel abandoned here because they [staff] don't abandon you … What's fair is fair and it has to be said, right?!" **(Bert)**

However, this point links on to the gender dissimilarities between the participants.

In reference to Maslow's hierarchy of needs (see Box 5.4.1), what one needs to consider is that the older Maltese men of our past generation have always been used to having their basic needs met since everything would be done for them. Bearing this in mind, therefore, the concept of being looked after, even if in a care home such as SVPR, would appear to be a norm or something that is expected, so from this point of view, they did not perceive that their dignity was diminished or threatened.

However, in reference to the women being interviewed, this aspect of being 'in need of others' was a major threat at the core of their own humanity as it impacted upon their self-worth, value and personal identity. This concept can be better appreciated when associated to their previous role and position in society in relation of their 'being' – a woman. In fact, this was a common theme for all the female participants, irrespective of whether they were still married (Nora), single or widowed. When highlighting snippets about their life history, it emerged that this cohort vividly represents the era of the "unpaid jobs". In essence most of the female participants were housewives, [and house care applies also to the single ladies within the sample group on the basis of their gender role within the household, in that they looked after their siblings and were in charge of the house chores and the cooking - which is the case of Kelly, who from a young age, had a sort of ‘surrogacy’ role on behalf of her mother].

Therefore, irrespective of marital status, all the women stated to have lived a hard life, in reference to multi-tasking between looking after their large families (having children one after the other *e.g.* Fiona who had 7 live births and 4 miscarriages), helping their husband with agricultural work and farming, and caring for elderly parents (informal care *e.g.* Kelly). For the two women who entered the workforce, this meant that their earnings were to support the family, *i.e.* parents and siblings (*e.g.* Liz - single), whilst another participant (*e.g.* Mary) upon school completion, worked for nearly seventeen years. She married ‘late’ and this was the reason that she left her job.

This also links to the role of the woman in society and the concept of being ‘house proud’ which was a common subject amongst the female participants, yet again, it was also a factor which had a negative impact on their personal identity, since being in a care home left them with no sense of purpose, role or "hope" for the future.

Therefore, consistent with the literature (IFSW, 2012), the women within the sample group were disproportionately ‘poor’ in relation to lower degrees of formal education, social security measures structured around men’s labour market experiences, interrupted participation in the labour market due to caregiving for children and others, and patriarchal family structures.

Nonetheless, the female participants were satisfied with the provision and level of medical care *per se*, as expressed by Fiona:

> ‘… when it comes to medical care, they’re good here’. **(Fiona)**

Yet, it was the lack of sensitivity demonstrated by the staff (in reference to the generation gap), the disrespect towards an ageing cohort and the contempt towards upholding fundamental values of respect, kindness, courtesy and unity.

> "It’s a question of how we were brought up, when people cared … now it’s all rush, rush, rush … where’s the security of the human kind ". **(Liz)**

Similarly, to Baillie’s doctoral research (2007) which was a case study focusing on patient dignity in an acute hospital setting, the researcher believes that the same concept applies to a long-term care setting. Since SVPR is predominantly a nursing care facility, consequently, nurses also have a constant presence in the residents’ care environment and in the same way, other health care professionals (HCPs) visit residents on the various wards "with varying frequency and for limited periods of time. Nurses therefore have more control over the immediate care environment with potentially greater impact" (Baillie, 2007) on residents' experiences of care, including their dignity. Furthermore, the same applies to the care workers (*i.e.* the Carers) since they work within the nursing team.

In fairness, for a person who is in long-term care, it is difficult to distance oneself from a past situation or attribute an unpleasant episode to a singular event, experience or memory, because in contrast to an acute setting which is seen as 'temporary' – a care home is perceived as 'permanent'. In truth, some of the participants were able to manage, process or accept their situation by adapting to their environment and through the use coping mechanisms, but this was not the same for all of the participants.

In terms of life satisfaction, the participants in this sample group referred to their past in terms of being hard-working, having a sense of pride due to their accomplishments and happiness, even though they had a hard life full of sacrifices. But in terms of their admission to the care home compounded by widowhood and loss of family members seems to have invoked a sense of grief for a life once lived.

> "I've already died … I died, along with my husband". **(Janice)**

Some lived for their children but 'longed for their time to come' so that they could be reunited with their deceased husband (Fiona and Grace), others had regrets and lack of closure linked to spousal arguments (Eric) or regrets due to their inability to continue on with their hobbies *e.g.* a passion for a collection of vintage cars (Alan), for one participant, life satisfaction was defined as "a closed book" (Charles).

A point which needs to be clarified is that all the participants felt that they had done their best throughout their lives, and to provide for their family as best as they could and in the situation that they were in. Therefore, in relation to their thoughts about death, it is the researcher's opinion that it was not a question of longing for death because of what the health care system can term as depression or due to suicidal ideation. Again, the researcher is not a qualified mental health care professional and in addition, the GDS-SF test itself, used for this research study would lead anyone to think that most of the participants were threading in between a mild to a moderate form of depression, if not verging onto severe depression.

However, Pachana, *et al.,* (2010) cautioned that endorsing any specific screening instrument would be inappropriate, as no measure has been identified as applicable to all individuals or in all contexts. The researcher agrees with this affirmation. In fact, considering the type of chronic illness and various co-morbidities of the participants, their decline in functional ability and increasing levels of dependence, and after listening to each individual’s experience ranging from the reason of their admission to SVPR, glimpses into their life history and daily lived-in experiences at the facility – it would appear that despite everything, these people are truly resilient and that in their own manner, they seem to battle on a daily basis with keeping their own coping mechanisms in check or at best, trying to preserve their own dignity.

The researcher believes that people have inner strength and yes, at the best of times people need a helping hand, support and guidance in order to be facilitated through their healing process. The researcher’s major concern is that there seems to be a correlation between depression being overrated and labelled onto older adults whom for most through no choice of their own have found themselves in a nursing home, "locked up in here" (Mary) or "thrown in here" (Charles).

Furthermore, for the older person living in a care home, the situation is permanent and therefore anything which diminishes one’s dignity can be ongoing with the risk of having a major effect on one’s emotional well-being.

Chapter 6

Conclusion

6.1 Implications for ageing and long-term policy

The degree to which the older individual retains or does not retain “everyday competence” (*i.e.* the ability to function independently vs. rely on others for basic self-care) (Smith and Baltes, 2007; Knight and Losada, 2011) determines the need for supports in the living environment. However, one must be mindful on the importance of balancing safety with the person’s need for autonomy and quality of life. So much so, that the running of any care home must not be based on regimented schedules or stiff routines just because it makes it ‘easier’ for the policy makers, regulators and the healthcare workforce, especially when taking into consideration that the older adults arrive at the door step of a care home, not out of choice.

As an older adult’s functional ability declines, the environment becomes increasingly important in maximizing their functioning and maintaining their quality of life (Lawton, 1989; Wahl, *et al.*, 2012) [cited in APA Council of Representatives, 2013]. Therefore, in relation to the findings in this study, it suffices to say that first and foremost, a care home should not be the promoter of a custodial environment – a place to ‘baby-sit the old’.

To this effect, Chippendale and Bear-Lehman (2010) highlight that the current trend in Western societies who are facing a growing proportion of older people, is to support older people to remain in their homes as long as possible, so-called ageing in place. However, until provision of such measures which offer a valuable opportunity to our local older adult population become viable, then, the current function and organisation of our local long-term care system needs to be addressed and re-visited.

Haak, *et al.*, (2007) confirm that the home is not only a central and meaningful place for older persons but also a place for activities, where events occur on the old peoples’ own terms and where they feel secure. In their research, the authors found that independence in daily activities among the very old (80+) is strongly linked to aging in place, and that independence is highly valued and reinforces the older person’s sense of self.

Therefore, in order to promote ageing in place and safeguard the ‘sense of self’ amongst our residents in long-term care, there needs to be a structural re-organisation of the facility, in this case, SVPR. And on this note, to merely renovate a ‘hospital ward’ into a more aesthetically pleasing environment does not do away with the fact, that the place still remains reminiscent of a hospital ward, only prettier. Furthermore, sitting on a chair in a long corridor with one's back to the wall for hours on end, hardly qualifies towards embracing the concept of active ageing – and in fairness, this is yet another buzz word which has been over-used by this generation.

Therefore, in the same manner as Haak, *et al.,* (2007) [cited in Eklund, *et al.,* 2013] who termed it is essential to enable older adults to continue performing daily activities in their own homes even when they become frail, likewise, residents need to be empowered to achieve and maintain their maximum potential and be provisioned with meaningful activities that enhance their dignity within the care home.

Indeed, there is what the participants' referred to as, *The Entertainment Services* at SVPR and a few of the participants did mention that they are "taken out" but considering the total population of older adults at this facility, reportedly, the chances of regular excursions merely fall within a frequency of once a month, if not longer. Additionally, this type of service seems to apply for the residents who are more mobile or seemingly, "the same chosen few".

Nevertheless, the researcher poses the question as to why residents have to leave their ward in order to pursue an activity, instead, of having an 'activity room' in each ward which is more accessible to all.

Likewise, going back to the concept of 'home', then it is necessary to ensure provision of adequate seating arrangements which encourage social interactions, rather than being left to hang out dry in a corridor. Not to mention the 'back in bed' syndrome by 5.30 p.m. It is not surprising therefore, that residents exhibit sleeping problems, since reportedly, some may be awake by two in the morning leaving them exhausted during the day, this in turn creates a vicious cycle of becoming irritable and moody due to sleep deprivation.

If the ultimate goal of Healthy Ageing is to promote the quality of life which includes a sense of happiness, satisfaction and richness (Ad Hoc Committee, 2001), then older persons should be viewed as valued members of our society, each with individual abilities, behaviours, values and life experience. They should not be seen as individuals with problems and limitations, but rather as persons having the strength, resilience, resourcefulness and capabilities as was evidenced in the findings of this study.

Good mental health is important to everybody’s daily functioning and although it is hard to define, nevertheless, it is more than the absence of mental illness and includes concepts such as self-efficacy, self-worth and empowerment (Royal College of Psychiatrists, U.K., 2010). Moreover, well-being is a positive outcome that is meaningful for people and for many sectors of society, because it tells us that people perceive that their lives are going well. Good living conditions are fundamental to well-being and tracking these conditions is important for public policy (National Center for Chronic Disease Prevention and Health Promotion: Division of Population Health, 2013). The resultant state could be life satisfaction, a sense of purpose, self-esteem, happiness, security, independence, etc., or a sense of high “quality of life”. Conversely, it could be unhappiness and even depression (Worrall, 1980).

The health of older adults must be considered in the context of events throughout the lifespan. Furthermore, MIPAA asserts, and IFSW (2012) supports, that advancing health and well-being in old age requires not only individual efforts but also governmental commitment to creating - in partnership with non-governmental organizations and the private sector - a social, physical, and economic environment conducive to healthy ageing.

According to the World Health Organization, the geriatric population will reach 2 billion in 2050. It is hoped that "this increase will undoubtedly enhance scientific research in the field of geriatrics" (Drzał-Grabiec, *et al.*, 2013).

Whilst, Formosa elucidates on the fact, that in the foreseeable years, an increasing number of Maltese citizens will live into advanced age and supporting the needs of older persons will represent a tough challenge (Formosa, 2015b). It is therefore important that the government teams with the gerontology educators who are responsible for preparing tomorrow’s professionals to serve an increasingly ageing population. There is no doubt that an examination of workforce literature predicts that there will be a need for substantial numbers of trained ageing specialists in the years ahead (*ibid.*).

To reiterate from the literature review, Sinha (2012) warns that long-term care requires specialised leaders and skilled staff to care for some of the most vulnerable people in our society. However, Formosa (2015b) evidences that Malta is already experiencing some key shortages in workforce preparedness.

> "Given the available demographic projections one must ask if institutions of higher education — especially the University of Malta and the Malta College for Arts, Science and Technology — are doing their utmost to provide the required number of applied Gerontological personnel that is needed to serve the interests and need of the growing older adult population" (Formosa, 2015b, pp. 47-48).

6.2 Study Outcome

The core importance of this research study is to build awareness of dignity issues and to increase capacity among the care workforce within the healthcare system in dealing with these issues.

This needs to be achieved by actively meeting expectations of care of the individual service users in such a way that staff are able to see beyond the illness, beyond the disability, so as to see a person for who he or she really is, together with an appreciation and respect of their life history. In this manner, it is hoped that care staff can create a positive experience for residents.

For older people living with disabilities, preservation of maximum functional capacity and societal integration within the care home are crucial. Therefore, the feeling of belonging, being accepted, valued and validated, supported, empowered, in control, feeling alive rather than existing, connected and even loved, can enhance residents' emotional well-being, quality of life and promote dignity when under threat.

The culture of care is also in part a product of the wider institutional culture and this in turn is influenced by government agendas (Gallagher, *et al.*, 2008).

It is therefore being suggested to take heed from *the Dignity Challenge* (Dignity in Care Network, 2013) as the researcher concludes that this discussion supports the inadequacy in supporting the *10 Dignity Do's* proposed by the National Dignity Council (2016).

6.3 Recommendations for research

In reference to '*The 10 Dignity Do's'* promoted by the National Dignity Council (2016) *and* the *'Dignity Challenge'* (Dignity in Care Network, 2013), it is hereby being recommended that a Dignity Campaign be launched across the board, in all local care homes so as to help staff ensure that residents are treated as unique individuals who are respected and valued just because they are human (*ibid*.).

The objectives for this proposed dignity campaign are:

1. To build awareness of dignity issues in care homes.
2. To increase capacity among the care workforce within the healthcare system in dealing with these issues.
3. To actively meet expectations of care of service users
4. To recognise and respect the emotional attachment that older people have to their personal belongings.
5. To create a positive experience and enhance emotional well-being of residents.
6. To improve quality of life of older adults in long-term care settings.

Therefore, in view of the above listed objectives related to how residents' dignity can be promoted in care homes and owing to the results from this dissertation, a list of recommendations for policy, practice and education are addressed in Section 6.3.1.

6.3.1 Recommendations for policy, practice and education

Policy:

1. Promoting residents' dignity must be everybody's business.

2. *The National Minimum Standards for Care Homes for Older People* assert that the promotion of older people's dignity in care homes is important, thus, both the government and individual care homes must develop and implement follow-up policies which ensure that the application of these standards are being upheld by each local care home.

3. Care homes should provide a physical care environment that is conducive to residents' dignity: one that incorporates the true feeling of 'home' as a meaningful place which is conducive towards social interaction and activity; enables privacy (*e.g.* reducing the number of people per room occupancy) and has adequate resources (*e.g.* there needs to be an allowance for people's personal possessions).

4. Facility systems should prevent unnecessary bodily exposure and thus, the expectation that highly dependent residents must wear attire that exposes them must be reviewed (*e.g.* for female residents – ensure that a lady can wear her bra if she so wishes to rather than leaving her without it because 'it's more practical' or offer suggestions such that a dress be altered having buttons running down the front instead of being 'torn' at the back; indeed this could be seen as an added expense for those concerned, such as, the relatives, but it is definitely a far better option in the long-run).

5. There should be policies in place to guide staff in dealing with situations where residents' dignity is at risk.

6. The wards at SVPR should be resourced with experienced staff in the field of geriatrics and gerontology who exhibit strong leadership skills at ward level and who are committed to resident dignity.

7. A stable team of staff, displaying the necessary skill sets is required within the ward environment at SVPR so as to ensure appropriate continuation of care and connectedness with the residents.

8. The promotion of residents' dignity should be a written expectation in job descriptions of all staff working with residents in care home, and staff in leadership positions.

9. Education about human dignity should be mandatory for all staff working with patients/residents/clients (service users).

10. When transfers and temporary relocation to other wards (or sections in a care home) occur, the management ought to ensure that residents are grouped together with their friends, thus promoting social support and enabling residents to feel more comfortable.

11. Residents’ complaints should be taken seriously and an effective complaints procedure must be put in place. Disciplinary action should be taken and seen to be taken against staff who violate policy of procedures.

Practice:

1. All staff working in care homes must take individual responsibility for promoting residents' dignity.

2. Staff should use interactions that make residents feel comfortable (humour, reassurance, friendliness and professionalism); in control (by taking time to provide them with information and explanations, offering choices, gaining consent and promoting independence) and valued (helpfulness, consideration, showing concern for residents as individuals and courteousness).

3. Staff must provide privacy within the environment, by not intruding without warning and invitation, minimising bodily exposure and promoting auditory privacy.

4. Experienced and senior staff members should display the role modelling behaviour that promotes the importance of dignity to more junior staff, whilst offering ongoing guidance as necessary.

5. All staff should reflect on their own behaviour with residents and take action if they consider a resident's dignity is at risk due to the environment or staff behaviour.

6. Staff must recognise residents' vulnerability to their dignity being threatened in care homes and be extra vigilant in situations where a loss of dignity is more likely to occur.

<u>Education</u>:

1. Training in the full breadth of Gerontological disciplines as it is important to appropriately equip healthcare professionals for practice: starting from university related courses and through continual professional development of qualified staff.

2. Sensitivity training and empathy training for all staff across the board who are in contact with older adults, that is both healthcare professionals and administrative personnel - ranging from the carers to the management, (and to include the domestic personnel).

3. Implementation of yearly appraisals and competency performance reviews for staff – to ensure that training provided to staff is utilised and put into practice.

4. Education should include the role of staff behaviour and awareness of situations where residents are particularly vulnerable to a loss of dignity, while emphasising that promotion of dignity should occur throughout clinical practice and consistently during every interaction with older people. This can be obtained through the use of interactive and simulated care scenarios.

5. Staff should be educated about how residents themselves promote their dignity and the importance of social support from other residents.

6. More experienced staff should be educated about legal and professional responsibilities to promote residents' dignity, managing ethical dilemmas, the importance of role modelling dignity-

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Appendices

Appendix 1A

Approval by Faculty and University Research Ethics Committees

To be completed by Faculty Research Ethics Committee

We have examined the above proposal and advise

[✓ **Acceptance**] **Refusal** **Conditional acceptance**

For the following reason/s:

Signature

Date 12.01.16

To be completed by University Research Ethics Committee

We have examined the above proposal and grant

[✓ **Acceptance**] **Refusal** **Conditional acceptance**

For the following reason/s:

Signature

Date 15/4/2016

Gmail Anabel Scolaro <anabel.scolaro@gmail.com>

Re: Scolaro Anabel - SWB 253/2015

Helen Grech <helen.grech@um.edu.mt> 3 March 2016 at 20:33
To: Anabel Scolaro <anabel.scolaro@gmail.com>
Cc: Marvin Formosa <marvin.formosa@um.edu.mt>, Charmaine Agius <charmaine.agius@um.edu.mt>, Anabel Scolaro <anabel.scolaro.98@um.edu.mt>, UNIVERSITY RESEARCH ETHICS COMMITTEE <research-ethics.committee@um.edu.mt>

Dear Ms Scolaro,
Following submission of the revised documents, I am pleased to inform you that your proposal is approved.
The hard copy will be forwarded in due course.
Good luck with the study.
Sincerely
Helen Grech
Chair, UREC

Professor Helen Grech
Head, Department of Communication Therapy
Deputy Dean, Faculty of Health Sciences
University of Malta, MSD 2090
Tel: +356 2340 1858

☒ Displaying Banner for Auto signature IALP Dublin 2016.png

On 1 March 2016 at 07:14, Anabel Scolaro <anabel.scolaro@gmail.com> wrote:

> Dear Prof. Grech,
>
> As requested, kindly find the attached soft copy in pdf. format of my UREC proposal SWB 253/2015 with the necessary amendments.
>
> I shall be forwarding the hard copy to Ms. Charmaine Agius.
>
> For your convenience, and ease of reference, I have also attached a second document which lists the amendments carried out including the page number. (Kindly note that this particular attachment is at the very end of this e-mail).
>
> Thanking you for your time and assistance.
>
> Best regards,
>
> Anabel Scolaro
>
> **SCOLARO Anabel - UREC Amendments - 29.02.16.pdf**
>
> On 23 February 2016 at 13:07, Helen Grech <helen.grech@um.edu.mt> wrote:
>
> > Dear Ms Scolaro,

Appendix 1B

Permission Letters

Anabel Scolaro
'Oratory Court', Block A, Flat 4,
Oratory Street,
Cospicua,
BML 1508.

7th November 2015

Attn:

Dr. Josianne Cutajar
Chief Executive Officer
Ministry for the Family and Social Solidarity
St. Vincent de Paul Residence

Ref: Request for permission to conduct a research study at St. Vincent de Paul Residence

Dear Dr. Cutajar,

My name is Anabel Scolaro and I am a qualified physiotherapist currently working in Critical Care at Mater Dei Hospital.

At present, I am reading for a course in Master of Gerontology and Geriatrics at the University of Malta (course intake: 2014-2016), Faculty for Social Wellbeing, Department of Gerontology.

Following successful completion of my first academic year, the board members of the Department of Gerontology (formerly known as the Gerontology Unit) approved my proposed dissertation, namely, '*Dignity in Care Homes for Older People: A Qualitative Study*', under the supervision of Dr. Marvin Formosa.

The aim of this study is to explore the lived experience of this heterogeneous cohort in order to accurately capture and describe the phenomena of what dignity means to older men and women residing in a long-term care facility in Malta, and their expectations of care.

For this reason, I would like to request for your permission to carry out my research study within St. Vincent de Paul Residence. Additionally, it would be greatly appreciated if I could purposefully select a sample of 20 people from 4 different wards (2 male wards and 2 female wards), with whom I may conduct semi-structured interviews. Let it be noted that confidentiality will be respected and maintained at all times.

At your convenience, it would be a pleasure to schedule a meeting with your good self, should you require further clarification about the proposed study, to discuss amenable wards and other pertinent information. Furthermore, upon completion of the study, I would be honoured should you accept a copy of my dissertation.

Whilst looking forward to receiving a favourable reply, I would like to take this opportunity to thank you in advance for your time and consideration of my request.

Sincerely,

Anabel Scolaro

Anabel Scolaro
B.Sc. (Hons.) Physiotherapy, SRP, Malta.
Registration No. 122
I.D. Card No. 406275 (M)
Mob. No. 99890649

26/11/15

Approved

Cutajar

Anabel Scolaro <anabel.scolaro@gmail.com>

RE: Request for permission to conduct a research study at St. Vincent de Paul Residence

---

Cutajar Josianne at MFSS-SVPR <josianne.cutajar@gov.mt> 10 November 2015 at 22:38
To: Anabel Scolaro <anabel.scolaro@gmail.com>, Fiorentino Ronald at MFSS-SVPR <ronald.fiorentino@gov.mt>
Cc: Marvin Formosa <marvin.formosa@um.edu.mt>, Anabel Scolaro <anabel.scolaro.98@um.edu.mt>, Scolaro Anabel at MEH-Rehabilitation Services-Health <anabel.scolaro@gov.mt>

Dear Anabel

We thank you for considering SVP as part of your research. Please contact Dr Fiorentino to discuss in more details so that we can give you the green light vise a vie ethical and operational clearance to conduct the study among our vulnerable residents.

Good luck with your studies

Dr Josianne

CEO SVPR

St. Vincent De Paul Residence

t: +356 22912499 e: josianne.cutajar@gov.mt | www.activeageing.gov.mt

MINISTRY FOR THE FAMILY AND SOCIAL SOLIDARITY

St Vincent de Paul Residence

From: Anabel Scolaro [mailto:anabel.scolaro@gmail.com]
Sent: Monday, 09 November 2015 01:23
To: Cutajar Josianne at MFSS-SVPR
Cc: Marvin Formosa; Anabel Scolaro; Scolaro Anabel at MEH-Rehabilitation Services-Health
Subject: Ref: Request for permission to conduct a research study at St. Vincent de Paul Residence

Anabel Scolaro
'Oratory Court', Block A, Flat 4,
Oratory Street,
Cospicua,

BML 1508.

7th November 2015

Attn:

Ms. Josianne Cutajar
Chief Executive Officer
Ministry for the Family and Social Solidarity

St. Vincent de Paul Residence

Ref: Request for permission to conduct a research study at St. Vincent de Paul Residence

Dear Ms. Cutajar,

My name is Anabel Scolaro and I am a qualified physiotherapist currently working in Critical Care at Mater Dei Hospital.

At present, I am reading for a course in Master of Gerontology and Geriatrics at the University of Malta (course intake: 2014-2016), Faculty for Social Wellbeing, Department of Gerontology.

Following successful completion of my first academic year, the board members of the Department of Gerontology (formerly known as the Gerontology Unit) approved my proposed dissertation, namely, '*Dignity in Care Homes for Older People: A Qualitative Study*', under the supervision of Dr. Marvin Formosa.

The aim of this study is to explore the lived experience of this heterogeneous cohort in order to accurately capture and describe the phenomena of what dignity means to older men and women residing in a long-term care facility in Malta, and their expectations of care.

For this reason, I would like to request for your permission to carry out my research study within St. Vincent de Paul Residence. Additionally, it would be greatly appreciated if I could purposefully select a sample of 20 people from 4 different wards (2 male wards and 2 female wards), with whom I may conduct semi-structured interviews. Let it be noted that confidentiality will be respected and maintained at all times.

At your convenience, it would be a pleasure to schedule a meeting with your good self, should you require further clarification about the proposed study, to discuss amenable wards and other pertinent information. Furthermore, upon completion of the study, I would be honoured should you accept a copy of my dissertation.

Whilst looking forward to receiving a favourable reply, I would like to take this opportunity to thank you in advance for your time and consideration of my request.

Sincerely,

Anabel Scolaro

B.Sc. (Hons.) Physiotherapy, SRP, Malta.
Registration No. 122
I.D. Card No. 406275 (M)
Mob. No.
99890649

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Anabel Scolaro <anabel.scolaro@gmail.com>

RE: Request for permission to conduct a research study at St. Vincent de Paul Residence

Anabel Scolaro <anabel.scolaro.98@um.edu.mt> 11 November 2015 at 02:36
To: Cutajar Josianne at MFSS-SVPR <josianne.cutajar@gov.mt>
Cc: Anabel Scolaro <anabel.scolaro@gmail.com>, Fiorentino Ronald at MFSS-SVPR <ronald.fiorentino@gov.mt>, Marvin Formosa <marvin.formosa@um.edu.mt>, Scolaro Anabel at MEH-Rehabilitation Services-Health <anabel.scolaro@gov.mt>

Dear Dr. Cutajar,

I would like to thank you for your prompt reply to my e-mail.

I will duly contact Dr. Fiorentino and seek his guidance on the correct measures to follow and the way forward.

Once again, I am much obliged for your time and positive reply.

Best regards,

Anabel Scolaro

[Quoted text hidden]
--
Anabel Scolaro

Anabel Scolaro <anabel.scolaro@gmail.com>

RE: Request for permission to conduct a research study at St. Vincent de Paul Residence

---

Anabel Scolaro <anabel.scolaro@gmail.com> 16 November 2015 at 00:43
To: ronald.fiorentino@gov.mt
Cc: Cutajar Josianne at MFSS-SVPR <josianne.cutajar@gov.mt>, Marvin Formosa <marvin.formosa@um.edu.mt>, Scolaro Anabel at MEH-Rehabilitation Services-Health <anabel.scolaro@gov.mt>, Anabel Scolaro <anabel.scolaro.98@um.edu.mt>

Dear Dr. Fiorentino,

I trust this e-mail finds you well.

In reference to the previous correspondence threads, I would be grateful if we could schedule a meeting at your earliest convenience, so as to discuss further the necessary requirements with regards to ethical and operational clearance, as highlighted by Dr. Cutajar.

May I take this opportunity to thank you in advance for your time and support. It is highly appreciated.

Sincerely,

Anabel Scolaro
[Quoted text hidden]

Anabel Scolaro <anabel.scolaro@gmail.com>

RE: Request for permission to conduct a research study at St. Vincent de Paul Residence

---

Fiorentino Ronald at MFSS-SVPR <ronald.fiorentino@gov.mt> 20 November 2015 at 15:13
To: Anabel Scolaro <anabel.scolaro@gmail.com>
Cc: Cutajar Josianne at MFSS-SVPR <josianne.cutajar@gov.mt>, Marvin Formosa <marvin.formosa@um.edu.mt>, Scolaro Anabel at MEH-Rehabilitation Services-Health <anabel.scolaro@gov.mt>, Anabel Scolaro <anabel.scolaro.98@um.edu.mt>

Anabel,

Can you come up with a couple of dates in order to juggle around in my diary?

Regards

Dr Ronald Fiorentino MD MBA (Henley) PG Dip.Ger.(Hons)

Medical Superintendent

St. Vincent de Paul

Ingieret Road, Luqa

Tel: 22912203

From: Anabel Scolaro [mailto:anabel.scolaro@gmail.com]
Sent: Monday, 16 November 2015 00:43
To: Fiorentino Ronald at MFSS-SVPR
Cc: Cutajar Josianne at MFSS-SVPR; Marvin Formosa; Scolaro Anabel at MEH-Rehabilitation Services-Health; Anabel Scolaro
Subject: Re: Request for permission to conduct a research study at St. Vincent de Paul Residence

[Quoted text hidden]

RE: Request for permission to conduct a research study at St. Vincent de Paul Residence

Fiorentino Ronald at MFSS-SVPR <ronald.fiorentino@gov.mt> 25 November 2015 at 08:50
To: Anabel Scolaro <anabel.scolaro@gmail.com>
Cc: Cutajar Josianne at MFSS-SVPR <josianne.cutajar@gov.mt>, Marvin Formosa <marvin.formosa@um.edu.mt>, Scolaro Anabel at MEH-Rehabilitation Services-Health <anabel.scolaro@gov.mt>, Anabel Scolaro <anabel.scolaro.98@um.edu.mt>

Confirm.

Dr Ronald Fiorentino MD MBA (Henley) PG Dip.Ger.(Hons)

Medical Superintendent

St. Vincent de Paul

Ingieret Road, Luqa

Tel: 22912203

From: Anabel Scolaro [mailto:anabel.scolaro@gmail.com]
Sent: Tuesday, 24 November 2015 19:25
To: Fiorentino Ronald at MFSS-SVPR
Cc: Cutajar Josianne at MFSS-SVPR; Marvin Formosa; Scolaro Anabel at MEH-Rehabilitation Services-Health; Anabel Scolaro
Subject: Re: Request for permission to conduct a research study at St. Vincent de Paul Residence

Dear Dr. Fiorentino,

Indeed, I confirm our meeting for Thursday, 26th November at around noon.

Thanks a miliion for your time.

Best regards,

Anabel

On 24 November 2015 at 14:38, Fiorentino Ronald at MFSS-SVPR <ronald.fiorentino@gov.mt> wrote:

Hi Anabel,

Can we meet Thursday 26h Nov at around 12.00noon?

R

Dr Ronald Fiorentino MD MBA (Henley) PG Dip.Ger.(Hons)

Medical Superintendent

St. Vincent de Paul

Ingieret Road, Luqa

Tel: 22912203

From: Anabel Scolaro [mailto:anabel.scolaro@gmail.com]
Sent: Sunday, 22 November 2015 20:31

To: Fiorentino Ronald at MFSS-SVPR
Cc: Cutajar Josianne at MFSS-SVPR; Marvin Formosa; Scolaro Anabel at MEH-Rehabilitation Services-Health; Anabel Scolaro
Subject: Re: Request for permission to conduct a research study at St. Vincent de Paul Residence

Dear Dr. Fiorentino,

Thank you very much for your reply.

If possible, I would really appreciate if we could meet up during this coming week: 23rd - 27th November 2015.

As it stands, I need to submit the UREC application form together with all my relevant documentation before 9th December 2015.

As regards to timings, I can make myself available at any time during the day, which is most convenient to you.

Thanking you again for your time and assistance.

I await your reply.

Best regards,

Anabel

Appendix 2A

Recruitment Letter for Participants

‘Oratory Court’, Block A, Flat 4,
Oratory Street,
Cospicua,
BML 1508,
Malta.

Dear Sir/Madame,

My name is Anabel Scolaro and I am reading for a course in Master of Gerontology and Geriatrics at the University of Malta. I am currently conducting my dissertation research study on ‘***Dignity in Care Homes for Older People***’. The purpose of this research is to accurately capture and describe what dignity means to older men and women residing in a long-term care facility in Malta, and their expectations of care.

My study aims to add to the relatively limited research and scholarly literature available on this subject within the context of Malta. Therefore, my research could serve as a stepping stone in contributing towards the understanding of what affects residents’ dignity and how dignity can be promoted in residential care, as well as, improve quality of life.

In order to conduct my research, I would like to interview residents, like yourself, residing at St. Vincent de Paul Residence and ask about what dignity means to you and how being in residential care has affected your dignity.

The research will be carried out during a one-time meeting, at your convenience. The duration of the interview will last from 45 minutes to 90 minutes and if you have no objections, the interview will be tape recorded.

To be eligible for the study, participants must have the mental capacity to make this decision and be of sound psychological aptitude to take on the interview. Therefore, participants who score above a certain cut-off point on a brief test of mental ability and mood stability, will be able to participate in the study. Scoring above this cut-off indicates that you will be able to understand the nature and purpose of the study so that you can make an informed decision about whether to take part.

If you do choose to participate, please rest assured that the information collected will be treated confidentially and no names will be used in the study and final report. To ensure that there is no personally identifiable information, the names will be coded.

You need only answer the questions you want to and can ask for the interview to stop at any time. The use of tape recording will be with your permission and all tapes will be erased after the study is completed. If you decide to take part, you will be asked to sign a consent form to indicate that you have agreed to be interviewed.

Kindly be aware that even if you are eligible, your participation in this study is completely voluntary and you can withdraw from the study at any time, without giving a reason. There will be no consequences should you choose not to participate, and any benefits accorded to you will not be affected by such a choice.

This research study has been reviewed and approved by the Faculty Research Ethics Committee and the University Research Ethics Committee, University of Malta.

If you would like to confirm your participation in this study, kindly contact me on the following numbers:
Mobile number: **9989 0649** or Telephone number: **2180 1971**

Should you have any queries in regards to the research study, please do not hesitate to contact me or my Supervisor, Dr. Marvin Formosa on mobile number: **7963 4015**.

I would like to take this opportunity to thank you for taking the time to read this information.

Sincerely,

Anabel Scolaro
I.D. Card No.: 406275 (M)

Appendix 2B

Ittra ta’ Reklutaġġ għall-Parteċipanti

Oratory Court, Blokka A, Appartament nru. 4,
Triq l-Oratorju,
Bormla,
BML 1508,
Malta.

Għażiż/a Sinjur jew Sinjura,

Jiena jisimni Anabel Scolaro u qiegħda nagħmel kors f'livell ta' Master fil-Ġerontoloġija u l-Ġerjatrija fl-Università ta' Malta. Bħalissa qiegħda nikteb it-teżi tiegħi dwar ***Id-Dinjità ta' Persuni fid-Djar tal-Kura għall-Anzjani***. L-għan ewlieni ta' din ir-riċerka huwa sabiex nikseb tagħrif waqt li niddeskrivi aħjar xi tfisser id-dinjità għall-irġiel u n-nisa li qed jgħixu f'dar tal-kura għall-anzjani f'Malta u l-ħarsien tal-ħtiġijiet tagħhom.

Ir-raġuni wara studju bħal dan, hija l-ammont żgħir ta' riċerka u letteratura akkademika dwar dan is-suġġett, speċifikament fil-kuntest Malti. Għalhekk, ir-riċerka tiegħi tista' sservi bħala pass ′l quddiem lejn aktar għarfien dwar affarijiet li jkasbru jew jgħollu d-dinjità tar-residenti li qed jgħixu fid-djar tal-kura għall-anzjani u għaldaqstant, il-mod kif l-kwalità tal-ħajja tista' tiġi mħarsa.

Sabiex inkun nistà nwettaq din ir-riċerka, qed infittex li nintervista residenti bħalek, li qed jgħixu ġewwa r-residenza ta' San Vinċenz de Paul biex nistaqsik xi mistoqsijiet dwar il-fehma tiegħek dwar xi tfisser d-dinjità għalik u b'liema mod id-dinjità tiegħek qed tiġi affettwata minħabba il-fatt li qed tgħix ġewwa dar tal-kura għall-anzjani.

Ir-riċerka ser tinġabar matul laqgħa waħda biss, biex tkun iktar ta' konvenjenza għalik. It-tul tal-intervista ser iddum minn 45 minuta sa 90 minuta u jekk ma ssib ebda problema, l-intervista se tiġi rrekordjata.

Biex ikunu jistgħu jipparteċipaw f'dan l-istudju, il-parteċipanti għandhom ikollhom il-kapaċità mentali biex jieħdu din id-deċiżjoni u l-kapaċità psikoloġika biex jieħdu sehem fl-intervista. Dawk il-parteċipanti li jiksbu riżultat 'l fuq minn ċertu punteġġ, f'eżami fil-qosor dwar il-memorja u l-burdata, ser ikunu jistgħu jipparteċipaw fl-istudju. Punteġġ adegwat jindika li inti kapaċi tifhem in-natura u l-għan tal-istudju sabiex inti tista' tieħu deċiżjoni infurmata dwar jekk tridx tieħu sehem.

Jekk tagħżel li tieħu sehem, jekk jogħġbok ibqa' ċert/a li l-informazzjoni miġbura mingħandek se tibqa' kunfidenzjali u ebda isem oriġinali mhu se jiġi msemmi waqt l-istudju jew miktub fir-riżultati tar-rapport finali. L-informazzjoni tiegħek personali mhux se tkun identifikabbli u saħansitra, l-ismijiet ħa jiġu kkodifikati.

Għandek l-għażla li twieġeb biss għal dawk il-mistoqsijiet li inti tixtieq u li tista' tistaqsi għall-intervista li tieqaf fi kwalunkwe ħin. L-użu ta' *tape recording* jintuża biss bil-permess tiegħek u t-*tapes* kollha se jiġu mħassra wara li jintemm l-istudju. Jekk tiddeċiedi li tieħu sehem, inti ħa tkun mitlub/a tiffirma formula ta' kunsens biex tindika li qbilt li tiġi intervistat/a.

Jekk jogħġbok kun af li, anki jekk int eliġibbli, l-parteċipazzjoni tiegħek f'dan l-istudju hija kompletament volontarja u tista' tirtira mill-istudju f'kwalunkwe ħin, mingħajr ma għandek għalfejn tagħti raġuni. Tkun xi tkun l-għażla tiegħek, mhux ser ikun hemm konsegwenzi u l-benefiċċji tiegħek mhux se jiġu affettwati mill-għażla tiegħek.

Din ir-riċerka ġie riveduta u approvata mill-Kumitat tal-Fakultà tar-Riċerka fl-Etika u l-Kumitat tal-Università tar-Riċerka fl-Etika, Università ta' Malta.

Jekk tixtieq tipparteċipa f'dan l-istudju, int ġentilment mitlub/a li ċċempel fuq in-numri li jidhru hawn taħt:

numru tal-mowbajl: **9989 0649** jew numru tat-telefown: **2180 1971**

F'każ li għandek xi mistoqsijiet dwar din r-riċerka, jekk jogħġbok, tista' ċċempel lili jew lis-Superviżur tiegħi, Dr. Marvin Formosa fuq dan in-numru tal-mowbajl: **7963 4015**.

Nixtieq nirringrazzjak bil-quddiem tal-ħin li ħadt biex taqra din l-informazzjoni.

Tislijiet,

Anabel Scolaro
Numru tal-Karta tal-Identità: 406275 (M)

Appendix 3A

Participant Identification Code: ____________

Consent Form

Title of Project: Dignity in Care Homes for Older People: A Qualitative Study

Name of Researcher: Anabel Scolaro

The nature of this Research Project and my rights regarding participation in it have been explained to me.

This is to confirm that I .... hereby agree to participate as a volunteer in this study with the understanding that:

1. There will be no risks to me resulting from my participation in this research.
2. My identity will be safeguarded.
3. The information gathered will be anonymised and that it will be used for the sole purpose of this study.
4. I am free to withdraw at any time and that I can refuse to answer any questions without comment, knowing that my medical care or legal rights will not be affected.
5. I agree that my interview will be recorded and the information will be used for the research only.
6. I have been informed that the researcher will keep all information collected [audio tapes and written transcripts of audio tapes] in a locked filing cabinet and that the researcher will erase all tapes and destroy my contact and ward details upon completion of the study.
7. Finally, I have been given an opportunity to ask for clarifications and all such questions have been answered to my satisfaction.

In case of any difficulty in regards to the research study, I can contact Anabel Scolaro on:

Telephone number: **2180 1971** Mobile number: **9989 0649**

☐ I confirm that I have read and understood this consent form.

☐ This consent form was read to me and I have understood what it encompasses.

Signature:	Signature: ....
(Participant)	(On behalf of participant, if applicable)
I.D. card number:	I.D. card number: ....
Date:	
Researcher:	Supervisor: …..
Ms. Anabel Scolaro	**Dr. Marvin Formosa** Head, Department of Gerontology, Faculty for Social Wellbeing, University of Malta. Mobile number: **7963 4015**

2 Signed Copies: 1 for participant; 1 for researcher

Appendix 3B

Kodiċi ta' Identifikazzjoni tal-Parteċipant: ____________

Formula ta' Kunsens

Titlu tal-Proġett: Id-Dinjità ta' Persuni fid-Djar tal-Kura għall-Anzjani: Studju Kwalitattiv

Isem tar-Riċerkatriċi: Anabel Scolaro

L-għan ta' din ir-riċerka u d-drittijiet dwar il-parteċipazzjoni tiegħi fi ħdan dan il-proġett ġew spjegati bis-sħiħ u l-informazzjoni meħtieġa ingħatat b'mod ċar.

Jiena .... qed nagħti l-kunsens tiegħi li nieħu sehem bħala voluntier/a f'dan l-istudju bil-ftehim li:

1. Il-parteċipazzjoni tiegħi f'din ir-riċerka mhijiex se tkun ta' ebda riskju għalija.
2. L-identità tiegħi mhijiex se tkun magħrufa.
3. L-informazzjoni miġbura se tkun anonimizzata u se tintuża biss għall-iskop uniku ta' dan l-istudju.
4. Naf li ma għandi l-ebda dmir nagħmel dan u li nistà nirtira f'kwalunkwe ħin, kif ukoll nista' nirrifjuta li nirrispondi il-mistoqsijiet, mingħajr ma nagħti raġuni u li għaldaqstant, il-kura medika u d-drittijiet legali tiegħi mhumiex se jiġu kompromessi.
5. Jiena naqbel li l-intervista tiegħi tiġi rrekordjata u l-informazzjoni ser tintuża għar-riċerka biss.
6. Ġie spjegat lili, li r-riċerkatriċi se żżomm l-informazzjoni kollha miġbura [tejps tal-awdjo u t-traskrizzjonijiet bil-miktub tat-tejps tal-awdjo] ġewwa kexxun li jissakkar u li r-riċerkatriċi ser tħassar it-tejps kollha u teqred id-dettalji tiegħi u l-identifikazzjoni tas-sala, meta jintemm l-istudju.
7. Jien ġejt mogħti/mogħtija l-opportunità li nistaqsi għal aktar tagħrif dwar il-proġett u ninsab sodisfatt/a li l-mistoqsijiet tiegħi ġew kollha mwieġba.

F'każ ta' xi diffikultà dwar l-istudju tar-riċerka, nistà nistaqsi għal Anabel Scolaro fuq:

In-numru tat-telefown: **2180 1971**

In-numru tal-mowbajl: **9989 0649**

☐ Jiena nikkonferma li din il-formula ta' kunsens qrajtha jiena stess u fhimt kollox.

☐ Din il-formula ta' kunsens ġiet moqrija lili u jiena fhimt kollox.

Firma: .... (Tal-parteċipant)	Firma: .... (Tal-qarrej tad-dikjarazzjoni) *(jekk tapplika)*
Numru tal-karta tal-identità:	Numru tal-karta tal-identità: ....
Data:	
Riċerkatriċi: .... **Ms. Anabel Scolaro**	Superviżur: .... **Dr. Marvin Formosa** Kap tad-Dipartiment tal-Ġerontoloġija, Il-Fakultà għat-Tisħiħ tas-Socjetà, Università ta' Malta. Numru tal-Mowbajl: **7963 4015**

2 Kopji ffirmati: 1 għall-parteċipant; 1 għar-riċerkatriċi

Appendix 4A

Participant Identification Code: ____________

Consent Form for Audio-Recorded Interview

This is to confirm that I hereby agree and consent to have my interview audio-recorded and understand that the information will be used for the research only.

☐ I confirm that I have read and understood this consent form.

☐ This consent form was read to me and I have understood what it encompasses.

Signature:	Signature: ....
(Participant)	(On behalf of participant, if applicable)
I.D. card number:	I.D. card number: ....
Date:	
Researcher:	Supervisor: ....
Ms. Anabel Scolaro	**Dr. Marvin Formosa** Head, Department of Gerontology, Faculty for Social Wellbeing, University of Malta. Mobile number: **7963 4015**

2 Signed Copies: 1 for participant; 1 for researcher

Appendix 4B

Kodiċi ta’ Identifikazzjoni tal-Parteċipant: ____________

Formula ta’ Kunsens għal-Intervista Awdjo-Rrekordjata

Jiena qed nagħti l-kunsens tiegħi sabiex l-intervista tiegħi tiġi awdjo-rrekordjata u nifhem li l-informazzjoni ser tintuża għar-riċerka biss.

☐ Jiena nikkonferma li din il-formula ta’ kunsens qrajtha jiena stess u fhimt kollox.

☐ Din il-formula ta’ kunsens ġiet moqrija lili u jiena fhimt kollox.

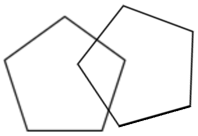
Firma:	Firma: ....
(Tal-parteċipant)	(Tal-qarrej tad-dikjarazzjoni) *(jekk tapplika)*
Numru tal-karta tal-identità:	Numru tal-karta tal-identità: ....
Data:	
Riċerkatriċi:	Superviżur: ....
Ms. Anabel Scolaro	**Dr. Marvin Formosa** Kap tad-Dipartiment tal-Ġerontoloġija, Il-Fakultà għat-Tisħiħ tas-Socjetà, Università ta’ Malta. Numru tal-Mowbajl: **7963 4015**

2 Kopji ffirmati: 1 għall-parteċipant; 1 għar-riċerkatriċi

Appendix 5A

Participant Identification Code: ____________

Standardised Mini-Mental State Examination (SMMSE)

QUESTION		TIME ALLOWED	SCORE
1	a. ***What year is this?***	10 seconds	/1
	b. ***Which season is this?***	10 seconds	/1
	c. ***What month is this?***	10 seconds	/1
	d. ***What is today's date?***	10 seconds	/1
	e. ***What day of the week is this?***	10 seconds	/1
2	a. ***What country are we in?***	10 seconds	/1
	b. ***What province are we in?***	10 seconds	/1
	c. ***What city/town are we in?***	10 seconds	/1
	d. ***IN HOME – What is the street address of this house?*** ***IN FACILITY – What is the name of this building?***	10 seconds	/1
	e. ***IN HOME – What room are we in?*** ***IN FACILITY – What floor are we on?***	10 seconds	/1
3	**SAY:** ***I am going to name three objects. When I am finished, I want you to repeat them. Remember what they are because I am going to ask you to name them again in a few minutes.*** Say the following words slowly at 1-second intervals **-** ***ball / car / man***	20 seconds	/3
4*	***Spell the word WORLD. Now spell it backwards.***	30 seconds	/5
5	***Now what were the three objects I asked you to remember?***	10 seconds	/3
6	**SHOW** wristwatch. **ASK:** ***What is this called?***	10 seconds	/1
7	**SHOW** pencil. **ASK:** ***What is this called?***	10 seconds	/1
8	**SAY:** ***I would like you to repeat this phrase after me: No ifs, ands or buts.***	10 seconds	/1
9	**SAY:** ***Read the words on the page and then do what it says.*** Then hand the person the sheet with CLOSE YOUR EYES on it. If the subject reads and does not close their eyes, repeat up to three times. Score only if subject closes eyes	10 seconds	/1
10	**HAND** *the person a pencil and paper.* **SAY:** ***Write any complete sentence on that piece of paper.*** (Note: The sentence must make sense. Ignore spelling errors).	30 seconds	/1
11	**PLACE** *design, eraser and pencil in front of the person.* **SAY:** ***Copy this design please.***  Allow multiple tries. Wait until person is finished and hands it back. Score only for correctly copied diagram with a 4-sided figure between two 5-sided figures.	1 minute	/1
12	**ASK** the person if he/she is right or left-handed. Take a piece of paper and hold it up in front of the person. **SAY:** ***Take this paper in your right/left hand (whichever is non-dominant), fold the paper in half once with both hands and put the paper down on the floor.*** Score 1 point for each instruction executed correctly.	30 seconds	
	Takes paper correctly in hand		/1
	Folds it in half		/1
	Puts it on the floor		/1
	TOTAL TEST SCORE		**/30**

Directions for Administration of the SMMSE

1. Before the questionnaire is administered, try to get the person to sit down facing you. Assess the person's ability to hear and understand very simple conversation, *e.g.* '*What is your name?*' If the person uses hearing or visual aids, provide these before starting.

2. Introduce yourself and try to get the person's confidence. Before you begin, get the person's permission to ask questions, *e.g.* '*Would it be all right to ask you some questions about your memory?*' This helps to avoid catastrophic reactions**.** Then Say: **'***I am going to ask you some questions and give you some problems to solve. Please try to answer as best you can*'**.**

3. Ask each question a maximum of three times. If the person does not respond, score zero.

4. If the person answers incorrectly, score zero. Accept that answer and do not ask the question again, hint, or provide any physical clues such as head shaking, etc.

5. The following equipment is required to administer the instrument: A watch, a pencil, an eraser, Page 2 of the SMMSE score sheet with **CLOSE YOUR EYES** written in large letters and two five-sided figures intersecting to make a four-sided figure, a space for the person to write down a sentence and a blank piece of paper.

6. If the person answers - '*What did you say?*' - do not explain or engage in conversation, merely repeat. Merely repeat the same directions a maximum of three times.

7. If the person interrupts (*e.g.* queries '*what is this for?*'), just reply: '*I will explain in a few minutes, when we are finished. Now if we could proceed please, we are almost finished*'.

Source: https://www.ihpa.gov.au/sites/g/files/net636/f/publications/smmse-guidelines-v2.pdf

Scoring Guidelines

❖ ***Scoring WORLD backwards (Question 4) -*** (IHPA, 2014)

This task accounts for 17% of the total score. It is essential to score it reliably. There are many different ways and “systems” for scoring WORLD backwards.

Originally, Dr. Folstein advised that the score is “the number of letters in the correct order.” The authors suggest the following method. Score ORDER not SEQUENCE.

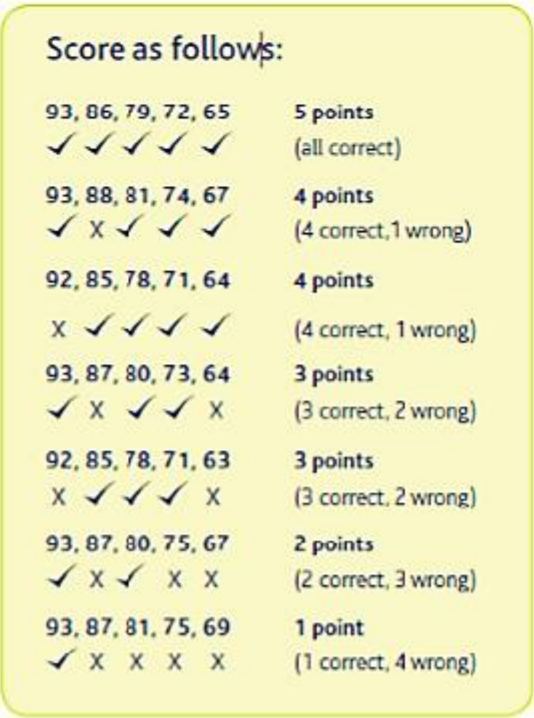
- Simply write down the correct response: D L R O W.
- Now place the last five letters the person said below.
- Now draw lines between the same letters on the response given and DLROW.
- These lines MAY NOT CROSS.
- The person’s score is the maximum number of lines that can be drawn, without crossing any.
- In SMMSE there are many different ways to score this task, but this method has been found to be simple, reliable and easy to apply.

W	O	R	L	D

❖ ****Scoring of serial sevens (alternative to question 4)*** - (IHPA, 2014)

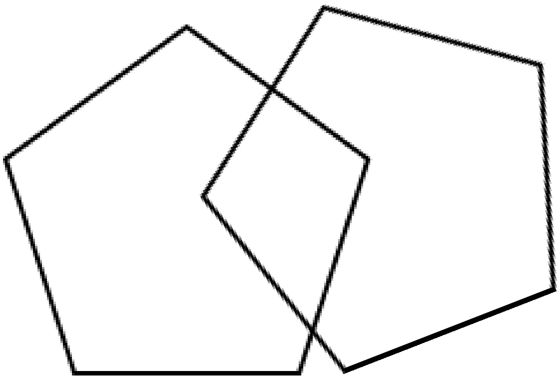
The serial sevens task is presented as an alternative to spelling 'world' backwards. The two tasks are not equivalent. The serial sevens is an easier task, and the scoring is easier. It can be used as an alternate to spelling world backwards in people who are illiterate.

- **Say:** Subtract seven from 100 and keep subtracting seven from what's left (write down person's reply).
- Once person starts – do not interrupt – allow him/her to proceed until five subtractions have been made.
- If person stops before five subtractions have been made, repeat the original instruction keep subtracting seven from what's left (maximum three times).



Score as follows:

93, 86, 79, 72, 65 ✓ ✓ ✓ ✓ ✓	**5 points** (all correct)
93, 88, 81, 74, 67 ✓ X ✓ ✓ ✓	**4 points** (4 correct,1 wrong)
92, 85, 78, 71, 64 X ✓ ✓ ✓ ✓	**4 points** (4 correct, 1 wrong)
93, 87, 80, 73, 64 ✓ X ✓ ✓ X	**3 points** (3 correct, 2 wrong)
92, 85, 78, 71, 63 X ✓ ✓ ✓ X	**3 points** (3 correct, 2 wrong)
93, 87, 80, 75, 67 ✓ X ✓ X X	**2 points** (2 correct, 3 wrong)
93, 87, 81, 75, 69 ✓ X X X X	**1 point** (1 correct, 4 wrong)



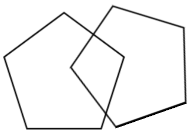
CLOSE YOUR EYES

Provided by the Alzheimer’s Drug Therapy Initiative for physician use.
Source: https://kaiserhealthnews.files.wordpress.com/2014/05/adti_smmse-gds_reference_card.pdf

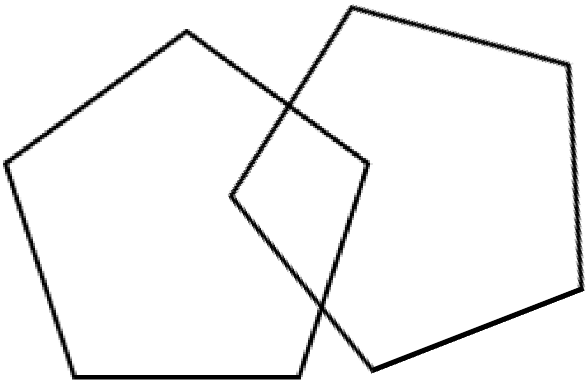
Appendix 5B

Kodiċi ta’ Identifikazzjoni tal-Parteċipant: ____________

Standardised Mini-Mental State Examination (SMMSE) - (Verżjoni bil-Malti)

MISTOQSIJA		HIN PERMESS	PUNTEĠĠ
1	a. ***F’liema sena qegħdin?***	10 sekondi	/1
	b. ***F’liema staġun qegħdin?***	10 sekondi	/1
	c. ***F’liema xahar qegħdin?***	10 sekondi	/1
	d. ***X’inhi d-data tal-lum?***	10 sekondi	/1
	e. ***X’ġurnata tal-ġimgħa hi?***	10 sekondi	/1
2	a. ***F’liema pajjiż qegħdin?***	10 sekondi	/1
	b. ***F’liema distrett qegħdin?***	10 sekondi	/1
	c. ***F’liema belt/raħal qegħdin?***	10 sekondi	/1
	d. ***FID-DAR – Tista’ ttini l-indirizz ta’ din id-dar?*** ***FIL-FAĊILITÀ – X’inhu l-isem ta’ dan il-bini?***	10 sekondi	/1
	e. ***FID-DAR – F’liema kamra qegħdin?*** ***FIL-FAĊILITÀ – F’liema sular qegħdin?***	10 sekondi	/1
3	**GĦID HEKK:** ***Ħa nsemmi tliet oġġetti. Meta ngħidhom, nixtieqek tirrepetihom warajja. Ftakar x’inhuma għax se nitolbok tgħidhomli dalwaqt.*** Għid il-kliem li ġej bil-mod f’intervall ta’ sekonda bejniethom – **ballun / karozza / raġel**	20 sekondi	/3
4	***Spelli l-kelma DINJA. Issa spelliha b’lura.***	30 sekondi	/5
5	***Issa għidli x’kienu t-tliet oġġetti li tlabtek tiftakar.***	10 sekondi	/3
6	**URI** l-arloġġ tal-idejn. **SAQSI:** ***X’inhu dan?***	10 sekondi	/1
7	**URI** lapes. **SAQSI:** ***X’inhu dan?***	10 sekondi	/1
8	**GĦID:** ***Nixtieqek tirrepeti din il-frażi warajja: Min, meta, fejn u għalfejn.***	10 sekondi	/1
9	**GĦID:** ***Aqra dak li hemm fuq il-karta u agħmel dak li qed jintalablek.*** Newwel il-karta bil-kliem AGĦLAQ GĦAJNEJK lill-persuna. Jekk il-persuna taqraha u ma tagħlaqx għajnejha, irrepeti sa tliet darbiet. Agħti l-punteġġ biss jekk il-persuna tagħlaq għajnejha.	10 sekondi	/1
10	**NEWWEL** lapes u karta lill-persuna. **GĦID:** ***Ikteb sentenza sħiħa li trid fuq il-karta.*** (Nota: Trid tkun sentenza li tagħmel sens. Injora liż-żbalji ortografiċi)	30 sekondi	/1
11	**POĠĠI** stampa, gomma u lapes quddiem il-persuna. **GĦID: Ikkopja din l-istampa jekk jogħġbok.**  Ħalli lill-persuna tipprova iktar minn darba. Stenna sakemm il-persuna tlesti u tnewwillek lura l-karta. Agħti punteġġ biss jekk l-istampa tkun ikkupjata tajjeb b’figura b’4 naħat bejn żewġ figuri b’5 naħat.	minuta	/1
12	**SAQSI** lill-persuna jekk hijiex leminija jew xellugija. Ħu karta u żommha quddiem il-persuna. **GĦID:** ***Aqbad il-karta b’idejk il-leminija/ix-xellugija*** *(skont l-id li mhijiex dominanti),* ***itwi l-karta min-nofs biż-żewġ idejn u poġġi l-karta mal-art.*** Agħti punt wieħed għal kull istruzzjoni segwita korrettament.	30 sekondi	
	Taqbad il-karta bl-id it-tajba		/1
	Titwiha min-nofs		/1
	Tpoġġiha mal-art		/1
	PUNTEĠĠ TOTALI TAT-TEST		**/30**

D	I	N	J	A



AGĦLAQ GĦAJNEJK

Provdut mill-*Alzheimer's Drug Therapy Initiative* biex jintuża mit-tabib.
Riżorsa: https://kaiserhealthnews.files.wordpress.com/2014/05/adti_smmse-gds_reference_card.pdf
Verzjoni bil-Malti meħuda (u irranġata min ir-riċerkatriċi) minn:
http://activeageing.gov.mt/en/Documents/NMS_MT.pdf

Appendix 6A

Participant Identification Code: ____________

Geriatric Depression Scale: Short Form

Information given to the Participant:

- Choose the best answer for how you felt over the past week.
- Answer the following questions with a YES or NO answer.

Information for the Researcher:

- Read these questions to the participant.
- **Do Not** show the sheet to the participant.
- Circle the answer as provided by the participant.

1.	Are you basically satisfied with your life?	YES / **NO**
2.	Have you dropped many of your activities and interests?	**YES** / NO
3.	Do you feel that your life is empty?	**YES** / NO
4.	Do you often get bored?	**YES** / NO
5.	Are you in good spirits most of the time?	YES / **NO**
6.	Are you afraid that something bad is going to happen to you?	**YES** / NO
7.	Do you feel happy most of the time?	YES / **NO**
8.	Do you often feel helpless?	**YES** / NO
9.	Do you prefer to stay at home*, rather than going out and doing new things?	**YES** / NO
10.	Do you feel you have more problems with memory than most?	**YES** / NO
11.	Do you think it is wonderful to be alive now?	YES / **NO**
12.	Do you feel pretty worthless the way you are now?	**YES** / NO
13.	Do you feel full of energy?	YES / **NO**
14.	Do you feel that your situation is hopeless?	**YES** / NO
15.	Do you think that most people are better off than you are?	**YES** / NO

*** Substitute the word 'home' with room or ward to reflect the participant's living environment.**

Answers in **bold** indicate depression. Score 1 point for each bolded answer.

A score of	> 5 points	is suggestive of depression
A score of	≥ 10 points	is almost always indicative of depression.
A score of	> 5 points	should warrant a follow-up comprehensive assessment

Source: GDS-15 (Short Form): http://www.stanford.edu/~yesavage/GDS.html (This scale is in the public domain) **(Greenberg, 2012)**.

Appendix 6B

Kodiċi ta’ Identifikazzjoni tal-Parteċipant: ____________

Skala ta’ Dipressjoni Ġerjatrika – Verżjoni Qasira

Informazzjoni mogħtija lill-Parteċipant:

- Għażel l-aħjar tweġiba fuq kif ħassejtek matul il-ġimgħa li għaddiet.
- Wieġeb **IVA** jew **LE** għal dawn il-mistoqsijiet li ġejjin.

Informazzjoni għar-Riċerkatriċi:

- Aqra dawn il-mistoqsijiet lill-parteċipant.
- **Turix** il-karta lill-parteċipant.
- Għamel ċirku madwar it-tweġiba mogħtija mill-parteċipant.

1.	Tħossok sodisfatt/a b’ħajtek?	IVA / **LE**
2.	Naqqast ħafna mill-attivitajiet u interessi oħra tiegħek?	**IVA** / LE
3.	Tħoss li ħajtek hi vojta?	**IVA** / LE
4.	Ta’ spiss tħossok imdejjaq/imdejjqa?	**IVA** / LE
5.	Tkun f’burdata tajba, ħafna mill-ħin?	IVA / **LE**
6.	Tibżà li jista’ jiġrilek xi ħaġa ħażina?	**IVA** / LE
7.	Tħossok ferħan/a, ħafna mill-ħin?	IVA / **LE**
8.	Tħoss li ma tistax tgħin ruħek?	**IVA** / LE
9.	Tippreferi toqgħod id-dar*, milli toħroġ u tagħmel affarijiet ġodda?	**IVA** / LE
10.	Tħoss li għandek problema akbar minn ħaddieħor, (bil-memorja) biex tiftakar?	**IVA** / LE
11.	Taħseb li hija xi ħaġa sabiħa li inti ħaj/ħajja bħalissa?	IVA / **LE**
12.	Tħossok li kif inti bħalissa, m’inti tajjeb/tajba għal xejn?	**IVA** / LE
13.	Tħossok mimli/mimlija b’enerġija?	IVA / **LE**
14.	Tħoss li m’hemmx tama fis-sitwazzjoni li tinsab fiha?	**IVA** / LE
15.	Tħoss li ħaddieħor qiegħed f’pożizzjoni aħjar minn tiegħek bħalissa?	**IVA** / LE

***Biddel il-kelma ‘dar’ ma kamra jew sala sabiex tirrifletti l-ambjent fejn qed jgħix il-parteċipant.**

It-Tweġibiet **f'tipa skura** jindikaw Dipressjoni. Agħti punt wieħed għal kull tweġiba f'tipa skura.

Punteġġ ta’	> 5 points	Jissuġġerixxi li hemm dipressjoni
Punteġġ ta’	≥ 10 points	Huwa ħafna drabi indikattiv ta’ dipressjoni
Punteġġ ta’	> 5 points	Tiġġustifika valutazzjoni komprensiva ta’ segwietu

Riżorsa: GDS-SF (15-item) - http://www.stanford.edu/~yesavage/GDS.html (Greenberg, 2012)
Verzjoni bil-Malti GDS-LF (30-item): (Gerada and Ferry)
Verzjoni bil-Malti GDS-SF (15-item): Traduzzjoni u irrangar minn ir-Ricerkatrici, Anabel Scolaro, B.Sc. (Hons.) Physiotherapy, SRP Malta.

Appendix 7A

Information Sheet on concerns about Loss of Memory

Are you concerned about having loss of memory?

We've all misplaced keys, blanked on an acquaintance's name, or forgotten a phone number. When we're young, we don't tend to pay much attention to these lapses, but as we grow older, sometimes we worry about what they mean.

It's important to remember that memory loss doesn't automatically mean that you have major cognitive problems. There are many other reasons why you may be experiencing cognitive problems, including stress, depression, and even vitamin deficiencies. That's why it's so important to go to a doctor to get an official diagnosis if you're experiencing problems.

Reversible causes of memory loss

Sometimes, even what looks like significant memory loss can be caused by treatable conditions and reversible external factors, such as:

- **Depression.** Depression can mimic the signs of memory loss, making it hard for you to concentrate, stay organized, remember things, and get things done. Depression is a common problem in older adults — especially if you're less social and active than you used to be or you've recently experienced a number of important losses or major life changes (retirement, a serious medical diagnosis, the loss of a loved one, moving out of your home).
- **Vitamin B12 deficiency.** Vitamin B12 protects neurons and is vital to healthy brain functioning. In fact, a lack of B12 can cause permanent damage to the brain. Older people have a slower nutritional absorption rate, which can make it difficult for you to get the B12 your mind and body need. If you smoke or drink, you may be at particular risk. If you address a vitamin B12 deficiency early, you can reverse the associated memory problems and treatment is available.
- **Thyroid problems.** The thyroid gland controls metabolism: if your metabolism is too fast, you may feel confused, and if it's too slow, you can feel sluggish and depressed. Thyroid problems can cause memory problems such as forgetfulness and difficulty concentrating. Medication can reverse the symptoms.
- **Alcohol abuse.** Excessive alcohol intake is toxic to brain cells, and alcohol abuse leads to memory loss.
- **Dehydration.** Older adults are particularly susceptible to dehydration. Severe dehydration can cause confusion, drowsiness, memory loss, and other symptoms. It's important to stay hydrated (aim for 6-8 drinks per day). Be particularly vigilant if you take diuretics or laxatives or suffer from diabetes, high blood sugar, or diarrhoea.
- **Side effects of medication.** Many prescribed and over-the-counter drugs or combinations of drugs can cause cognitive problems and memory loss as a side effect. This is especially common in older adults because they break down and absorb medication more slowly. Common medications that affect memory and brain function include sleeping pills, antihistamines, blood pressure and arthritis medication, muscle relaxants, anticholinergic drugs for urinary incontinence and gastrointestinal discomfort, antidepressants, anti-anxiety medications, and painkillers.

When to see a doctor for memory loss

For any queries or concerns about your health, it is always best to speak to your doctor.

It is strongly advisable to consult a doctor when memory lapses become frequent enough or sufficiently noticeable to concern you or a family member. If you get to that point, make an appointment as soon as possible to talk with your doctor and have a thorough physical examination. Your doctor can assess your personal risk factors, evaluate your symptoms, eliminate reversible causes of memory loss, and help you obtain appropriate care.

Source: http://www.helpguide.org/articles/memory/age-related-memory-loss.htm#doctor

Appendix 7B

Informazzjoni dwar tħassib fuq Telf ta’ Memorja

Tħossok imħasseb/imħassba dwar jekk għandekx xi telf ta’ memorja?

Kulħadd jista’ jgħid li xi darba jew oħra f’ħajtu poġġa iċ-ċwievet f’xi post u wara ma setax jiftakar fejn poġġihom, jew dlonk nesa xi isem familjari, jew nesa xi numru tat-telefown. Fiż-żgħożija, għandna tendenza li ma tantx nagħtu każ żbalji ta’ dan it-tip, iżda kif nixjieħu, kultant nibdew ninkwetaw dwar x’jista’ jfisser dan.

Huwa importanti li wieħed jiftakar li t-telf ta’ memorja ma tfissirx awtomatikament li inti għandek xi problemi konjittivi jew li qed titlef il-menti. Hemm ħafna raġunijiet oħrajn għalfejn inti tista’ t’esperjenza problemi ta’ sura konjittiva u dawn jinkludi affarijiet bħal: stress, dipressjoni, u anke nuqqas ta’ ċertu vitamini. Għalhekk huwa importanti ħafna li tmur għand tabib biex tikseb dijanjosi uffiċjali jekk int qiegħed/qiegħda tesperjenza ċerti problemi.

Kawżi riversibbli ta’ telf ta’ memorja

Kultant, anke dak li wieħed iqis bħala telf ta’ memorja sinifikanti jista’ minflok jkun kkawżat minn kondizzjonijiet oħra jew fatturi esterni li huma riversibbli u li jistu’ jiġu imfejqa, bħal:

- **Dipressjoni**. Ħafna drabi is-sintomi tad-dipressjoni jixbhu s-sintomi tat-telf tal-memorja. Jista’ jagħti l-każ li tinduna kemm qed tkun diffiċli għalik biex tikkonċentra, biex tibqa’ organizzat, biex tiftakar l-affarijiet u biex tagħmel l-affarijiet normali ta’ kuljum. Id-dipressjoni hija problema komuni fl-anzjani - speċjalment jekk inti naqqast minn attivitajiet ċiviċi u ma bqajtx attiv/a bħal ma kont qabel jew forsi riċentement esperjenzajt numru ta’ telfiet importanti f’ħajtek jew għaddejt minn bidliet kbar f’ħajtek, bħal pereżempju, l-irtirar mix-xogħol/ħriġt bil-pensjoni, dijanjosi medika serja, it-telf ta' xi ħadd maħbub, jew m’għadekx tgħix fid-dar tiegħek.

- **Vitamina B12**. Il-vitamina B12 tikkontribwixxi għaċ-ċelluli ħomor, żżomm il-ġisem u n-nervituri jiffunzjonaw tajjeb u hija vitali sabiex l-funzjonament tal-moħħ jibqa’ b'saħħtu. Fil-fatt, in-nuqqas ta’ din il-vitamina B12 tista' tikkawża ħsara permanenti lill-moħħ. L-anzjani għandhom rata aktar baxxa ta’ assorbiment tan-nutriment, u għaldaqstant jista’ jkun diffiċli għalik li tikseb l-ammont neċessarju ta’ din il-vitamina B12, li tant hija meħtieġa għall-moħħ kif ukoll għall-ħtieġa tal-ġisem. Jekk tpejjep jew tixrob, tista’ tkun f'riskju akbar. Jekk inti tħares n-nuqqas ta’ din il-vitamina B12 kmieni, inti tista' tevita problemi li huma assoċjati mat-telf tal-memorja. Madankollu, hemm kura li hija disponibbli ukoll, fil-forma ta’ injezzjoni li tingħata kull xahar.

- **Problemi tat-Tirojde**. Il-metaboliżmu tagħna huwa kkontrollat mill-glandola tat-tirojde: jekk il-metaboliżmu tiegħek huwa mgħaġġel, inti tista’ tħossok konfuż jew imħawwad, filwaqt li jekk il-metaboliżmu tiegħek huwa għajjien, inti tista' tħossok mitluq u mdejjaq. Problemi tat-tirojde jistgħu jikkawżaw problemi ta’ memorja bħal pereżempju, tibda tinsa u jkollok diffikultà biex tikkonċentra. Il-medikazzjoni tista’ tgħin u twaqqaf dawn is-sintomi.

- **Abbuż mill-Alkoħol**. Konsum eċċessiv ta’ alkoħol huwa tossiku għaċ-ċelloli tal-moħħ, u l-abbuż mill-alkoħol iwassal għal telf ta' memorja.

- **Nuqqas ta’ Ilma**. L-anzjani huma partikolarment suxxettibbli għal problemi fis-saħħa minħabba n-nuqqas ta’ konsum tal-ilma. Maż-żmien, l-għatx jinħass inqas u ċerti mediċini jgħollu r-riskju ta’ nixfa, għalhekk l-ilma huwa meħtieġ speċjalment fejn tittieħed il-fibra fid-dieta. Jekk inti mdorri li ma tixrobx biżżejjed ilma, kun af, li nuqqas kbir ta’ ilma fil-ġisem jista’ jikkawża konfużjoni, ngħas, telf ta' memorja u sintomi oħra. Huwa importanti li tixrob biżżejjed ilma (għamel mod li tixrob minn 6-8 tazzi ilma (jew likwidu ieħor) kuljum) sabiex iżżomm il-kliewi jaħdmu tajjeb. Oqgħod attent speċjalment jekk qed tieħu dijuretiċi (pilloli tal-urina) jew lassattivi (pilloli tal-ippurgar) jew issofri mid-dijabete, zokkor għoli fid-demm, jew d-dijarea.

- **Effetti Sekondarji ta' Medikazzjoni**. Ħafna mediċini li huma kemm bir-riċetta jew mingħajr jew inkella taħlita ta' mediċini, jistgħu bħala effett sekondarju, jikkawżaw problemi konjittivi (tal-moħħ/il-menti) u telf ta' memorja. Dan huwa speċjalment komuni fl-anzjani minħabba li maż-żmien, il-ġisem (il-fwied jew il-kliewi) jkisser u jassorbi l-medikazzjoni aktar bil-mod. Mediċini komuni li jaffettwaw il-memorja u l-funzjoni tal-moħħ jinkludu pilloli tal-irqad, antistamini (għall-allerġiji), dawk tal-pressjoni u tal-artrite, kif ukoll mediċini li jirrilassaw l-muskoli, drogi antikolinerġiċi għall-inkontinenza urinarja u skonfort gastrointestinali (f'imsaren), mediċina kontra d-dipressjoni, mediċini kontra l-ansjetà, u analġeżiċi (mediċini ta' użu għall-uġigħ).

Meta għandek tara t-tabib għal telf ta' memorja

Għal kwalunkwe mistoqsijiet jew tħassib dwar is-saħħa tiegħek, huwa dejjem aħjar li tkellem lit-tabib tiegħek.

Inti mħeġġeġ li tikkonsulta tabib jekk il-problemi ta' telf fil-memorja qed jiġru ħafna ta' spiss jew notevoli biżżejjed li jwasslu għal tħassib, kemm lilek jew lil membri tal-familja tiegħek. Jekk tasal f'dan il-punt, għamel appuntament minnufih sabiex titkellem mat-tabib tiegħek, ħalli jagħmillek vista u eżami fiżiku komplut.

It-tabib tiegħek jista' jivvaluta l-fatturi tiegħek rigward riskju personali, iqis is-sintomi tiegħek, jelimina l-kawżi riversibbli li qed joħolqu t-telf tal-memorja, u jgħinek tikseb kura xierqa.

Riżorsa: http://www.helpguide.org/articles/memory/age-related-memory-loss.htm#doctor

Appendix 8A

Information Sheet on Depression

Depression in Older Adults

What is it like to have depression?

Feeling low or sad is not the only sign of depression. You may:

- Lose interest in life - you can't enjoy the things you usually do.
- Feel tired for no reason. You just don't feel like doing anything. Simple things take a big effort.
- Lose your appetite - and weight.
- Feel restless - and find it hard to relax.
- Worry more than is usual for you.
- Want to avoid people.
- Feel snappy or irritable with people.
- Sleep badly. You may wake an hour or two earlier than usual and find that you can't get back to sleep.
- Lose confidence in yourself.
- Feel useless or a burden to others.
- Notice that you can't concentrate properly.
- Feel panicky.
- Feel bad or guilty. You dwell on things from the past and may get things out of proportion
- Think about suicide - at some point most people with severe depression will feel like ending it all.
- Some physical illnesses can give you symptoms that are similar to those in depression. For example, loss of appetite or poor sleep can be caused by thyroid problems, heart disease or arthritis.

Confusion and memory problems:

Depression, worry and anxiety can affect your memory and make you feel confused. You may worry that you are suffering from dementia (a permanent loss of memory) when it is actually just depression.

How do you know when it's time to get help?

If your feelings:

- Are worse than you would expect
- Have gone on for several weeks
- Interfere with your life
- Mean that you can't face being with other people
- Make you feel that life is not worth living
- Worry you are causing concern to friends or family
- Include thoughts of harming or killing yourself.

What should you do?

Talk to your doctor. They are quite used to helping people with depression and will know what to do. You are not wasting your doctor's time by asking for help.

I don’t want to bother the doctor - depression isn’t a real illness.

Older people tend to think more about physical problems than about feeling depressed. You may have been brought up not to bother the doctor unless you have a physical complaint. Sometimes the first sign of depression can be a constant worry about having a physical illness, even when your doctor can’t find anything wrong with you. If your doctor tells you that you are depressed, it may feel as though you are not being taken seriously. This isn’t the case. Depression can be treated just like any illness.

Source:

http://www.cornwallfoundationtrust.nhs.uk/DocumentsLibrary/CornwallFoundationTrust/OurServices/ComplexCareAndDementia/DepressionInOlderAdultsShortVersion.pdf

Appendix 8B

Informazzjoni dwar id-Dipressjoni

Dipressjoni fl-Anzjani

Kif tinduna li għandek id-dipressjoni?

Li tħossok f'burdata ħażina jew imdejjaq mhuwiex l-uniku sinjal ta' dipressjoni. Tista':

- Titlef l-interess fil-ħajja ta' kuljum – ma tiħux gost bl-affarijiet li tagħmel is-soltu.
- Tħossok għajjien/a mingħajr ebda raġuni. Tħossok li ma għandek aptit tagħmel xejn. Affarijiet sempliċi tarahom bħala sforz kbir.
- Titlef l-aptit – u l-piż.
- Tħossok aġitat/a – u ssibha diffiċli biex tirrilassa.
- Tinkwieta aktar mis-soltu tiegħek.
- Trid tevita n-nies.
- Tħossok urtat/a man-nies.
- Torqod ħażin. Jista' jkun li tqum siegħa jew sagħtejn aktar kmieni mis-soltu u ssib li ma tistax terġa' torqod.
- Titlef il-kunfidenza fik innifsek.
- Tħossok li m'inti tajjeb/tajba għal xejn jew ta' piż għal ħaddieħor.
- Tinduna li ma tistax tikkonċentra sewwa.
- Tħossok li qed tippanikkja.
- Tħossok ħażin jew ħatja. Thewden fuq affarijiet mill-passat u tista' tkabbar l-affarijiet aktar milli huma.
- Taħseb dwar is-suwiċidju – jkun hemm mumenti fejn persuni li għandhom dipressjoni qawwija, jħossuhom li jridu jtemmu ħajjithom.
- Ċertu mard fiżiku jista' jagħtik sintomi li huma simili għal dawk ta' dipressjoni. Pereżempju, telf ta' aptit jew rqad batut jistgħu jiġu kkawżati minn problemi tat-tirojde, mard tal-qalb jew artrite.

Konfużjoni u problemi ta' memorja:

Dipressjoni, inkwiet u ansjetà jistgħu jaffettwaw il-memorja tiegħek u jġegħluk tħossok konfuż/a. Inti tista' tinkwieta li qiegħed/qiegħda tbati mid-demenzja (telf permanenti ta' memorja) meta attwalment tkun biss dipressjoni.

Kif tkun taf meta wasal iż-żmien biex tfittex l-għajnuna?

Jekk is-sentimenti tiegħek (il-mod kif qed tħossok):

- Huma agħar milli tista' tistenna.
- Huma 'l fuq minn diversi ġimgħat.
- Jinterferixxu mal-ħajja tiegħek.
- Jwasslu li inti ma tistax issib ruħek mdawwar/mdawra ma' nies oħra (tippreferi tevita okkażjonijiet soċjali).
- Jġegħluk tħossok li m'hemmx skop li tgħix ħajtek.
- Jinkwetawk li qed tikkawżaw tħassib lill-ħbieb jew tal-familja.
- Jinkludu ħsibijiet li tweġġa' jew toqtol lilek innifsek.

X'għandi nagħmel?

Kellem lit-tabib tiegħek. Huma pjuttost mdorrija jgħinu lin-nies li għandhom id-dipressjoni u se jkun jafu x'għandhom jagħmlu. Inti mhux ħa tkun qiegħed/qiegħda taħli l-ħin tat-tabib tiegħek billi tistaqsi għall-għajnuna.

Ma rridx intellef it-tabib – id-dipressjoni mhijiex marda reali.

L-anzjani għandhom tendenza li jaħsbu aktar dwar problemi fiżiċi milli dwar id-dipressjoni bħala kawża tal-mard tagħhom. Jista' jagħti l-każ li inti kbirt bil-fehma li ma tmurx tara tabib sakemm ma jkollokx probema fiżika.

Xi kultant l-ewwel sinjal ta' dipressjoni tista' tkun tħassib kostanti dwar il-fatt li għandek mard fiżiku, anke meta t-tabib tiegħek ma jistax isib xi ħaġa ħażina fik. Jekk it-tabib tiegħek jgħidlek li inti għandek dipressjoni, int tista' tħossok daqslikieku t-tabib mhux qed jieħdok bis-serjetà. Dan mhuwiex il-każ. Id-dipressjoni tista' tiġi ttrattata bħal kull mard ieħor.

Riżorsa: : **http://www.cornwallfoundationtrust.nhs.uk/DocumentsLibrary/CornwallFoundationTrust/OurServices/ComplexCareAndDementia/DepressionInOlderAdultsShortVersion.pdf**

Verżjoni bil-Malti: Traduzzjoni minn ir-Riċerkatrici, Anabel Scolaro, B.Sc. (Hons.) Physiotherapy, SRP Malta.

Appendix 9A

Information Sheet on Abuse

What is Adult Safeguarding?

Safeguarding adults is about protecting those at risk of harm (vulnerable adults) from suffering abuse or neglect.

Abuse can happen anywhere. It can happen at home, in a residential or nursing home, in a hospital, at work or in the street. There are different types of abuse, which include:

- **Physical abuse** - being hurt or harmed either deliberately or through rough, careless or thoughtless behaviour.
- **Emotional abuse or bullying** - Being humiliated or put down or made to feel anxious or frightened.
- **Financial abuse or theft** - someone using your money or possessions in a way that you don't want.
- **Neglect** - not being given the things you need to feel safe and comfortable or not making sure you get the care or treatment you need.
- **Sexual abuse** - being made to do something that you don't want to do.

Anyone can be vulnerable to abuse at some time in their life. The person who is responsible for the abuse is often well known to the person abused. They could be:

- A paid carer or volunteer.
- A health worker, social care or other worker.
- A relative, friend or neighbour.
- Another resident or service user.
- An occasional visitor or someone who is providing a service.
- Someone who deliberately exploits vulnerable people.

What should I do next?

If you are being abused or concerned about someone else being abused, it is very important to talk about your concerns.

It can be difficult for the abused person to talk to someone about what is happening, especially if:

- The person abusing them is otherwise someone they love, such as a family member.
- They feel guilty.
- The person abusing them is someone they depend on for care or financial support.
- They feel frightened of what might happen if they tell someone.

Whom can I ask for support?

You can obtain help just by talking to someone you trust or by talking to the professionals at St. Vincent de Paul Residence, such as:

- The Management
- The Regulatory Authority
- The Social Worker, or
- The Commissioner of Mental Health and Elderly

Source: http://patient.info/health/safeguarding-adults-leaflet

Appendix 9B

Informazzjoni dwar l-Abbuż

X'inhi is-salvagwardja tal-adulti?

Is-salvagwardja tal-adulti hija l-protezzjoni mogħtija lil dawk il-persuni li huma f'riskju ta' ħsara (*e.ż.* adulti vulnerabbli) minn konsegwenza ta' abbuż jew minn nuqqas ta' attenzjoni.

L-Abbuż jista' jsir kullimkien. Dan jista' jiġri fid-dar, f'dar tal-kura għall-anzjani, fi sptar, fuq ix-xogħol jew fit-triq. Hemm tipi differenti ta' abbuż, li jinkludu:

- **Abbuż fiżiku** – meta tiġi mweġġa' minn xi ħadd jew issirlek il-ħsara, deliberatament jew permezz ta' mġiba mhux xierqa.

- **Abbuż emozzjonali jew *bullying*** – meta tiġi umiljat/a jew imġiegħel/imġiegħla tħossok inqas minn ħaddieħor jew li m'inti tajjeb/tajba għal xejn, jew imġiegħel/imġiegħla tħossok anzjuż/a jew imbeżża'.

- **Abbuż finanzjarju jew serq** – meta xi ħadd juża l-flus tiegħek jew affarijiet tiegħek b'mod li inti ma tridx.

- **Negliġenza (nuqqas ta' attenzjoni)** – meta ma tingħatax l-affarijiet li għandek bżonn sabiex tħossok sikur/a u komdu/a jew ma tkunx qed tikseb l-kura jew trattament li għandek bżonn.

- **Abbuż sesswali** – meta tiġi sfurzat/a biex tagħmel xi ħaġa li inti ma tridx tagħmel.

Kulħadd jista' jkun vulnerabbli għal abbuż f'xi żmien fil-ħajja tagħhom. Il-persuna li hija responsabbli għall-abbuż hija ta' spiss magħrufa sew minn il-persuna li qed tiġi abbużat/a.

Dawn jistgħu jkunu:

- Xi ħadd impjegat biex jieħu ħsiebek jew voluntier.
- Ħaddiem tas-saħħa, kura soċjali jew ħaddiem ieħor.
- Qarib, ħabib jew ġar.
- Residenti oħra jew utent tas-servizz.
- Viżitatur okkażjonali jew xi ħadd li qed jipprovdi s-servizz.
- Xi ħadd li deliberatament jisfrutta nies vulnerabbli.

X'nista' nagħmel?

Jekk inti qed tiġi abbużat/a jew imħasseb/imħassba dwar xi ħaddieħor li qed jiġi abbużat, huwa importanti ħafna li titkellem dwar it-tħassib tiegħek. Jista' jkun diffiċli għall-persuna abbużata li tkellem lil xi ħadd dwar dak li qed jiġri, speċjalment jekk:

- Il-persuna li qed t'abbuża minnhom, huwa xi ħadd li jħobbu, bħal membru tal-familja.
- Il-persuna abbużata tħossha li għandha tort.
- Il-persuna li qed t'abbuża minnhom huwa xi ħadd li jiddependu fuqu għall-kura jew l-appoġġ finanzjarju.
- Huma jħossuhom beżgħana dwar x'jista' jiġri jekk jgħidu lil xi ħadd.

Lil min nista' nitlob għall-appoġġ?

Tista' tikseb għajnuna billi tkellem lil xi ħadd li inti tafda jew billi tkellem lill-professjonisti fi ħdan ir-Residenza ta' San Vinċenz de Paul, bħal:

- Il-Maniġment
- L-Awtorità Regolatorja
- Is-*Social Worker*, jew

Il-Kummissarju għas-Saħħa Mentali u għall-Anzjani

Riżorsa: http://patient.info/health/safeguarding-adults-leaflet

Verżjoni bil-Malta: Traduzzjoni mir-Ricerkatrici, Anabel Scolaro, B.Sc. (Hons.) Physiotherapy, SRP Malta.

Appendix 10A

Participant Identification Code : ____________

Interview Schedule

A) Participant Profile

Gender:	***Male / Female***
Age	
Date of Birth	
Place of Birth	
Marital Status	☐ Single ☐ Civil Union ☐ Married ☐ Separated ☐ Divorced ☐ Widowed
Do you have any children?	Yes / No
How many?	
Level of Education	☐ Never attended school ☐ Primary School ☐ Secondary School ☐ Post-Secondary School ☐ University ☐ Post-University Level
Previous Occupation	
Subjective Health Status	Good / Fair / Poor
Self-reported or diagnosed chronic illness(es)	

B) ADLs

The following 6 functions will be assessed in order to establish the participant's ability to perform activities of daily living in an independent manner.

Ask: *Do you require supervision, direction or personal assistance in the following activities of daily living?*

ACTIVITIES	
1. *BATHING*	NO / YES – Give examples:
2. *DRESSING*	NO / YES – Give examples:
3. *TOILETING*	NO / YES – Give examples:
4. *TRANSFERRING*	NO / YES – Give examples:
5. *CONTINENCE [URINARY & FAECAL]*	NO / YES – Give examples:
6. *FEEDING*	NO / YES – Give examples:

C) Interview Schedule for the Participant

Thank you for accepting to take part in this study. The interview will be audio- recorded and the tapes will be identified by a number instead of your name so that you remain anonymous. The information you give is confidential and the recordings will be erased at the end of the research. There are no right or wrong answers, so feel free to provide honest answers to the questions asked.

Interview Questions: 1-16

OPENING QUESTIONS

1) What is the reason that you were admitted to St. Vincent de Paul Residence?

2) How long have you been in residential care?

3) Can you please describe your experience of care at St. Vincent de Paul Residence?

4) How frequently do you have contact with your family members? [***E.g.:*** *Ask specifically for each individual*].

To probe more information relating to dignity, the following questions will also be asked:

5) Dignity, [***e.g.:*** *'for some people, it signifies respect ... '*] is often mentioned as being important in healthcare services. What does the term dignity mean to you?

6) What aspects of care do you consider important?

7) Do you think the staff treat you with a sense of dignity?
(a) What do they do? (b) How would you like to be treated in terms of dignity?

8) What are the factors which help to maintain your dignity while in residential care at St. Vincent de Paul Residence?

9) What are the factors which hinder the maintenance of your dignity while in residential care at St. Vincent de Paul Residence?

10) Has there been any occasion when you felt that you lost, or could have lost, your dignity?
a) If so, when did this happen?
b) What do you think/feel may have caused it?
c) What effect did the staff have on the situation – [***Probe*** *if not understood,* ***e.g.:*** *Whether the staff made the situation better or worse, and if so, how?*]
d) Was there anything else that the staff could have done in this situation to help promote your dignity?

EFFECT OF THE WARD ENVIRONMENT

11) To what extent do you feel that the ward environment has affected your dignity?

12) Is there anything more that could be done to the ward environment to promote your dignity? If so, how?

LIFE ATTITUDE

13) Many people have a lot of attitudes about many things, ***e.g.,*** work, love, etc. What is your attitude about life? [***Probe*** *if not understood,* ***e.g.:*** *What is LIFE to you? What do care most about in life, etc.?*]

14) As you look back on your life, are you satisfied?

15) What changes would you like to see taking place at St. Vincent de Paul Residence in order to improve the service provided? What suggestions do you have?

CONCLUDING QUESTION

16) Is there anything about your dignity that has been left out in this interview?

PROBES - *The following are examples of other probes which will be used:*

"What do you mean?" / "Would you like to clarify on that?" / "Can you give examples?" / "Would you like to explain further on this/that?"

Appendix 10B

Kodiċi ta’ Identifikazzjoni tal-Parteċipant: ____________

Skeda tal-intervista

A) Profil tal-Parteċipant

Ġens:	***Raġel /Mara***
Età	
Data tat-twelid	
Post tat-twelid	
Stat Ċivili	☐ Ġuvni/Xebba ☐ Miżżewweġ/Miżżewġa ☐ Unjoni Ċivili ☐ Separat/a ☐ Divorzjat/a ☐ Armel/Armla
Għandek tfal?	Iva / Le
Kemm għandek?	
Livell ta’ edukazzjoni	☐ Qatt ma mort skola ☐ Skola Primarja ☐ Skola Sekondarja ☐ Skola Post-Sekondarja ☐ Università ☐ Livell Post Universitarju
Xogħol li kont twettaq qabel	
Stat ta’ Saħħa kif irrappurtat mill-parteċipant	Tajjeb / Mhux Ħażin / Batuta
Mard kroniku, kif irrappurtat mill-parteċipant jew mir-riżultat tad-dijanjożi	

B) ADLs

Is-6 funzjonijiet li ġejjin se jiġu vvalutati sabiex tiġi stabbilità l-kapaċità tal-parteċipant li jwettaq/twettaq l-attivitajiet tal-ħajja ta’ kuljum b'mod indipendenti:

Staqsi: *Għandek bżonn superviżjoni, għajnuna jew assistenza personali għal dawn l-attivitajiet tal-ħajja ta' kuljum li se nsemmi?*

ATTIVITAJIET TAL-HAJJA TA’ KULJUM	
1. *BIEX TAĦSEL LILEK INNIFSEK*	LE / IVA – Agħti eżempji:
2. *BIEX TILBES*	LE / IVA – Agħti eżempji:
3. *IĠJENE PERSONALI*	LE / IVA – Agħti eżempji:
4. *MOBILITA’*	LE / IVA – Agħti eżempji:
5. *KONTINENZA [TAL-URINA U TAL-IPPURGAR]*	LE / IVA – Agħti eżempji:
6. *IKEL*	LE / IVA – Agħti eżempji:

C) Skeda tal-Intervista għall-Parteċipant

Grazzi talli aċċettajt li tieħu sehem f'dan l-istudju. L-intervista se tkun irrekordjata u t-'tapes' se jkunu identifikati b'numru minflok b'ismek sabiex inti tibqa' anonimu/a. L-informazzjoni li se tagħti hija kunfidenzjali u dan ir-'recording' se jiġi mħassar fit-tmiem ta' din ir-riċerka. M'hemm l-ebda tweġibiet tajbin jew żbaljati, għaldaqstant nitolbok tħossok liberu/a li tipprovdi tweġibiet onesti għal dawn il-mistoqsijiet li ġejjin.

Mistoqsijiet tal-Intervista: 1-16

FTUĦ

1) X'inhi r-raġuni li inti dħalt fir-Residenza ta' San Vinċenz de Paul?

2) Kemm ilek f'din id-Dar ta' Kura?

3) Tista' jekk jogħġbok tiddeskrivi l-esperjenza dwar il-kura tiegħek ġewwa r-Residenza ta' San Vinċenz de Paul?

4) Kemm-il darba jkollok kuntatt mal-membri tal-familja tiegħek? [*Eż.: Speċifikament staqsi għal kull individwu/a*].

Sabiex tinkiseb aktar informazzjoni relatata mad-dinjità, il-mistoqsijiet li ġejjin se jintalbu wkoll:

5) Dinjità, [***eż.:*** *'għal x'uħud, tfisser ir-rispett ...']* hija ta' spiss imsemmija bħala importanti fis-servizzi tas-saħħa. Xi tfisser id-dinjità għalik?

6) Liema aspetti tal-kura taħseb li huma importanti għalik?

7) Taħseb li l-istaff jikkurawk b'sens ta' dinjità?
(a) X'jagħmlu? (b) Kif tixtieq li tiġi ttrattat/a f'termini ta' dinjità?

8) Liema huma l-fatturi li jgħinu biex tinżamm id-dinjità tiegħek waqt li qed toqgħod fi ħdan ir-Residenza ta' San Vinċenz de Paul?

9) Liema huma l-fatturi li jfixklu l-manutenzjoni tad-dinjità tiegħek waqt li qed toqgħod fi ħdan ir-Residenza ta' San Vinċenz de Paul?

10) Kien hemm xi drabi meta inti ħassejt li tlift, jew stajt tlift, id-dinjità tiegħek?
a) Jekk iva, meta seħħ dan?
b) X'taħseb jew xi tħoss li setgħet kienet il-kawża?
c) X'effett kellhom l-istaff fuq is-sitwazzjoni? – [***Staqsi*** jekk mhux mifhum, ***eż.:*** *Jekk l-istaff għamlux s-sitwazzjoni aħjar jew agħar, u jekk iva, kif?*]
d) Kien hemm xi ħaġa oħra li l-istaff setgħu għamlu f'din is-sitwazzjoni sabiex jgħinu u jippromwovu d-dinjità tiegħek?

L-EFFETT TAL-AMBJENT TAS-SALA

11) Sa liema punt tħoss li l-ambjent ġewwa s-sala affettwatlek id-dinjità tiegħek?

12) Hemm xi ħaġa aktar li jista' jsir fl-ambjent tas-sala biex id-dinjità tiegħek tiġi mħarsa aktar? Jekk iva, kif?

ATTITUDNI LEJN IL-ĦAJJA

13) Ħafna nies għandhom ħafna attitudnijiet dwar bosta affarijiet, *eż.*, ix-xogħol, l-imħabba, eċċ. X'inhi l-attitudni tiegħek lejn il-ħajja? [***Staqsi*** *jekk mhux mifhum,* ***eż.:*** *Xi tfisser għalik IL- ĦAJJA? X'inhi l-aktar ħaġa għal qalbek fil-ħajja, eċċ.?]*

14) Hekk kif tħares lura lejn ħajtek, tħossok sodisfatt/a?

15) Liema bidliet tixtieq tara li jseħħu ġewwa r-Residenza ta' San Vinċenz de Paul sabiex jitjieb is-servizz ipprovdut? X'suġġerimenti għandek?

GĦELUQ

16) Hemm xi ħaġa dwar id-dinjità tiegħek li tħalliet barra f'din l-intervista?

Mistoqsijiet - *Eżempji ta' mistoqsijiet oħra li jistu' jiġu wżati jekk hemm bżonn ta' aktar tagħrif fuq suġġett partikolari.*

"Xi trid tfisser?" / "Tixtieq tiċċara dak li qed tgħid?" / "Tista' tagħti eżempji?" / "Tixtieq tispjega ruħek aħjar dwar dan/din?"

Appendix 11

Katz's Activities of Daily Living (ADLs) - 6 items (Shelkey and Wallace, 2012)

ACTIVITIES **POINTS (1 OR 0)**	**INDEPENDENCE:** **(1 POINT)** **NO** supervision, direction or personal assistance	**DEPENDENCE:** **(0 POINTS)** **WITH** supervision, direction, personal assistance or total care
BATHING **POINTS:** __________	(1 POINT) Bathes self completely or needs help in bathing only a single part of the body such as the back, genital area or disabled extremity.	(0 POINTS) Needs help with bathing more than one part of the body, getting in or out of the tub or shower. Requires total bathing.
DRESSING **POINTS:** __________	(1 POINT) Gets clothes from closets and drawers and puts on clothes and outer garments complete with fasteners. May have help tying shoes.	(0 POINTS) Needs help with dressing self or needs to be completely dressed.
TOILETING **POINTS:** __________	(1 POINT) Goes to toilet, gets on and off, arranges clothes, cleans genital area without help.	(0 POINTS) Needs help transferring to the toilet, cleaning self or uses bedpan or commode.
TRANSFERRING **POINTS:** __________	(1 POINT) Moves in and out of bed or chair unassisted. Mechanical transferring aides are acceptable.	(0 POINTS) Needs help in moving from bed to chair or requires a complete transfer.
CONTINENCE **POINTS:** __________	(1 POINT) Exercises complete self-control over urination and defecation.	(0 POINTS) Is partially or totally incontinent of bowel or bladder.
FEEDING **POINTS:** __________	(1 POINT) Gets food from plate into mouth without help. Preparation of food may be done by another person.	(0 POINTS) Needs partial or total help with feeding or requires parenteral feeding.

TOTAL **POINTS** ______	**6** indicates full function *i.e.* Independent	**4** indicates moderate impairment *i.e.* Semi-Independent	**2 or less** indicates severe functional impairment *i.e.* Dependent

(Shelkey and Wallace, 2012 slightly adapted from Katz, Down, Cash, *et al.*, 1970)

Appendix 12

National Minimum Standards for Care Homes for Older People

THE PRINCIPLES UNDERPINNING THE STANDARDS

Person- Centred Care
Care homes shall adopt a person-centre care approach by subscribing to the need for a recognition of and connection with the person, focusing on residents' strengths and goals, and the centrality of interpersonal relationships.

Dignity
All residents shall be able to live in dignity and security, and be completely free of exploitation, abuse and discrimination.

Privacy
Each resident’s privacy shall be respected at all times.

Physical and Mental Well-being
Each resident shall be provided with the medical and nursing care needed to retain optimal physical and mental health, and is provided with the opportunities and facilities to enable him/her to continue to be physically and mentally active, and to maintain the highest level of independence possible.

Self-fulfilment
Each resident shall be provided with opportunities to achieve his/her full potential through easy access to social, recreational, cultural, educational, productive and spiritual resources.

Autonomy/Empowerment
Each resident shall have a right to autonomous decision-making, and where capacity for autonomous decision-making is not present, the legally appointed representative (as defined in glossary) shall be consulted on all decisions pertaining to the resident including, but not restricted to, decisions related to admission to and discharge from a care home, medical and care decisions, and decisions involving finances and legal matters. Decisions shall only be taken after a full informed consent process with the resident or his/her legally appointed representative.

Equality
All residents shall be treated with respect, regardless of their age, sex, race or ethnic origin, disability, cognitive level, marital or family status, beliefs, and sexual orientation.

Right to Complain and Right to Legal Recourse
Every resident or his/her legal representative shall be provided with clear information and mechanisms to allow for the expression of complaints and for seeking legal recourse as necessary without any repercussions on the resident’s rights, freedom and quality of life. A standard complaint form will be available for the expression of such complaints to the regulator.

Active Ageing in Care Homes

The licensee shall undertake to promote a culture of Active Ageing in the Care Home consistent with Malta's National Strategic Policy for Active Ageing (Parliamentary Secretariat for Health, 2014). The mission of the home must go beyond the traditional concept of "elderly care" and shall enable residents to realize their full potential for physical, social, and mental wellbeing. The home shall provide an environment where residents are enabled to engage in productive activities, and a healthy, independent and secure lifestyle.

The licensee shall undertake to respect and actively promote the residents' autonomy by engaging in the process of informed consent in all aspects of care, including the identification and involvement of a legally appointed substitute decision maker if necessary. The licensee shall also ensure the protection of residents from all forms of abuse through policies and procedures for prevention and reporting of actual or suspected abuse, and clear procedures for responding to all forms of reported or suspected abuse in a timely and sensitive manner. Residents' independence shall be enabled across all levels of care, including but not restricted to the promotion of independent activity, access to community resources, and participation in society to the extent possible.

The licensee shall also undertake to promote a culture that encourages independence in activities of daily living including, but not restricted to, policies and procedures that promote:

(a) continence and independent personal care to the fullest extent possible,
(b) independent activity,
(c) falls prevention, and
(d) prevention of pressure sores.

Any deviation from these policies and procedures shall be clearly documented and formally addressed in the individual plan of care. The licensee shall promote a holistic approach to the welfare of the resident, incorporating mental, psychological, physical, cultural, social, emotional, sexual and spiritual welfare of all residents.

(Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2015, pp. 9-10)

List of Tables

Table 1: Test Results (n = 14)

Description of Participants’ Overall Health Status						
Participant	**Age**	**Maximum Scores for Each Individual Test**				
		SMMSE __/30	**GDS** __/15	**Subjective Health**		**ADLs** __/6
				Good = 3 *Fair = 2* *Poor = 1*		
Alan	79	25	1	Good	3	3
Bert	84	24	**5**	Fair	2	1
Charles	91	25	4	Fair	2	2
David	80	24	3	Good	3	3
Eric	81	24	3	Fair	2	6
Fiona	81	27	**5**	Good	3	2
Grace	76	25	**6**	Poor	1	1
Helen	78	30	2	Fair	2	1
Isabel	65	29	**6**	Fair	2	1
Janice	87	27	**10**	Poor	1	2
Kelly	81	26	**6**	Fair	2	6
Liz	79	28	2	Fair	2	3
Mary	73	30	**5**	Good	3	6
Nora	76	29	**10**	Poor	1	1

Table 2A: Group 1 - Males

GROUP 1 - MALES - PARTICIPANTS' PROFILE					
Name	**M 01**	**M 02**	**M 03**	**M 04**	**M 05**
Gender	M	M	M	M	M
Admission to SVPR	2 years	1 year, 6 months	1 year	2 years, 6 months	4 years (spent 1 month at Roseville – private care home)
SMMSE (Total score = 30) **(Cut-off score = 24)**	25	24	25	24	24
GDS (Total score = 15) **(Cut-off score = 10)**	1	5	4	3	3
Age	**79**	**84**	**91**	**80**	**81**
Date of Birth	18/12/1936	23/12/1931	03/10/1924	16/02/1936	04/02/1935
Place of Birth	Msida	Valletta	Birżebbuġa	Floriana	Żurrieq
Civil Status	Single	Widow (over 24 yrs. ago)	Single	Married	Widow (8 years ago; daughter passed away)
Number of Children	N/A	7 (1 daughter deceased 27 yrs. ago)	N/A	2	2
Education	Secondary School	Primary School Standard 4	Primary School Standard 4	Secondary School	Attended classes held 'after hours'
Previous Occupation	Photographer	Last job - Ambulance Driver; Previously a soldier as a young adult	Fitter at Water Works Corporation for the last 30 years of his working career, previously a stone mason	Clerk (state)	Last job: Messenger; Started out as a labourer in constructions
Subjective Health	Good	Fair	Fair	Good	Fair
Self-reported or diagnosed chronic illness (es)	NIL	Osteoarthritis (OA) both knees. L > R Note: Needed Bilateral TKR. Op. not performed - reportedly due to contraindication to G.A. & Age	Partial Urinary Incontinence Ashamed that he needs to use nappy Visual Impairment but still able to read – no spectacles	Diabetes (NIDDM) Prostate Problems Decreased vision Wears spectacles	Diabetes (NIDDM) Prostate Problems Hypertension

Katz's ADLs (6 items)	3	2	2	3	6
Activities unable to perform independently					
Bathing or Showering	**Dependent** Washed by staff – bed bath	**Dependent** Washed by staff – bed bath	**Dependent** Washed by staff – bed bath	**Semi-Independent**	**Independent**
Dressing	**Independent**	**Semi-Dependent** Needs Assistance with Lower Body	**Semi-Dependent** Needs Assistance with Lower Body	**Independent**	**Independent**
Toileting	**Dependent** Wears Nappy	**Dependent** Wears Nappy	**Dependent** Wears Nappy since 2 years	**Dependent** Wears Nappy	**Independent**
Transferring (Mobility)	**Independent** Uses ZF Walks medium to long distances Ind. in Transfers	**Independent** Uses GF Transfers: Needs MH x1 with sit to stand Walks short to medium distances	**Independent** Uses RF Decreased Vision – No Spectacles Uses RF Walks short to medium distances Ind. in Transfers Severely kyphotic/scoliotic Walks bent over towards Rt. / at waist	**Independent** Uses a walking stick Wears spectacles	**Independent** without use of mobility aid Able to walk long distances Good Social
Continence	**Dependent** Incontinent of Urine	**Dependent** Double Incontinent	**Dependent** Partially Double Incontinent	**Dependent** Double Incontinent	**Independent**
Feeding	**Independent**	**Independent**	**Independent**	**Independent**	**Independent**

Table 2B: Group 2 - Female

GROUP 2: FEMALE - PARTICIPANTS' PROFILE	
Name	**F 06**
Gender	F
Length of stay at SVPR Admission to SVPR	1 year ago
SMMSE (Total score = 30) **(Cut-off score = 24)**	27
GDS (Total score = 15) **(Cut-off score = 10)**	5
Age	**81 years**
Date of Birth	25/04/1935
Place of Birth	Siġġiewi
Civil Status	Widower (since 6 years)
Number of Children	7 (+ 4 miscarriages)
Education	Never went to school
Previous Occupation	Housewife
Subjective Health	Good
Self-reported or diagnosed chronic illness (es)	▪ Worries that she might have Cancer and her children are not telling her. ▪ Colostomy bag + Permanent urinary catheter – since 1 year and 4 months
Katz's ADLs (6 items)	3
Activities unable to perform independently	
Bathing or Showering	**Dependent** Washed by staff – bed bath or occasionally uses a basin and washes upper body by the bedside
Dressing	**Independent**
Toileting	**Dependent** Requires staff assistance for cleaning/care of colostomy bag & urinary catheter
Transferring (Mobility)	**Independent** Uses RF - Walks medium to long distances - Ind. in Transfers
Continence	**Dependent**
Feeding	**Independent**

Table 2C: Group 3 - Females

GROUP 3: FEMALES - PARTICIPANTS' PROFILE			
Name	**F 07**	**F 08**	**F 09**
Gender	F	F	F
Admission to SVPR	1 year ago	2 years, 3 months ago	8 years ago
SMMSE (Total score = 30) **(Cut-off score = 24)**	** 20/24 = 25/30 (Q4. Numbers)	30/30	** 22/23 = 29
GDS (Total score = 15) **(Cut-off score = 10)**	6	2	6
Age	**76 years**	**78 years**	**68 years**
Date of Birth	12/01/1940	03/06/1938	12/07/1947
Place of Birth	Naxxar	Cospicua	Mosta
Civil Status	Widower (husband deceased 1 month ago)	Widower (husband died 2 years and 3 months ago; One son died 14 years ago, aged 42)	Single
Number of Children	4	4	0
Education	Primary School	Primary school 5th year level	School Leaving – age 15
Previous Occupation	Housewife	Housewife	Never worked – lived with parents
Subjective Health	Poor	Fair	Fair
Self-reported or diagnosed chronic illness (es)	Left-sided hemiplegia Diabetes (IDDM) Decreased Vision/Cataracts	OA Headaches h/o left knee fracture requiring surgery Hypertension Diabetes (NIDDM)	Wheelchair bound
Katz's ADLs (6 items)	2	2	1
Activities unable to perform independently			
Bathing or Showering	**Dependent** Washed by staff – bed bath	**Dependent** Washed by staff – bed bath	**Dependent**
Dressing	**Semi-Dependent** Needs Assistance mainly with Lower Body – Participant tries her best to assist upper body	**Semi-Dependent**	**Dependent**
Toileting	**Dependent** Wears Nappy	**Dependent** Wears Nappy since 2 years	**Dependent** Wears Nappy

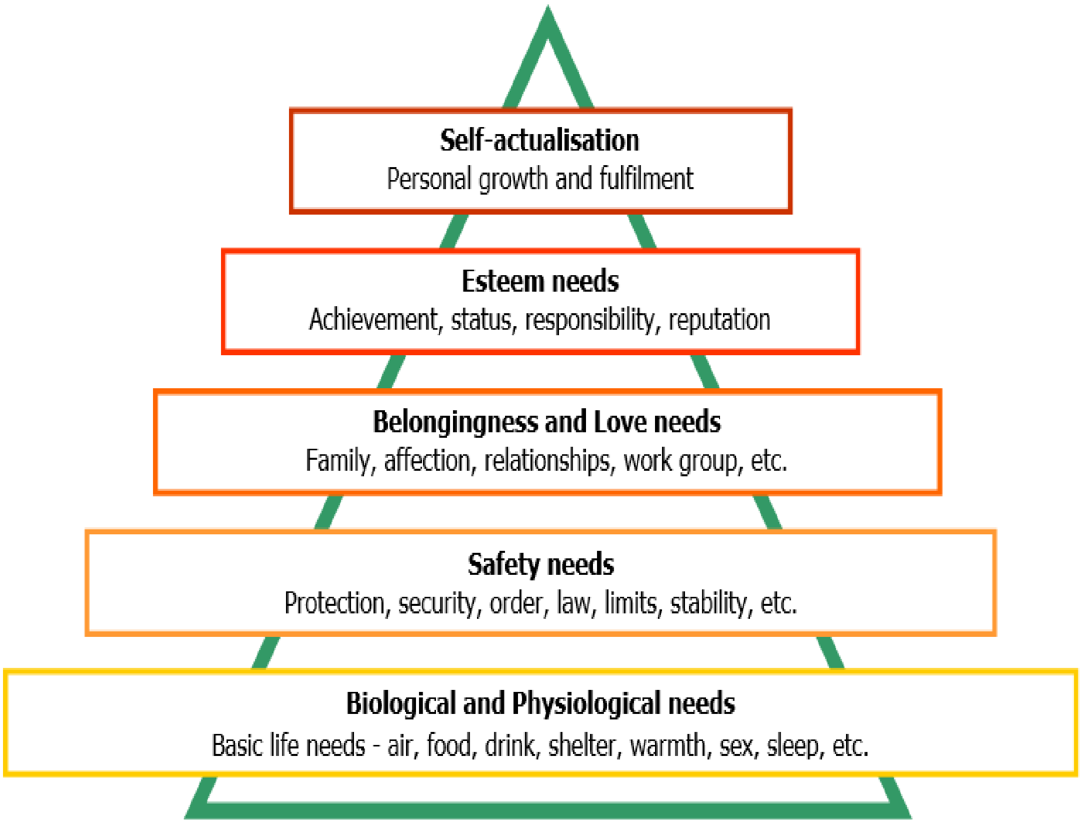
Transferring (Mobility)	**Dependent** Hoisted in/out of bed and is WH/CH bound	**Independent** Uses GF	**Dependent** Hoisted in/out of bed and is WH/CH bound
Continence	**Dependent** According to resident – she is continent	**Dependent** Partially Double Incontinent	**Dependent** Incontinent of urine and wears nappy
Feeding	**Independent**	**Independent**	**Independent**

Table 2D: Group 4 - Females

GROUP 4: FEMALES - PARTICIPANTS' PROFILE					
Name	**F 10**	**F 11**	**F 12**	**F 13**	**F 14**
Gender	F	F	F	F	F
Admission to SVPR	1 year ago	10 years ago	10 years ago (3 days after her sister, Kelly was admitted to SVPR)	2 years, 6 months ago	1 year, 3 months ago Previously at MDH – ITU – Ward and RHKG 1 year
SMMSE (Total score = 30) **(Cut-off score = 24)**	27	26 (Q.4: numbers)	28	30	29
GDS (Total score = 15) **(Cut-off score = 10)**	10	6	2	5	10
Age	**87 years**	**81 years**	**79 years**	**73 years**	**76 years**
Date of Birth	26/09/1928	06/02/1935	15/06/1936	02/06/1942	13/07/1939
Place of Birth	Żejtun	Siġġiewi	Siġġiewi	Hamrun	Żurrieq
Civil Status	Widower (since 7 years and 7 months later her closest child and youngest of her sons died at age 51)	Single	Single	Widowed (2 years)	Married
Number of Children	6	N/A	N/A	1 son	3
Education	School – till 12 years of age	School – age 15 (*ta' bil-fors*)	5th year	Secondary school – till 14 years of age	From 8 to 12 years of age (*ta' bil-fors*)
Previous Occupation	Housewife	None – lived with parents and cared for them	Nurse	Worked in a factory for 16½ years - Supervisory role. Stopped working when she married and became a housewife	Housewife
Subjective Health	Poor	Fair	Fair	Good	Fair
Self-reported or diagnosed chronic illness (es)	On Oxygen therapy since 1 year Uses face mask or nasal	Hypertension Diabetes (NIDDM) Low Back pain – limps	Hypertension Diabetes (IDDM) Cholesterolaemia	Hypertension Diabetes (IDDM) Bilateral AKA - Left LL 3 yrs. ago & R LL 2 yrs. Ago	Permanent urinary catheter since 3 years

	prongs – constant O2 during the night Anxious	due to left leg discrepancy	Severe Arthritis - both hands Decreased shoulder range of movement – forward flexion and abduction		Diabetes (NIDDM) LBP Decreased sensation and movement in Lower Limbs
Katz's ADLs (6 items)	2	6	2	6	1
Activities unable to perform independently					
Bathing or Showering	**Dependent** Washed by staff – bed bath	**Independent**	**Dependent** Washed by staff – bed bath	**Independent** Uses basin and washes self on the bed. Hair is washed by staff	**Semi-Independent** Tries to assist as much as possible
Dressing	**Semi-Independent**	**Independent**	**Semi-Independent**	**Independent**	**Dependent**
Toileting	**Semi-Independent** Wears pull-ups but requires assistance with cleaning	**Independent** Wears underwear	**Semi - Independent** Wears pull-ups but requires assistance with cleaning	**Independent** Does not wear underwear for practical reasons, when using & transferring on/off toilet	**Dependent** Permanent urinary catheter + wear nappy
Transferring (Mobility)	**Independent** RF + portable O2 cylinder on base with wheels. Requires assistance with artefacts	**Independent** Without mobility Walks medium to long distances Ind. in Transfers	**Independent** Uses RF Walks short to medium distances	**Independent** WH/CH bound - Bilateral AKA Maintains good Upper Limb strength & range of movement Good WH/CH management	**Dependent** Hoisted in/out of bed and is WH/CH bound
Continence	**Semi-Independent** **Partial urinary incontinence**	**Independent**	**Dependent** Partially Double Incontinent – uses pull-ups	**Dependent** Partially Double Incontinent	**Dependent**
Feeding	**Independent**	**Independent**	**Independent**	**Independent**	**Independent**

Table 3: Maslow’s Hierarchy of Needs



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