

**The public respite care service for older people in Malta: An evaluation**

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**A dissertation submitted in partial fulfilment of the requirements of the  
Master of Gerontology and Geriatrics**

**Department of Gerontology  
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## ABSTRACT

As the global population ages, the necessity for caregiving inexorably amplifies. Respite care was developed to help caregivers deal with the demands brought about by their role and it may be provided in a variety of forms. This study aimed to carry out an evaluation of the publicly-funded residential respite care service for older people in Malta.

This study adopted an interpretative stance and a qualitative approach was used. Data were collected through (i) participant observations at the three publicly-funded residential respite care sites for older persons in Malta, (ii) interviews with twelve caregivers who made use of residential respite for their care recipients at the aforementioned sites, and (iii) elite interviews with three service providers responsible for overseeing residential respite care services in the three different sites respectively. Data were thematically analysed.

The findings revealed divergent views and a discrepancy in the type of service provided at the three sites. The three main emerging themes were: the push factor to residential respite, the residential respite experience and reconsidering respite: a commodity or a necessity? Each theme was subdivided into further sub-themes. Most of the caregivers who sought the service were taking care of older persons who required high levels of assistance. For caregivers, residential respite meant primarily a temporary pause from their duties. However, they reported feelings of ambivalence when deciding at which time point to make use of the service. Care recipients viewed residential respite mainly as a time for compromising. Some felt that they were losing their identity and their scope in life was dwindling away. Feelings of apprehension and fear were also reported. Nevertheless, others underlined positive experiences and found their stay relatively satisfactory. Service providers acknowledged the importance of communication with all stakeholders to enhance service provision.

The findings provide a sound platform to continue consolidating and ensuring an effective, timely and accessible publicly-funded residential respite care service as it is one of the links that solidifies and complements the chain of community care support services. Thereby, every effort should be made to provide the best possible service to ensure integration, collaboration and continuity of care in order to sustain caregivers with their role in caring for older persons in need of assistance.

*Keywords: respite, residential respite, older persons, caregivers, care recipients*

## DEDICATION

*I dedicate this dissertation to my late beloved mother-in-law Giulia who inspired me to embark on this journey but sadly passed away in the process. I will always remember her positive personality and her appreciation towards the simplicity and beauty of life even in times of sorrow and pain.*

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## DEFINITION OF TERMS

The following definitions apply to the context of this research study:

***Respite care:*** a variety of care services aimed at allowing informal caregivers to take a short break from their responsibilities. Respite care may be provided in the community, in facility-based units or in an institution. Respite care services are based on the setting, the needs of the service users, the length and pattern of use and the quality of services provided. Services may include in-home respite, host family respite, day centres, night shelters and temporary stays in a residential care setting. Duration of the break may range from few hours per day to a number of weeks per year. Respite breaks may be publicly-funded, private or provided by volunteers engaged through organisations. For the purpose of this study, respite care is discussed in view of caregivers and older persons who experienced residential respite care (Bamford et al., 2009; Denning, 2013; O’Connell, Hawkins, Ostaszkievicz & Millar, 2012, Vandepitte et al., 2016).

***Residential respite:*** also known as in-patient or institutional respite care. Refers to when an individual requiring assistance is admitted temporarily to a residential care setting. The period of time may vary from an overnight stay up to a few days or weeks depending on the situation. Bookings for residential respite care are planned in advance (pre-booked) with the specific day of admission and discharge and may be provided on a regular basis, however the service may also be availed on in cases of emergency also known as emergency respite (Bruen & Howe, 2009; Jeon, Brodaty & Chesteron, 2005; Neville, 2004; Neville & Bryne, 2007).

***Publicly-funded residential respite for older persons:*** residential respite services for older persons completely subsidised by the state. The three publicly-funded residential respite sites in this research study were Casa Leone (church-run nursing and residential care home), Saint Elizabeth Home (private nursing and residential care home) and Saint Vincent de Paul (‘a sui-generis’ [stand-alone] long-term care facility) (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2014a, p. 55). At Casa Leone XIII, the state has a church-public partnership scheme, at Saint Elizabeth Home, the state has a private-public partnership scheme whereas Saint Vincent de Paul is a public funded entity (Diacono, 2014;

Mifsud, 2016; Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2016).

**Care recipient:** a person requiring support and assistance from others. The person may be residing on his or her own or may be living with someone providing help. A care recipient may require help; to perform his or her personal care, with transferring and mobility, with medical needs and to engage in social activities (Disability and Aged Information Service, 2012). In this study, the term care recipients, refers to those individuals who experienced at least once a temporary stay at one of the aforementioned residential respite care sites. In this study, since care recipients had to be 60 years of age or older to make use of the service, they were at times referred to as older persons (United Nations, 2014).

**Caregiver:** any individual, such as a family member, friend or neighbour, who is providing, regular ongoing help to another individual on at least a weekly basis without payment for the care provided. The caregiver may live with or separately from the care recipient (Anderson et al., 2000). In this study, caregiver refers to an individual who made use of residential respite for his or her care recipient at one of the above mentioned sites. Informal, primary and family caregivers are subsequently termed as caregivers.

**Service providers:** in the study, service providers refer to the individuals overseeing the provision and coordination of the publicly-funded residential respite service in the three different sites respectively.

## **CHAPTER 1**

### **INTRODUCTION**

## **1.1 Population ageing and caregiving**

A decrease in fertility rates, coupled with a decline in mortality levels and remarkable improvements in health including an increase in life expectancy at birth, resulted in a conspicuous increase in the number of older persons (United Nations, 2015). The world has been experiencing global and unprecedented demographic changes since the mid-twentieth century. Literature clearly shows that population ageing is happening in almost all of the countries (Bongaarts, 2009; Eurostat, 2016; He, Goodkind & Kowal, 2016; Morse, 2007; Rowland, 2012).

The proportion of older persons in the world population is expected to reach 21.1 percent by the year 2050 (United Nations, 2015). Worldwide, the number of older persons aged 60 years or over is anticipated to further than double, from 841 million people in 2013 to more than two billion by the year 2050 (United Nations, 2014). It is envisaged that by the year 2050, only 33 countries will have less than seven percent of their total population aged 65 years or more (He et al., 2016). This phenomenon has significant implications for various aspects of human life namely; social, physical, psychological, spiritual, cultural, economic and political.

Globally, the share of older persons aged 80 years or more referred as the 'oldest-old' was 14 percent in 2015 and is envisaged to rise to 20 percent by the year 2050. Consequently, the present era has been termed the 'age of ageing' (United Nations, 2015). The total population of Malta by the end of 2015 was estimated to be 434,403, quarter of who were persons aged 60 years or over (NSO, 2016). During the last decade (2005 to 2015) when compared with other European countries, Malta registered the highest increase in the number of individuals aged 65 years or older from 13.3 percent to 18.1 percent (5.2 percent increase) (Eurostat, 2016). Due to the above demographic trends, the extent of informal care for older persons has exponentially increased.

As people age, they are more likely to experience chronic health-related issues which may possibly result in a drastic decrease in their level of independence (Mortimer & Green, 2015). A change in the functional capacity of an individual can take place over a period of time or it can happen unexpectedly. When the decline in function is staggered, family members have the time to prepare and adjust for the changes gradually however when the change is abrupt one is more likely to end up in a state of shock. Whether sudden or gradual, a change in

function has a twofold effect, primarily an impact on the quality of life of the individual experiencing a loss in his or her level of functional performance and a ripple effect on the quality of life of his or her close family members who are expected to offer their support (Bauer & Sousa-Poza, 2015).

The extent of caregiving differs according to the care recipient's dependency levels, the diagnosis and stage of the disease (Dwyer, 1995). Consequently, caregivers need constant backup to be able to sustain their support, learn new skills and continue providing the best possible care for their older family members in their own home context (Greenwood, Habibi & Mackenzie, 2012). It is imperative for caregivers to seek respite from their responsibilities from time to time. Caregivers are likely to be providing care because of a prior relationship with the care recipient. This type of relationship can be either biological or non-biological. Caregivers are often spouses, partners, siblings, adult children, grandchildren, nieces or nephews and any other family relatives. Sometimes close friends and neighbours also provide care on a regular basis (Family Caregiver Alliance, 2014).

Caring for an older family member at home can be exceptionally rewarding however it can be a daunting challenge as well. Apart from being a fundamental source of support to the individuals they care for, caregivers are crucial to the health care system and they also consolidate the concept of 'ageing- in-place' (Davey, 2006; Horner & Boldy, 2008; Wiles, Leibing, Guberman, Reeve & Allen, 2012). Moreover, caregivers are the key providers in the welfare system as they play a pivotal role in reducing the national health care expenditure and they underpin community care policies (Bauer & Sousa-Poza, 2015; Droes, Bereebaart, Meiland, Van Tilburg & Mellenbergh, 2004; Stolz, Uden & William, 2004). The needs of caregivers are very often overlooked resulting in increased levels of stress, burn out, emotional and psychological difficulties which ultimately pose a challenge to the cohesiveness of the family, health services and society as a whole (Formosa, 2015; Ziemba, 2002). Lack of respite services was found to be associated with caregiver burnout, neglect, crisis and abuse (Dunbrack, 2003). Decline in general function, increased risk of falls and development of pressure sores were found to be associated with caregivers who did not have adequate coping strategies (Elliott & Pezent, 2008). Moreover, care recipients who required high levels of assistance were found to be at an increased of abuse from their caregivers when the latter demonstrated marked levels of depression, distress and ill-health (Beach, Schulz, Williamson, Miller, & Weiner, 2005).



Integrated community care is pivotal to meet the complex needs of both the older persons and their caregivers. Respite is recognised as an essential component within the continuum of care. The latter concept encompasses a coordinated system across health, social psychological and economical services to ensure that care is provided in a cohesive way. It directs the person seeking care through different health services that offer a variety of support and interventions (Cox, 1997). Continuum of care is not a new concept, it has been recognised as one of the priority issues requiring urgent policy action in care provision (United Nations, 2008).

The scope of respite is to “offer relief to caregivers, not only to contribute to their well-being but also to assist them in maintaining their relative at home” (Cox, 1997, p. 511). The rationale underpinning respite care is to provide caregivers with an opportunity for some ‘time-off’ from their caring responsibilities so they can restore and boost their energy levels and find time to address facets of their everyday lives that they had been overlooking due to their caring commitments (Gilmour, 2002; Greenwood et al., 2012; Lund et al., 2014). Respite care can act as a buffer to combat the consequences of stress the care giving role generally brings with it (Dimech et al., 2009; Evans, 2013). Further discussion pertaining to the definition of respite care is presented in Chapter 2.

Issues pertaining to informal caregiving, respite care and their impacts have been extensively investigated in various countries (Bauer & Sousa-Poza, 2015; Mortimer & Green, 2015). In their review on the available Spanish respite services, Garces, Carretero, Rodenas & Aleman (2010) reported that both respite (referring to home help, day centre and residential or night-time respite) and psychosocial programs were found to be the main systems that support caregivers to continue coping with their stressful life situations. To reduce the onus brought about by caregiving, amalgamation of respite services and psychosocial educational programs was also suggested as a preminent solution. Results from a qualitative study carried out in the United Kingdom exploring the experiences of caregivers on respite at home reported that respite permitted caregivers with a short get away from their caring responsibilities and continuance with everyday chores (Green et al., 2012). Benefit from the service was dependent on the type of relationship the caregiver had with the care worker. Dual benefits from respite were reported as caregivers felt that apart from benefitting themselves, care recipients were also benefitting from the service.

A number of local studies exploring various aspects related to informal care giving in relation to respite care services were carried out in Malta (Azzopardi, 1996; Cutajar, 2009; Dimech et al., 2009; Fenech, 2006; Grixti, 1999; Haber, 2011; Innes, Abela & Scerri, 2011; Said, 2011). However, there is still a paucity of empirical data focusing on the direct experiences of caregivers and care recipients on residential respite care. This merits further investigation to voice out and bring to light the experiences, needs and challenges encountered by both cohorts.

## **1.2 Aim and Objectives**

The aim of this study is to carry out an evaluation of the publicly- funded residential respite care service for older people in Malta. In order to fulfill this aim, the study included the following objectives:

- Exploring caregivers' understanding of residential respite care service for older persons.
- Establishing the underlying factors that lead caregivers to seek residential respite care for their care recipients.
- Identifying the needs and challenges experienced by caregivers and older persons when making use of residential respite care.
- Exploring the outcome/s residential respite care may have in terms of physical, social and emotional health of the caregivers and older persons when making use of residential respite.
- Exploring the views and challenges experienced by service providers of residential respite care.

On this account, the aims and objectives of this study intended to address the gaps in the local situation.

## **1.3 Methodology and Research Design**

This study adopted an interpretative stance as it sought to voice out, understand and provide insight into the meaning of residential respite care for older persons from caregivers, care recipients and service providers' point of view. A qualitative approach was adopted. Data were collected through (i) participant observations during field visits at the three publicly-funded residential respite care sites for older persons in Malta, (ii) face to face semi-structured interviews with twelve caregivers who made use of residential respite for their care

recipients at the aforementioned sites and (iii) elite interviews with three service providers responsible for overseeing residential respite care services in the three different sites respectively. Data were analysed using a thematic analysis approach.

#### **1.4 Outline of Chapters**

The following chapter presents the literature review on the subject under study. It starts by delving into caregiving in later life, the factors leading caregivers to seek respite care and a discussion on the different forms of respite care with focus on residential respite. Moreover, barriers to access respite care and outcomes of respite care are also highlighted. The theoretical framework discusses the theories chosen to guide this research. This chapter ends with an overview of the Maltese context in order to familiarise the reader with the setting. Chapter 3 provides a comprehensive description of the methodology, the research design and methods used. Chapter 4 presents the results of this study and discusses them in light of the literature retrieved. The conclusion drawn from this study and implications for ageing and community care are presented in chapter 5. The latter chapter underlines the recommendations for research, policy, practice, service development and education. It ends with a discussion of the strengths and limitations of this study.

## **CHAPTER 2**

### **LITERATURE REVIEW**

## **2.1 Introduction**

This literature review sheds light on the current implications of population ageing including demographic trends, the characteristics of caregivers, factors leading caregivers to seek respite care, the barriers and outcomes of respite care. Moreover, it provides a portrait of respite care pertaining to the Maltese scenario. A rigorous literature search was carried out using a number of databases including PubMed, Medline, Web of Science, the Cumulative Index of Nursing and Allied Health Literature (CINHAL) and Cochrane Library. Moreover, a search was also carried out amongst the Maltese and Gozitan population. Keywords used included: ‘informal caregivers’, ‘caregivers’, ‘primary caregivers’, ‘family carers’, ‘elderly’, ‘respite’, ‘respite care’, ‘residential respite’, ‘older persons’ and ‘formal support’.

## **2.2 Caregiving in later life**

As our population ages, the necessity for caregiving inexorably amplifies bringing about transformations in the living arrangements of older persons with regard to the younger family members. This phenomenon is generating changes in the economic support systems including state and private systems targeting children, adults and older persons (United Nations, 2015). An increased level of frailty and requirements for higher levels of support are frequently related with advanced age. The need for more assistance to cope with such ailments will present significant challenges in the coming years, predominantly in healthcare, as the number of potential caregivers is not progressing at the same rate as the growing number of care recipients (Bault, 2012; Lund et al., 2014). While the demand for caregivers is constantly increasing, the number of available and potential caregivers is consistently decreasing. The majority of caregivers of older individuals tend to be spouses, who themselves are ageing and they often require support and assistance (Cheung & Hocking, 2004). The dwindling number of caregivers may be attributed to a number of factors including the diminishing family size and structure, the rising number of divorce rates, improved levels of women’s participation in the workforce and migration of adult children (Brown & Lin, 2012; Neville & Byrne, 2007; Robine, Michael & Herrmann, 2007).

Indisputably, against a backdrop of an ageing population, one of the major targets ageing policy is striving to reach the provision of satisfactory levels of care to senior citizens experiencing deterioration in both physical and cognitive performance skills and who are still residing in the community. When evaluating this facet, one must acknowledge the

fundamental input provided by caregivers who play a key role in the provision of such care. Caregivers' responsibilities are likely to include assistance with personal and instrumental activities of daily living, social and emotional support. In fact, provision of care entails attending to all the needs of the person requiring care. Although caregivers are often depicted as the fulcrum of a society's care supply, their contribution is often overlooked and underreported in social statistics (Bauer & Sousa-Poza; 2015; Bettio & Veraschchagina, 2010; Greenwood, Habibi & Mackenzie, 2012).

Caregiving was found to induce both positive and negative effects on caregivers (Beach, Schultz, Yee & Jackson, 2000; Gray, Hahn, Thapsuwan, & Thongcharoenchupong, 2016). Various studies underlined increasing feelings of proximity with the care recipients, resilience and spiraling of self-esteem due to an optimistic reception to the type of care provided (Boerner, Schulz & Horowitz, 2004; Haley, LaMonde, Han, Burton & Schonwetter, 2003; Harmell, Chatillon, Roepke & Mausbach, 2011). Nevertheless, various implications on the caregiver mainly social, economic, physical and psychological were also highlighted (Capistrant, Moon, Berkman & Glymour, 2012; Chatillon et al., 2013). These implications were found to influence the type and quality of care the caregiver provided to the care recipient (Yin, Zhou & Bashford, 2002). The role of a caregiver encompasses a substantial number of psychological adjustments including the addition of new responsibilities, better coping strategies, changing roles and higher levels of adaptation (Bauer & Sousa-Poza, 2015; Riggs & Peel, 2016; Van Bruggen et al., 2016).

Literature shows that apart from increasing the risks for socioeconomic adversity, care provision can be physically wearing, mentally taxing and requires a significant amount of time and dedication which often ends up having repercussions on the well-being and career progression of the caregiver (Cheung & Hocking, 2004; Redfoot, Feinberg & Houser, 2013). In line with this, Stockwell-Smith, Kellett and Moyle (2010), reported that caregivers often complained of role frustrations due to disturbed sleep, poor health and lack of social life leading to isolation from their social circle of friends. The needs of the caregivers should be addressed contiguously since decline in their health and social well-being might end up in hospitalisation of both the caregiver and care recipient (O'Connell et al., 2012).

Schneider, Trukeschitz, Muhlmann and Ponocny (2013) carried out a study to explore whether care provision to a senior dependent person foresaw employees' plans to exchange

jobs or leave the labour market. Gender-specific roles were found to be still preponderant, mostly concerning workforce performance. Caregiving commitments namely time restraints attributed with caregiving and the category of care required were found to have an effect on the decision of both male and female workers to swap jobs or leave the workforce. Female workers expected to provide care to older family members and young children, were more likely to opt to swap their job due to clashes imposed by time required for work and time devoted to caregiving. Flexitime regimes were found to be a useful strategy to create a balance between the two. The male workers' probability of leaving the workforce was found to be related to the amount of individual care they had to provide to their care recipient.

A gendered perspective is opportune at this point. From a young age, males are portrayed by society as the primary breadwinners and providers while females are stereotyped as mothers and primary caregivers (Lee & Tang, 2013). The typical caregiver is most likely to be middle aged or young-old women often a spouse, a daughter or daughter-in-law (Bauer & Sousa-Poza, 2015; Bookman & Kimbrell, 2011; Lima, Allen, Goldscheider & Intrator, 2008; Mack & Thompson, 2004). The 'Caregiving in the United States Report' (2015), highlighted the results of a joint study carried out between the National Alliance for Caregiving and the American Association of Retired Persons (ARRP). In line with other studies (Erol, Brooker & Peel, 2016; Greenwood, Habibi & Mackenzie, 2012; Salin, Kaunonen & Astedt-Kurki, 2009; Singh, Hussain, Khan, Irwin & Foskey, 2015; United Nations, 2015), the majority of caregivers were reported to be females (60 percent) while their average age was 49 years (National Alliance for Caregiving and AARP, 2015). The majority of caregivers were providing care to a relative (85 percent). Of the latter, 49 percent were providing care for a parent or parent-in law whereas one in ten caregivers were providing care to a spouse. Additionally, this report highlights that seven percent of the caregivers were 75 years of age or older. Almost a quarter of the participants (24 percent) had been providing care for five years or more.<sup>1</sup>

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<sup>1</sup> According to a report issued by the European Commission, having a close rapport with the care recipient, no form of specialised training, no official salary, an extensive list of different duties and no fixed working schedule were amongst the common characteristics which were found to fit the profile of a typical caregiver (Traintafillou et al., 2010).

### **2.3 Factors leading caregivers to seek respite care**

Various researchers accentuated on the importance of implementing effective supportive strategies to assist caregivers in maintaining their demanding roles as well as enhancing the well-being of the care recipient. Such strategies are likely to delay admission to long-term care facilities (Grant et al., 2003; Nehen & Hermann, 2015; Vandepitte et al., 2016). Extant literature indicates that although respite is amid the most commonly requested family support services, it is not always accessible and affordable to a considerable number of caregivers (Evercare and National Alliance for Caregiving, 2006).

Stolz, Uden and William (2004) in their systematic review reported that a considerable number of caregivers mentioned the need of support referring mainly to assistance in domestic activities of daily living rather than in personal activities of daily living. Caregivers sought back up and reassurance from health professionals. Their care recipient's health as well as their own health, limited freedom and emotional struggles were other factors that lead caregivers to seek respite care. Caregivers were anxious of the possibility of experiencing social isolation and yearned to set up connections with others either for communal or for edifying reasons. Although caregivers needed and wanted different forms of respite, it was rather complicated to demonstrate that caregivers really benefitted from respite care. Albeit support was being provided, it was not discussed and planned together with the caregivers and care recipients to ensure that it met their actual needs, implying that the service providers and the caregivers had different points of views regarding the meaning of support.

Results generated from qualitative study carried out with 17 caregivers in Australia highlighted that the type of relationship the caregiver had with the care recipient effected how caregivers sustained their caring responsibilities (Singh et al., 2015). Emerging themes from the interviews included the shifts and changes caregivers go through when taking the role of a caregiver. Such adjustments included the living arrangements, the caregiver's approach to caring, family conflicts arising due to responsibility of care and lack of support from other family members. Financial strain, the inability to balance work and care, multiple responsibilities including efficiency in merging the caregiver's role with other roles and commitments in life and limited flexibility from the service providers were other factors that lead caregivers to seek assistance. Caregivers claimed that they sought support through family and friends and through formal support groups. They also felt the need to seek



professional counseling to help them come to terms with the emotional strain the caring role brings with it (*ibid.*).

A quantitative Australian study carried out amongst 526 participants revealed that older caregivers who had been providing care for a very long period of time were more likely to opt for respite (Vecchio, 2008). In contrast, caregivers who did not seek respite care were likely to be partners or spouses, females, had children below the age of fifteen years, had someone else who provided care when they were unavailable and were not engaged in the workforce. Caregivers who were English speaking, residing in scheduled areas and receiving government pensions were more likely to use respite when compared to their counterparts. The researcher highlighted the importance of focusing more on providing individualised care according to the caregivers' needs rather than providing a system which caters for all. The study concluded that a crucial factor in choosing to use respite depended a lot on the type of family relations i.e. the caregiver and care recipient relationship and commitments towards other family members. Similarly, Braithwaite (2000) reported that the type of caregiver-care recipient relationship is a crucial factor in determining the caregiver's level of satisfaction with the kind of care provided. The caregiver's overall well-being and contentment with life was reported to increase with a pleasant relationship whereas a flawed relationship was found to generate increased levels of stress and apprehension.

Robinson, Fortinsky, Kleepinger, Shugrue and Porter (2009) reported the results of a large-scale cross-sectional study. Healthier individuals were more likely to take up caregiving roles. Absences from work, feeling miserable and secluded due to lack of support were found to cause caregiver burnout which increased the likelihood of having the care recipient institutionalised. This study drew attention to the importance of having adequate community-based long-term care services including specific training and tutoring, respite, physical and mental health support that targeted and met the needs of the caregivers and care recipients especially those facing challenging circumstances.

## **2.4 Respite care**

The emerging concept of respite care programmes to support caregivers can be traced to the late 1940's and early 1950's in the United Kingdom (De Larcy & Belf 1957; Isaacs & Thompson, 1960 as cited in Neville & Byrne, 2007; Nolan & Grant, 1992 as cited in

Cotterill, Hayes, Flynn & Sloper, 1997). Respite care may be beneficial to caregivers of care recipients who have different care needs including children or adults with special needs, terminally ill patients, older persons and individuals with behavioral issues and persons with cognitive and intellectual impairment (Aoun, Kristjanson, Currow & Hudson, 2005; Hancock & Jarvis, 2005; Shanley, 2006; Trememan, Corkery, Dowdney & Hammond, 1997). One finds various definitions of 'respite care' but generally it is referred to in literature as the "provision of short-term relief from the tasks associated with caregiving" (Family Caregiver Alliance, 2014, online source). Chappell, Reid & Dow (2001, p. 212) defined respite as a "pause, a temporary cessation, or an interval of rest". On the other hand, Trememan et al. (1997, p. 548) delineated respite care as "shared care of a person with learning difficulties and/or physical disabilities, either at home or in a short-term residential setting, in order to give the family a break from the routine care taking". Jeon et al. (2005, p. 298) defined respite care as "an arrangement to allow caregivers relief or 'time-out' from their care commitments, which may be provided on a regular basis or in emergencies". The latter definition was deemed the most appropriate for this study as it provides a thorough statement of the salient points pertaining to residential respite care for older persons.

It has been consistently reported (Garces et al., 2010; Redfoot et al., 2013) that most of the time, caregivers end up providing informal care without sufficient community care support services that address the caregivers' and care recipients' needs. While utilization of services can be perceived as a coping strategy, lack of formal support is often linked with caregiving crisis over time (Strang & Haughey, 1999). Although respite has been found to be one of the most preferred and required types of support systems for caregivers, the use of respite among caregivers is fairly limited even among those who are overwrought (Ashworth & Baker, 2000; Brandao, Ribeiro & Martin, 2016; Montgomery, Marquis, Kosloski, Schaefer & Karner, 2002; Phillipson, Jones & Magee, 2014; Reinhard, Levine & Samis, 2012; Van Exel, Graaf & Brouwer, 2008). Lack of awareness on the availability of different types of services and assistance from family and friends were factors related to lack of use of formal services. Male caregivers and caregivers with a low level of education were more likely to be unaware of respite services (Strain & Blandford, 2002) whereas care recipients' children were more likely to use respite than care recipients' spouses (Deimling & Looman, 1993; Pinguart & Sorensen, 2011; Robinson, Buckwater & Reed, 2013). Caregivers whose care recipients needed assistance with activities of daily living were reported to be significantly more likely to use respite services (Toseland, McCallion, Gerber & Banks, 2002). Moreover, caregivers

who sought respite were found to be undergoing complex and demanding caregiving situations that resulted in physical symptoms of stress (Dal Santo, Scharlach, Nielsen & Fox, 2007; Kosloski, Montgomery & Youngbauer, 2001).

Chappell et al. (2001) carried out a study to explore caregivers' point of view on what respite meant to them. Following this, a typology was developed and the prevalence of the different meanings was established. The researchers analysed whether the different meanings varied systematically with a number of social and demographic variables. The researchers divided the themes into two groups, internal and external respite. External respite denoted taking breaks as a separation in some form from their care giving role whereas internal respite referred to frequent breaks without removing themselves from their care giving scenario. Caregivers providing care to older and more dependent care recipients were more likely to opt for external respite care. The study highlighted different meanings of respite founded on the experience of caregivers themselves. Approximately half of the participants classified respite as activities and circumstances which momentarily provided relief from their care giving concerns. The study concluded by urging policymakers to explore and understand the real needs of caregivers prior setting up services. In this way, services provided are more user friendly, effective and efficient (*ibid.*).

In a concept analysis of respite for older persons, Evans (2013) reported a significant misunderstanding about the inherent meaning, the extent and the end results generated from respite. Respite is depicted as an intricate process that is founded on a coalition between the caregiver, the care recipient and the service provider. Service provision relies on the type of support and engagement purveyed by the supplier. Whereas, for caregivers, support is mainly having time to rest and address their personal needs and opportunities to learn and ameliorate their skills, support for care recipients revolves around creating the appropriate occasions to enhance their overall well-being. Engagement relates to a variety of activities that both the caregiver and the care recipient are able to participate in during the respite period. The focal point of such activities should be to address the clients' needs. Such activities may include; family training and educational sessions, enrollment into support groups for caregivers and in-depth evaluation of the medical, functional and social status of the care recipients and follow up-stimulation activities targeted at improving their difficulties. Since caregivers and care recipients have different needs which are continuously changing, respite services need to cater for this diversity.

Respite services should aim to provide an all-inclusive package not simply a temporary break for the caregiver. Freedom, support and connection are the three components resulting from respite. While the caregivers are provided with time to rest and attend to their needs, the care recipient has some free time from the caregiver and an occasion to leave the home context. At respite, caregivers should be empowered to continue with their role by benefitting from the necessary community care support services and care recipients should be encouraged to reach their maximum level of independence. Connection focuses on providing and facilitating links with society, such as participation in support groups which cater both for the caregiver and the care recipient. Respite care has a twofold effect as the caregiver and the care recipient gain in dissimilar ways (*ibid.*).

Zarit, Stephens, Townsend and Greene (1998), in their study on the effects of adult day care use, reported that to actually benefit for respite, caregivers need to make use of this service on a constant basis, at least a couple of days per week and in stipulated periods of time. While a significant number of studies accentuated the positive aspects attributed with respite care, a Cochrane review reported neither significant benefits nor negative effects when using respite care (Lee & Cameron, 2004). Ten years later an update of the aforementioned review on respite care for people with dementia and their caregivers failed to show a significant conclusion on the effectiveness of respite care to care recipients. There was a paucity of published data on outcomes of respite care for the care recipients. The focus of research on respite care targeted more the outcomes from the caregivers' point of view. Further research is warranted to address this concern. Since diverse respite care services were found to have dissimilar effects on those benefitting from the service it was suggested to study and review each type of respite care service separately (Maayan, Soares-Weiser & Lee, 2014). A systematic review investigating the effectiveness of respite care in supporting caregivers of persons with dementia found day care services effective in diminishing caregiver burden and in controlling behaviour issues in care recipients. However, day care services alone were reported to increase the likelihood of earlier admission to long-term care facilities in some of the cases (Vandepitte et al., 2016).

Most of the discussed studies amalgamated community and residential respite together in their analysis. There is an emerging need to study the effectiveness attributed from each service separately. Due to paucity of local data on residential respite care in Malta this study

will focus solely on evaluating the publicly-funded residential respite care service for older persons. The following section will introduce the concept of residential respite care.

## **2.5 Residential respite care**

While the older person is being cared for outside the home context, the caregiver takes a break from his or her routine care arrangements (Neville & Byrne, 2007). The services offered during residential respite care may vary from one facility to another. There are those facilities that in addition to accommodation, nursing care, assistance with personal activities of daily living and provision of meals and laundry, provide a comprehensive team assessment as well. When indicated, family training sessions and home visits are carried out to better address the needs and to ensure that the care recipient returns back home in the best possible state aiming to facilitate the caregivers' role as much as possible (Dimech et al., 2009).

In an evaluative study exploring various types of respite care, residential respite care was deemed as the second most favoured type of respite amongst caregivers. Despite this, residential respite was highly criticised. Poor standards of care, lack of communication, unsatisfactory levels of understanding, limited empathy from staff and lack of continuity of care were some of the concerns voiced by caregivers (O'Connell et al., 2012). These findings are similar to those of King and Parsons (2005) who reported that caregivers were preoccupied about their care recipient's general deterioration following a short stay in a residential respite facility.

Neville and Byrne (2007) performed a literature review on the effect of residential respite care concerning the behaviour of older persons with dementia. The authors reported that two out of six studies found that care recipients using residential respite care demonstrated a decrease in their behaviour symptoms during their stay while one study reported deterioration in general health two days after discharge with return of usual behaviour in two weeks' time. Their findings are comparable to those of Vandepitte et al. 2016, who in their systematic review reported that findings pertaining to short-stay institutional respite care were rather mixed. Out of four studies, investigating the impact of temporary residential admission, one reported positive effects on the sleep quality of caregivers (Lee, Morgan & Lindsay, 2007) while another study highlighted positive effects on the behaviour of the care recipients (Neville & Bryne, 2006). Additionally, another study (Neville & Bryne, 2008) reported

increased levels of distress after a period of short-stay institutional respite as individuals with dementia found it rather difficult to adapt to new environments and on going back home, they had to take time to re-adjust to their usual routine causing more strain on their caregivers. Hence, caregivers should be better informed and supported throughout so that the perks generated from respite are not wasted.

Results from a qualitative study exploring the views of wife and daughter caregivers who frequently relied on residential respite care to support coping at home brought to light the different caring relationships the participants were experiencing, mainly those who wanted to be together and those who felt obliged to be together with their care recipient (Salin & Astedt-Kurki, 2007). Previous life situations were found to have an impact on caring roles. Participants felt that respite provided them with a break from their responsibilities and they did not feel distressed by leaving their care recipient in a ward environment. Religious beliefs were found to inspire family values and results from this study showed such ideologies had an effect on the caregiver's attitudes towards caring for their older family members. This research calls upon the importance of efficient communication between respite team members and the family to be in a better position to comprehend the family's life context and not solely that of the care recipient. Respite team members should be cautious and urge caregivers to use respite to avoid critical periods. Team members should pose apposite questions and empower both caregivers and care recipients to hang on to their individual independence regardless of their bond of reliance (*ibid.*).

Salin et al. (2009) reported the preliminary results from a study carried out in Finland to investigate the role of institutional respite care in sustaining older people to continue residing in their own home. Following the period the care recipient was in respite care, the majority of caregivers reported that they felt much or rather recharged. Nevertheless, some caregivers reported dissatisfaction with the care provided to their care recipients. Consequently they had to visit regularly resulting in a limited break from their responsibilities. When discussing the level of functional performance skills of their care recipients following respite, the majority of caregivers reported no change or little improvement while only one respondent reported noticeable deterioration. The author stresses on the importance of addressing the well-being of the whole family thus it is recommended that respite care nurses devote more time and make their utmost to work in partnership with caregivers by communicating effectively in order to share common goals. This situation can only be achieved by setting up regular

meetings to ensure satisfactory collaboration among all the individuals providing care to the older person mainly all the different professionals involved, community care providers and the family (*ibid.*).

Strang and Haughey (1999) also highlighted that residential respite care was linked with recovering and re-establishing energy levels and opportunities to attend to much awaited holidays. The authors recommend more sensitivity to the needs of the caregivers from the service providers and availability of social support resources to empower caregivers to take a temporary break. In line with this, Salin, Kaunonen and Astedt-Kurki (2013) stressed on the importance of building a trustful relationship between caregivers and service providers to ensure the maximal benefits of respite care. Moreover, they emphasised the importance for nurses to be active listeners to acknowledge the struggles that most of the caregivers go through. Additionally, Upton and Reed (2005) outlined that use of respite in the cases of care recipients with dementia relies on reaching a balance to address the psycho-physical demands of the person with dementia and simultaneously providing the caregiver with the adequate skills and resources.

In a qualitative study, Phillipson and Jones (2011) explored the caregivers' perceptions on the use and non-use of residential respite care. The participants were caring for individuals with dementia. Caregivers who made use of residential respite care perceived utilising this service when they could not cope. It served as a break when they needed it most. When other family members and friends supported their decisions to apply for residential respite care they felt more relieved to make use of the service. Some of the caregivers claimed that after using respite they were in a better position to provide more positive care as respite gave them adequate time to de-stress. As a result this postponed institutionalisation of their care recipient. On the other hand, other caregivers opted to apply for residential respite care to facilitate the transition to permanent institutional care for their care recipient. They used the respite period to evaluate the standards and quality of care of certain long-term care facilities and to build a rapport with the staff in case they decided to admit their care recipient for long-term care to that particular facility. The authors highlighted the importance of establishing a clear understanding of the underlying reasons related to the use of residential respite. This is imperative as the goals will differ according to what the caregiver and care recipient intends to achieve from respite (*ibid.*).

Some of the participants did not opt to use residential respite care as at the time of the study they were coping without too much intricacy, however they considered using respite as a last resort in case of an emergency or when their care recipient's health deteriorated. Inadequate quality of care arising from mistrust in formal care, lack of availability when the service is required, preoccupation that the care recipient would not want to attend, deterioration in the general function of the care recipient following respite, not satisfying their obligations as caregivers and losing control over their care recipient were all reasons associated with non-use. The authors recommended respite units which cater only for individuals who need respite and do not house older persons for permanent stays, reaching caregivers at a time point before they face a crisis and skill-building training. The latter would be ideal for those caregivers who are likely to renounce the use of residential respite care. Care providers are urged to make significant service upgrades to ensure high standards of quality of care. Promotion of the positive aspects related to residential respite care is likely to result in earlier and recurrent use of residential respite care (*ibid.*).

## **2.6 Meeting the needs of the caregivers**

In their study on exploring what caregivers do during respite time, Lund, Castera and Wright (2009) highlighted that nearly half of the participants were not pleased with how they used up their respite period. Some of the participants carried out activities that raised their strain levels which lead to episodes of frustration. These results implied that displeasure and lack of satisfaction might be related to the misuse of respite time that could have been alternatively used to address the participant's unique requirements and wishes. Furthermore, an association with increased levels of caregiver strain, depression and lack of satisfaction with respite time was also reported (*ibid.*).

In 2014, Lund et al. emphasised the importance of concentrating on respite activities that address the caregivers' individual needs. Caregiver's well-being is likely to increase if their needs are met. They reported that their intervention 'Time for Living and Caring' (TLC) is founded on the supposition that when caregivers make use of respite they will gain the most if they take advantage of this period to best address their personal unique needs. Their study showed how respite time could serve as a golden opportunity to explore, enquire and obtain other services which both the caregiver and the care recipient may benefit from (*ibid.*).



Chiu, Wesson and Sadavoy (2013) conducted a study using a quasi-experimental pre-post intervention design to investigate the effectiveness of the 'Coaching, Advocacy, Respite, Education, Relationship and Stimulation' (CARERS) program with 73 caregivers taking care of family members with dementia. The researchers emphasised that feelings can easily blur the caregivers' ability to comprehend and deal with difficulties resulting in decreased competence to search for support and lessens their judgment and management skills. The program consisted in ten weekly group sessions focusing mainly on problem-solving therapy founded on cognitive-behavioural therapy ideology and simulation targeted towards assisting caregivers to overcome challenges and help them to steer better emotional feelings while caring for their care recipients. The aforementioned program was found to generate a statistically significant increase in caregivers' ability to cope better with their emotions. After completing the program, participants reported greater achievements in the way they perceived their caregiving capability skills. Lund et al. (2014) similarly shed light on the importance of research in adequate evaluation kits and tools to facilitate the caregivers' role and help them manage better difficult situations to avert crisis.

A recent exploratory, cross-sectional study on formal support for caregivers to older individuals with dementia was carried out in eight European countries (Lethin et al., 2016). Results from this study reported that support, counselling and education were the most offered forms of support for caregivers from when their care recipient was diagnosed with dementia to the intermediate stage with a reduction in the late to the end of life phase. Very few caregivers used these types of support systems although an increase in use was noted in the intermediate stage. Although day care and respite care at home were available, only a very small number of caregivers opted to make use of such services. To better comprehend these results, reference to the model of patient-centred access to health care is necessary. This model delves into the two aspects involved when using the health care system: the supply and the demand. Accessibility of services depends on approachability, acceptability, availability, accommodation, affordability and appropriateness while using the service might rely on the caregiver's attitudes, capability to look for, attain and interrelate with the available services. The extent of accessibility of services relies on the quality of the health care system, providers and organisations. National guidelines in health care warrant a definitive level of care and assistance to all individuals. Additionally protocols reconcile the health care schemes and institutions to endeavour towards quality and time-honoured goals. This study reported that countries with national protocols on dementia care were more conscious of

enrolling professionals specialised in dementia care when offering support to persons with dementia and their caregivers (*ibid.*).

## **2.7 Barriers to access respite care**

Family conflicts often arise due to lack of agreement when considering outside assistance. Caregivers might refuse to apply for respite because of guilt feelings, lack of trust and fear that their loved one will not be cared for at the same level (Mockus-Parks & Novielli, 2000). A review exploring the factors associated with the non-use of respite services by caregivers of individuals with dementia, portrays the need to revise the type of services being offered. Such services should focus on addressing the individual needs of the caregivers and care recipients. Barriers to respite use included lack of knowledge on the type of services being provided, fear of disruption of daily routine, difficulty to settle in a new environment, financial issues, problems to access transport services, lack of confidence in formal systems to understand and manage behavioural issues attributed with dementia (Phillipson et al., 2014).

Stockwell-Smith et al. (2010) also highlighted that uncertainty about the quality of care and lack of awareness on the formal community care support services discouraged caregivers from making use of the service. Moreover, conflicting advice and rumours from former respite users were found to influence caregivers' decision regarding use of community support services. Caregivers felt obliged to care for their family members as they wanted to reciprocate previous support provided by their care recipient and they expected the same care if they were in the same situation. Caregivers were unable to trust others with care provision and therefore unable to delegate work accordingly. Despite this, in time of crises they had to rely on formal support for their relatives. Caregivers who had made use of formal community support services were disappointed in the inconsistency of the services provided due to fragmentation and lack of continuity of care. This left a negative effect on the care recipient such as during help in personal activities of daily living skills. Caregivers alluded to the extremely bureaucratic system when they tried to apply for basic community support service. Moreover, some of the caregivers reported feelings of discomfiture and frustration when they had to apply for formal community support services as they alleged that they were not good enough. Similar findings were previously delineated by Glendinning, Hirst and Harris (2005). Stockwell-Smith et al. (2010) referred to the importance of comprehending caregivers' needs and expectations and the challenges they encounter when seeking formal support service.

Van Exel et al. (2008), explored the attitudes of caregivers towards respite care. Based on a sample analysis of 249 participants, the majority of the caregivers were females, were not engaged in employment at the time of the study, reported an adequate health status and claimed that they were reasonably content with their life. The participants were divided into three different categories; required and sought respite (32 percent), required but did not request for respite (37 percent) and those who felt that they did not need respite (31 percent). The group of caregivers who required and sought respite were fairly older, had a lesser educational level, were less often engaged in the workforce, benefited from a healthier status and were more satisfied when compared with participants who required but did not request respite and with those participants who did not feel the need for respite.

The care recipients of participants, who required and sought respite care, were more likely to be females and residing in the same dwelling. Caregivers who required but did not request respite were found to have an inferior quality of health, were less content and for the most part, their care recipient had a bad to fair health situation. Moreover, the care provided by this group of caregivers lasted the longest and the care recipients were likely to be their partners. The researchers highlighted that since caregiving is a cost-effective substitute to formal care, it is imperative to recognise the efforts made by caregivers as they are contributing tremendously toward the healthcare sector (*ibid.*).

## **2.8 Outcomes of respite care**

Caregivers who used respite reported a significantly lesser level of burden and significantly higher morale (Kosloski & Montgomery, 1993). Likewise, improved physical and emotional health was amongst the benefits reported by caregivers who made use of respite care (Theis, Moss & Pearson, 1994). Results generated from a systematic review on respite care in frail older persons, highlighted a positive effect on morale, anger and hostility but no impact on anxiety (Shaw et al., 2009). Shorter interventions were reported to have less positive effects than longer interventions. Augmented rates of institutionalisation were reported following respite care. Still, this does not necessarily denote that respite is a stepping stone for long-term care admissions but it may imply that respite was offered tardily in the caregiving vocation (*ibid.*).

Qualitative analysis revealed that uptake of respite care was related to: the level of awareness on the type of services available, the quality of the service provided, if the service was tailored in a way that met the needs of both the caregiver and care recipient, any inconveniences related to respite use, the caregiver and care recipient relationship and the caregiver's overall approach towards care provision and respite. This systematic review concluded that the evidence on the positive effects of respite on caregivers was rather restricted and feeble. Respite interventions varied and most often the type of respite provided was inadequately explained. Apart from insufficient good-quality trials, economic analysis of respite was also rather limited. The following points were highlighted; the need for more awareness, education and training to facilitate the role of caregivers, to target caregivers early, the importance of continuation of care, more feasible transport systems and activities that stimulate and engage care recipients (*ibid.*).

## **2.9 Theoretical Framework**

Over the years a substantial number of theories and models were developed in an attempt to address the multitude of facets attributed with the intricacy of the caregiving experience. The Social Network Theories (Task-specific theory and the Hierarchical-compensatory theory), the Social Support Theories (Direct effect theories and Stress-related theories), the Behavioural Health Model of Service Utilisation and the Practice-Oriented Service Model (Cho, 2007; Montgomery, Kwak & Kosloski, 2016) amid others, all proposed pertinent arguments to this research study. However, the Family Systems Theory by Murray Bowen (1954 cited in Bowen, 2004), together with the Caregiver Identity Theory (Montgomery & Kosloski, 2013), were the two main theories chosen to guide this research. Indeed, to understand better the caregivers' and care recipients' point of view on residential respite care, it is imperative to start by understanding the concept of the family unit and how the family reacts when faced with challenging situations.

The Family Systems Theory (FST) is a theory of human behaviour that perceives the family as an emotional unit and utilises systems to depict composite interactions within the unit. In FST, every member has regulations to respect and responsibilities to adhere to. Loyalty, obligation and mutual benefit are the underlying family ties that concatenate generations (Bowen, 2004). The emphasis is on the interaction between the family members as they are

interdependent, such that a change in one family member is likely to affect every other member of the family as well as the family structure. Family members are highly influenced by the feelings of those around them as they have a deep affect and react to each other's feelings, thoughts and actions. Individuals constantly seek attention, support and approval from other members of the family. Additionally, they respond to the needs, expectations and distress of each other. Family members of all ages are stronger when they retain intergenerational emotional connection. Becoming increasingly dependent on other members of the family may pose a challenge to the unity of the family structure. Thereby, if one of the family members is emotionally distressed due to his or her loss of functional independence, it is likely to have repercussions on the emotional well-being of the other family members. Due to a high degree of emotional interdependence in the family structure, members try to create a protective and sheltered environment. However, distress can evoke tension in the family unit resulting in number of conflicts and members of the family might end up feeling vulnerable, detached and uncontrolled (Goldenberg & Goldenberg, 2012).

Older persons who experience changes in their physical, cognitive and functional performance skills frequently depend on their family members to provide assistance with issues concerning their health and social support to continue residing in their own home context (Roberto & Jarrott, 2008). Wright and Leahey (2009) argued that when a family member gets sick and requires assistance, the whole family is subjected to distress and the family plays an indispensable role. A life course perspective facilitates insight regarding the way older persons interact within the context of their own family (Dannefer & Setterson, 2010). Different kinds of caregiving relationships differ greatly in the terms of the extent and quality of support provided. Such relationships are formed by previous experiences and instigated when the older person needs assistance (Cho, 2007). Older adults seeking assistance tend to have a sequential order of preferences. Primarily they turn to their spouses/partners, when not possible they turn to their children followed by other relatives, friends and neighbours and ultimately to formal support. King, Atienza, Castro and Collins (2002) highlighted that daughter caregivers experienced more role strain than spouse caregivers since daughters experienced reversed roles and found it more strenuous to meet mutual expectations.

Montgomery and Kosloski (2013) in the Caregiver Identity Theory delved into the intricate process leading to the caregiving role. They stipulated that initially the caregiving role is

typically attained in a methodical way such as through a family relationship. Social norms play an integral part in this process. Since caregiving is a dynamic process the caregiving role constantly changes. This finally results in a transformation in the relationship caregivers experience with their care recipients leading to a change in the caregivers' identity. Although, some family members may try to assist in the provision of care to lessen the negative effects on the primary caregiver, other family members may not fully understand the caregiving scenario and what it actually entails (Ziemba, 2002). When crisis arises and the needs of the care recipient surpass the competence of the caregivers, families may seek support from formal services. Despite the availability of different community care support services targeted to offer respite to caregivers, not many caregivers opt to use formal support services (Jarrot, Zarit, Stephens, Townsend & Greene, 2005). Thereby, the combination of informal care and formal support is an intervention strategy that merits further investigation.

Respite apart from reinforcing family systems, safeguards the well-being of both caregivers and care recipients. The bio-psychosocial needs of the care recipient and the family's adapting and coping competence need to be periodically and thoroughly addressed. Respite adds to the robustness of community-based long-term care support services as it facilitates continuation of care, diminishes family strain and thereby assists preservation of the family unit. For care to be considered of adequate quality, respite services must be person-centred and family-focused. In this way the specific needs of both the care recipient and his or her family members are thoroughly addressed (Hannum et al., 2007). Person- and family-centred care (PFCC) is defined as "an orientation to the delivery of health care and supportive services that considers an older person's needs, goals, preferences, cultural traditions, family situation, and values" (Feinberg, 2012, p. 1). PFCC is putting the patient's wishes first and then the family's capacity to meet those needs. It identifies and reinforces the responsibility of caregivers as driving forces of support for older persons who need persistent assistance due to deterioration in their functional capabilities. This approach regards and consciously involves the older person's caregivers as pertinent when devising and delivering support services.

A prevailing theoretical framework in the context of caregiving is the Stress Process Framework (Pearlin, Mullan, Semple & Skaff, 1990) founded on the transactional theory of Stress and Coping by Lazarus and Folkman (1984). This framework categorises a variety of factors into four main domains; the background features of the caregiver context, stressors,

mediators of stress and effects or manifestations of stress. The background features of the caregiver context refer to the demographic profile of the caregiver and the type of past relationship the caregiver had with the care recipient. Stressors include the difficulties and challenges caregivers encounter when fulfilling their roles such as role strains and conflicts arising from their caregiving obligations. Mediators of stress refer to the type and level of social support and coping skills while outcomes of stress refer to the caregiver's well-being including the physical, psychological and social aspect and their capability to continue providing care. With its prominence on the caregiving context and resultant strains, the Stress Process Framework simplifies the miscellany of the caregiving experience and provides a better understanding for the progress of multi-component intervention programmes (Montgomery, et al., 2016).

## **2.10 The Maltese Context**

In Malta in 1901, 34.1 percent of the population was aged between 0 to 14 years while 5.4 percent of the population was 65 years or older (Rallu & Blum, 1991). However, there was a dramatic change in subsequent decades. In 2016, the 0 to 14 years age group was reported to represent 15 percent of the total population whereas the 65 years and older age group makes up 19.1 percent of the whole population (Central Intelligence Agency, 2016). Whereas at the onset of the 20<sup>th</sup> century life expectancy in the Maltese islands was about 46 years for females and 43 years for males, in 2016 the estimated females' life expectancy at birth increased to 82.8 years whilst that of males increased to 78 years (Rallu & Blum, 1991; Central Intelligence Agency, 2016). By the year 2055, the Maltese cohort of individuals who are 65 years or over is projected to increase from 19.1 percent to 27.6 percent (NSO, 2016) (Table 2.1).

Table 2.1: Projected total Maltese population: 2035 and 2055 (based on 2013 data)

	2015	2035	2055
<b>Total</b>	434,403	461,048	472,918
0-14	61,889	68,726	72,403
15-24	52,822	49,790	48,583
25-34	64,546	49,589	56,019
35-44	59,813	59,557	56,608
45-54	53,316	63,839	50,840
55-64	59,276	56,751	57,861
65-74	50,138	47,257	59,115
75+	32,603	65,539	71,489

Source: NSO, (2016)

Community care for older persons in Malta is mainly provided by the state, the private sector, the church and the family (Farrugia-Bonello, 2015). In the past, medical care, physical comfort and professional security were the government’s main agenda regarding the well-being of older persons. As a result, older persons were often institutionalised to ensure that they were safely taken care of. However throughout the years, there was a paradigm shift in social policy and the focus is now towards older persons ageing actively in the community while institutionalisation is left as a last route (Troisi, 2007). Nearly three decades ago, the Secretariat for the Care of the Elderly was entrenched within the Ministry of Social Policy. The rationale underpinning this secretariat was to introduce and implement policies and ensure that adequate community services were set up to address the needs of older persons. The Secretariat for the Care of the Elderly was reallocated under the auspices of the Ministry of Health, Elderly and Community Care in 2003. A decade later, the Secretariat changed its name to The Secretariat for Rights of Persons with Disability and Active Ageing. This secretariat continuously strives to promote the equality for persons with disability and older persons in order to protect and empower them to participate actively and lead an independent life in the community (Farrugia-Bonello, 2015). In 2013, the *National Strategic Policy for Active Ageing: Malta 2014-2020* was launched (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2013). It is founded upon three pillars mainly active participation in society, engagement in the labour market, and independent living.



Additionally, the *National Strategy of Dementia 2015-2023* was launched in April 2015 (Parliamentary Secretariat for Right of Persons with Disability and Active Ageing, 2014b).

It is well known that the majority of Maltese families have always provided care to their older family members and are to some extent still likely to supply such care (Haber, 2015). However, it is imperative to note that during the last twenty years there was somewhat a change in the family unit framework. Such change resulted due to divergent views regarding sexual behavior and marriage. Consequently, this created a shift towards a more profane perception regarding the family unit (Miljanic-Brinkworth, 2015). In the coming years, this may generate an impact on the different facets underpinning the concept of caregiving. Despite the fact that caregiving is at times provided due to the lack of any substitute forms of care, one must not overlook the concept of intergenerational solidarity and values of selflessness and respect towards other family members (Formosa, 2015). A study on long-term care in Europe and North America reported that Maltese citizens are firm believers in the provision of care to senior family members within one's own family unit (Huber, Rodrigues, Hoffman, Gasior & Marin, 2009). Likewise, Troisi and Formosa (2006) in a national background report for Malta reported that if presented with an option, older persons choose to be taken care of in their own home environment by their family members.

Locally, caregivers can apply for the carers' pension and the social assistance for carers. In the budget for 2017, the government announced a reform with a substantial increase in the carers' allowance with the aim of encouraging caregivers to continue providing care to their loved ones in their own home context. Additionally, more funds will be allocated to continue expanding the Live-in-Carer scheme. Older persons waiting to be admitted into a residential home (application for long-term care must have been submitted before the 12<sup>th</sup> of October 2016) have the possibility of employing a care worker of their preference and they are entitled to proportionate financial backing from the government. Besides, an in-home respite service was also proposed to ensure adequate social support and prevent caregivers from being socially excluded (Scicluna, 2017). The in-home respite service is in the pipe-line and will be provided in different packages to meet the needs of caregivers especially those responsible for caring for persons with dementia or those whose care recipients are too frail to travel out of their own home context (Active Ageing and Community Care Directorate, personal communication, March 2017). Moreover, it was also declared that married people

who are the primary caregivers and take their parents to live with them will be eligible for an additional allowance (Times of Malta, 2016).

Community care services for older persons include evaluations and follow ups from the CommCare Assessment Unit, the Dementia Intervention team, rehabilitation at Karen Grech Hospital, home help, telecare plus, telephone rebate, meals on wheels, domiciliary nursing, a national dementia helpline, handy man service, incontinence service, Kartanzjan, social work services, three night shelters in Malta and one in Gozo, a dementia day centre at Saint Vincent de Paul long-term facility and one in G ajnsielem, Gozo and 21 traditional day centres distributed throughout the island of Malta. In October 2014, a new concept of active ageing hubs in collaboration with local councils was introduced whereby five hubs were opened in Malta, one is in the pipeline and two in the sister island of Gozo (Active Ageing and Community Care Directorate, personal communication, January 2017). A number of non-governmental organisations and voluntary organisations provide ongoing support to caregivers and care recipients.

### **2.11 Residential respite care in Malta**

The conception of residential respite care in Malta started at Zammit Clapp Hospital in 1991. At that time, utilisation of beds for respite was not fixed and was dependent on availability and suitability of cases. Residential respite care was offered either on a regular basis (2 weeks in, 6 to 8 weeks out) or a one off holiday admission for older dependent persons whose caregivers needed a break (maximum stay 2 weeks) (Dimech, 1998; Fiorini, 1999). Apart from residential respite care, Zammit Clapp also offered respite care at the day hospital (Fiorini, 1999). Since Zammit Clapp Hospital was a rehabilitation hospital, input by the multidisciplinary team was tailored to meet the care recipients' and caregivers' needs. Residential respite service at Zammit Clapp was free of charge. In 1996 respite services at Zammit Clapp Hospital were ceased and resumed in 1998 (Dimech, 1998).

In June 1995, Saint Vincent de Paul started providing a formal residential respite service. It started with three beds at Ru ar Briffa Complex. In April, 1998 the number of beds increased to five while in July of the same year the number of beds increased to seven. At one point in time, the facility was responsible for the provision of nine respite beds, due to an addition of

two respite beds in the dementia friendly wards. This unit was consultant led and all patients were comprehensively assessed upon admission by an interdisciplinary geriatric team. The service was offered against payment (a deduction from the National insurance pension) (Dimech, 1998). For some time, respite requests were being channeled to Mtarfa home (three beds were being sporadically used) and other community homes. However, the service noticeable diminished in 1998. Respite care at Mtarfa and other community homes was against payment (*ibid.*).

Presently, the state is responsible for the provision of residential respite beds at three different facilities in Malta namely Saint Vincent de Paul, Casa Leone XIII and St. Elizabeth Home and at Villa San Lawrenz in Gozo. In October 2014, there was an increase in the number of residential respite beds in Malta. This increase was due to public-church partnership of 14 respite beds within Casa Leone XIII. In January 2015, two respite beds provided through private-public partnership were launched at Villa San Lawrenz in Gozo (Diacono, 2014; Gozo News, 2015). In June 2016, a number of the respite beds at Saint Vincent de Paul were temporarily transferred to another ward within the same premises. This change took place due to major structural refurbishment being carried out within Ruzar Briffa complex. Despite a change in the environment and a decrease in the number of beds, the same service is provided and all individuals are assessed by the geriatric interdisciplinary respite team. In August 2016, the state funded five respite beds at Saint Elizabeth Home through the public-private partnership scheme. During January to December 2016 (both months included) the four aforementioned facilities hosted 349 older persons in all. ( entru Servizz Anzjan, personal communication, January 2017). Residential respite services provided by the state are all free of charge.

Residential respite care may be availed of for a maximum period of three weeks up to three times a year equivalent to 63 days annually. Duration may be extended beyond three weeks for valid reasons. Caregivers need to book the respite dates beforehand as booking for respite is on a first come first served basis. In case of crisis, emergency admissions to respite are permissible. Caregivers need to fulfil the inclusion criteria namely; that they are providing care to an individual who is 60 years of age or over, is residing in the community and needs assistance, they will honour the dates agreed on and they intend to continue providing care in the community following discharge from respite (Dimech et al., 2009). Upon admission to respite, the caregivers must fill in and sign a declaration agreement including date of

admission and date of discharge. If the dates are not respected by the applicants and there are no valid reasons for not abiding with the pre-agreed dates, the applicants have to pay a stipulated fee of €60 per day ( entru Servizz Anzjan, personal communication, October 2016).

Results from a study on the role of residential respite care at Saint Vincent de Paul reported that the main caregivers of older persons were either spouses or daughters, implying that women were the main providers of informal care (Grixti, 1999). The type of residential respite care provided was based on the input of multidisciplinary team members working closely with the care recipient and the family. The author accentuated that residential respite care apart from providing a temporary break to caregivers can also serve as a small rehabilitation unit to sustain a system of extended community care. Moreover, the study disclosed that at the time of the study, caregivers were satisfied with the type of respite service provided and did not feel the need for more respite care provision (*ibid.*). Conversely, more than a decade later, in their study on the experiences of caregivers who were responsible for the care of a family member with dementia, Innes et al. (2011) reported that caregivers were unsatisfied with respite care services provided at the time of the study. They felt that respite services were time restricted and professionals lacked sufficient knowledge regarding dementia and how to best deal with it. As a result, caregivers felt that they were left alone in finding alternative ways on how to provide the best care for their care recipient (*ibid.*).

Another study carried out by Dimech et al. (2009) sought to explore the multi-dimensional characteristics and the need for inter-disciplinary input associated with residential respite care. The most common mentioned reasons given by caregivers when asked what lead them to seek respite care were, 'break in care', followed by 'to go on holiday' and 'poor carer health'. The least common reasons given included 'to have a trial in a home', 'convalescence after illness of a dependent elderly' and 'rehabilitation of the elderly dependent'. Results following the cognitive assessment of the participants varied considerably from cognitively preserved (23 percent) to moderate to severe dementia (65 percent). Additionally, results from the Barthel Index showed that more than half of the participants were highly to very highly dependent, 23 percent had a low dependency level, three percent had a medium dependency level while 22 percent were fully independent. Despite the latter group being fully independent in their ADLs, their caregivers still felt the need to apply for respite. This

implies that the needs of older persons and their caregivers are not solely physical but encompass social and emotional needs as well. Additionally, results generated from this study implied the dire need for interdisciplinary team input in order to provide effective and adequate care to the care recipient and caregiver. Furthermore, it shed light on the pivotal role of respite in preventing and delaying admissions to long-term care. For this to be effective and sustainable, there needs to be a strong communication between the respite unit and community care services to follow up respite users and their caregivers (*ibid.*).

Results from a small scale study on the effectiveness of Maltese community-based services to help older persons continue living in the community revealed that residential respite services were mainly recommended by the family doctor in order for the informal caregiver to take a short break (Cutajar, 2009). Out of the 26 participants only two respondents made use of residential respite care. One participant reported overall satisfaction with the service and he made recurrent use while the other participant felt homesick. Both respondents felt that overall the residential respite service was good however they accentuated on individualised care in order to simulate the home environment.

A qualitative study on the experiences of caregivers who were responsible for the care of older family members highlighted that gender played a significant role in becoming a caregiver (Fenech, 2006). The path by which individuals become caregivers was found to have an effect on the way caregivers perceived their caring experience. Disagreement with siblings regarding the degree of care offered and juggling between different commitments was reported to induce physical and psychological stress on the primary caregiver. This study also highlighted that the time and demands care required, left no room for interaction with other family members and for pursuing personal activities (Fenech, 2006). Haber (2011) carried out a study on family caregivers of dependent older persons in Gozo. Results from this study outlined that role loss, restricted lifestyles, caregiving strains, complex family dynamics, social isolation and difficulty to reintegrate back into society after the care recipient passed away were all implications arising from caregiving.

Azzopardi (1996) highlighted the importance of social work as a factor in respite care for families having member/s with disabilities. Comprehensive respite was viewed as a major tool in offering temporary relief for these families and at the same time ensuring that the individual with disability and other siblings have a stimulating environment. Respite was

recommended as a feasible way to reinforce the commitment of family members towards their care recipient, to preserve family unity and avoid the risk of institutionalization. Results from a qualitative study on the perceptions of caregivers on respite care for persons with disability revealed that caregivers had mixed feelings about respite (Said, 2011). They experienced guilt for opting to use respite but simultaneously they felt that they needed to rest and regain back their energy to continue providing care. The study pointed out the need for more awareness about the benefits of respite care for potential users and for the general public to reduce any misconceptions including social stigma. Support groups and educational programs about respite care were recommended (*ibid.*).

Despite the growing body of studies exploring respite care, there is a dearth of research focusing solely on one method of respite care creating difficulties when interpreting results. A comparative lack of up to date accurate information on the current local situation exists and this study aims to address this gap. The next chapter provides a thorough description of the methodology used to conduct this study.

**CHAPTER 3**

**METHODOLOGY, RESEARCH DESIGN**

**AND METHOD**

This chapter provides an overview of the rationale and philosophical assumptions underpinning the methodology for this research, the study design, the steps taken in data collection and analysis and ethical considerations.

### **3.1 Aim and Objectives**

The aim of this study was to carry out an evaluation of the publicly-funded residential respite care service for older people in Malta. In order to fulfill this aim, the study included the following objectives:

- Exploring caregivers' understanding of residential respite care for older persons.
- Establishing the underlying factors that lead caregivers to seek residential respite care for their care recipients.
- Identifying the needs and challenges experienced by caregivers and older persons when making use of residential respite care.
- Exploring the outcome/s residential respite care may have in terms of physical, social and emotional health of the caregivers and older persons when making use of residential respite.
- Exploring the views and challenges encountered by service providers of residential respite care.

### **3.2 Qualitative Research**

The underpinning philosophical stance for this study is the 'interpretative social science' also referred to as 'interpretivism' which represents a key approach to social science research. The German sociologist Max Weber claimed that social science ought to examine social action with a reason. Furthermore, he asserted that researchers should gain an understanding of the personal drives that form a person's inner emotions and influence choices to react in certain ways (Neuman, 2014). A central tenet of this approach is that "interpretative social scientists want to learn how the world works so that they can acquire an in-depth understanding of other people, appreciate the wide diversity of lived human experience, and better acknowledge shared humanity" (Neuman, 2014, pp. 108-109). This study sought to provide insight into the meaning of residential respite from the caregivers, care recipients and service providers' point of view. In view of this, interpretivism was deemed the most appropriate to



answer the research aim and objectives since it “focuses on how people manage their practical life and treat social knowledge as a pragmatic accomplishment” (*ibid.* p. 109). In order to understand what is meaningful to the individuals under study researchers using interpretive social science tend to opt for qualitative research.

Qualitative research encompasses a naturalistic approach to the world and it was considered appropriate for this study since the aim and objectives revolved around harnessing and exploring the lived experiences of the participants under study (Bryman, 2008; Parahoo, 2006). According to Creswell (2013), experiences can be best explored through a qualitative study. The majority of empirical studies on residential respite care adopted a qualitative methodology (Phillipson & Jones, 2011; Salin & Astedt-Kurki, 2007; Salin et al., 2013; Svensson, Bergh & Jakobsson, 2011). One of the strengths of qualitative research is that it gives us an excellent view of what is the real life for the participants in the study since the main focus is on naturally occurring ordinary events (Patton, 2002). Qualitative researchers make conclusions founded on perspectives therefore they tend to collect as much as information as possible for later analysis (Berg, 2012). Since the focus of qualitative research is on the profundity of the inquiry rather than measurement of facts, generalisability in qualitative research is limited (Cormack, 2000). Qualitative research is often condemned for being too descriptive and results are often criticised due to the subjective role of the researcher (Goulding, 2002). However, in qualitative research this subjectivity is considered an asset since it offers a deeper understanding of the phenomenon being studied (Neuman, 2014). Qualitative research apart from allowing comprehension of underlying reasons or views sheds light into the problems and guides the development of ideas or hypothesis for potential quantitative research (Denzin & Lincoln, 2000).

### **3.3 Research Design**

A research design, outlines the “framework for the collection and analysis of data. A choice of research design reflects decisions about the priority being given to a range of dimensions of the research process” (Bryman, 2008, p. 46). Thereby, a research design encompasses the complete strategy adopted to answer the research question (Parahoo, 2006). This study adopted a non-experimental design. Prior to embarking on this study, permissions to conduct the study were sought from the Director at the Active Ageing and Community Care Directorate and the Chief Executive Officer at Saint Vincent de Paul long-term care facility.

Ethical clearance was granted from the Faculty for Social Wellbeing's Research and Ethics Committee (FREC) and the University Research and Ethics Committee (UREC) (Appendices A,B,C).

### **3.3.1 Sampling and Recruitment**

Since statistical representativeness is not sought in qualitative research, a *purposive sample* of twelve caregivers who made use of residential respite care services for their senior family members at Saint Vincent de Paul, at Casa Leone XIII and Saint Elizabeth Home between January 2016 and December 2016 (both months included) was recruited.

A meeting was held with personnel at 'entru Servizz Anzjan' responsible for overseeing the provision of residential respite care at Casa Leone XIII and Saint Elizabeth Home. Another meeting was held with the personnel at Saint Vincent de Paul who are responsible for the provision of residential respite care at this long-term care facility. Both sites acted as 'gatekeepers' after permissions from the director at the Active Ageing and Community Care Directorate, the chief executive officer at Saint Vincent de Paul, the Faculty for Social Well-Being Research Ethics Committee and the University Research Ethics Committee were granted.

*Purposive sampling* also referred to as subjective, judgment or selective sampling is a sampling technique where the researcher depends on his or her own judgment on who will be the most informative or representative when selecting members of the population to partake in the study (Crossman, 2017). A strategy for purposeful sampling is *maximum variation sampling* also known as maximum diversity sample or maximum heterogeneity sample (Cohen & Crabtree, 2006). Since the researcher was interested in comprehending and attaining greater insights into how a phenomenon is seen and understood from various angles, maximum variation sampling was used to "ensure as wide a variation as possible in terms of the dimension of interest" (Bryman, 2008, p. 419). Thereby, this technique provided the opportunity to maximise the multiformity pertinent to the research question due to the diversity in the participant's characteristics namely the caregivers' relationship to their care recipients (Cohen & Crabtree, 2006).

Since maximum variation sampling is often criticised for high levels of bias and low levels of reliability and vulnerability to errors in judgment by researchers, the researcher ensured that

her judgment was based on clear criteria and a sound theoretical framework. The researcher asked both gatekeepers regarding the possibility of sending invitations to recruit potential participants with different types of relationships with their care recipients to increase heterogeneity. The following relationships were indicated; daughter, son, spouse, partner, daughter in-law, son-in-law, niece, nephew, granddaughter, grandson, friend and/or neighbour in order to elicit maximum variation sampling. In addition to purposive sampling, the following selection criteria were adopted to facilitate effective participation selection (Patton, 2002).

#### **3.3.1.1 Inclusion Criteria**

Caregivers who experienced at least one period of publicly-funded residential respite care for their care recipients at Casa Leone XIII and/or Saint Elizabeth and/or St. Vincent de Paul between January 2016 and December 2016 (both months included).

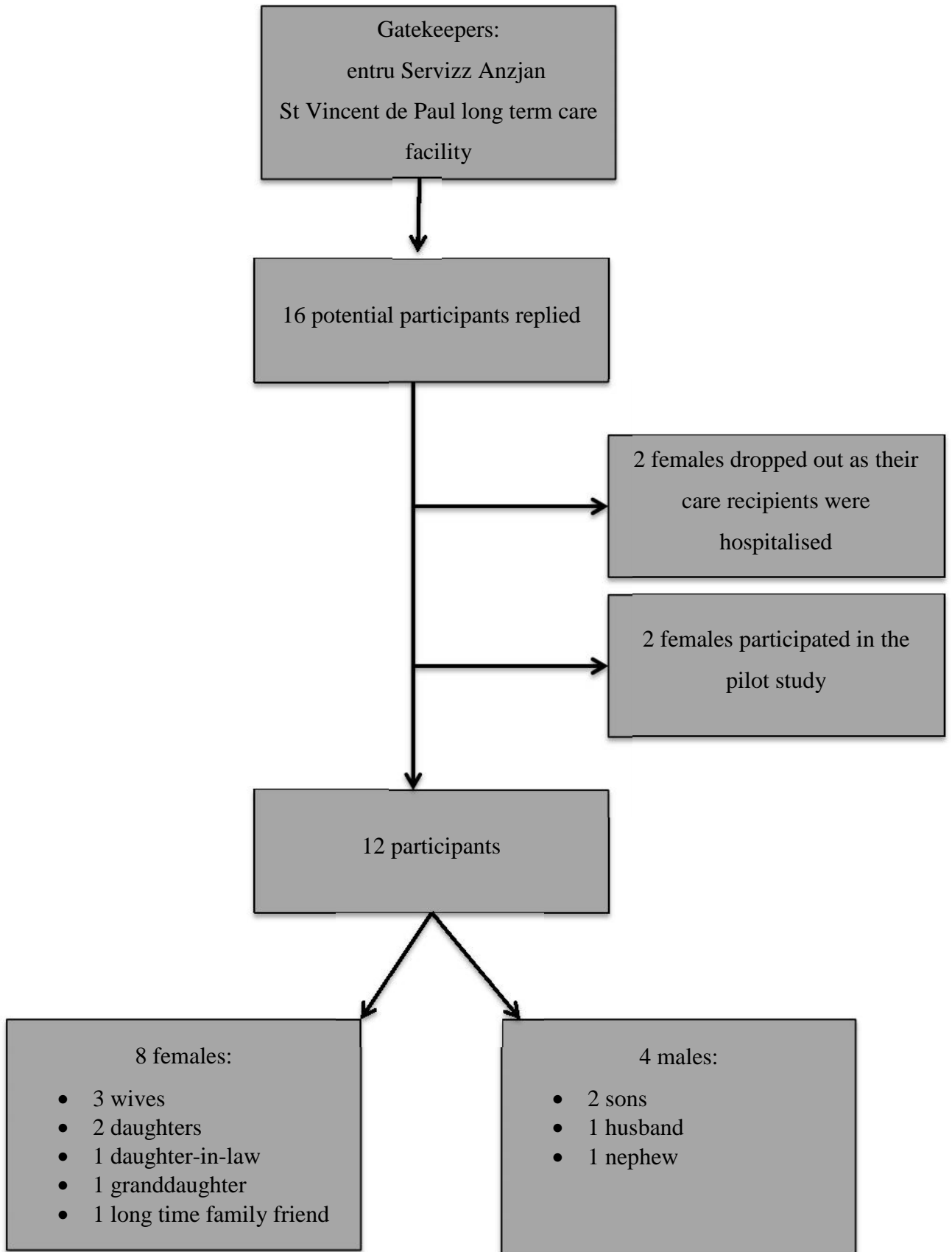
#### **3.3.1.2 Exclusion Criteria**

Caregivers who made use of residential respite care service offered by the private sector, the church sector and/or at San Lawrenz Gozo.

Invitation letters were sent to eligible participants (caregivers) by personnel at ‘*entru Servizz Anzjan*’ and at Saint Vincent de Paul. In the invitation letter, the purpose of the study was explained (Appendices D, E). Eligible caregivers who showed interest to participate were invited to contact the researcher by phone, e-mail or by post (a form together with a self-addressed envelope was provided) in order to clarify any questions (Appendix F, G). All information was provided in both the English and Maltese language. After ten days, potential participants were sent a reminder by ‘*entru Servizz Anzjan*’ and Saint Vincent de Paul regarding their participation in the study. When no response was received within ten days following the reminder, no further reminders were sent. The next potential participant on the list was contacted until the researcher informed both gatekeepers that saturation of data were reached and no further interviews were indicated. Once potential participants agreed to take part in the study, they were given an appointment to attend for an interview. From the sixteen caregivers who replied back only four were males (two sons, a husband and a nephew). Equal distribution of gender was not possible due to the low response rate from the male gender, thereby all the latter were interviewed. From the twelve females who replied there

were a daughter in-law, a granddaughter, a longtime family friend, five wives and four daughters. Following contact, two of the potential participants dropped out as their care recipients were hospitalised, eight of the females took part in the final study whereas two females (a daughter and a wife) participated in the pilot study. Saturation of data was reached following 12 interviews. This is consistent with Guest, Bunce and Johnson (2006) who underlined that saturation of data is often reached following 12 participants. Interviews were conducted either in the participant's own home or at a convenient place for them. This promoted comfort and participation as otherwise it would have been difficult for the caregiver to be relieved off their duty.

Figure 3.1 Recruitment of caregivers



### **3.3.1.3 Applying for Respite Services in Malta**

All applications from citizens who opt to make use of community care services including residential respite care are received at ‘*entru Servizz Anzjan*’ in Valletta. The application (Appendix P) can be retrieved either online or can be obtained directly from ‘*entru Servizz Anzjan*’. The application form has to be filled in jointly by the caregiver requesting respite and a medical doctor. It has to be signed in by the care recipient as long as the latter is able to make an informed decision. Upon receiving the form, personnel at ‘*entru Servizz Anzjan*’ process and pass on the form to the Commcare Assessment Unit for vetting. One of the aims of this unit is to link health and social care services in the community by regulating and coordinating community care services and by managing care plans for individuals especially those who are unable to travel (Active Ageing, 2016). Two health care professionals (nurses) from this unit carry out a home visit to verify that the information in the application form reflects the actual situation.

The older person (care recipient) is assessed comprehensively using the Barthel Activities of Daily Living Index (Colin, Wade, Davies & Horne, 1988) (Appendix Q) which is an ordinal scale to measure functional performance, the Mini Mental State Examination (Folstein, Folstein & McHugh, 1975) (Appendix R) which is a thirty point questionnaire used to measure cognitive impairment and the Cognitive Incapacity and Behaviour Assessment (Bass, McClendon, Deimling & Mukherjee, 1994) (Appendix S) where caregivers provide information about possible symptoms that may not be noted during formal visits by the medical doctor or other care professionals. The home environment, current use of medication/s, any history of falls, past surgical histories, level of support, skin condition, any behavioural issues such as wandering tendencies, current use of any community care services, the social situation and the main reasons which lead caregivers to apply for respite are all noted to obtain a holistic picture of the situation within the person’s own home context. The assessors also note, if a long-term care application to a residential home has already been filled in, they make a summary of the problems identified and action taken and document if any referrals to the Commcare Assessment Unit interdisciplinary team are required. After the evaluation is completed it is returned back to ‘*entru Servizz Anzjan*’. All documentation is reviewed from a nursing management aspect and at times a dementia expert is also consulted to ensure that the respite site chosen best suites the best interest of the care recipient. Those eligible are offered residential respite care for a maximum period of three weeks at one of the aforementioned sites ( *entru Servizz Anzjan*, personal communication, January 2017).

## **3.4 Data Collection**

### **3.4.1 Phase 1: Field Visits**

Research based on the naturalistic enquiry is based on people's experiences of the retrospective and the present world. Observing and participating in phenomena of human relations including interaction with other individuals, with places, with things, and with states of being is fundamental to understanding the span and intricacies of the human experience. Since the same study cannot be replicated under precisely the identical circumstances due to the time factor, a description of the context and setting is fundamental (Bailey, 1997; Creswell, 2013). Apart from being a naturally inductive process, observational field notes help to "contextualize the interview material" (Smith, Flowers & Larkin, 2009, p. 73). In this study, a participant observation technique was adopted. Four important aspects that were taken into consideration in preparation for the field visits included learning to be flexible, organization of self, defocusing and being self-aware and having knowledge on oneself (DeWalt & DeWalt, 2002; Neuman, 2014). Through participant observations, the researcher came across significant issues for a comprehensive perceptive of the research problem.

Following permissions, contacts were made with personnel at the three sites and meetings were held at each site respectively. The rationale underpinning these meetings was to, introduce self as the researcher, explain the aim and objectives of the study and to understand better how the residential respite system operates at each site (Kawulich, 2005). All the managers and personnel were very informative and they were also helpful in facilitating the visits.

Field visits were mainly carried out during different times both during the week and the weekends at the beginning of December 2016 till the end of January 2017. Due to time constraints, two months were deemed adequate for this study. Different times were chosen to gain a better understanding of the context. In this way, the researcher could observe the relationships among different individuals i.e. older persons admitted for residential respite, different staff (namely care workers, nurses and any other health care professionals) and caregivers and relatives visiting their care recipients while at respite. The individual's behaviour could be observed within the residential context. The researcher could observe what individuals were doing when at respite and how frequently and with whom they were interacting. The familiarisation with the different settings proved to be very useful throughout the study. Initially, it was noted that some of the staff (mainly care workers) were conscious

that there was a researcher in the facility (also known as the Hawthorne effect), however after some time they got used to the idea and continued with their usual tasks accordingly. During the field visits, the researcher tried to remain as neutral as possible while trying to connect with the whole system keeping in mind the potential impact that the researcher's participation might have on the people and processes under study (Neuman, 2014).

Prior to communicating with the older persons making use of residential respite, the researcher had to wait for the necessary permissions from the management of the respective facilities. The latter acted as gatekeepers to ensure that the necessary ethical considerations were adhered to at all times. They identified older persons who were able to actively engage in a conversation and who were aware of past and current events in their life. Gate keepers informed older persons and their relatives about the study and obtained the necessary consent from both parties before the researcher could ask specific questions to older persons related to their experience of residential respite (Appendix H, I). Older persons with dementia, those with severe mental health issues or learning difficulties were observed during the field visits but were not interviewed. This was a rather long process since older persons admitted for residential respite changed and the researcher had to wait until contacts and permissions were granted each time. A fundamental aspect during the field visits was that the researcher had to constantly make a conscious effort to be objective as much as possible and recall events accurately when recording observations.

The scope of the observational field notes taken at the three different sites was to capture and document detailed information in order to define and understand better the services offered at the three sites. Similarities and differences were highlighted (Bryman & Bell, 2007). Thereby, the reader could understand better the context the researcher was referring to at the time of the study.

### **3.4.2 Phase 2: Interviews**

Following the field visits, data for the caregivers was collected via face to face semi-structured interviews which consisted of open-ended, neutral and descriptive questions (Appendix J, K). The interview guide was devised by the researcher following a comprehensive literature review to ensure that all areas were covered. Furthermore, it was reviewed by the research supervisor. When “used effectively and sensitively, semi-structured interviews can facilitate rapport and empathy, and permit great flexibility of courage” (Smith



et al., 2009, p. 66). This often results in affluent and remarkable information. Each participant was asked to attend one face to face interview. No inducement was offered. Each interview was held by the researcher and lasted between 45 and 60 minutes depending on the participants' responses. Participants were free to choose their language of preference. A conceptual translation of the interview into the Maltese version was carried by two independent professionals proficient in both the Maltese and English language.

Written informed consent was obtained from all participants prior to the interview and for digital recording of the interview (Appendix L, M). Participants were informed that they had the right to withdraw from the study at any time without giving a reason for doing so and that there were no negative repercussions. Following each interview the researcher kept record of all the impressions and observations and behaviors noted during the interviews in a reflective diary. Each interview was transcribed verbatim by the researcher. Moreover, the Maltese transcribed interviews were translated into the English language. Data were held securely on a password protected computer in line with the regulations of the Data Protection Act (2002).

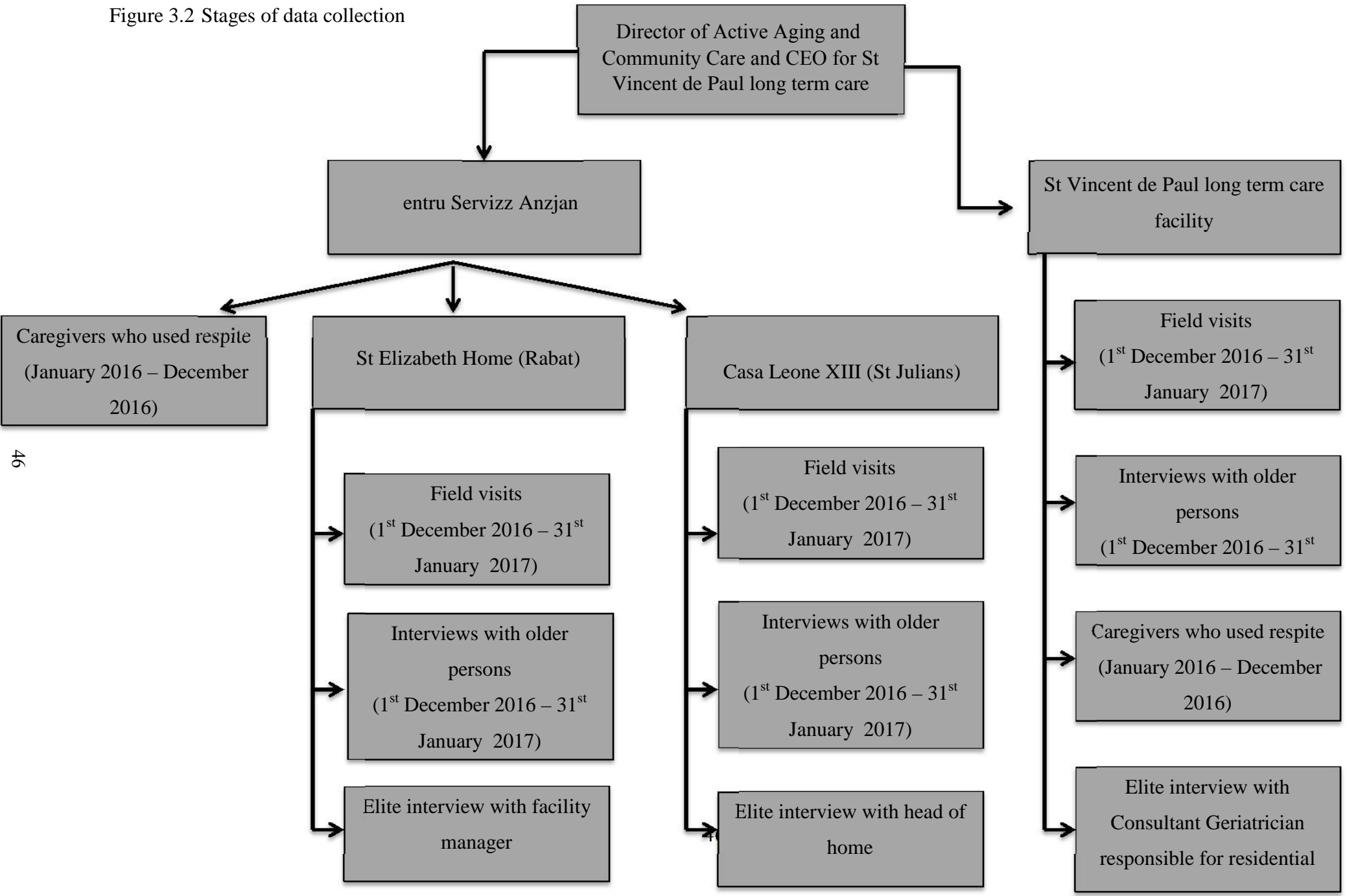
All data collected was deleted and destroyed once the study was completed. The interview schedule was piloted with two caregivers (a wife and a daughter) who did not form part of the final sample. The pilot study provided a filter for the research instrument to ensure that it was appropriate and not too complicated (Wood & Ross-Kerr, 2006). Furthermore, it provided the researcher with an approximate time-frame for the interviews and gave her the opportunity to practice the interview schedule. After the pilot study was carried out no amendments were deemed necessary. The two participants reported that the questions asked were easily understood.

### **3.4.3 Phase 3: Elite Interviews**

Another semi-structured interview schedule (Appendix N) was devised specifically to explore the views of the management responsible for the three facilities under study. Elite interviews are held with personnel at the top of a status hierarchy in a specific field with the aim of providing an insightful evaluation of the services. This enriches the conclusions by providing a detailed and richer background from professionals within the management system (Beamer, 2002). One of the limitations of this tool is the subjectivity inherent in the responses generated which might offer an element of incoherence with the day to day running of the

service (Hochschild, 2009). Following permission and consent, interviews were carried out with Head of Home of Casa Leone XIII, the Facility Manager at Saint Elizabeth Home and the Consultant Geriatrician responsible for residential respite at Saint Vincent de Paul.

Figure 3.2 Stages of data collection



### 3.5 Data Analysis

“True meaning is rarely obvious on the surface” this can only be achieved “through a detailed examination and study of the text, by contemplating its many messages, and seeking the many connections among its parts” (Neuman, 2014, p. 103). Acknowledging that the researcher had some pre-existing knowledge of residential respite care, it felt important to apply bracketing in order to avoid influencing the overall research process. Bracketing is “a strategy of interpretive social science researchers to identify the taken-for-granted assumptions of a social scene and then set them aside or hold them in temporary abeyance” (*ibid.* p. 108). The researcher made her best to remove her past assumptions, pre-conceptions and experiences to become more overt to events when collecting and analysing data.

Following the interviews, data were transcribed verbatim and was analysed through coding and thematic analysis. During the data analysis, the three types of qualitative data coding as suggested by Strauss (1987) were adhered to. The first step was *open coding*. This entailed reading and re-reading the transcripts, the field notes and the reflective diary. Notes from the reflective diary about non-verbal communication conveyed throughout the interviews were analysed. Initial codes and themes were assigned in order to reduce the voluminous data collected into categories. This was followed by going through the transcript line by line and highlighting keywords which appeared to be significant so as to identify the different and/or similar messages the respondents wanted to portray. This led to the development of the emerging themes. The emerging main themes were established and after they were assigned a colour code. The second step, *axial coding*, focused on making connections and links among themes. Transcripts were re-read, codes were organised and links between concepts and key analytic categories were discovered. Each theme was typed on a separate document and all the parts of the transcripts that were pertinent to that theme were cut and pasted to the relevant documents. The last stage of coding referred to as *selective coding*. This entailed analysis of preceding codes to classify and choose data that sustained the conceptual coding categories that were developed. In this way similar findings were grouped together to depict a well presented picture of the whole situation (Cook, 2001). Moreover, the observational field notes were used to place the transcribed information within a context. This provided a complete picture and better understanding of the concepts and themes generated (Bowling, 2002).

### **3.6 Research Trustworthiness**

The Lincoln and Guba (1985) model of trustworthiness was utilised. This model is based on four facets of trustworthiness namely; credibility, confirmability, transferability and dependability. Credibility is one aspect that refers to the extent to which analysed data reflects what the participants wanted to convey in the given context (Carter & Porter, 2000). The establishment of trustworthiness in qualitative research is partially dependent on member checking with ones informants ensuring that the interpretations of their experiences reflect their perspective. In view of this, a verbal summary was given by the researcher after completion of each interview to confirm that the researcher fully understood the participants' views. Observational field notes taken prior conduction of the interviews helped out to consolidate credibility. Triangulation of data were used as apart from carrying out interviews, observational field notes and a reflective diary were kept. Hence, the credibility of the study was augmented (Cook, 2001; Creswell, 2013).

Confirmability was ensured by taking all the necessary precautions to avoid bias as much as possible. The researcher adopted the role of a listener rather than a speaker during the interviews to prevent influencing the respondents. Additionally, consultation with another researcher to analyse data were done to explore and interpret information more in depth (Creswell, 2013; Lincoln & Guba, 1985).

Dependability refers to how consistent the findings would be when analysed by other researchers to enhance the accuracy of the findings (Creswell, 2013). This is also referred to as reliability (Neuman, 2014). An independent experienced researcher carried out the coding of six transcripts. Following this, the codes were compared. The independent researcher reviewed the emergent themes after the 12 transcripts were coded. Transferability refers to the extent to which findings are applicable to contexts outside the study situation and the way in which they can be transferred to said contexts. Additionally, it depends on the depth of the information collected (Creswell, 2013; Lincoln & Guba, 1985). The researcher provided a through description of the context and participants under study. Findings were sustained by direct quotes allowing readers a holistic perspective on the topic.

### **3.7 Ethical Considerations**

The ethical principles of voluntary participation, autonomy, non-maleficence and beneficence were respected (Bailey, 1997). Before the study could be undertaken permission was granted from the Research Ethics Committee of the Faculty for Social Wellbeing (FREC) and the University Research and Ethics Committee (UREC). A participant information sheet was sent to all potential participants through the gate keepers in order to prevent coercing anyone into participating and therefore protecting the principles of voluntary participation and autonomy. Prior each interview written informed consent was obtained. Strict confidentiality was adhered to throughout the whole research process and participants were free to withdraw from the study at any time without any repercussions. By participating in this study respondents had the opportunity to talk through their experiences and this might have provided them with a good occasion to discuss unresolved issues. Each interviewee was given a code and pseudonyms were used for participant's names to protect confidentiality. Data were password protected and kept secure in a place accessible only to the researcher. In order to address issues of reciprocity and responsibility, at the end of each interview participants were told that they would be provided with feedback about the research findings. They were shown appreciation for their time and participation. To balance the benefits and risks, the researcher showed sensitivity to the vulnerability of respondents and strove to make the process as equitable as possible.

This chapter provided a through description of the methodology, research design and method used to answer the research aim and objectives. The next chapter will present the findings and discussion of this research study.

## **CHAPTER 4**

### **FINDINGS AND DISCUSSION**

## **4.1 The Empirical Sources**

This chapter presents this findings and discussion in light of the literature retrieved. The scope of this study was to conduct an evaluation of the publicly-funded residential respite care service for older persons in Malta. While, older persons and caregivers benefit from the service in different ways, service providers are responsible towards offering a service which targets the needs and meets expectations of both the caregivers and care recipients. Hence, the findings were sourced from; (1) twelve caregivers who made use of publicly-funded residential respite care services at least once (during January to December 2016 both months included) at Casa Leone XIII and/or Saint Elizabeth home and/or Saint Vincent de Paul long-term care facility; (2) field notes, participant observations and conversations with older persons who were temporarily residing in one of three above mentioned sites (individuals who were using residential respite during the beginning of December 2016 till the end of January 2017) and (3) elite interviews conducted with three service providers responsible for overseeing residential respite care services in the three different sites respectively.

### **4.1.1 The Caregivers**

Table 4.1 provides an overview of each caregiver. The purpose is to place the reader within the context of the caregivers' situation in order to better understand the findings. Apart from using pseudonyms, the name of the site at which the individual was placed was not indicated to further safeguard confidentiality.



#### Box 4.1: Profile of caregivers

**Joseph** is a 41 year old married man and has been taking care of his 84 year old mother for the last eleven years. He works full-time and his mother resides with him and his family. During his caregiving experience, he used residential respite for his mother twice. Both periods were availed during last year. Joseph reported that his mother is independent for feeding and grooming but requires assistance for bathing and dressing. She is continent with pull-ups and uses a commode. She is able to transfer with assistance and walks short distances with a frame. Joseph claimed that his mother does not exhibit any particular issues with short term memory, is aware of past and current events in her life and has insight into her own limitations.

**Philip** is a 66 year old married man. He is a pensioner and has been caring for his 88 year old mother for the last five years. She resides on her own but very nearby to Philip's residence. During his caregiving experience, he used residential respite for his mother five times. Last year he used it once. Philip asserted that his mother requires help in all activities of daily living (ADL's) except for feeding.<sup>2</sup> She makes use of a commode at day time but wears a nappy at night time. She transfers with minimal physical assistance and support of frame and walks a few steps with support from a frame. According to Philip, she is aware of past and current events in her life and has insight into her own limitations.

**Karen** is a 69 year old married female who has been taking care of her 69 year old husband for the last twelve years since he sustained a stroke (a cerebrovascular accident). During her caregiving experience, she used residential respite for her husband fourteen times. Last year she used it twice. Her husband is dependent in all ADL's. He is dually incontinent and makes use of nappies. He uses a wheelchair and is hoisted in and out of bed with a lifter. He is aware of past and current events in his life and has insight into his own limitations.

**Romina** is a 59 year old married female and she has been taking care of her 90 year old father-in-law for the last five years following his wife's death. Romina and her husband do not reside in the same dwelling as her father-in-law but live in the same locality. During her caregiving experience, she used residential respite for her father-in-law once, during last year. Her father-in-law manages to transfer independently and walks short distances with a frame. He manages to carry out his basic personal needs independently but requires assistance with his instrumental activities of daily living (IADL's). He is aware of past and current events in his life and has insight into his own limitations.

**Simone** is a 64 year old married female who takes care of her 86 year old mother and 59 year old brother who has multiple disabilities. They have been residing together for thirty-one years. She started caring for her mother during the last 5 years and she has used residential respite for five times in all. Last year she used it once. Simone claimed that her

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<sup>2</sup> Activities of Daily Living (ADL's) may be divided into basic activities and domestic and community activities also known as instrumental activities of daily living. Activities of daily living encompass functional mobility (bed mobility, transfers, ambulation and wheelchair mobility) and personal care (feeding, grooming, oral hygiene, continence and toilet hygiene, bathing and dressing) whereas IADL's entail a sequence of life functions which are fundamental to maintain an individual's immediate environment. These include management of one's medication, clothing care, cleaning, shopping, meal preparation, money management, household maintenance and care of others (Foti, 2001; Fricke, 2010).

mother requires moderate physical assistance with bathing and dressing but otherwise she is independent for feeding, grooming and toileting. Her mother ambulates short distances with a frame. She is aware of past and current events in her life and has insight into her own limitations.

**Luke** is a 43 year old married male who works full-time and has been taking care of his 78 year old uncle for the last three years. His uncle is a bachelor and resides on his own but within walking distance from his nephew. During his caregiving experience, Luke used residential respite twice. Both periods were availed during last year. His uncle is able to transfer in and out of bed with minimal physical assistance, he is able to walk short distances with a frame. He is able to eat independently, he makes use of a urinary bottle and a commode, wears a nappy for night time and requires maximal assistance for bathing and dressing. His uncle keeps up to date with current affairs and has a sound knowledge of what is happening around him.

**Eliza** is a 63 year old married female who has been taking care of her long-time family friend for the last ten years. Her care recipient has been residing in the same dwelling for the last seven years. During her caregiving experience, Eliza used respite twice. During last year she used it once. Eliza reported that her care recipient was diagnosed with early onset Alzheimer's disease several years ago. He has fluctuating mood swings, severe memory loss and gets easily confused. He requires help in all ADL's including feeding. He needs to be hoisted in and out of bed onto wheelchair and vice-versa and is dually incontinent. He makes use of nappies for toileting.

**Pauline** is an 83 year old married female who has been taking care of her 84 year old husband for the last four years. They have no relatives in Malta as her two children both reside abroad. Pauline reported that her husband was diagnosed with dementia and he had rapid cognitive impairment in the last couple of years. During her caregiving experience, she used residential respite for her husband once, during last year. Pauline has to supervise her husband constantly as he has a tendency to wander. At times she finds his behavior quite challenging especially when he gets frustrated and agitated. He needs to be assisted for all his ADL's except for feeding. He makes use of nappies for toileting. He walks independently but is unsafe at times as he loses balance.

**Kate** is a 54 year old separated female who has been taking care of her 76 year old mother for the last four years. She reported that her mother was diagnosed with dementia a couple of years ago. Kate does not reside in the same residence with her mother and they do not live in the same locality. Kate has other siblings one of whom has mental health issues and at times he requires her care as well. During her caregiving experience, Kate used residential respite for her mother once, during last year. Her mother requires assistance in all her ADL's and spends most of the day in an armchair. According to Kate, her mother is experiencing issues with her short term memory and at times she gets very suspicious as well. Kate's mother needs maximal physical assistance of one person and frame to transfer from bed to armchair and vice-versa. She is able to walk very few steps with a frame and assistance.

**Alfred** is a 76 year old married male who has been taking care of his 75 year old wife for the last decade. They have three children and one of them lives abroad. Alfred reported that his wife was diagnosed with dementia about eleven years ago. He reported that she gets easily confused, is disoriented most of the time, gets easily suspicious and often ends up feeling agitated. During his caregiving experience he used respite once, during last year. His wife requires maximal physical assistance in all her ADL's including feeding and lately she has deteriorated in mobility. She requires maximal physical assistance to transfer from bed to armchair and vice-versa. She is able to walk very few steps with assistance and a frame.

**Jane** is a 35 year old married woman who has been taking care of her 91 year old grandmother for the past three years. They both live in the same residence. Jane has an eleven year old daughter. According to Jane, her grandmother was diagnosed with dementia approximately four years ago. During her caregiving experience, Jane used residential respite for her grandmother once, during last year. Her grandmother gets easily frustrated and agitated and she finds it very difficult to deal with her mood swings. Regarding ADL's, her grandmother has adequate functional mobility including transferring in and out of bed and on and off an armchair with minimal physical assistance and she walks with supervision. She requires assistance with bathing and dressing, she makes use of the toilet with prompts and wears incontinence pads and feeds self independently.

**Connie** is a 73 year old married woman who has been taking care of her 80 year old husband for the last four years. Connie stated that her husband was diagnosed with dementia about five years ago. She explained that at times he gets very frustrated, loses track of time, gets easily disoriented and encounters difficulty to control his agitation as well. During her caregiving experience, Connie used residential respite service for her husband twice. Both periods were availed during last year. Her husband manages to transfer with help of one person and support of frame. He manages to walk few steps but is unsafe if he left on his own. Besides, her husband requires assistance for almost all of his ADL's except for feeding.

Table 4.1 Demographic characteristics of the caregivers and their care recipients

Caregiver	Age & Gender	Employment	Relationship with person they care for	Care-recipients age	Site	Frequency	Reason	Years of Caring	Same or different dwelling
Joseph	41, Male	Full-time	Mother	84	Same Nursing and Residential Care Home	Twice within last year	1) To make home adaptations 2) Caregiver burn-out	11	Same
Philip	66, Male	Pensioner	Mother	88	All three sites	5 times in all Once last year	Periodical breaks due to caregiver burn-out	5	Different-Same locality
Karen	69, Female	Housewife	Husband	69	All three sites	14 times Twice within last year	Periodical breaks due to caregiver burn-out	12	Same
Romina	59, Female	Housewife	Father-in-law	90	Nursing and Residential Care Home	Once	Trial for long-term care	5	Different-Same locality
Simone	64, Female	Housewife	Mother	86	All three sites	5 time Once within last year	Periodical breaks due to caregiver burn-out	5	Same
Luke	43, Male	Full-time	Uncle	78	Two different Nursing and Residential Care Homes	Twice within last year	1) Work related travels 2) Caregiver burn-out	3	Different-Same locality
Eliza	63, Female	Housewife (early retirement)	Long time family friend	72	Two different Nursing and Residential Care Homes and Long-term facility	Twice within last year	1) Recovery after surgical intervention 2) To prepare for an important family event	10	Same

Table 4.1 Demographic characteristics of the caregivers and their care recipients (*continued*)

Caregiver	Age & Gender	Employment	Relationship with person they care for	Care-recipients age	Site	Frequency	Reason	Years of Caring	Same or different dwelling
Pauline	83, Female	Housewife	Husband	84	Long-term facility	Once within last year	To visit family abroad	4	Same
Kate	54, Female	Housewife	Mother	76	Nursing and Residential Care Home	Once within last year	Caregiver burnout	4	Different locality
Alfred	76, Male	Pensioner	Wife	75	Long-term facility	Once within last year	Caregiver burnout	10	Same
Jane	35, Female	Housewife (stopped working from part-time)	Grandmother	91	Nursing and Residential Care Home	Once within last year	Caregiver burnout	3	Same
Connie	73, Female	Housewife	Husband	80	Same long-term facility	Twice within last year	Caregiver burnout	4	Same

## 1.2 The Three Respite Care Sites

The following information was elicited from the field notes, participant observations and elite interviews carried out with service providers at the three sites offering publicly-funded residential respite services. A head of home, a facility manager and a consultant geriatrician participated in the elite interviews.

### Box 4.2 Profile of Casa Leone XIII (Church Residential and Nursing Care Home)

*Physical Environment:* Casa Leone XIII is located at St. Julian's and offers private and publicly-funded long-term and residential respite to older persons. At the time of data collection, there were fourteen publicly-funded residential respite beds. The home is surrounded by a large garden and to gain access one has to pass through a gate either on foot or by a vehicle. To main building is accessible either through a ramp or a few steps. Upon entering the main door, there is a reception desk and there is a register where one needs to fill in his or her particulars upon entering and upon leaving the home. A receptionist is available during office hours however during the evenings and on weekends one can enter the premises by pressing the code. Safety features were installed to decrease the risk of having older persons wandering outside the premises and to have more control over who has access to the home. Casa Leone XIII was built many years ago and refurbishments were made to cater for the older person's needs as time passed by. However, wide, large corridors still dominate the premises and most of the time older persons were noted to be sitting outside their rooms accompanied either by relatives or care workers. It was noted that individuals who made use of a wheelchair found it rather difficult to access the internal gardens. Although there are signs to facilitate the individual's orientation around the home premises, and rails and ramps to facilitate mobility in corridors, the home environment is still not dementia friendly. There is one very large dining room and during lunch and dinner hours the majority of older persons admitted for long-term care together with respite users are encouraged to use this room. It was noted that although the rooms were adequately warm, the corridors were rather cold and some parts of the home were rather humid.

There is a chapel on the ground floor level which is accessible to the public from both outside and inside the home. At the time of the study, there were fourteen publicly funded respite beds which were distributed in five different rooms on two different floors. Bathrooms were accessible and fully equipped including a nurse call system. It was noted that since not all the respite rooms were situated next to each other, it was rather difficult for the respite users to mix together and most of the respite users ultimately ended up mixing and socialising with the rest of older persons admitted for long-term care. The two bedded rooms are usually allocated to couples for more privacy.

*Social Environment:* It was noted that the nurses and a good number of care workers were foreigners. At times, both the nurses and foreign care workers encountered difficulty to communicate with some of the older persons. They had to ask for assistance either from the care workers working in the same shift with them or from the relatives who were visiting. It was also noted that some of the nurses and care workers tried their best to communicate in Maltese and they knew quite a few phrases. While some of the respite users were able to

communicate in English others found it very frustrating as they were only fluent in the Maltese language and kept asking the same question several times until they were understood and their needs were attended to.

*Respite package and services:* Respite bookings are akin to a hotel booking system. As soon as one respite user leaves the facility another respite user can utilise the service. It all depends on the demand for the service i.e. the number of applications received at ‘*entru Servizz Anzjan*’. There are times when the beds are all occupied at one point in time (peak seasons) and there are times when some of the beds are vacant (low seasons). If a caregiver asks for an extension during the off-peak season, the extension is more likely to be granted subject to bed availability however extensions are only permissible after the case has been reviewed and approved by ‘*entru Servizz Anzjan*’. The management of the home needs the necessary approvals from the latter department to be able to accommodate the caregiver’s requests as otherwise if approval is not obtained the older person has to be discharged back home. ‘*entru Servizz Anzjan*’ is responsible to ensure that all necessary arrangements are made and there is a monetary fine if the stipulated dates are not adhered to. Christmas time and Summer time are considered as peak seasons as caregivers are more likely to go abroad or have planned events. In view of this, applications have to be submitted in advance to ensure that dates requested are confirmed.

The package includes accommodation on a full-board basis including laundry and assistance with all ADL’s according to the respite user’s needs including (bathing and dressing, changing of diapers as required, toilet use, grooming, feeding and transferring in and out of bed and if indicated assistance and supervision when the individual is walking to ensure safety). Moreover, medications as prescribed by the doctor are distributed by nurses. Transport for hospital appointments is also provided. If an individual requires a doctor, the nurse either calls the private general practitioner of the individual or the medical doctor of the nearest health centre. Respite users are accompanied by care workers from the facility for hospital appointments if the relatives are not attending. Visitors are allowed from nine till half past eleven in the morning and from half past three till eight in the evening.

Caregivers may phone for an appointment to visit the home prior the older person’s short stay at the home and details are given by personnel at the home. Caregivers receive a list of items they need to bring to the home while the older person is staying there including clothes, nappies, medications, toiletries and any equipment the person requires such as wheelchair and walking aids. Various activities including crafts, bingo, physical groups, music sessions and other leisure sessions to target cognition and provide sensory input are held by the activity co-ordinator and both the older persons admitted for long-term care and respite users are encouraged to engage. Participation in daily mass depends according to the respite user’s wishes. Outings are also held from time to time and respite users are invited to participate as well.

#### **Box 4.3 Profile of Saint Elizabeth home (Private Residential and Nursing Care Home)**

*Physical Environment:* St. Elizabeth home is situated in Rabat, Malta. It was recently refurbished into a modern, nice and welcoming home. In fact, the entrance resembles a hotel lobby. At the time of the study, the home was catering for 70 older persons however another wing was being constructed to increase the number of older persons up to 150. The home had five publicly-funded respite beds. It was noted that the receptionist operated the automated door to ensure that none of the older persons wandered off the home premises. The atmosphere in the home was pleasant and the décor and soft furnishings created a tranquil and peaceful environment. The home is located in a busy road. Safety features were installed to prevent persons with cognitive impairment especially topographical orientation difficulties to access the road. There were different colour-coded signs to facilitate orientation around the premises especially for persons with cognitive impairment and issues with topographical orientation.

At the time of data collection, there were no specific rooms allocated for respite users however rooms were assigned according to the needs of the individuals using respite. It was noted that all rooms were wheelchair accessible and had ample space for wheelchair maneuverability and had the necessary amenities including a small fridge. The furniture was modern and there was a nurse call system as well. The facility manger explained that beds are allocated according to the care recipient's needs. Respite users are encouraged to use the common areas and dining rooms to engage socially with other older persons residing permanently in the home. They are provided with the opportunity to engage in activities and outings held at the home like the other long-term care older persons. The respite package funded by the state at St. Elizabeth home is identical to the respite package provided at Casa Leone XIII. However, emphasis was made on the importance of getting to know the potential older persons who will be temporarily staying at the care home and his or her caregivers during a pre-admission meeting. With regards to extension, the same protocol used at Casa Leone XIII applies to Saint Elizabeth home as well.

*Social Environment:* The personnel working at this particular home were noted to be professional, approachable and attentive to the older person's needs. Similar to Casa Leone, a number of foreigners together with Maltese persons were working directly with the older persons.



#### **Box 4.4 Profile of Saint Vincent de Paul long-term care facility (a public entity)**

Saint Vincent de Paul long-term care facility is situated at Luqa. Apart from providing long-term care to older persons, the site hosts individuals requiring residential respite care. Once a potential respite user is referred to this facility from ‘ entru Servizz Anzjan’, the management of this facility takes on the responsibility of ensuring that the admission and discharge dates are adhered to and if any extensions are requested they have to be approved directly by the senior management of the facility. Prior admission, the consultant geriatrician on the respite team contacts the caregiver to confirm the reasons underlying the application and clear any misconceptions. Emphasis is made on the fact that residential respite is not a stepping stone to long-term care and once the days allocated for respite are used the older person has to go back to the community. Individuals admitted for residential respite at this long-term care facility usually are either highly dependent or have severe cognitive and behavioural issues. In particular cases, such as those of individuals experiencing wandering tendencies and challenging behavior, constant supervision may be allocated after discussion is held with all members of the team.

*Physical Environment:* At the time of the study, the respite ward was undergoing major structural refurbishment and to keep the service going, the respite beds were transferred to another ward. Two rooms one for males and one for females were allocated for residential respite use. Both rooms had an en-suite respectively. The bathroom facilities were wheelchair accessible and adapted with the necessary equipment. The ward had different access points (four in all), two of the access points led to two other wards while the two other access points led to two internal yards. It was noted that in both these yards, there were parking spaces and access to motor vehicles making it quite dangerous if an individual wandered out of the ward on his or her own. As a result, the majority of individuals admitted for residential respite with wandering tendencies often ended up with constant supervision. The ward was not dementia friendly and at the time of data collection, it was awaiting refurbishment as well. The ward staff and respite team had to use either the social worker’s office or the activity room in a nearby ward to be able to communicate and discuss certain issues in a private environment as all the rooms in this ward were being used. Older persons were encouraged to use the dining room during meal times and when not possible the ward staff brought food in the older person’s room.

As stated earlier on, a significant number of the respite users had cognitive impairment with wandering tendencies and encountered difficulty to communicate. Other users in this facility were highly dependent in their functional performance skills. It was noted that the team members ensured that they got a good detailed history by contacting the relatives when necessary especially since a significant number of the respite users were poor historians. Most of the relatives were invited to attend the ward round in order to discuss with them various medical aspects, the functional performance of the individual and get a better picture of the social situation at home. The team members made every effort to get a clear picture of the likes and dislikes of the respite user through a life history interview with the caregivers to ensure that the care plan addressed the needs of the respite user and of his or her caregivers.

*Social Environment:* The ward staff and respite team were professional in their approach and it was noted that regular visits were carried out by a senior nursing manager to ensure that protocols and standard operating procedures were being adhered to and any difficulties were discussed accordingly. The majority of the nurses were Maltese however a significant

number of care workers especially those assigned to constant supervision were foreigners. Communication difficulties were noted as most of the time, the Maltese staff had to explain and facilitate conversations with the older persons.

*Respite Package:* Apart from providing all the above mentioned services, at Saint Vincent de Paul, the older person is thoroughly assessed by an interdisciplinary geriatric respite team. Both at Casa Leone and St. Elizabeth home, the respite user is assessed from a nursing point of view but a full multidimensional comprehensive assessment is not possible as this is not included in the package. While at Casa Leone XIII and St. Elizabeth Home, nurses and care workers are available on a twenty four hours, seven days a week roster, a medical doctor is not available on site. On the contrary, medical assistance at Saint Vincent de Paul is available around the clock. At this long-term care facility, the older person is comprehensively assessed by different members of the team including a consultant geriatrician, a consultant psychiatrist if needs be, a medical doctor, nurses, a physiotherapist, an occupational therapist, a social worker and a speech and language pathologist.

A care plan is set up and goals are discussed accordingly. In some cases, referrals are also made to the tissue viability nurse, the dentist, the ophthalmologist, the continence nurse, the nutrition nurse and the podiatrist. All of these services are offered at the facility and the older person does not need to go at Mater Dei Hospital for such appointments. Routine blood tests are also taken on admission and there is also an X-Ray machine. Every effort is made to ensure that the older person benefits from the service he or she requires during his/her short stay at the facility. Moreover, ward rounds are held weekly to monitor and discuss the respite user's bio-psychosocial situation and discharge planning. The social worker carries out sessions with caregivers who require further help and support in the community.

Family training sessions and home visits are also offered as part of the package. The aim is to restore the older person's level of functional performance as much as possible and support the caregiver to continue providing care to the older person in the community. Communication with community care support services is held to facilitate the process for the caregivers. Unlike Casa Leone and St. Elizabeth Home, medication and nappies are supplied by the facility as well. Laundry is also provided as long as the clothes are clearly labeled. The visiting hours are from ten in the morning till eight in the evening. Mass is held daily and members of the staff from the Active Ageing Unit accompany respite users as well as older persons admitted for long term care who wish to participate in mass.

While respite users are encouraged to engage in activities held by the Active Ageing Unit, those respite users who usually attend the Activity Centre (a day respite centre which is situated at Saint Vincent de Paul and caters for individuals diagnosed with dementia who are still residing in the community) are not able to attend the Activity Centre while making use of residential respite care service at the facility. The researcher was told that since there is a high demand for the service, other individuals residing in the community may attend instead of those individuals benefitting from residential respite care. Once they are back home, they resume their usual schedules, however when using residential respite they are not allowed to attend.

### 4.1.3 Older persons admitted for residential respite care

Table 4.3 portrays the profile of twelve older persons who were using residential respite at one of the three different sites and who engaged in conversations with the researcher about their experience of residential respite during the data collection.

#### Box 4.5 Care recipients' profiles

**ikku** is a 90 year old gentleman who was admitted to residential respite for the first time. He is a widower and resides with his daughter and her family. He started feeling a burden on his family since he became incontinent. He regarded respite as a time of sacrifice as he had to part with his belongings. He was at a point in time when he was feeling lonely, disengaged and did not perceive any purpose in his life. He thought that while at respite he was going to receive medical attention and therapeutic intervention but he was mistaken as he received none apart from assistance in completing his ADL's. He is fully dependent in ADL's except for feeding. He requires maximal physical assistance of two persons to transfer in and out of bed onto wheelchair. He requires assistance to maneuver around with a wheelchair.

**Pawlu** is a 90 year old gentleman who was experiencing residential respite for the first time. Apart from giving his caregiver a break, Pawlu wanted to experience what residing in a home with others meant prior deciding if he was ready to leave his residence and reside permanently in a residential care home. He is a widower and is taken care of by his children at home. He found respite a convenient place where he could converse with others and combat boredom in his life. The fact that he could participate daily in mass was imperative for him as at home he was mostly confined indoors. He is almost independent in all ADL's as he requires minimal assistance for bathing and dressing only. He walks short distances with a frame and made use of a wheelchair for long distances.

**Anna** is the primary caregiver to her sister Pawla who was also admitted to residential respite in the same room. Anna had a motor vehicle accident and sustained injuries to her pelvis. Consequently, she required six weeks bed rest and was unable to care for her sister. Their nephew applied for both of them to be admitted jointly to respite until they found a live-in-carer. It seemed that residential respite was the only option and their nephew had applied for an extension until he found a carer to look after them at home. Anna is bedbound and requires full assistance to perform all ADL's. What bothered Anna most was that she had to attend appointments at Mater Dei Hospital. She dreaded to go due to the hassle with transportation.

**Pawla** was admitted to residential respite as her sister (Anna) could no longer care for her. She had polio during her childhood and as a result she ended up requiring assistance in completing her ADL's. She did not like the fact that she was away from her home but acknowledged that there was no other option but to wait until her sister's situation hopefully improved. Pawla was concerned regarding the fact that at home her sister used to assist her to transfer while at respite they started using a hoister. She was afraid that on going back home she would not be able to transfer with help of one person anymore. She reported that she would have certainly benefited from therapy while at respite but unfortunately this was not provided at the site.

**Maria** is an 81 year old female who was experiencing residential respite for the second time. She resides with her son who works night shifts and she spends most of the nights on her own. Although she preferred to stay at home, respite gave her the opportunity to engage in conversations with others and to eat decent meals. She was happy with the service provided and felt secure especially at night. If her son applied again she would not hesitate to use the service again knowing it was for a short period of time. Maria is able to walk long distance with a frame and she is independent for all ADL's except for bathing and dressing.

**Doris** is a 93 year old female who reported that she resided on her own but her daughter lived nearby. She was using residential respite for the first time as her daughter went abroad. Doris reported that she would have stayed on her own but her daughter insisted on her coming to respite for her own peace of mind. She found the schedule rather restrictive and missed the privacy of her own home. Doris is fully independent in all ADL's and is able to walk independently.

**Lela** is a 76 year old female who was using respite for the first time following an operation for spinal stenosis. It was her option to apply as she did not want to put further strain on her 80 year old husband. She got to know about respite from one of the educational talks held at her local church centre. Lela required bed rest and while at respite she was able to follow the doctor's orders however she said that if she was at home she would not be able to resist not doing any house chores. She requires assistance in bathing and dressing otherwise she manages on her own.

**Manuel** is an 80 year old gentleman who reported that he was using residential respite for the second time. He resides with his son and family. He came to respite as his son needed a break and some privacy time with his family. Manuel claimed that he was satisfied with the service and that he engaged in a number of activities held. He said that he does not want to bother the staff as he saw them quite busy. The fact that no one else was residing in his room was an asset as he had full privacy. He is able to walk independently and is fully independent in all ADL's.

**Vince** is a 77 year old gentleman who was using respite for the first time. These last couple of years he had been residing with his siblings as his health was deteriorating. He alternated from one sibling's house to the other every week. His siblings had all agreed on sending him to respite thus when they told him, he felt that he had no choice but to try out their suggestion. Although rather hesitant to come to respite, he was finding his stay comfortable and did not bother using the service again as long as it was for a short period of time. The fact that the other bed was not occupied was an asset for him as he had full privacy. He was impressed with the bathroom facilities and he felt safe that he had a nurse call system as well. He is able to walk with a stick and requires assistance for bathing and dressing otherwise he is fully independent for the rest of his ADL's.

**Angela** is a 70 year old lady who was using respite together with her husband. She was residing in a two bedded room. She was undergoing treatment for a progressive disease and she was the primary caregiver to her husband. She had been taking care of her husband for the last nine years and her husband was fully dependent on her following a stroke. She claimed that if it was not for respite she had no idea what she would have done until she regained back her strength to continue taking care of her husband. She found the service

provided extremely beneficial and she had applied for three extensions and opted to use all the nine weeks at one go instead of taking the three weeks staggered during one year. The fact that she was together with her husband was very important to her and she felt that at times nine weeks in a year were not enough and it would be ideal if exceptions are made according to the individual's needs. It was only when she was stranded that she used the service. She requires assistance with bathing and dressing otherwise is independent for the rest of her ADL's.

**Katrin** is an 85 year old woman who was admitted as an emergency respite as her sister who was her primary caregiver was admitted to hospital. Katrin reported that she wished she could have stayed at home as this was the first time she was out of her own home, at the mercy of others but it was not an option she had as her other relatives had insisted on admitting her to respite until her sister's condition improved. She was very frail and initially was rather reluctant and hesitated to let the care workers handle her. She requires maximal assistance with all her ADL's apart from feeding. She is able to walk short distances with a frame and supervision.

**Susan** is a frail 86 year old lady in a wheelchair who was using respite for the second time as her live-in-carer went abroad for six weeks. Susan reported that as long as she knew she was going back home she consented to use residential respite. She was familiar with the service and she felt she was being taken care of in a very good way. Susan is fully dependent in all ADL's and she is hoisted in and out of bed onto wheelchair.

Table 4.2 Emerging themes and sub-themes following data analysis.

Themes	Sub-themes
The push factor to residential respite	Becoming a caregiver
	More than just a daily struggle
	Need for a break before it is too late
The residential respite experience	A time to compromise
	A glimpse to institutional care
	More than a place to stay
Reconsidering respite: A commodity or a necessity?	An ambivalent decision
	Recommending respite: benefits to self and other

## **4.2 Push factor to residential respite**

### **4.2.1 Becoming a caregiver**

The age of the caregivers (total of eight females and four males) varied from 35 years to 83 years while the age of their care recipients (total of six females and six males) varied from 69 years to 91 years. The youngest caregiver was taking care of the oldest care recipient. One of the caregivers had a primary level of education, eight had a secondary level of education, two had a post-secondary level of education and one had a tertiary level of education. Two of the caregivers were working on a full-time basis, one stopped from working on a part-time basis to take full care of her care recipient, two were pensioners, one opted for early retirement and six were housewives (their primary occupation was always as homemakers) . Whereas eight of the caregivers were residing in the same residence with their care recipients, three lived nearby either in the same street or a few minutes away and only one lived in a different locality. Half of the caregivers stated that they had submitted a long-term care application for their care recipients, two were considering the possibility of applying and four had no intention of applying. Most of the caregivers and care recipients were related by consanguinity (lineal generational or collateral bonds) or by affinity. Only one relationship was based on a long-time friendship. The characteristics of caregivers in this study are similar to those described by other authors (Bauer & Sousa-Poza, 2015; Bookman & Kimbrell 2011; Erol et al., 2016; Lima et al., 2008; Mack & Thompson, 2004).

The participants' caregiving experience ranged from three to twelve years. Most of them reported that it was not their first experience of providing direct care. They mentioned that caring was always an inner part of their personality and mostly they learnt how to care from previous situations. Two of the male caregivers mentioned that earlier on they took care of their father but their role was not as intense as their current one. Another male caregiver reported that prior to his mother, he had cared for an aunt and two of his neighbours. This is supported by Salin and Astedt-Kurki (2007) who reported that previous life situations had an impact on caring roles.

Different levels of informal support from other family members were highlighted by the caregivers. Some felt adequately supported while others felt that they had very limited choice on whom to turn to. Lack of constant support and understanding from other siblings placed considerable pressure on certain caregivers to take full responsibility for their care recipients.

Family conflicts arising due to responsibility of care was also accentuated by Singh et al. (2015). Furthermore, three of the caregivers (two males and one female) clarified that to a certain extent their role as caregivers was imposed on them by their care recipients. They reported that they were always very close to their care recipients and the latter chose them specifically to continue caring for them. A similar caregivers' profile was reported by other researchers as well (Salin et al., 2009; Singh et al., 2015; Traintafillou et al., 2010).

While half of the caregivers (five females and one male) reported that it was their decision to take on the role of caregivers, three caregivers (two females and one male) regarded their role as partially imposed and partly their decision. It is interesting to note that all the spouses, both the male and females reported that becoming caregivers to their spouses was an instant decision as they felt it was their duty to care for their loved ones. They all stated that if the situation had to be reversed, their spouse would have done the same for them. Braithwaite (2000) highlighted that the type of caregiver-care recipients' past and present relationships played a key role in determining the caregiver's level of satisfaction with the kind of care provided. Reciprocating their love by providing continuous care and support gave meaning and value to their life. This statement is clearly illustrated below:

*“I am sure my wife would have cared for me, if the situation was reversed. We have been married for fifty-four years and it is my duty as her husband to take care of her, now that she needs me more than ever...I know that what I do, I do it in the best possible way I can to keep her happy and comfortable as she deserves after all”*  
(Alfred).

#### **4.2.2 More than just a daily struggle**

It was rather difficult for the caregivers to quantify the exact number of hours they dedicated directly in caring for their care recipients. However on average, hours of care dedicated directly to the care recipient's needs varied from an average of 20 hours per week to round the clock care with few hours of rest in between. Caregivers who were residing in the same dwelling with their care recipients especially spouses were more likely to spend more hours with their care recipients than those who were not residing in the same residence. Half of the caregivers reported that they often encountered difficulties (on a daily basis) to deal with their

care recipients especially when it came to assist them with their personal activities of daily living.

Six caregivers mentioned that they knew that since their care recipients were diagnosed with dementia they expected lack of compliance but at times it was too much to handle. Two of the latter mentioned that when their care recipient's behaviour became too challenging and unmanageable they felt helpless and two mentioned that they contacted the Dementia Helpline for support. Level of care required as reported by the caregivers varied from carrying out most of the IADL's to providing maximal physical assistance in all ADL's including hoisting the care recipient out of bed as well as carrying out all the IADL's. To reiterate on previous discourse, Toseland et al. (2002) reported that caregivers whose care recipients needed assistance with activities of daily living were more likely to use respite services.

All caregivers mentioned different aspects on how their role was affecting their life. Some caregivers confided that they perceived their care recipients from another lens especially those whose care recipients was experiencing cognitive impairment or those whom their care recipients required maximal physical assistance. Some caregivers accentuated that as time went by, their relationships went through a transition and some were still dealing with role reversal. One of the caregivers clarified that at times, she perceived her mother as if she was her daughter and she ended up taking the maternal role. One of the spouses mentioned that the way she perceived her relationship with her husband changed completely when compared to what it was before he started experiencing cognitive decline. Although she acknowledged that he was still her husband and she was ready to do anything for him, now their relationship was more as if he was her son and she became his mother. Linking back to the literature, a shift in responsibilities is commonly reported (Riggs & Peel, 2016; Van Bruggen et al., 2016). Whereas financial constraints were highlighted by two female caregivers, spending less quality time with other family members including their children, grandchildren and spouses was mentioned by nine of the caregivers.

Caregivers were feeling that they had multiple roles in their life and due to this, they were missing out on important events and bonds with other close family members. Therefore their role had an impact on the whole family not merely on themselves. These findings echo those of Singh et al. (2015). Schneider et al. (2012) highlighted that female caregivers were more



likely to opt to swap their job due to clashes imposed by time required for work and time devoted to caregiving. Similar to the findings reported by Bauer and Sousa-Poza (2015) and Van Bruggen et al. (2016), caregivers felt squashed between different roles and somewhat felt guilty that they were not distributing their attention equally on all their loved ones as was described by Jane, who said,

*“I feel that the relationship I have with my daughter is not as it should be...she comes to ask me something and attempts to talk with me and I have to leave her in the middle of a conversation to go and check on my grandma...I worry since this is a very crucial time to strengthen the bond with my daughter and instead I end up giving full attention to my grandma...even with my husband, really it is not that simple...”* (Jane).

All of the caregivers mentioned that their care recipients had several co-morbidities. Similar to the findings of Dimech et al. (2009) some of the older persons using residential respite had more extensive difficulties than others and as a result they required different levels of assistance and support. The conditions they mentioned included combinations of hypertension, diabetes mellitus, hyperlipidemia, depression, anxiety, Parkinson’s disease, dementia, cerebrovascular accident, arthritis, prostate enlargement and/or cardiovascular disease. A number of caregivers (six of the seven caregivers who were 60 years or older) stated that they had to deal with their own health issues as well apart from those of their care recipients. They claimed that they were on medication for their own health issues and had to attend to their own hospital appointments on a regular basis. Cheung and Hocking (2004) reported that the majority of caregivers of older persons tend to be spouses, who themselves are ageing and require support and assistance. Moreover, Stolz et al. (2004) highlighted caregivers’ own health issues as one of the main driving forces that lead caregivers to seek respite care for their care recipients.

Three caregivers reported that they were suffering from severe arthritis, another two stated that they were suffering from severe sciatic pain, one of whom had cardiovascular problems as well. One caregiver claimed that she underwent two operations to repair a recurrent hernia. Five caregivers (three of whom were young caregivers) reported that there were times when they were feeling overwhelmed, stressed and their care recipients were gradually becoming a burden at times as they were feeling that they had too much to cope with. This is in line with

the findings of Ziemba (2002) who reported increased levels of stress, burn out, emotional and psychological difficulties resulting from caregiving. Besides, Yin et al. (2002) highlighted that implications from caregiving were found to influence the type and quality of care the caregiver provided to the care recipient. Moreover, Beach et al. (2005) reported that care recipients who require high levels of assistance from their caregivers are predisposed to a higher risk of abuse especially if their caregiver is suffering from depression, distress and ill health. Likewise, Dunbrack (2003) argued that inadequate respite services are associated with caregiver burnout, neglect crises and abuse. This draws attention to address the needs of caregivers in a timely manner since decline in their health and social well-being might initiate a cascade of events leading up in hospitalisation of both the caregiver and care recipient (O'Connell et al., 2012).

Most of the caregivers whose care recipients required a substantial amount of physical assistance were primarily concerned with the repercussions resulting from caregiving on their own physical health while those whose care recipients had cognitive impairment complained of both physical and emotional strain but seemed to dwell more on the psychological strains caregiving was inducing on them. Findings reported by Kosloski et al. (2001) and Dal Santo et al. (2007) illustrated that complex and demanding caregiving situations compelled caregivers to seek respite care. As conveyed by Eliza, who said,

*“People were telling me I was running downhill but I felt alone and had nowhere to go until my friend told me about respite” (Eliza).*

Ambivalence about caregiving was highlighted through various scenarios depicted by the caregivers when referring to their daily situations. Most of them made reference to the highs and lows they experienced. Despite the various implications their caregiving role was having on their well-being and quality of life, all caregivers mentioned feelings of contentment and fulfillment at some point in time. They reported that from their end they felt that they were doing everything in their power to ensure that their loved ones were cared for in the most dignified and respectful way possible. Positive effects of caregiving were also highlighted by a number of researchers (Beach et al., 2000, Boerner et al., 2004; Haley et al., 2003, Harmell et al., 2011). Although feelings of exhaustion and burden were frequently conveyed, some of the caregivers implied that they were willing to continue with their role as long as they had

the physical and the psychological strength and they found adequate forms of support. This was clarified below by Simone who said that,

*“I do my role out of the love I have for my mother and my brother...I do get tired at times and I do grumble quite often but I wouldn't have it any other way...at the end of the day I feel exhausted but serene as I feel that I am doing the best I can for my loved ones. I am their family, if it was not for me and my husband they have no one else to take care of them...at least once in a while I take them for respite”* (Simone).

#### **4.2.3 Need for a break before it is too late**

Most of the caregivers stated that as years went by, the intensity of their role increased profoundly. They found themselves resorting and embracing more formal care support as they felt the need to balance their own needs and emotions. The community support services that were availing themselves of mainly encompassed telecare, the pharmacy of your choice scheme, general assistance for bathing and dressing, domiciliary therapeutic sessions (enablement programme), assistance with changing of nappies, homehelp, the incontinence service (nappies free of charge or at a subsidised price), day centres and the dementia activity centre. The latter two services were being used as a form of day respite few days per week. In addition, the Dementia Support Group, the Dementia Helpline and support from a community social worker were other forms of support that were mentioned.

Although the aforementioned formal community support services served to alleviate the strains of caregiving on a daily basis, most of the caregivers confided that to truly pause from their responsibilities they needed to resort to residential respite for their care recipients. Albeit, this choice brought about a number of dilemmas with it, as most felt that it was a moral obligation to take care of their care recipients and they referred to residential respite as a choice out of necessity. Others delved on their hesitancy to give up caregiving even for a short time despite being overwhelmed with their role. Some reported they felt stuck in their role and they sought residential respite for their care recipient once they realised that the situation was becoming untenable and they were facing a crisis implying that they left this option as a last resort. This is supported by Reinhard et al. (2012) and Phillipson et al. (2014) who reported that respite among caregivers is fairly limited even among those caregivers who

are overwrought. Nonetheless, others reported that they booked residential respite for their care recipient at least once a year to take a well-deserved holiday. Knowing that they had the necessary arrangements sorted for their care recipient while they were abroad was what kept them going. They reported that initially it was hard to let go but feelings of guilt abated as the whole family gained from the break. These findings are similar to those highlighted by Strang and Haughey (1999) who reported that residential respite was linked with much awaited holidays.

For most of the caregivers residential respite meant a secure place and a support mechanism where they could safely leave their care recipients for a brief period of time in order to attend to their needs, recharge their energy and continue caring for their loved ones once discharged back home. Some caregivers highlighted that once they had approval from their family and friends they felt better about using residential respite for their care recipients. This is in line with the findings of Phillipson and Jones (2011). Most of the caregivers stated that to truly benefit from the service and detach themselves completely from their responsibilities for a short space of time, the place and service they were going to leave their care recipients at, had to meet their expectations. Most of the caregivers clarified that they expected good quality standard of care in order for their care recipients to return back home without deteriorating and preferably in better shape. Otherwise, the time they used to restore themselves while their care recipient was at respite would be futile.

Some of those caregivers who were awaiting for their care recipients to be admitted for long-term care viewed residential respite as filling the gap until the latter were admitted permanently to a residential care home for older persons. Moreover, some of the caregivers who were residing in the same dwelling with their care recipients mentioned that for them residential respite meant having some privacy and taking a break in their own home without feeling constantly analysed by the latter. Since some of the care recipients and caregivers were receiving a number of community support services, they reported that different people were coming and going in their own home and they experienced moments where they yearned for some privacy. Residential respite care for their care recipients was the only solution to enjoy privacy in their own home without being constantly interrupted by others. These findings are in line with those of Svensson et al. (2011).

Eliza explained that for her residential respite meant,

*“A family-oriented place which you can use when you feel you can’t cope any longer, it is more or less like a pit stop. They assess the person needing care and also inquire about the needs of the person providing care. Most important I expect they provide some realistic solutions on how to handle difficult situations”*(Eliza).

Caregivers got to know about the service from a variety of sources at different time points during their caregiving role. Sources identified included, distant family members and friends who had already used the service for their care recipients, educational programs held on local television stations, ‘*entru Servizz Anzjan*’ (they phoned to ask what services they could avail themselves of when they were in a crisis), the Dementia Activity Centre, the Dementia Support Group and from Mater Dei Hospital when their care recipients were hospitalised. During the elite interviews, service providers pointed out that they often encountered caregivers who thought that residential respite could be used solely, in cases of illness or when caregivers had to be hospitalised and there was no one to take care of their care recipients.

Similar to the findings of Dimech et al. (2009), reasons for using residential respite varied considerably. The main reason for using residential respite was caregiver burnout. Some opted to take a break locally and still visit their care recipients regularly while others preferred to go abroad to detach completely. Other reasons included to go abroad to visit family and for work related purposes, to prepare for an important family event, to make arrangements in caregiver’s home to accommodate the care recipient’s needs following discharge from hospital, as a trial for long-term care (to check how the care recipient adapted to a residential home environment and simultaneously evaluate the services provided at the home where residential respite was provided) and to recuperate after the caregiver had to undergo surgical interventions.

Publicly-funded residential respite care for older persons in Malta may be availed of three times a year for a maximum period of three weeks each time. When considering the number of years the caregivers had been caring for their care recipients and the number of times they utilised respite, overall they reported minimal use of respite. During their caregiving experience, one caregiver used residential respite fourteen times, two used it five times, four used it twice and five used it only once. During January to December 2016, eight of the

caregivers resorted to residential respite once whereas four caregivers used it twice. Three caregivers reported that they asked for an extension following the original dates they had applied for and two said that they were granted this extension. Some of the caregivers mentioned that they would have considered using residential respite at an earlier stage during their caregiving role if they had known about it before. This is in line with the findings of Strain and Blandford (2002). In contrast, one of the caregivers perceived resorting to residential respite for his spouse as a sign of weakness from his end. He used this service as a last resort upon persistence from his children. He reported that initially he refrained from using respite as he asserted that,

*“It is not my style to delegate...not my style at all...I truly believe in doing what I have to do but at one point I couldn’t deal with all the strain and I had to try out respite especially since my children insisted...they kept telling me that I needed a break” (Alfred).*

In line with the above, Phillipson and Jones (2011) reported that a number of caregivers associated respite with not satisfying their obligations. During the elite interviews, it was accentuated that although a number of the caregivers were aware of respite services, they only resorted to the service when they were completely burnt out. Unfortunately, when the caregivers use the service as a last resort they have a lot of unresolved issues and the respite time is often too limited to find a solution for all of these problems.

### **4.3 The residential respite experience**

#### **4.3.1 A time to compromise**

Whereas caregivers perceived residential respite mainly as a temporary pause for when their responsibilities became physically and emotionally taxing, care recipients referred primarily to residential respite as a time for compromising. Although in most cases it was not directly their choice, most of the older persons claimed that they consented to be admitted to residential respite as they acknowledged that their caregivers were entitled to take a short break from time to time. Some of the older persons admitted that their caregivers had shattered their dreams and missed major milestones in their personal life in order to care for them. These findings echo those of Svensson et al. (2011). As a further matter, some of the older persons accentuated that they felt powerless, insecure, vulnerable and disconcerted as

they felt that their opinion did not matter any longer and consequently they had to do what their caregivers thought was best for them. They dwelled on the psychological distress related with their transition from being independent to becoming dependent on others. Some mentioned that their scope in life was dwindling away and they felt that their end in this life was soon approaching. Since their caregivers resorted to residential respite it meant that they were truly becoming an encumbrance. One of the older persons elucidated how his siblings instigated the idea of respite and he felt he had no choice but to accept and adhere to their suggestion. A few of the older persons claimed that for them going to residential respite meant a time of sacrifice as they had to part with their home and their personal belongings. This made them feel as if they were losing their identity. This is clearly expressed by Katrin;

*“Upon leaving my home, I said to myself, only God knows if I will come back again, it makes you feel so sad having worked so hard and ending at the mercy of others” (Katrin).*

According to a substantial number of older persons, their relatives did not always explain clearly what residential respite care entailed. Consequently, this brought about an element of fear and apprehension especially among first time users. They feared the unknown. Most of the first time users claimed that it was a ‘*shock*’ for them as for some it was their initial time out of their own home for an extended period of time and they were new to a formal care support setting. It took them quite long to assimilate their new context. Another element highlighted by an older person in one of the residential homes was the misconception about the type of services he was anticipating to receive not only from his caregiver but from his family doctor as well. He remarked that,

*“When my doctor told me about respite I thought it was going to be like Karen Grech so I thought I go and give it a try... maybe I will go home a bit better. Once I had been at Karen Grech for a number of months and there were doctors and nurses they took blood and did a lot of tests... and there were therapists there to help me walk but here... it is so different there is no doctor and no therapists... if I knew what I was going to find here [referring to the facility], I would have resisted coming here for sure” ( ikku).*

In line with the above findings, Svensson et al. (2011) underlined that care recipients experiencing residential respite care expected to receive frequent therapeutic sessions and medical reviews. In contrast, older persons who either lived alone or spent ample time on their own were likely to be more satisfied and reasonably pleased with services provided during their short-term stay when compared to those who lived with a caregiver who spent most of the time with them. Some of the older persons reported that while at home, they experienced feelings of boredom and loneliness. Hence, residential respite provided them with a positive experience as they had the opportunity to engage socially and in a way managed to combat loneliness. One of them reported that;

*“My son works long hours, at least here [referring to the facility] I can talk with someone and have a decent conversation” (Maria).*

Likewise, some of the caregivers mentioned that while at residential respite, their care recipients had the opportunity to socialise with others and as a result the latter felt less inundated by feelings of pessimism and helplessness. At the same time the caregivers felt less guilty for sending their care recipients to respite as they felt that their care recipients benefitted as well. Some of the older persons and a few of the caregivers mentioned that through residential respite they had the opportunity to meet with others going through similar situations and they could discuss with one another what they were experiencing. Two of the older persons explained that while at respite, they felt protected at night time. Their main concern at their own home particularly during the night was that they felt lonely and insecure. A few of the older persons stated that although initially they were disinclined to be admitted for a short stay in a facility, they found their stay relatively satisfactory and some found it more comfortable than they anticipated.

#### **4.3.2 A glimpse to institutionalised care**

Lack of privacy and limited choice and control such as having to fit into an established routine including early lunch and dinner times were highlighted by some of the older persons. For some, it was really frustrating to share a room with others. Older persons who happened to be placed with roommates who had challenging behavior reported that they found it difficult to adapt, as their roommates were rather disruptive. They reported that they had to constantly monitor their personal things as others kept fidgeting and rummaging in other



people's belongings. Since they were unable to safely lock away their belongings they constantly feared that their privacy was going to be invaded. As a result, they were likely to ask their caregivers to take them home earlier. This was clearly illustrated below;

*"...here there is no privacy, by drawing the curtain, you can still hear them shouting...it is so inconvenient especially at night time...[sighs]... as soon as my daughter comes I will beg her to take me back home immediately"* (Doris).  
[Participant said this in a hushed voice to make sure no one would hear her].

The aforementioned account concurs with a statement recounted by one of the caregivers who reported that during her last stay at respite, his mother implored him to take her back home earlier as she could not stick her roommate's patronising attitude. The older persons' experience of respite depended a lot on with whom they happened to be placed at the time they were using respite. Therefore their experience varied considerably from one stay to another. Similar findings were reported by Skilbeck et al. (2005) and Svensson et al. (2011).

In all the three different sites, persons admitted for a short stay often ended up mixing with other older persons who were residing there permanently especially during meal times, mass and other activities held in the common areas. As a result, few of the older persons admitted for respite often ended up fearing that they would end up on a permanent basis as they thought that their children might have tricked them into coming for respite and leaving them at the facility permanently. Some of them conveyed mixed feelings of anger and sadness as they felt betrayed to some extent. Doris expressed her fear of being left permanently at the site when she stated that;

*"...after all...I hope she [her daughter] comes to pick me up as soon as she comes from abroad as I don't want to end up here forever like that lady... [referring to another resident with whom she was talking to prior we walked into a private area to start the conversation] she told me that her daughter brought her here a few months ago and never took her back, that's what I am afraid of now"* (Doris).

On the other hand, almost all of the caregivers whose care recipients were admitted for residential respite but were awaiting a permanent admission for long-term care implied that they felt surprised that during their visits they noticed and spoke with older persons who were admitted permanently and were in a better shape than their care recipients. Considering that at the three sites older persons admitted for long-term care were likely to mix with older persons using residential respite, caregivers were prone to encounter and observe the former and ended up making their own assumptions. Consequently, a few of the caregivers inferred that it was unfair that they had to take their care recipients back home and continue dealing with their everyday struggles while other individuals who in their opinion were much better, simply stayed there permanently. For these caregivers, long-term care for their care recipients seemed to be the only solution to end their everyday ordeals. This was clearly illustrated in the following statement;

*“ While at respite, I saw other persons who were permanent residents and who had less needs than my mother...it makes you think how easy it would be just to come to see her...I mean...we have applied for long-term care quite long ago but we are still waiting...”* (Joseph).

Concern about the inappropriateness of settings was also highlighted during one of the elite interviews. It is imperative that neither the older persons nor their caregivers feel that the former were just slotted into a vacant bed. Appropriate residential respite settings catering specifically for the diverse needs of older persons and their caregivers need to be set up. Conversely, some of the older persons who were relatively independent attempted to assist others who were more dependent and the former felt fortunate that they could still retain some form of independence. Consequently, this alleviated their morale and they felt more motivated. A number of older persons found the bathroom facilities easy to use and accessible and they had to rely less on care workers for assistance whereas others remarked that hand rails in corridors gave them the opportunity to walk without asking for help. While only a few of the older persons complained about the type of food they were being served and the type of assistance provided, more of them delved on the way in which the service was delivered. Insensitivity from staff due to limited quality time for communication was reported in some cases. Another vital facet that was pointed out was being treated with dignity and respect especially while being assisted with their intimate care needs. One of the older

persons explained her appreciation to the basic elements of common courtesy and etiquette she received from a particular care worker while assisting her with her ADL's.

*“Even when they are washing me... not all of them are the same... one of them is really gentle and sweet and she even brushes my hair and towel dries it very carefully, it matters to me... she takes time to talk with me, it's nice to feel that I am not just a number to her and she is not in a rush to get me over and done with like some of the others (referring to other care workers)” (Pawla).*

Moreover, most of the older persons confided that most of the time, care workers went an extra mile to provide a good service. However, they found it truly frustrating to communicate with foreign staff as although the staff made their utmost to facilitate communication they often took extensive time to understand what the older persons wanted to convey and this evoked feelings of frustration. One of the older persons explained clearly that;

*“ ...I already need my hearing aid to help me communicate with others...let alone having to understand their accent... [sighs]...sometimes I get so tired repeating the same things, I just stop trying...I don't understand them and they don't understand me...it really is frustrating” (Anna).*

On a related note, difficulties to communicate with staff were also highlighted by some of the caregivers. One of the latter mentioned that she was not very fluent in the English language and when she had to explain her care recipient's condition she felt particularly uncomfortable. She was mostly concerned on how her care recipient would communicate once she left her on her own. Furthermore, a few of the caregivers portrayed how they had to adopt a new caring perspective that they had never experienced before namely caring from a distance. This brought about its own challenges as well. Losing control over the care recipients was reported as one of the reasons associated with non-respite use (Phillipson & Jones, 2011). One of the caregivers referred to an instance when she had to be extremely cautious and diplomatic on how to voice out certain issues that she felt apprehensive about as she did not want to jeopardise her care recipient's stay in any way. This created anxiety about the level and type of care being provided and this caregiver found it extremely difficult to completely detach herself from what was actually happening at the facility. As a result, she

felt that she did not take the break she needed. Increased levels of caregiver strain and depression were also reported by Lund et al. (2009).

One of the caregivers confided that prior to accessing residential respite, she did not anticipate the communication difficulties she experienced. She felt that there were a lot of things that were left unsaid and she would have felt much better if the care workers and nurses allocated more time to give feedback on how her care recipient was doing. Some of the staff made her feel that since her care recipient was under their care, she was no longer in-charge of her care recipient's needs. She asserted that whenever she inquired about something some of the staff made her feel as if she was intruding and doubting their level of care. Consequently, she explained that she became constantly vigilant of what was happening and she had a hard time adjusting her perspective and letting others take over without interfering. She implied that it was not an easy task she seemed to handle very well and instead of taking a full break she ended up wasting most of her time visiting her care recipient. Likewise, other authors argued that, to pause completely from their role, it was imperative for caregivers to ensure that care providers were proficient, approachable and zealous to provide safe and high quality care to their care recipients (Salin & Astedt-Kurki, 2007; Stolz et al. 2004).

Importance of communication was also highlighted by the service providers. All mentioned that communication with both the caregivers and care recipients is a core part of the service. Inadequate communication creates barriers and lack of trust in the service provided, hence this should be avoided at all costs. Lack of trust and confidence in the formal support systems were amongst the barriers to access respite care (Mockus-Parks & Novielli, 2000; Phillipson et al., 2014). A patient and family centred approach was advocated. Salin et al. (2013) stressed on the importance of efficient communication between the respite team members and the family to be in a better position to comprehend the family's life context and not solely that of the care recipient. To address language barriers, foreigners are teamed up with locals and are continuously encouraged to familiarise themselves with the Maltese language, culture and traditions. Moreover it was stressed that although language barriers do not facilitate communication, attitudinal barriers do not facilitate productive communication.

### **4.3.3 More than just a place to stay**

In all the three sites, it was noted that older persons had access to a number of activities. Despite continuous efforts from the staff to empower older persons to engage in various activities, a few of the older persons preferred to disengage and spend a considerable amount of time sitting and staring. Some of the older persons complained about the type of activities being held however they were noted to refuse to join in activities when staff came to recruit them. Nevertheless religious activities including mass were attended by most of the older persons.

Concern with deterioration in functional mobility and functional performance skills was another factor mentioned concomitantly by both some of the older persons and a number of caregivers. Moreover, caregivers whose care recipients had cognitive impairment echoed their concern that the first few days following discharge from residential respite the latter took quite a while to settle but gradually they found back their routine. Some of the caregivers were particularly worried that their care recipients ended up losing their functional performance skills instead of improving. This created further problems once they were discharged back home. This concern was clearly illustrated below by one of the caregivers who was admitted with her care recipient after she sustained a motor vehicle accident.

*“If she had some therapy she would not have deteriorated this much now...it is going to be more difficult to cope now once we are back at home” (Anna).*

In line with the above, Salin et al. (2009) reported that most of the caregivers highlighted that the level of functional performance of their care recipients did not improve as much while at respite. The need for support and empathy was stressed by a number of caregivers. Furthermore, when they accessed respite care they sought support in taking complex-decisions about their care recipient's needs. They asserted that through input by professionals they learnt new skills on how to deal with their ordeals. Nevertheless, caregivers whose care recipients had been placed for residential respite at Saint Vincent de Paul prior to being placed in either one of the two other sites, highlighted a discrepancy in the type of service being provided. They accentuated that at Saint Vincent de Paul, their care recipients were thoroughly assessed by a team of different healthcare professionals while the respite package provided at Casa Leone XIII and Saint Elizabeth Home was more of an accommodation and provision of assistance with basic care needs. They mentioned that as

soon as their care recipient was admitted at Saint Vincent de Paul, a thorough medical and functional performance evaluation by the doctor, nurses and therapists was carried out. Some of the caregivers mentioned that they were invited to family training sessions and ward rounds to discuss their care recipient's progress. In addition, if they were unavailable while their care recipient was at the respite unit, contacts were made even after they their care recipient was discharged back home. From those interviewed, only one care recipient was admitted first to one of the residential care homes catering for publicly-funded residential respite and then to Saint Vincent de Paul on the second time his caregiver applied for respite. A difference in the type of approach and support she experienced was clearly highlighted in the following statement;

*“...the second time we used respite, at Saint Vincent, it was different from when he went to [named the facility]. At Saint Vincent, he was seen by a doctor and there were a number of nurses in the ward... they even phoned me while he was there to check my needs and spoke to me about services offered in the community and before he came back home they came to check the house and gave me advice on how I can manage better” (Eliza).*

Upton and Reed (2005) outlined the importance of equipping the caregivers with the necessary skills and resources to deal with the daily struggles. Moreover, Evans (2013) highlighted that respite services should aim to provide an all-inclusive package not simply a temporary break from the caregiver. Respite is depicted as an intricate process that is founded on a coalition between the caregiver, the care recipient and the service provider.

#### **4.4 Reconsidering respite: a commodity or a necessity?**

##### **4.4.1 An ambivalent decision**

When asked if they were willing to be admitted again for a short period of time, some of the older persons claimed that although it was not their primary choice, they would not mind coming back as long as it was for a short period of time and their caregivers guaranteed that they were going to take them back home eventually. Those older persons who had a positive experience seemed eager to re-use the service. However, a concern voiced out by most of the older persons was with whom they will be placed and at which site they will be sent in the

event that their caregivers applied for them to use residential respite on other occasions. One of the older persons clarified that,

*“Really and truly...I thought it was going to be different and I would not like to come again but I do not exclude to come back since I cannot think only of myself but I also have to think of my children. At least they get to have a break once in a while” ( ikku).*

Almost all of the caregivers stated that they would reconsider using the service as overall, despite a few mishaps, they found the service beneficial. They referred to several positive outcomes including regaining back their own health to continue caring, learning new skills and getting help and support by getting to know about and being referred to community care services they were unaware of. Other outcomes included having a point of reference in difficult and disheartening moments and learning to trust more formal support services. However, lack of co-operation and veiled comments about not wishing to re-experience residential respite from some of their care recipients made it extremely difficult for those caregivers who felt the need to re-apply for residential respite more often. Despite acknowledging that respite prevented caregiver and family breakdown, some of the caregivers confided that they had a very hard time to decide at which time point to use residential respite and sometimes they cancelled their bookings due to feelings of guilt.

Similar to the findings of Said (2011), although residential respite provided some of the caregivers with sufficient time to re-boost their energy levels, some of the caregivers pointed out that they felt somewhat uneasy to leave their care recipients behind them. This was particularly highlighted by those caregivers whose care recipients had cognitive impairment. They confided their concern and anxiety that if something awful happened to their care recipients while at respite, the latter would have been unable to relate what happened. Hence, emotional barriers such as guilt feelings added a layer of difficulty to those caregivers who were in a dire need of a break and who re-considered using residential respite again. Previous negative experiences by both care recipients and caregivers and added burdens on the caregiver once the older person was discharged back home from respite were challenges underlined by a number of caregivers. In addition, other challenges highlighted were being unable to stay away and letting go of their care recipients for a short space of time, limited trust in formal care systems, feelings of over protectiveness for their care recipients and

communication difficulties with care providers in getting the message across. In one of her comments, Jane illustrated her ambivalent feelings as follows;

*“When we arrived...I started telling them about everything...how I do everything at home... [referring to the nurses and care workers]... I felt a bit awkward and guilty to leave her and the first two days I cried so much and I couldn't resist not to go and see her...but I needed a break badly and if I hadn't left her I don't know what would have happened as I was in such a bad shape at the time”* (Jane).

Similar findings were also illustrated in the findings of King and Parsons (2005) and O'Connell et al. (2012). Bureaucracy in applying to residential respite in time of crisis was highlighted by one of the caregivers. He explained that he could not wait for the application to be processed and he had to resort to private respite until the application was administered. He stated that;

*“... I needed respite for my uncle immediately as he couldn't move well...actually he was stuck... when we arrived home from Mater Dei. When I phoned to ask to admit him for a few weeks for respite, they told me to fill in the form and take it to Valletta as soon as possible...for me that was too complicated as first I had to go to the doctor...it was too much of a hassle... they already had all the details as we used respite a few months before...”* (Luke)

One caregiver insisted that if her care recipient was to be re-admitted to the same site she was likely to cancel her break however she would definitely re-use the service if her care recipient was admitted at another site. Her decision was attributed with a negative experience from a particular site. Notwithstanding the above-mentioned implications, some of the caregivers confided that they were already planning to re-apply for residential respite care for their care recipients. According to these caregivers, the positive benefits they got from using residential respite far outweighed the negative outcomes.



#### **4.4.2 Recommending respite: Benefits to self and others**

When caregivers were asked whether they would recommend the service to others, all claimed that they had suggested residential respite on various occasions and intended to continue mentioning and recommending the service to other caregivers experiencing similar situations. In line with the above, Simone stated that;

*“It is not the first time I mentioned respite to others...of course...why not? I feel that since I gain peace of mind, I don’t mind telling others to do the same”*  
(Simone).

One of the caregivers recommended a residential respite unit solely for persons with dementia that could be availed on frequently (regular weekend breaks) instead of having access to three periods per year. This is illustrated in the following statement,

*“It would be really useful to have a section like the Activity Centre to be used for weekends where the person can sleep, you take them on Friday and you can pick them up on Monday. The staff would really know the person, she will get used to the place and we can use it from time to time more often”* (Jane).

To reiterate on previous discourse, caregivers also mentioned the importance of being allocated the same site for respite as it would prevent unnecessary stresses as both the care recipient and the caregiver would have already familiarised themselves with the whole system. This was highlighted below;

*“I wish they don’t change the place where they send them for respite as we get to know the staff and the system and even he will know what to expect not something new every time”*(Karen).

Svensson et al. (2011) reported that care recipients found that changing sites created unnecessary annoyance as they had to adapt to a new physical and social environment. In line with the above, elite interviewees reported that they often encounter caregivers and care recipients requesting to use the same site for residential respite. They all reported that while they understand the reasons behind these requests and they provide the necessary feedback, they do not have a direct say from their end regarding the site in which the older person is re-

admitted. They implied that ultimately, it is personnel from ‘ entru Servizz Anzjan’ who make the final decision concerning the site in which the individual is placed for his or her next residential respite stay. All elite interviewees accentuated on the importance of ongoing communication with ‘ entru Servizz Anzjan’ in order to facilitate continuity of care resulting in a more effective service to both the caregivers and the care recipients. Furthermore, one of the elite interviewees stated that care providers should be adequately trained to address the multifaceted needs of the caregivers and not focus solely on the needs of the care recipients as caregiving is an intricate journey that involves the whole family.

Further suggestions pointed out by both the older persons and caregivers interviewed included the importance of therapeutic sessions to avoid deterioration, adequate privacy levels preferably by having single or two bedded rooms, adequate care settings for persons with challenging behavior, more social engagement through meaningful activities and having a residential respite unit which is more central and easily accessible by public transport. At all the three sites, respite users were being encouraged to engage in activities with other older persons admitted for long-term care. This often created conflicts for both the caregivers and the care recipients. Indirectly, this type of setting was found to encourage some of the caregivers and some of the care recipients to consider long-term care prematurely. It is beneficial to provide residential respite care in long-term care settings as one can make use of the available human resources such as in the case of health care professionals and specialised services offered within the facility. However, this should be done with caution as mixing respite users with older persons admitted for long-term care could serve as a stepping stone to institutionalisation.

Two of the service providers accentuated on the importance of consolidating the present community care services. A robust and reliable community care support system is fundamental to apply the concept of ageing in place for older persons requiring different levels of assistance.

One of the service providers stated that;

*“...this is crucial especially since at times caregivers refrain from using these services due to inconsistency with the provision of care such as not having a short time frame when the nurse or care worker is coming to wash their care recipient. Some of the caregivers complain that they can’t wait the whole morning not knowing when they are coming, some say at times they come at seven, at times they come at ten and when the nurse comes they would have already washed their relative as he or she would have been soiled since five in the morning”.*

The next chapter discusses the implications for ageing and community care, presents recommendations for policy, practice and education and discusses the strengths and limitations of this study.

## **CHAPTER 5**

## **CONCLUSION**

## **5.1 Introduction**

The concept of 'ageing-in-place' is prevalent in current ageing policy. A robust and reliable community care support system is fundamental to apply this notion to older persons requiring different levels of assistance. Informal support provided by caregivers including family members and friends is pivotal since it forms an integral part of the health and social care system (Horner & Boldy, 2008). Injecting funds in enriching caregivers with the necessary skills and opportunities to continue caring for frail and dependent older persons in the community is the optimal investment towards consolidating the concept of 'ageing-in-place'.

## **5.2 Implications of respite care for ageing in place**

Findings from this study support those of Cutajar, (2009), Reinhard et al. (2012), Phillipson et al. (2014) and Brandao et al. (2016) who reported that despite highlighting the need for residential respite, low usage of this service was reported. Mostly, caregivers tend to use this service as a last resort when their role becomes a daily struggle. Consequently, they do not benefit fully from the service. Indeed, strategies to address low service utilisation must seek to profoundly explore and understand better the experiences of caregivers who resort to residential respite care for their care recipients (Phillipson & Jones, 2011). An imperative point to keep in mind is that early intervention improves the return on later investment. Therefore, information campaigns to increase public awareness about the availability of community care services including residential respite care to ensure timely access is necessary. The general public should be well informed about the different types of services provided and on when, where and how to get support.

Caregivers' decision to apply for residential respite for their care recipients is complex and incorporates substantial tradeoffs often resulting in conflicting perceptions about using the service. Similar to the finding of Phillipson and Jones (2011), this study underlined that when their decision to use respite is supported by family and friends, caregivers are more likely to benefit, use the service more regularly and avoid cancellations. Therefore, if there is more public awareness, family and friends are more likely to acknowledge the need for caregivers to take a break and counsel them accordingly. In turn, caregivers will feel less stigmatised and keener to utilise more the service. Notably, this study revealed that older persons reported feelings of fear and apprehension due to lack of discussion and full information regarding the type of service they were expecting both by their caregivers and their family medicine specialists when the application was completed. Misconceptions attributed to the type of

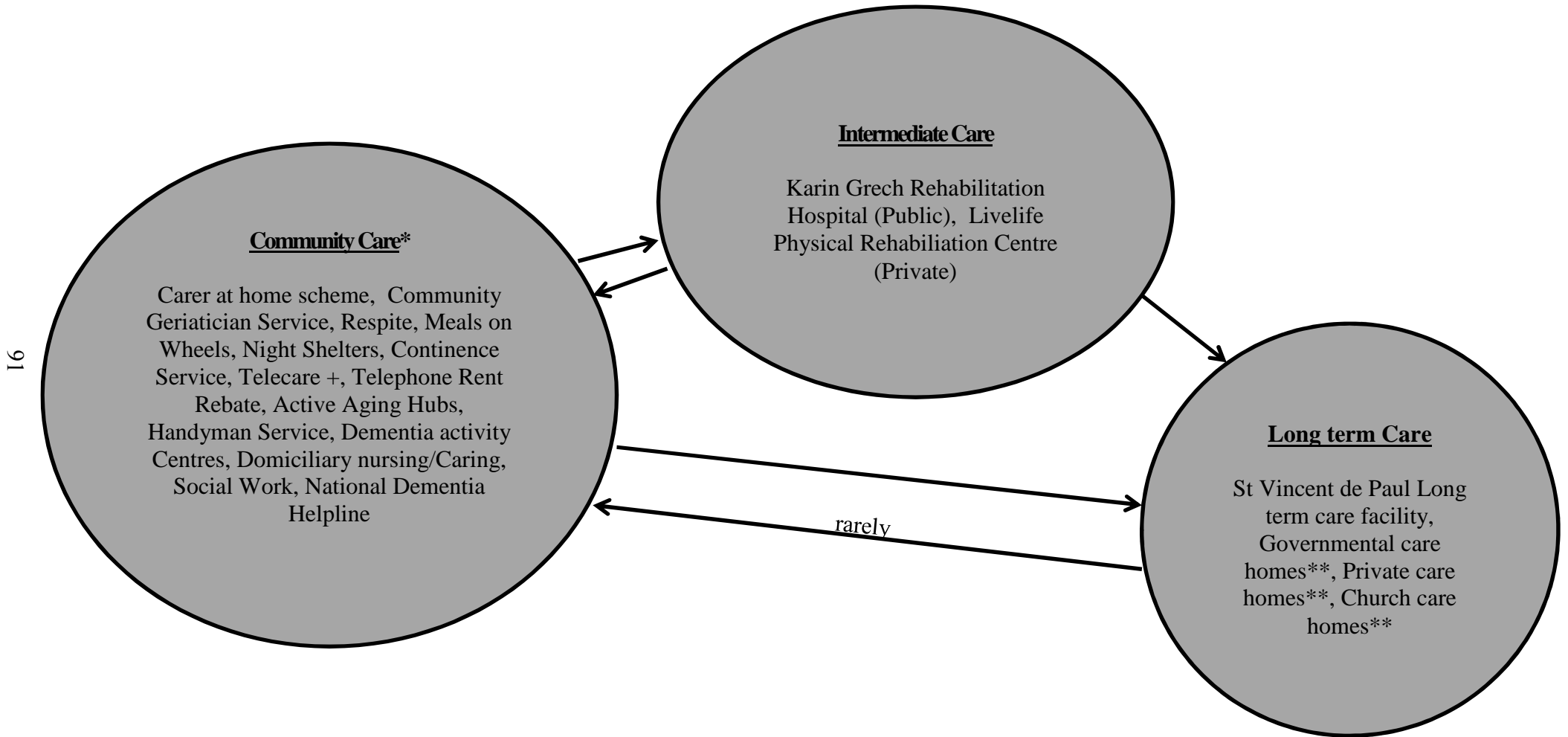
service they were told to expect was another facet that resulted in disappointment with the type of service provided. In an era of patient and family-centered-care, better informing older persons regarding the type of service they are expected to experience is obligatory. While it is vital to target caregivers at risk, it is equally important to instill awareness and educate caregivers and older persons regarding the role of residential respite and its benefits so they can access the service earlier on in their journey and prevent crisis as much as possible. Health care professionals working within the primary healthcare sector have a window of opportunity to delay admissions to long-term care as they should be on the lookout and detect causes for concern at an early stage and refer to the most appropriate services based on the needs of the individual and his or her significant others before issues escalate and become unmanageable. Family medicine specialists need to work in partnership with other allied health care professionals to intervene and target intervention at an early stage. Social workers have a significant role and are considered key workers in advocating residential respite care to lessen caregiving burden (Azzopardi, 1996; Brandao et al., 2016). Adequate follow-up through regular reviews is essential since the needs of the older person and those of his or her family are continuously changing. Another factor that must be taken into consideration is that a considerable number of caregivers are older persons themselves. Thereby, supporting and educating caregivers to identify, understand and address their own self-care needs not merely their physical needs but their emotional and psychological well-being by utilising formal community support care services including residential respite for their care recipients from time to time is paramount.

*The National Dementia Strategy* (Parliamentary Secretariat for the Rights of Persons with Disability and Active Ageing, 2014b) underlines the importance of providing flexible respite services to offer a choice and cater for the diverse needs of both caregivers and their care recipients. Moreover, the *National Strategic Policy for Active Ageing* (Parliamentary Secretariat for the Rights of Persons with Disability and Active Ageing, 2013) accentuates the need for strengthening residential and community-based respite services for older persons including respite care in the home setting for the provision of social protection and prevention of social exclusion of caregivers. Following the launch of this policy, the residential respite care sites for older persons increased from one site to three sites however the type of service given still needs to be consolidated. Findings from this study revealed that type of respite package offered at Casa Leone XIII and at Saint Elizabeth Home differed considerably from that provided at Saint Vincent de Paul. The former two sites were more of a sheltered

accommodation while the latter site provided an all-inclusive package covering health and social care needs with the aim of re-enabling the older person and equipping the caregiver with the necessary skills and training to continue caring at home. It is true that not all older persons admitted for residential respite require a high level of assistance. Moreover, most of the persons with dementia who require round the clock care and individuals who need a high level of assistance are generally admitted to Saint Vincent de Paul for residential respite. However, it is worth noting that at all the three sites there were older persons with different care needs who would have benefitted greatly if an all-inclusive package was available.

A fundamental aspect to prevent institutionalisation is continuum of care. As underlined in the findings, the multiple needs of older persons and their caregivers are constantly changing. Since older persons move in and out of the system in a non-linear way and at different time points, having a coordinated network of support services in place will facilitate timely access and delivery (Troisi, 2013). Additionally, this system will ensure a balanced and smoother transition to the different level and type of care required (Figure 5.1). Continuum of care prevents fragmentation and duplication of services as it helps to identify gaps, overcome barriers and inequities in access and delivery of services.

Figure 5.1: Continuum of care in Malta for the older persons



\*Evaluations and follow-ups are carried out by the CommCare Assessment Unit and when indicated by the Dementia Intervention Team.

\*\* A mix between Nursing and Residential Care Homes



The scope of residential respite care should not aim solely on providing a sheltered accommodation for the older person while the caregiver takes a break but should focus more on evaluating thoroughly the multifaceted needs of both the older person and the caregiver. It should serve as a hub for the older person to restore and optimize their functional capacity as much as possible and for caregivers to gain the necessary tools to continue with their role. A geriatric interdisciplinary respite team is instrumental in providing the necessary input to caregivers and older persons alike since members of the team serve as channels for both cohorts to open up about sensitive issues. Provision of residential respite care can be quite a challenging task for service providers as it involves constant admissions and discharges of different individuals with a variety of needs. If the older person is admitted to the same residential respite site, it would be easier for all parties involved, unless the older person and his or her caregiver object due to a previous negative experience or for any other valid reasons. If this system is adopted, the older person and the caregiver would have already familiarised themselves with the site, the regulations and the staff and the service providers would have already gained insight and better understanding of the care recipient's and caregiver's situation following previous admissions. Moreover, service providers would be able to foresee issues which may arise and explore feasible strategies.

As the name implies, residential respite care is provided within a long-term care setting therefore every effort should be made to avoid the risk of the service being used as a stepping stone for long-term care. It is worth mentioning that all the sites catering for residential respite must have a dementia-friendly environment since a considerable number of older persons admitted for residential respite are experiencing cognitive impairment and changing places creates further challenges. Ensuring that older persons are placed at the same site for residential respite consolidates the argument that their stay would be more beneficial as they would be more familiar with the setting. At the time of the study, all three sites had older persons admitted for residential respite mixing up with older persons admitted for long-term care. Encouraging older persons using residential respite to mix up with older persons in long-term care may raise various issues. Having a residential respite unit within a long-term care setting facilitates access to input from a number of professionals and services available on site. However, as underlined by Phillipson and Jones (2011), amalgamating individuals admitted for respite with older persons in long-term care should be done with caution. Another aspect is that presently older persons diagnosed with dementia who are admitted for residential respite end up mixing with older persons having multiple physical care needs.

Although every effort is done by service providers to avoid having them placed in the same room, this is not always feasible. In their local study Innes et al. (2011) came to similar conclusions. Respite at home was one of a viable alternatives highlighted by participants in their study.

### **5.3 Summary of findings**

Indeed, the findings of this study revealed divergent views regarding the use of publicly-funded residential respite care for older persons. Caregivers who sought residential respite care for their care recipients were taking care of older persons who required high levels of assistance. Some of the caregivers felt adequately supported by other family members while others felt that they had very limited choice on whom to turn to. Whereas caregivers perceived residential respite mainly as a temporary pause from when their responsibilities became physically and emotionally taxing, care recipients referred primarily to residential respite as a time for compromising. Few of the older persons claimed that for them residential respite meant a time of sacrifice as they had to part with their home and their personal belongings. This made them feel as if they were losing their identity. Lack of privacy and limited choice and control such as having to fit into an established routine including early lunch and dinner times, having to share a room with another person who had challenging behaviour or a patronising attitude were other aspects highlighted by some of the older persons. Nonetheless, some of the older persons experiencing residential respite underlined positive experiences including having the opportunity to combat loneliness by engaging in activities and socialising with others and feelings of security and protection especially at night. Some of the older persons highlighted that they found their stay relatively satisfactory and some found it more comfortable than they anticipated since they felt that they had a new purpose in life as they felt productive by assisting others who were more dependent than themselves.

Most of the caregivers clarified that they expected consistent and good quality standard of care in order for their care recipients to return back home without deteriorating and preferably in better shape. Otherwise, the time they used to restore themselves while their care recipient was admitted for residential respite would be futile. Caregivers who were residing in the same dwelling with their care recipients referred to residential respite as the only solution to enjoy privacy in their own home without being constantly interrupted by others. While few

made use of respite periodically to take a holiday, others resorted to residential respite at times of emergency when they were overwhelmed and burnt out.

Lack of co-operation from the care recipients to use the service, not knowing about the service earlier, deciding at which time point to access the service, emotional barriers about letting go of their care recipients for a short space of time, limited trust in formal care systems, feelings of over protectiveness for their care recipients and communication difficulties with care providers in getting the message across were some of the challenges reported by caregivers. Previous negative experiences by both care recipients and caregivers and added burdens on the caregiver once the older person was discharged back home from residential respite were other challenges underlined. Nonetheless, a number of positive outcomes were highlighted namely, gaining sufficient time for caregivers to re-boost their energy levels and regaining back their own health to continue caring, learning new skills and familiarising with innovative equipment to facilitate their role, getting support by getting to know about and being referred to community care services they were unaware of, having a point of reference in difficult and disheartening moments, recognising that their care recipients are benefitting from input provided and learning to trust more formal support services.

#### **5.4 Recommendations for research**

- Lack of co-operation from the care recipients to use residential respite was one of the factors that hindered caregivers from using the service. It is recommended that further in-depth research is conducted to explore the views of older persons' admitted for residential respite. Research will guide and inform better the development of meaningful programs for older persons while using residential respite.
- This study voiced out the experiences of care recipients, caregivers and service providers with regards to residential respite. Large scale quantitative studies are recommended to measure the effectiveness of residential respite care on the care recipients' and the caregivers' well-being. This will provide a baseline of the current local situation.

- It is recommended to conduct a qualitative study to explore the experiences of care providers (including healthcare professionals and care workers) working in residential respite care sites for older persons.
- In-home respite is another significant link that complements the community care support package as it will be supporting a certain category of caregivers. Since publicly-funded in-home respite service is in the pipeline, it would be interesting to carry out an evaluation on the effectiveness of this service once it is implemented and to compare it to the established residential respite care service.

## **5.5 Recommendation for policy, practice, service development and education**

- All health care professionals especially those working in the primary healthcare sector need to keep abreast with the current formal community care support services. Ongoing training, support and dissemination of information about innovative and ongoing developments in the provision of community care services is of major priority to ensure better collaboration and meaningful communication to be able to promote, refer and be better equipped to advise realistic and practical support.
- Ongoing evaluations need to be conducted to confirm that the community care support services provided are still addressing the dynamic needs of the older persons and their caregivers and to prevent individuals abusing the aforementioned services.
- Every effort should be made to ensure that care providers working within residential respite care settings do not generate more dependency levels but practice more patient-centered and family-focused care to continue supporting and empowering caregivers to provide home-based care. To ensure that caregivers and care recipients experience the maximal benefits attributed with residential respite care, care providers should receive adequate training to gain the necessary skills in initiating discussions regarding challenging family matters.

- Integrated care pathways need to be implemented to facilitate provision of care and ensure that the multifaceted needs of the older persons and the caregivers are thoroughly met. Key workers need to ensure co-ordination of care and confirm that care plans are commenced and implemented. Review of medications, new techniques, innovative equipment and formal community support services recommended when the older person was admitted for residential respite care should be followed up in the community and vice-versa to ensure adequate continuation of care. During family training sessions, it is imperative that a variety of medical equipment and innovative assistive technologies are available on site to provide an opportunity for caregivers to practice new techniques and for older persons to try out new equipment suggested.
- A stronger bond among all stakeholders is warranted. Caregivers are instrumental partners and should be seen as stakeholders in the care plan. Older persons with support needs can still contribute to the development and provision of services. Residential respite care providers, community care service providers including the Dementia Intervention Team, the CommCare Assessment Unit, day respite service providers, caregivers and care recipients need to work more in partnership to avoid fragmentation of services and ensure more cohesiveness through teamwork in the best interest of the older person and his or her caregiver.
- All the three publicly-funded residential respite sites apart from catering for a mixed group of older persons with multiple and diverse needs for short-term care provide long-term care for older persons. Therefore, it is being suggested that residential respite should be provided in a separate ward, unit or wing allocated solely for respite care. Besides, a specialised residential respite unit should be specifically set up for older persons experiencing dementia especially those with wandering tendencies and behavioural symptoms requiring short-term admissions. The care needs of the latter cohort differ considerably from those of older persons with multiple physical care needs who are wheelchair or armchair bound and may need external medical devices.
- The residential respite care environment should be tailored to facilitate and meet the care needs of the different care recipients. All the sites catering for residential respite should have dementia-friendly environments. It is suggested that a number of single

cubicles are available as lack of privacy when using residential respite was one of the concerns voiced out by some of the older persons.

- Pre-admission visits to potential caregivers and older persons using residential respite are essential to better prepare them for this new experience by familiarising themselves with the site, the staff and to clarify any misconceptions they might have.
- This study has highlighted that a considerable number of individuals making use of residential respite had multiple co-morbidities and required high levels of assistance therefore provision of residential respite should not focus solely on accommodation but should include an all-inclusive package to target the care needs of both the older persons and their caregivers. Professional education and support interventions are pivotal in preparing and assisting caregivers to sustain their indispensable role. The benefits of psycho-educational programs need to be better explored, implemented and evaluated. Caregivers and older persons should be empowered to participate actively in setting up such programs to ensure that their needs are thoroughly addressed.
- Setting up caregivers' support groups to consolidate the importance of caregiving in society and facilitating communication with non-governmental organisations such as the Malta Dementia Society is imperative. Caregivers would benefit more if they are trained and offered support on when and how to access services and on managing time more effectively when their care recipient is receiving some form of respite care.
- Recruiting and training volunteers through local councils and other organisations to regularly visit and socially engage older persons making use of residential respite might lessen the stress and feelings of guilt experienced by caregivers.

The findings of this study also highlighted the need for more flexibility on when to avail the days allocated for residential respite.

## **5.6 Strengths and Limitations**

This was the first local study that evaluated the three different sites providing publicly-funded residential respite care to older persons. Besides, it voiced out the experiences of older persons admitted for residential respite care, caregivers who sought the latter service for their care recipients and service providers in the three sites respectively. Triangulation of data were used since apart from conducting interviews, participant observations were used to augment the credibility of the study (Cook, 2001).

To combat researcher's bias, every attempt was made by the researcher to remove past assumptions, pre-conceptions and experiences to become more overt to events when collecting and analysing data (Neuman, 2014). Although the researcher tried to remain as neutral as possible during the field visits, some of the care providers may have acted in a way to please the researcher.

While the researcher prepared two interview guides, one in English and one in Maltese, most of the participants opted to answer the interview question in the Maltese language. Hence, the researcher being bilingual had to translate all the responses obtained to the English language in order to present the findings. This might have limited the richness of the findings. However, in order to counteract these possible limitations, after completion of each interview, the interviewees were given a verbal summary so as to confirm their responses. This ensured that the data collected was trustworthy and was not biased by the researcher. Furthermore, during the data analysis, an independent and experienced researcher conducted the coding of six transcripts. The independent researcher reviewed the emergent themes after all the transcripts were coded. This procedure was done to increase dependability of the findings (Creswell, 2013).

Although the findings of this study cannot be generalised due to the small sample size, maximum variation sampling was used to produce a heterogeneous sample. It would have been interesting to explore the care providers' experiences. However due to time and resource constraints this was not feasible. Although every attempt was made to avoid researchers' bias while carrying the interviews, the participants were aware of the researcher's professional background and may have tried to answer in a way to please the researcher. Hence, to combat such limitation the researcher made sure to be as objective as possible and avoid

making any form of judgement and bias that could have resulted in influencing the data collected.

Another limitation that the researcher encountered was that since data from the caregivers was collected retrospectively it was subjected to recall bias. Thus, the data collected relied on the participants' ability to remember specific details. Additionally, the gatekeepers at the three different residential respite sites chose the older persons who were eligible to be interviewed, therefore there was an element of selection bias. In spite of all these unavoidable limitations, the study objectives have been duly answered.

## **5.7 Conclusion**

Findings from the study provide a sound platform to continue implementing, consolidating and ensuring effective, timely, accessible and seamless formal community care support services to inspire, empower and sustain caregivers in maintaining their indispensable role in caring for older persons in need of assistance. Such services apart from being flexible need to be delivered in a synchronised and non-fragmented way to ensure that they meet and address the ongoing and multifaceted needs of both care recipients and caregivers. Since residential respite is one of the links that solidifies and complements the chain of community care support services, every effort should be made to provide the best possible service to ensure integration, collaboration and continuity of care. Providing an accommodation and assessing the care recipient on his own does not encompass a multidimensional approach to provide a complete picture of circumstances in life. Therefore, ongoing comprehensive care recipient and caregiver evaluations provide the opportunity to understand the barriers that limit caregivers from seeking help, identify risk factors which could be easily missed and target caregivers prior experiencing a crisis. Intervention should be based more on crisis prevention and not on crisis management strategies. Adequate training, education and support targeted at increasing the caregivers' competency skills in care provision including why, when and how to access services, maximising the level of functional independence of the care recipient and effective communication to promote better co-ordination of care are key factors for the provision of effective residential respite care.



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## **APPENDICES**



**Appendix A: Request for permission to the Director and Approval**

Roberta Sultana  
Block B4, Flat 4,  
Prof. Walter Ganado Street,  
Pembroke, PBK 1551

24<sup>th</sup> July 2016

Mr. Patrick Vella  
Director of Elderly and Community Care  
Sta. Venera

Dear Mr. Vella,

### **Re: Research Proposal**

I am Roberta Sultana a senior allied health professional occupational therapist who works at St. Vincent de Paul long-term care facility. I have been accepted by the Faculty of Social Wellbeing at the University of Malta to read for a Masters Degree in Geriatrics and Gerontology. As part fulfillment of this degree I am proposing to carry out a study entitled: *The public respite care service for older people in Malta: An evaluation*. The aim of this research is to provide an evaluation of the state residential respite care service for older persons, and empirical research shall be conducted at Casa Leone and St. Vincent de Paul long-term care facility.

In this respect, I wish to ask your Department's permission regarding the possibility of visiting Casa Leone on different occasions so that I will be in a better position to understand the context and the way the respite care system operates at this home.

Moreover, I wish to gain permission to send an invitation letter to a small number of potential informants (caregivers) through 'Ċentru Servizz Anzjan' (which shall act as a gatekeeper) to take part in a semi-structured interview. This means that I will not have direct access to the persons who applied and made use of the service. If eligible caregivers show interest to participate in the study, they shall be invited to contact me by phone, e mail or by post (a form together with a self-addressed envelope will be provided by the researcher) in order to clarify any questions they might have. After ten days, participants will be sent a reminder by 'Ċentru Servizz Anzjan' regarding their participation in the study. If no response is received within ten days following the reminder, no further reminders will be sent.

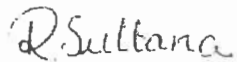
I am aware I have to adhere strictly to ethical issues relating to informed consent and confidentiality. Approval from the Faculty and University Research Ethics Committee will be sought. The study will be carried out under the supervision of Dr. Marvin Formosa from the University of Malta.

I am very grateful for your time in reading all this information and I really look forward for a positive reply to be able to carry out this research study. Your support for this project is greatly appreciated.

Should you require further information, I can be contacted on 79908974/ 22912220 or by e-mail: roberta.a.sultana@gov.mt.

Thanking you in advance.

Kind regards,

A handwritten signature in cursive script that reads "R. Sultana".

Roberta Sultana  
Senior Allied Health Professional - OT

## RE: Request for permission please

Vella Patrick A at MFSS-Elderly

Sent: 25 July 2016 19:19

To: Sultana Roberta at MFSS-SVPR

Cc: marvin.formosa@um.edu.mt; Pavia George at MFSS-Elderly; Camilleri Silvio A at MFSS-Elderly; Vella Alexander B at MFSS-Elderly

Dear Ms Sultana,

The Department for Active Aging & Community Care finds no objection to you performing data collection at Casa Leone as part of your research project "*The public respite care for older people in Malta: An Evaluation*" and to engage with a small number of caregivers through Centru Servizz Anzjan provided that all required approvals are obtained via University Research & Ethics Committee, and that all data protection and ethical considerations are safeguarded.

I would like to take this opportunity to wish you success in your studies.

Do not hesitate to contact the undersigned should you require any clarifications.

Best regards,

Patrick Vella

Director

Active Ageing & Community Care Directorate

t: +356 22788530 e: [patrick.a.vella@gov.mt](mailto:patrick.a.vella@gov.mt) | [www.activeageing.gov.mt](http://www.activeageing.gov.mt)

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PARLIAMENTARY SECRETARIAT FOR RIGHTS OF  
PERSONS WITH DISABILITY AND ACTIVE AGEING  
469, St Joseph High Road, Santa Venera

**From:** Sultana Roberta at MFSS-SVPR

**Sent:** 25 July 2016 16:38

**To:** Vella Patrick A at MFSS-Elderly

**Cc:** marvin.formosa@um.edu.mt

**Subject:** Request for permission please

Dear Mr. Vella,

Hope this e-mail finds you well. Attached please find information about the study I am planning to carry out as part fulfilment for the Masters Degree in Geriatrics and Gerontology. I am requesting your permission to be able to carry out the data collection pertaining to the study.

I look forward for a positive reply.

Yours sincerely

Roberta Sultana

Senior Allied Health Professional - Occupational Therapist

SVP

----- Original Message -----

Subject: FW: Request for permission please  
From: Sultana Roberta at MFSS-SVPR  
To: Vella Patrick A at MFSS-Elderly  
CC:

Dear Mr. Vella,

I am presently carrying out a study entitled 'The public respite care for older people in Malta: An Evaluation'. I now have ethics clearance from the University of Malta.

During an appointment I had at 'Centru Servizz Anzjan' they informed me that as from last August the state started providing residential respite at St. Elizabeth Home in Rabat, Malta. I would like to ask your permission to visit St. Elizabeth home and carry out observations as part of phase 1 of my study please. I am also carrying out observations at Casa Leone.

Many thanks and kind regards,

Roberta Sultana

---

**From:** Vella Patrick A at MFSS-Elderly  
**Sent:** 25 July 2016 21:00  
**To:** Sultana Roberta at MFSS-SVPR  
**Subject:** Re: Request for permission please

Anytime. Good luck Roberta

----- Original Message -----

Subject: RE: Request for permission please  
From: Sultana Roberta at MFSS-SVPR  
To: Vella Patrick A at MFSS-Elderly  
CC: [marvin.formosa@um.edu.mt](mailto:marvin.formosa@um.edu.mt)

Dear Mr.Vella,

Thank you so much for your prompt reply and for giving me permission to carry out the data collection once all required approvals are granted from the University Research and Ethics Committee.

I will be contacting in due course.

Kind regards

Roberta Sultana

---

**From:** [mef@trends.com.mt](mailto:mef@trends.com.mt) [[mef@trends.com.mt](mailto:mef@trends.com.mt)] on behalf of Marie Eleanor Farrugia  
[[mef@primecare.com.mt](mailto:mef@primecare.com.mt)]

**Sent:** 15 December 2016 14:44

**To:** Sciberras Maria at MFSS-Elderly

**Cc:** Vella Alexia at MEAIM; Camilleri Silvio A at MFSS-Elderly; Vella Patrick A at MFSS-Elderly; Sultana Roberta at MFSS-SVPR; Joseph Morley

**Subject:** Re: Request for permission please

Dear Maria,

Thank you for your email.

We have since been in contact with Ms Sultana who shall be visiting after the festive season.

Best Wishes to you and your family.

Regards,

Marie

Dr Marie Eleanor Farrugia

Managing Director

T: [+356 2703 5105](tel:+35627035105) | M: [+356 7909 1923](tel:+35679091923) | E: [mef@primecare.com.mt](mailto:mef@primecare.com.mt)

**Appendix B: Request for permission to the Chief Executive Officer and  
Approval**

Roberta Sultana  
Block B4, Flat 4,  
Prof. Walter Ganado Street,  
Pembroke, PBK 1551

24<sup>th</sup> July 2016

Dr. Josianne Cutajar  
Chief Executive Officer  
St. Vincent de Paul  
Luqa

### **Re: Research Proposal**

Dear Dr. Cutajar,

I am Roberta Sultana a senior allied health professional occupational therapist who works at St. Vincent de Paul long-term care facility. I have been accepted by the Faculty for Social Wellbeing at the University of Malta to read for a Masters Degree in Geriatrics and Gerontology. As part fulfillment of this degree I am proposing to carry out a study entitled: *The public respite care service for older people in Malta: An evaluation*. The aim of this research is to provide an evaluation of the state residential respite care service for older persons. I am proposing to carry out the data collection from both Casa Leone and St. Vincent de Paul.

In this respect, I am contacting your good self to request permission to document observational field notes and carry out participant observations at the respite ward as part of my research. The purpose is to give an in-depth description of the context I am referring to and to document my observations regarding the different services offered while the older person is for a short-stay at the respite ward.

I have contacted Mr. Patrick Vella (Director of Elderly and Community Care) to request permission regarding contacting relatives who made use of the respite service over the last year. Once permission is granted I intend to carry out semi-structured face to face interviews among a small number of informal caregivers who made us of either Casa Leone or St. Vincent de Paul. 'Centru Servizz Anzjan' will act as a gatekeeper.

I am aware I have to strictly adhere to ethical issues relating to informed consent and confidentiality. Approval from the Faculty and University Research Ethics Committee will be sought. The study will be carried out under the supervision of Dr. Marvin Formosa from the University of Malta.


I am very grateful for your time in reading all this information and I really look forward for a positive reply to be able to carry out this research study. Your support for this project is greatly appreciated.



Should you require further information, I can be contacted on 79908974/ 22912220 or by e-mail: roberta.a.sultana@gov.mt.

Thanking you in advance.

Kind regards,

A handwritten signature in cursive script that reads "R. Sultana".

Roberta Sultana  
Senior Allied Health Professional - OT

## RE: Request for permission please

Cutajar Josianne at MFSS-SVPR

Sent: 26 July 2016 07:27

To: Sultana Roberta at MFSS-SVPR

Cc: marvin.formosa@um.edu.mt

Dear Roberta

Well done on your studies and thank you for choosing to include the services at SVP in your research. While we wish you the best of luck we will be looking forward to the outcome and recommendations thereafter.

I am copying Dr Fiorentino so that you may liaise with him on this project.

Regards

Dr Josianne

CEO SVPR

St. Vincent De Paul Residence

t: +356 22912499 e: [josianne.cutajar@gov.mt](mailto:josianne.cutajar@gov.mt) | [www.activeageing.gov.mt](http://www.activeageing.gov.mt)

*Kindly consider your environmental responsibility before printing this e-mail*

MINISTRY FOR THE FAMILY AND SOCIAL SOLIDARITY

St Vincent de Paul Residence

**From:** Sultana Roberta at MFSS-SVPR

**Sent:** Monday, 25 July 2016 16:48

**To:** Cutajar Josianne at MFSS-SVPR

**Cc:** marvin.formosa@um.edu.mt

**Subject:** Request for permission please

Dear Dr. Cutajar,

I hope this e-mail finds you well. I have been accepted to read for a Masters Degree in Geriatrics and Gerontology and as part fulfilment for this degree I am planning to carry out a dissertation entitled: The public respite care service for older people in Malta: An evaluation. Attached please find further information regarding this study.

I look forward for a favourable reply.

Many thanks and kind regards,

Roberta Sultana



Saint Vincent  
De Paul  
Using Love to care for all

Office of Medical Superintendent  
St. Vincent de Paul  
Ingieret Road  
Luqa LQA 3301  
Tel: 2291 2203  
ronald.fiorentino@gov.mt

Roberta Sultana  
Block B4, Flat 4,  
Prof. Walter Ganado Street,  
Pembroke, PBK 1551

22nd December 2016

Ms Sultana,

Subject: Masters in Gerontology.

Reference is made to your letter addressed to Dr Cutajar – CEO SVP and referred to me.

There is **no objection** for your kindself to carry out your research at St.Vincent de Paul Long-term care Facility.

You are kindly reminded that all ethical and legal observations are to be upheld and participants are to be informed in writing and that consent is sought prior to the data collection. In those cases where consent cannot be obtained from the subject, consent must be sought for the relevant person. Filming, recording and photographs will only be allowed if consent is achieved and the privacy of the individual would be suitably preserved and that the integrity and privacy of the place, notably SVP would be safeguarded.

You are cordially also reminded that all ethical conditions as stipulated by the University of Malta or any other such entity that might have a legal / vested interest in your research are adhered to.

Wishing you all the best in your studies.

Regards

A handwritten signature in black ink, appearing to be 'R. Fiorentino', with a long horizontal flourish extending to the right.

Dr Ronald Fiorentino MD MBA (*Henley*)

PGDip.Ger (*Hons*), Dip.Ind.Rel (*Camb*)

**Appendix C: Approval from University of Research Ethic Committee**

**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: *T. Calafete*

Date: *14/10/2016*

**To be completed by University Research Ethics Committee**

We have examined the above proposal and advise

**Acceptance**

**Refusal**

**Conditional Acceptance**

For the following reason/s:

Signature: *nf*

Date: *14/11/2016*

**Appendix D: Invitation letter to participants (English version)**

Date: \_\_\_\_\_

**Participant Information Sheet**

**The public respite care service for older people in Malta: An evaluation**

Dear Madam/Sir,

I am Roberta Sultana and I work as a senior allied health care professional occupational therapist at Saint Vincent de Paul long-term care facility. I am undertaking a Masters degree in Geriatrics and Gerontology with the Faculty for Social Wellbeing at the University of Malta. As part fulfillment of this degree I am conducting a study entitled '*The public respite care service for older people in Malta: An evaluation*'. This study is being supervised by Dr Marvin Formosa from the Faculty for Social Wellbeing at the University of Malta who can be contacted on email [marvin.formosa@um.edu.mt](mailto:marvin.formosa@um.edu.mt) or office telephone 2340 3103

This study aims to provide an evaluation of the state residential respite care service for older people in Malta. As part of this research I would like to carry out a number of interviews with informal caregivers who made use of the residential respite service during the period from January 2016 till December 2016 (both months included).

I would like to invite you to take part in this study since you made use of the respite care service during the past year. Your participation in this study involves a one face to face semi-structured interview. The interview will be held at a place and time convenient for you. The interview will last approximately 45 minutes depending on your responses. The interview needs to be audio-recorded in order to capture every detail. If you give consent some phrases you say might be quoted however you will not be identified in any way.


If you accept to take part in the study, kindly complete the attached form and send it in the self-addressed envelope provided. I will contact you myself once you send me your details. If you prefer a quicker reply route, you can send me your details via e-mail on [roberta.a.sultana@gov.mt](mailto:roberta.a.sultana@gov.mt) or contact me personally on my mobile number on 79908974.

Confidentiality will be maintained at all times. The information collected during the interview will be password protected and kept in a secure cupboard. On successful completion of the study, all data collected will be destroyed. You are not obliged to participate in this study and can withdraw from it at any time. If you decide not to participate, this will not influence the care you receive in any way. No payment will be given for taking part in this study.

Your collaboration is very important as through your responses I will be able to understand better your views and experiences you encountered when using respite care. Results generated from the study have the potential improve the public respite service.

Thank you for reading this information sheet. If you have any further questions about the study do not hesitate to contact me on the contact details shown above.

Your sincerely,



Roberta Sultana  
Senior Allied Health Professional-Occupational Therapist



**Appendix E: Invitation letter to participants (Maltese version)**

## Ittra ta' Informazzjoni

### **The public respite care service for older people in Malta: An evaluation**

Għażiż/a Sinjur/a,

Jiena Roberta Sultana, naħdem bħala 'senior allied health professional occupational therapist' f' San Vincenz de Paul. Bħalissa qiegħda nagħmel riċerka bħala parti mill- 'Masters degree' f' 'Geriatrics and Gerontology' fi hdan il-Fakulta' għat-Tisħiħ tas-Socjeta' fl-Universita' ta' Malta. Bħala parti minn dan l-istudju qed nagħmel evalwazzjoni tas-servizzi pubbliċi tar-'respite' f' Malta għall-persuni anzjani. Dan l-istudju qiegħed isir taħt is-superviżjoni ta' Dr. Marvin Formosa mill-Fakulta' għat-Tisħiħ tas-Socjeta' mill-Universita' ta' Malta li jista' jigi ikkuntatjat b'imejl fuq marvin.formosa@um.edu.mt jew fuq dan in-numru 2340 3103.

L-iskop ta' dan l-istudju huwa li nipprovdu evalwazzjoni tas-servizzi pubbliċi li jipprovdu 'residential respite care' għall-persuni anzjani f'Malta. Bħala parti minn din ir-riċerka nixtieq nagħmel numru ta' intervisti ma persuni li jieħdu hsieb anzjani u għamlu użu mis-servizz tar-'respite' fil-perjodu bejn Jannar 2016 sa Diċembru 2016 (ix-xahrejn li huma inklużi).

Jiena nixtieq nistiednek biex tieħu sehem f'dan l-istudju għaliex inti għamilt użu mis-servizz tar-'respite care' din l-aħħar sena. Il-partecipazzjoni tiegħek tinvolvi li tieħu sehem f'intervista. L-intervista issir f'post u hin konvenjenti għalik. L-intervista tieħu bejn wieħed u ieħor hamsa u erbgħin minuta skont it-twegibiet tiegħek. L-intervista hemm bżonn li tiġi rrekordjata halli jkollna kull dettal. Jekk inti tagħti l-kunsens tiegħek xi wħud mill-frazzjiet jistgħu jiġu kkwotati imma inti mhux ser tiġi identifikat bl-ebda mod.

Jekk taċċetta li tieħu sehem f'dan l-istudju, jekk jogħġbok imla d-dettalji tiegħek fil-formula mehmuża ma' din l-ittra u ibgħatha fl-envelop pprovdut. B'hekk jiena nkun nista' nikkuntatjak skont id-dettalji li tkun bgħatli inti stess. Jekk tippreferi tista' tibgħtli d-dettalji tiegħek fuq roberta.a.sultana@gov.mt jew tikkuntatja lili personali fuq in-numru tal-mowbajl 79908974.

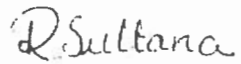
Il-kunfidenzjalita' ser tiġi assicurata kull hin. L-informazzjoni miġbura waqt l-intervista ser tinzamm f'kompjuter 'password protected' u ser tinzamm f'post sigur. Wara li l-istudju jkun twettaq kull informazzjoni miġbura tinqered. Mhux bilfors tippartecipa f'dan l-istudju u tista' tieqaf meta trid bla ebda konsegwenzi għalik. Jekk ma tippartecipax, l-għażla tiegħek mhux ser tinfluwenza bl-ebda mod is-servizzi li qiegħed tirċievi jew li ser tapplika għalihom. Mhux ser ikun hemm l-ebda hłas talli inti tieħu sehem.

Il-kollaborazzjoni tiegħek hija importanti hafna għax permezz tar-risposti tiegħek inkun nista' nifhem aħjar l-esperjenzi li inti għaddejt minnhom meta għamilt użu mis-servizz tar-'respite'. Ir-rizultati minn dan l-istudju għandhom il-potenzjal li jtejbu is-servizzi tar-'respite'.

Data: \_\_\_\_\_

Nixtieq niringrazzjak talli qrajt din l-informazzjoni. Jekk ikollok xi mistoqsijiet tiddejjaqx tikkuntattjani direttament fuq id-dettalji miktubin hawn fuq.

Dejjem tieghek,



Roberta Sultana  
Senior Allied Health Professional Occupational Therapist

**Appendix F: Potential participants' contact details from (English version)**

### Participant's Contact Details

*(If you accept to participate in this study kindly complete this form and send it in the envelope provided)*

Name: \_\_\_\_\_

Surname: \_\_\_\_\_

Home Address:

---

---

Home telephone number: \_\_\_\_\_

Mobile number: \_\_\_\_\_

E-mail: \_\_\_\_\_

Kindly indicate how you wish to be contacted *(please tick (✓) your preferred source)*

Home telephone

Mobile

Post

E-mail

Kindly indicate which is the best time to contact you *(please tick (✓) your preferred source)*

Morning

Afternoon

Evening

Thank you for your time and cooperation

**Appendix G: Potential participants' contact details form (Maltese version)**

### Dettalji tal-Partecipant/a

*(Jekk jgħogbok imla d-dettalji tiegħek jekk tixiteq tiegħu sehem f'dan l-istudju u ibgħata fl-envelop ipprovdut)*

Isem: \_\_\_\_\_

Kunjom: \_\_\_\_\_

Indirizz tad-dar:

---

---

Numru tat-telefone tad-dar: \_\_\_\_\_

Numru tal-Mowbajl: \_\_\_\_\_

Imejl: \_\_\_\_\_

Jekk jgħogbok indika kif tixiteq li nikkuntatjak (*Għamel sinjal (✓) hdejn il-mezz li tippreferi*)

Fuq in-numru tat-telefone tad-dar

Fuq il-mowbajl

Bil-post

Bl-imejl

Jekk jgħogbok indika fi x' hin tixiteq (*Għamel sinjal (✓) hdejn il-hin li tippreferi*)

Filgħodu

Wara nofs in-nhar

Filgħaxija

Grazzi tal-kooperazzjoni tiegħek

**Appendix H: Older persons' interview schedule (English version)**



**Interview guide for persons admitted temporarily for residential respite care during the participant observation phase.**

- 1) Is this your first experience here? Or else, have you ever been somewhere similiar to here?
- 2) What was the reason that you came here?
- 3) Who decided that you come here for a short period of time?
- 4) How are you spending your time here?
- 5) What type of activities are you participating in?
- 6) Is there anything that you like here?
- 7) Is there anything that you dislike here?
- 8) If you had to come here, would you come again?
- 9) If you had the oppportunity to change something, what would you change?

*Notes for the researcher*

Age (to be filled in if the person states his age or her age during the interview): \_\_\_\_\_

Level of assistance required for completion of personal activities of daily living: \_\_\_\_\_

Mobility (to indicate if the person is able to mobilise on his or her own or makes use of a frame or requires a wheelchair for mobility): \_\_\_\_\_

**Appendix I: Older persons' interview schedule (Maltese version)**

## **Mistoqsijiet gwida għal- intervista mal-persuni anzjani li qegħdin jagħmlu użu mis-servizz tar-‘residential respite’**

- 1) Din l-ewwel esperjenza tiegħek hawnhekk? Jew inkella ġieli mort x’imkien ieħor simili?
- 2) X' kienet ir-raġuni li ġejt hawnhekk?
- 3) Ta’ min kienet id-deċizjoni li tiġi hawnhekk għal fiit taż-żmien?
- 4) Kif qed tqatta' l-ħin tiegħek hawnhekk?
- 5) X' attivitajiet qiegħed\qiegħdha tipparteċipa fihom?
- 6) Hemm xi affarijiet li jgħoġbuk?
- 7) Hemm xi affarijiet li qegħdin jdejquk?
- 8) Kieku kellek tiġi hawn, terġa tiġi?
- 9) Kieku kellek l-opportunita’ li tibdel xi haġa, xi tbiddel?

### *Noti għar-riċerkatur*

Eta’ (timtela’ jekk il-persuna tgħid kemm għandha\għandu żmien waqt l-intervista’): \_\_\_\_\_

Livell ta’ għajjnuna għall- attivitajiet personali: \_\_\_\_\_

Mobilita’: jekk il-persuna timxi waħedha jew tagħmel użu minn xi apparat biex timxi bħal għajjnuna ta’ ‘frame’ jew sigġu tar-roti: \_\_\_\_\_

**Appendix J: Caregivers' interview schedule (English version)**

## Interview Schedule

### Section A: Demographic Profile of Informal care giver(s):

1. What is your relationship with the care recipient?

Prompt

*-mother/father/brother/sister/sibling/friend*

2. For how long have you been caring for this person?
3. How old is your care recipient?
4. Have you got any help from other family members/friends/neighbours/formal care/community care support services?
5. Do you co-reside with your care recipient or do you live in a different dwelling?
6. What is your highest level of education?
7. Are you currently employed?

Prompt

*If you live in a different dwelling do you live in the same locality of the person you take care of or in another locality?*

8. For how many hours per week do you provide care?
9. What type of care do you provide?

Prompt

*-ADL's: feeding, bathing, dressing, grooming, oral hygiene, continence, toilet use, transferring, mobility and stairs.*

*-IADL's: taking medication, cooking, laundry, cleaning, shopping, ironing, money management.*

10. Do you feel that there are any barriers that limit your ability to provide good care?
11. Was it your choice or was this role imposed on you?
12. What does this role mean to you?
13. Before you started to care for this person did you have any similar experiences?

Prompt

*-If yes, with whom?*

*-Did you feel prepared enough for this role?*

*-Did you receive any form of training prior starting your caring role?*

14. Has your role as a caregiver affected you in any way?

Prompt

*-In terms of: work, health, familial relationship, emotional well-being, leisure, economical aspect.*

*-Did your role in the family change in some way or another?*

*-What were the reactions from the rest of the family members?*

*-Did they offer any kind of support in the circumstance you found yourself into?*

*-Relationship (perceptions towards care recipients)*

15. Do you often feel the need to seek help?

**Section B: Respite Care**

16. How did you get to know about respite?

Prompt

*-Family/friends/social media*

17. How many times have you used respite?

Prompt

*-Where? (Casa Leone, Saint Vincent de Paul and Saint Elizabeth Home)*

*-For how long? (days/weeks)*

16. What type of service/s were you offered at respite?

*-Medical, Clinical, Social, Others*

17. In addition to residential respite, do you use other services?

Prompt

*-Community care support services/activity centre?*

18. What do you understand by the term residential respite care service?

19. What were the factors that led you to seek residential respite care?

20. What was your experience of residential respite service?

21. Did you encounter any challenges when using this service?

22. Were you satisfied with the service provided?

23. Were you given the dates that you applied for? Did you use the full period given?

24. Did the service meet your needs and expectations?

**Appendix K: Caregivers' interview schedule (Maltese version)**

## Gwida għall- Intervista

### Informazzjoni demografika fuq il-persuna/persuni li jagħti/u l għajjnuna

- 1) X'jiġi jew x'tiġi minnek il-persuna li qiegħda tirċievi l-għajjnuna tiegħek/ li inti tiehu ħsieb?

#### -Suggeriment

*-Missieriek/ommok/huk/ohtok/habib/a/il-girien tiegħek*

- 2) Kemm ilek tiehu ħsieb din il-persuna?
- 3) Kemm għandha/għandu zmien il-persuna li inti tiehu ħsieb?
- 4) Għandek xi tip ta' għajjnuna mingħand membri tal-familja/hbieb/girien/għajjnuna formali bħal servizzi provduti fil-kommunita'?
- 5) Inti toqgħod fl-istess residenza tal-persuna li toffrilha l-għajjnuna/ li tiehu ħsieb jew inkella toqgħod f' residenza oħra?
- 6) X'inhu l-għola livell ta' edukazzjoni tiegħek?
- 7) Inti bħalissa taħdem/impjegat?

#### -Suggeriment

*-Jekk inti ma toqgħodx go l-istess residenza toqgħod fl-istess lokalita' jew inkella go lokalita' oħra?*

- 8) Kemm il-siegha fil-gimgha tipprovdi l-għajjnuna tiegħek lil din il-persuna?
- 9) X'tip ta' għajjnuna taġti jew tipprovdi?

#### -Suggeriment

*-Attivitajiet ta' kuljum bażiċi: biex tiekol, biex tinħasel, biex tilbes, biex taġmel xagħra u taħsel sniena, kontinenza, biex tuża l-kamra tal-banju, biex tiċċaqlaq minn post għal ieħor, timxi u titla' t-taraġ.*

*-Attivitajiet ta' kuljum domestiċi/instrumentali: tiehu l-medicina, tisjir, hasil tal-ħwejjeġ, tindif, xiri, mġhodija u tqassim tal-flus.*

- 10) Thoss li hemm xi affarijiet li jillimitawlek l-abiltajiet tiegħek milli tipprovidi kura tajba?
- 11) Dan l-irwol kien għazla tiegħek jew kienet deċizzjoni imposta fuqek?
- 12) Xi jfisser ir- rwol tiegħek għalik?



13) Qabel bdejt toffri l-ghajjnuna tieghek lil din il-persuna kellek xi esperjenza/i simili?

-Suggeriment

*-Jekk iva, ma '/lil min?*

*-Thossok li kont preparat/a bizzejjed ghal dan ir-rwol?*

*-Ircivejt xi forma ta' tahrig qabel bdejt toffri l-ghajjnuna tieghek?*

14) L-irwol tieghek bhal persuna li qiegħed/qegħda toffri l-ghajjnuna affetwalek hajtek b'xi mod?

-Suggeriment

*-Qed nirreferi ghal fejn jidhol: xogħol, ir-relazzjoni tieghek mal-kumplament tal-familja, l-aspett emozzjonali tieghek, il-hin liberu tieghek, l-aspett ekonomiku*

*-L-irwol tieghek fil-familja tieghek inbidel b'xi mod?*

*-X'kienu r-rejazzjonijiet mil-kumplament tal-familja tieghek?*

*-Il-membri tal-familja tieghek offrewlek xi forma ta' support fic-cirkustanzi li sibt ruhek fihom inti?*

*-Relazzjoni (il-mod kif inti sirt thares lejn il-persuna li tiehu hsieb)*

13) Sikwit thoss il-bzonn li tfittex l-ghajjnuna?

**Sezzjoni B: Is-servizz tar-'Respite'**

14) Kif sirt taf bis-servizz tar-'respite'?

Suggeriment

*-Permezz tal-familja/hbieb/medja soċjali*

15) Kemm il-darba ghamilt uzu' mis-servizz tar-'respite'?

-Suggeriment

*-Fejn? (Casa Leone, San Vincenz de Paul u Saint Elizabeth Home)*

*-Ghal kemm zmien? (granet/gimghat)*

16) X'tip ta' servizz offrewlek ir-'respite'?

-Suggeriment

*-Mediku, Kliniku, Soċjali, Oħrajn*

17) Barra s-servizz ta l-‘residential respite’ tagħmel użu minn xi servizzi oħrajn?

-Suggeriment

*-Servizzi offruti fil-kommunita’/ Activity Centre*

18) Inti x’tifhem bil-frazi ‘residential respite care service’?

19) X’kienu l-fatturi li wassluk biex tagħmel użu mis-servizz tar-‘respite’?

20) Kif kienet l-esperjenza tiegħek meta għamilt użu mis-servizz tar-‘respite’?

21) Meta użat dan is-servizz iltqajt ma xi diffikultajiet?

22) Kont sodisfatt bis-servizz provdut?

23) Kont mogħti d-dati li inti applikajt għalihom? Għamilt użu mil-perjodu kollu li ġejt mogħti?

24) Is-servizz laħaq il-bżonnijiet u l-aspettativi tiegħek?

25) Kieku kellek tingħata l-opportunita’ li ttejjeb is-servizz, xi tbiddel?

26) Is-servizz tar-‘respite’ affetwak b’xi mod?

-Suggeriment

*-B’liema mod? Tista’ tagħti xi eżempji?*

27) Tikkonsidra terġa’ tagħmel użu minn dan is-servizz?

28) Inti tirrikommanda lil nies oħrajn bħalek (li qegħdin jiehdu ħsieb lil xi ħadd) jagħmlu użu minn dan is-servizz?

Qabel ma nagħlqu din l-intervista hemm xi ħaga oħra li xtaqt iżżid? Jekk jogħġbok ħossok liberu/a li tagħtini kwalunkwe suggeriment/i rigward xi affarijiet li jien forsi ma staqsejtekx dwarhom pero’ huma ta’ importanza għalik.

**Nixtieq niringrazzjak tal-partecipazzjoni u l-koperazzjoni li inti urejt f’ din l-intervista. Tiddejjaqx tikkuntatjani jekk għandek xi mistoqsijiet jew kummenti li tixtieq tgħaddi. Grazzi ħafna.**

**Appendix L: Consent form (English version)**

## CONSENT FORM

**Title of Project:** The public respite care service for older people in Malta: An evaluation.

**Please initial  
Box**

1. I confirm that I have read and fully understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction.
2. I understand that my participation is voluntary. I am free to withdraw at any time without giving any reason, without my medical care and legal rights being affected.
3. I understand that it is my right to refuse to answer any questions
4. I agree that the interview will be audio-recorded, am fully aware of the inconvenience which this may cause, and understand that full confidentiality shall be respected
5. I understand that the results achieved from the study will be published or reported, however I shall not be personally identified in any way, without my express written permission.
6. I agree that I will not receive any remuneration to take part in this study.
7. I agree to take part in the above study. (Researcher can be contacted on mobile number:79908974, e-mail address: roberta.a.sultana@gov.mt.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Academic Supervisor

**Appendix M: Consent form (Maltese version)**

## FORMULA TAL-KUNSENS

**Isem tal-Proġett:** The public respite care service for older people in Malta: An evaluation.

### Jekk jogħġbok ikteb l-inizzjali fil-kaxxa

1. Jiena nikkonferma li qrajt u fhimt l-informazzjoni kollha li nġhatat fil-karta għall- parteċipanti li ser jieħdu sehem fl-istudju msemmi hawn fuq. Jiena kelli l-oppunita` li nikkonsidra l-informazzjoni li ġiet mogħtija lili, insaqsi mistoqsijiet u kelli sodisfazzjon bit-twegibiet li nġhatajt.
2. Jiena nifhem li l-parteċipazzjoni tiegħi hija volontarja. Jiena nista'nieqaf mill-istudju f'kwalkwe ħin mingħajr ma' nagħti ebda raġuni u mingħajr ma tiġi affettwata l-kura tas-saħħa u d-drittijiet legali tiegħi.
3. Jiena nifhem li huwa dritt tiegħi li nirrifjuta milli nwieġeb għal xi mistoqsijiet.
4. Jiena naqbel li l-intervista tiġi 'audio-recorded' u jiena nifhem sewwa l-inkonvenjenzi li dan jista' joħloq, u nifhem li l-kunfidenzjalita' ser tiġi rispettata kull ħin.
5. Jiena nifhem li r-rizultati miksuba minn dan l-istudju ser jiġu ppublikati jew iddokumentati, pero`jiena mhux ser inkun identifikata personalment bl-ebda mod qabel ma jiena nagħti l-permess tiegħi bil-miktub.
6. Jiena naqbel li mhux ser nircievi hlas għall-parteċipazzjoni tiegħi.
7. Jiena naqbel li ser nieħu sehem f'dan l-istudju. Ir-riċerkatur jista'jiġi ikkuntattjat direttament fuq dan in-numru tal-mowbajl 79908974 jew imejl roberta.a.sultana@gov.mt.

\_\_\_\_\_  
Isem il-parteċipant/a

\_\_\_\_\_  
Firma

\_\_\_\_\_  
Data

\_\_\_\_\_  
Riċerkatur

\_\_\_\_\_  
Firma

\_\_\_\_\_  
Data

\_\_\_\_\_  
Supervajzer Akkademiku

**Appendix N: Elite interview schedule**

### Elite Interviews

1. From your experience, what is the scope of residential respite care? Is it possible to explain the process involved regarding the criteria adopted when your facility receives a referral from 'Ċentru Servizz Anzjan'?
2. What type of service is given to the older person and the caregiver once he or she is admitted at your facility?
3. Do you feel that residential respite services are catering for the needs of the caregivers and the care recipients residing in the community?
4. From your experience what are the main factors that lead caregivers to seek residential respite care?
5. Following the recent increase in the number of beds allocated for respite care, in your opinion, do you think that the supply is meeting the demand?
6. Where there any instances where the facility had to refuse individuals applying for residential respite care due to inadequate availability of beds?
7. Following the introduction of a financial fee (if the care recipient is left at the facility after a stipulated time), do you think this is decreasing the abuse on the system?
8. What are the main challenges that you usually encounter with residential respite care?
9. Do you think that having respite beds in sites hosting long-term care residents is more conducive to more admissions to long-term care?
10. Do you think there is enough awareness regarding the appropriate use of residential respite care? Can you mention any misconceptions related to respite care?
11. Do you feel that short-stay respite care services are actually delaying admission to long-term care facilities?
12. In your opinion what do policymakers need to do to support informal caregivers?
13. Would you recommend any other service/s that complement residential respite care?

*Before we conclude is there anything that you would like to add? Please feel free to give me any feedback and suggestions regarding what I might have not asked but is of importance to you.*

*Thank you once again for your participation and cooperation. Do not hesitate to contact me on [roberta.a.sultana.99@um.edu.mt](mailto:roberta.a.sultana.99@um.edu.mt) or on mobile number 79908974 if you have any further questions or comments. Thank you.*



**Appendix O: Permission letter and consent of Elite Interviewees**

Roberta Sultana  
Block B4, Flat 4,  
Professor Walter Ganado Street,  
Pembroke, PBK 1551

1<sup>st</sup> December 2016

**Re: Study on Residential Respite Care**

Dear Sir/Madam,

I am Roberta Sultana a senior allied health professional occupational therapist and I have been accepted by the Faculty for Social Wellbeing at the University of Malta to read for a Masters Degree in Geriatrics and Gerontology. As part fulfillment of this degree I am proposing to carry out a study entitled: *The public respite care service for older people in Malta: An evaluation*. My research supervisor is Dr. Marvin Formosa from the University of Malta.

The aim of this research is to provide an evaluation of the state residential respite care service for older persons. The study is going to be divided into different phases. *Phase 1*: participation observations during field visits at the sites providing the publicly-funded residential respite service for older persons in Malta. *Phase 2*: one-time face to face interview with caregivers who made use of the service in during January to December 2016. In *phase 3*, I intend to carry out elite interviews with the management who are responsible for the provision of residential respite in the respective facilities. The aim is to explore the views of service providers. In this regard, I would like to invite you to participate in face to face semi-structured interviews regarding the provision of the public residential respite care service to older persons. The interview schedule is being attached for your perusal.

I am very grateful for your time in reading all this information and I really look forward for your participation in this research study. Your support for this project is greatly appreciated.

Yours sincerely,



Roberta Sultana  
Senior Allied Health Professional – Occupational Therapist

**Appendix P: Local application for respite services**



## SERVIZZ TA' 'RESPITE'

<b>Użu Uffiċjali Biss</b>	
Numru tal-Applikazzjoni _____	Minn _____ Sa _____
Data	Informazzjoni

### L-APPLIKAZZJONI TRID TKUN MIMLIJA BID-DETTALJI KOLLHA BIEX TIĠI KKUNSIDRATA U PPROĊESSATA

#### SEZZJONI A: Timtela' mit-tabib tal-familja

##### 1. Dettalji dwar l-Applikant (carer):

Isem u Kunjom: \_\_\_\_\_

Numru tal-Karta tal-Identita' \_\_\_\_\_ Relazzjoni mal-anzjan \_\_\_\_\_

Indirizz ta' fejn joqgħod l-applikant: \_\_\_\_\_

Kodiċi Postali: \_\_\_\_\_

Numru tat-Telefon: \_\_\_\_\_ Mobile: \_\_\_\_\_

Hemm Prokura: IVA / LE - Jekk IVA inkludi kopja ma' din l-applikazzjoni.

##### 2. Dettalji dwar l-Anzjan/a:

Isem u Kunjom: \_\_\_\_\_

Numru tal-Karta tal-Identita': \_\_\_\_\_ Eta' \_\_\_\_\_

Stat Ċivili: \_\_\_\_\_

Indirizz fejn t/jgħix: \_\_\_\_\_

Numru tat-Telefon: \_\_\_\_\_ Mowbajl: \_\_\_\_\_

##### 3. Dettalji dwar ir-'Respite':

Din hija l-ewwel darba li qed issir applikazzjoni għas-Servizz ta' 'Respite'?  IVA  LE  
Jekk LE, l-aħħar dati li sar użu minn dan is-servizz: \_\_\_\_\_

Ikteb id-dati mixtieqa għal 'Respite'

Minn \_\_\_\_\_

Sa \_\_\_\_\_



X'inhuma r-raġunijiet għalfejn qed issir din it-talba? Ehmeż id-dokument relattiv.

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**4. Storja Medika**

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**5. Mediċini li t/jieħu l-Anzjan/a**

Mediċina	Doża	Kemm il-darba

6. Komunikazzjoni	Tajba	Mhux hażin	Batuta	Xejn
Smiegħ				
Kliem				
Vista				

**7. Stat Mentali**

Orjentament (Hin, Post u Persuna)

- Dejjem
- Kultant
- Kwazi qatt/Qatt

Memorja

- Tajba
- Nieqsa ftit
- Nieqsa ħafna

Alluċinazzjonijiet/Delużjonijiet



Ideat Paranojiċi  
Imġieba

- 
- Tajba
- Aġitata
- Aggressiva

Abbuż Droga/Alkohol

Speċifika: \_\_\_\_\_

8. Attività' ta' Kuljum	Indipendenti	Kapaċi bi ftit għajnuna	Jehtieġ għajnuna
Ikel			
Ilbies			
Iġene Personali			
Preparazzjoni tal-ikel			
Kontinenza			

### 9. Mobilita'

- Timxi distanzi twal bla għajnuna
- Timxi distanzi qosra bla għajnuna
- Timxi bl-għajnuna ta' *walking aid / bastun*
- Timxi meta mgħejjuna minn persuna
- Tidhol u toħroġ mis-sodda mingħajr għajnuna
- Tidhol u toħroġ mis-sodda bl-għajnuna
- Konfinata f'pultruna/sigġu tar-roti
- Fis-sodda l-ħin kollu

### 10. Kontinenza (għall-urina)

(għall-ippurgar)

- |  |  |
|--|--|
| <input type="checkbox"/> Kultant hemm problema     | <input type="checkbox"/> Kontinenti            |
| <input type="checkbox"/> Jintużaw ħrieqi           | <input type="checkbox"/> Kultant hemm problemi |
| <input type="checkbox"/> Jintuża sheath catheter   | <input type="checkbox"/> Jintużaw ħrieqi       |
| <input type="checkbox"/> Jintuża urethral catheter | <input type="checkbox"/> Għandu/ha kolostomija |

## 11. Bżonn ta' Kura

- Kura u/jew attenzjoni minima
- Assistenza medika
- Kura medika
- Tehid ta' mediċini
- Iġjene personali

- Ikel:
- NG tube
  - Peg feeding
  - Liquidised
  - Semi solids
  - Dieta Speċjali (speċifika)

- 
- Kura tal-ġilda (e.g. Pressure areas)
  - Bladder/bowel care
  - Bżonnijiet speċjali (speċifika)

- 
- Livell ta' dipendenza
    - Indipendenti
    - Bżonn ta' ftit għajjnuna
    - Dipendenti

## 12. Stat Soċjali

Joqgħod waħdu:

- Dejjem  Mhux dejjem  Qatt

*Jekk l-applikant jgħix dejjem jew xi daqqiet waħdu, agħti aktar dettalji:*

Jorqod waħdu

- Dejjem  Mhux dejjem  Qatt

Jirċievi viżiti:

- Inqas minn darba fil-ġimgħa  Kuljum/ta' spiss

Min huma dawk li jieħdu ħsiebu?

- Familjari  Hbieb/Girien  Komunita' bi ħlas  Hadd

Min jgħix mal-anzjan/a? Niżżel id-dettalji hawnhekk.



**Dipartiment għall-Anzjani  
u Kura fil-Komunità**

Elderly and Community Care Department



SEGRETARJAT PARLAMENTARI  
GĦAD-DRITTIJET TA' PERSUNI B'DIŻABILITÀ  
U ANZJANTA ATTIVA

1. Isem: \_\_\_\_\_ I.D. \_\_\_\_\_ Telefon \_\_\_\_\_  
\_\_\_\_\_
2. Isem: \_\_\_\_\_ I.D. \_\_\_\_\_ Telefon \_\_\_\_\_  
\_\_\_\_\_
3. Isem: \_\_\_\_\_ I.D. \_\_\_\_\_ Telefon \_\_\_\_\_  
\_\_\_\_\_

L-Anzjan/a tirrikjedi attenzjoni minn:

1. Carer (attenzjoni minima)
2. Carer (attenzjoni kontinwa)
3. Infermiera (attenzjoni minima)
4. Infermiera (attenzjoni kontinwa)

Isem \_\_\_\_\_ u \_\_\_\_\_ Kunjom \_\_\_\_\_ tat-Tabib: \_\_\_\_\_  
Numru \_\_\_\_\_ tal-Kunsill \_\_\_\_\_ Mediku: \_\_\_\_\_

Firma tat-Tabib \_\_\_\_\_ Data \_\_\_\_\_

Indirizz:

\_\_\_\_\_ Kodiċi Postali: \_\_\_\_\_

Numru tat-Telefon: \_\_\_\_\_ Mowbajl: \_\_\_\_\_

**Kunsens mill-Anzjan/a:**

Jiena naċċetta li nirċievi servizz ta' 'Respite' minn \_\_\_\_\_ sa \_\_\_\_\_

Isem u kunjom; \_\_\_\_\_ Isem u kunjom: \_\_\_\_\_

I.D. : \_\_\_\_\_ I.D. : \_\_\_\_\_  
\_\_\_\_\_

Firma: \_\_\_\_\_ Firma tax-xhud (tabib) \_\_\_\_\_  
\_\_\_\_\_





**SEZZJONI B: TIMTELA' MINN L-APPLIKANT (CARER)  
DIKJARAZZJONI TA' MIN JAGĦMEL IT-TALBA (CARER)**

Niddikjara li d-dettalji mogħtija minni f'din l-Applikazzjoni jew kif ġew moqrija lili huma korretti. Jiena nintrabat li meta jagħlaq iż-żmien stipulat tar-'Respite', l-anzjan/a jerġa' lura d-dar.

Isem id-dikjarant: \_\_\_\_\_

Numru tal-karta tal-Identita': \_\_\_\_\_

\_\_\_\_\_  
Firma tal-Applikant / Dikjarant

**Informazzjoni dwar is-servizz ta' 'Respite'**

1. Is-servizz ta' 'Respite' jagħti ftit żmien ta' mistrieħ lil min jieħu ħsieb lill-anzjani li għadhom jgħixu ġewwa darhom. Minħabba f'hekk, is-sodod li jintużaw għas-servizz ta' 'Respite' qegħdin hemm biss għal użu temporanju. L-anzjan għandu jikkupa s-sodda tar-'Respite' biss għal dak iż-żmien, kif mifthiem mal-Amministratur ta' dan is-servizz.
2. Din il-kopja tal-kuntratt meħmuż f'din l-applikazzjoni trid tkun iffirmata minn l-applikant kuranti (carer) biex l-applikazzjoni tkun tista' tiġi kkunsidrata.
3. It-tul ta' żmien mogħti għall-użu ta' sodda fir-'Respite' ivarja skond il-każ, iżda dan m'għandux ikun għal aktar minn tliet (3) ġimgħat.
4. Qabel l-anzjan/a t/jiddaħħal għar-'Respite' irid jerġa' jsir eżami mediku mit-tabib tal-familja mhux aktar kmieni minn tliet ijiem qabel, fuq il-formula taċ-ċertifikat li qed tiġi pprovduta ma' din l-applikazzjoni.
5. Jekk iċ-ċertifikat jindika li skont il-kundizzjoni tal-anzjan/a mhux addattat li jiddaħħal fir-'Respite', is-servizz ma' jinghatax.
6. Id-Dipartiment tal-Anzjani u Kura fil-Komunità ma' jerfa' l-ebda responsabbilita' illi ma' tkunx f'pożizzjoni li jonora l-applikazzjoni għal 'Respite'.
7. Għal kull applikazzjoni tingħata rċevuta.
8. L-applikant għandu jibgħat l-applikazzjoni, mimlija u ffirmata kif meħtieġ fl-indirizz:

**ĊENTRU SERVIZZ ANZJAN  
3, TRIQ ZEKKA  
IL-BELT VALLETTA**



9. Jekk tixtieq aktar informazzjoni ċempel fuq in-numru tat-telefon **2278 8806**, mit-Tnejn sal-Ġimgħa mit-08.00 – 14.00.
  
10. Id-Dipartiment qed joffri dan is-servizz skont id-disponibilità meta jkun qed jintalab is-servizz. Kull talba tiġi kkunsidrata u mistħarġa mill-istess Dipartiment. F'każ li t-talba tintlaqa', is-servizz jiġi offrut fil-postijiet indikati mill-istess Dipartiment.

ĊENTRU SERVIZZ ANZJAN  
3, Triq Zekka, Il-Belt Valletta  
Tel: 22788806/22788800  
Email: csa@gov.mt

**RESPITE SERVICE**

**COMPULSARY MEDICAL ASSESSMENT**

**This Medical Assessment MUST be completed by the Family Doctor and sent to the Respite Unit three (3) days prior to Admission for Respite. Failure to do so the booking will be cancelled.**

I, Dr \_\_\_\_\_ holder of Medical Registration Number \_\_\_\_\_

declare that I have examined Mr / Mrs \_\_\_\_\_

holder of Id. Card Number \_\_\_\_\_ and currently residing at

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

The Patient's medical Summary is as follows:

Current and Past Medical History:

1 _____	6 _____
2 _____	7 _____
3 _____	8 _____
4 _____	9 _____
5 _____	10 _____

**Drug History**

1 _____	7 _____
2 _____	8 _____
3 _____	9 _____
4 _____	10 _____
5 _____	11 _____
6 _____	12 _____

**Allergic to:**

\_\_\_\_\_  
\_\_\_\_\_

**Cardiovascular System: normal / abnormal**

Pulse: \_\_\_\_\_ BP \_\_\_\_\_

Heart Sounds: \_\_\_\_\_

**Respiratory: normal / abnormal**

Rate \_\_\_\_\_

Breath Sounds \_\_\_\_\_

**Abdomen: normal / abnormal**

Masses: \_\_\_\_\_ Liver / Spleen / Kidneys – normal / abnormal

Bowel sounds: normal / abnormal

**Lower Limbs: normal / abnormal**

Varicosities / ulcers / sores      Pulses: normal / abnormal.

CNS: normal / abnormal

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**Psychiatric.**

Cognition: normal / impaired      wanderer: no / yes  
Suicidal: no / yes      Depressed : No / Yes

**Routine Clinical Investigations:**      Blood Glucose (HGT):  
Urinalysis:  
Mini Mental Score Test

**I declare that :**

**1. The client is FIT / NOT FIT \* to enter into a Residential Home or Long-Term Care for Respite Care for a period of 1 / 2 / 3 weeks\*;**

**2. the medical examination was performed by myself and that the clinical assessment reflects the true findings as on:**

**\* (Delete as Applicable)**

Date

Signature

Rubber Stamp



**Dipartiment għal-Anzjani  
u Kura fil-Komunità**  
Elderly and Community Care Department

Centru Servizz Anzjan Valletta  
Numru ta Kuntatt: 227888000

**Formola ta' Ftejjim Kuntratwali.**

Jiena, li għandi l-kura u responsabilita \_\_\_\_\_ I.D. \_\_\_\_\_  
niddikjara illi naccetta l-kundizzjonijiet tas servizz tar- Respita għal perjodu mifthem  
ta' \_\_\_\_\_ gurnata u li nobliga ruhi illi nar il \_\_\_\_\_ narga niehu lil-  
\_\_\_\_\_ lura id-dar sas-satghejn ta` wara nofs inhar jgigifieri mhux aktar tard mis-  
2pm.

**Jekk jiena ma nzommx ma dan l-obligu, qed naccetta li nhallas is-somma ta '€60 għal  
kull gurnata li taccedi t-terminu miftiehem ta' Respita mad-Dipartiment. Minn issa qed  
niddikjara li qed nifhem u naccetta il-konsegwenzi jekk jien nonqos mill-obbligi tiegħi  
skond it-talba tiegħi għal dan is-servizz u dan il-ftehim iffirmat minni.**

Firma tal-kuratur \_\_\_\_\_

Isem u kunjom tal-kuratur \_\_\_\_\_

I.D. \_\_\_\_\_

Firma tal-Kap tar – Respita Unit \_\_\_\_\_

Isem u kunjom tal Kap \_\_\_\_\_

I.D. \_\_\_\_\_

Data \_\_\_\_\_

**Informazzjoni għal-persuni li ha jagħmlu uzu mis-servizz ta Respite.**

**X'inhur-Respite Unit**

Is-servizz tar-respite huwa servizz b'xejn li joffri l-gvern li l-ghan tiegħu huwa li joffri zmien ta' mistrieħ lil min jieħu hsieb l-anzjan fid-dar tiegħu. Dan isir billi l-anzjan jidhol fir-Respite Unit għal zmien qasir, generalment minn gimghatejn sa tlieta.

**X'joffri dan is-servizz**

Servizz ta akkomodazzjoni li jinkludi ikel u xorb.

Hasil ta hwejjeg tal-klijent

L-ikel jigi servut tlett darbiet kuljum kolazzjon, ikla tal-ofsinhar u fl-ghaxija.

Jigi provdut ukoll tea, kafe' u xi xorb iehor matul il-gurnata.

Klijent ha jinghata kura min nurses u carers 24/7.

Jekk klijent jkollu bzonn tabib jew kura ohra dan irid jithallas mil-klijent.

Home ha tipprovdi ukoll li kull karma tkun armata hospital bed, nursing call, kutri, lozor u mħaded.

**X'ikun hemm bzonn li klijent igib miegħu:**

Certifikat mediku mit-tabib tal-familja mhux aktar antik minn tlett ijiem qabel.

Il-lista tal-medicini.

Medicini u apparat mediku iehor li juza il-klijent.

Appuntamenti jew karti tal-isptar (discharge letters).

Il-kartuna safra / u jew roza.

Hwejjeg ta fuq u ta taht skond l-ammont ta graņeġ li jkun se jgatta' fir-Respite Unit.

Xugamani, facecloths, sapun, shampoo, toilet paper.

Zarbun sod u kommdu.

Ilma tal-flixxun ghax-xorb

F'kaz li l-klijent jghmel uzu minn dan l-apparat bhal Nuccali, hearing aid, walking aide , wheelchairs jew bastun dan irid jingieb mal-klijent.

F'kaz li klijent jagħmel uzu min hrieqi, pull ups jew incontinence pads dawn iridu jingabu mieghu.

Kwalinkwe apparat iehor li jghinu jkun kommdu biex jezercita l-attivitá ta kuljum eg pozati b'manku wiesgha, sponza b'manku twil etc.

### **X'informazzjoni għandha tingħata lil- nurse/senior carer in charge mir-Respite Unit**

Jekk l-anzjan hux qiegħed fuq dieta specjali eg soft food jew għandu xi intolleranza għal certu ikel eg. Gluten or lactose.

Jekk l-anzjan għandux bzonn għajnuna biex jagħmel l-attivitajiet ta kuljum , jinhasel, jilbes, jmur toilet.

Jekk l-klijent għandu xi problema ta komunikazzjoni jew ta memorja.

Jekk l-klijent hemm xi affarijiet li ma joghgbuhx jew li gieli kien aggressive jew affarijiet ohra partikolari.

### **F'Kaz ta' tibdil ta dati**

Jekk l-klijent ma jkunx ha jagħmel uzu mis-servizz important li cempel f'dawn in-numru biex tagħmel tibdil necessarju.

Numru ta kuntatt 22788806

Aktar informazzjoni relatata ma servizz:

Numri ta telefon li tista tagħmel uzu minnhom:

Dipartiment tal-anzjani Centru Servizz Anzjan Valletta - 22788800

Casa Leone – 21334063/79340809

Commcare Unit – 22589393

St Vincenz De Paul- 21224461



**Appendix Q: The Barthel Activities of Daily Living Index**

**THE  
BARTHEL  
INDEX**

Patient Name: \_\_\_\_\_

Rater Name: \_\_\_\_\_

Date: \_\_\_\_\_

**Activity** **Score**

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**FEEDING**

- 0 = unable
- 5 = needs help cutting, spreading butter, etc., or requires modified diet
- 10 = independent

\_\_\_\_\_

**BATHING**

- 0 = dependent
- 5 = independent (or in shower)

\_\_\_\_\_

**GROOMING**

- 0 = needs to help with personal care
- 5 = independent face/hair/teeth/shaving (implements provided)

\_\_\_\_\_

**DRESSING**

- 0 = dependent
- 5 = needs help but can do about half unaided
- 10 = independent (including buttons, zips, laces, etc.)

\_\_\_\_\_

**BOWELS**

- 0 = incontinent (or needs to be given enemas)
- 5 = occasional accident
- 10 = continent

\_\_\_\_\_

**BLADDER**

- 0 = incontinent, or catheterized and unable to manage alone
- 5 = occasional accident
- 10 = continent

\_\_\_\_\_

**TOILET USE**

- 0 = dependent
- 5 = needs some help, but can do something alone
- 10 = independent (on and off, dressing, wiping)

\_\_\_\_\_

**TRANSFERS (BED TO CHAIR AND BACK)**

- 0 = unable, no sitting balance
- 5 = major help (one or two people, physical), can sit
- 10 = minor help (verbal or physical)
- 15 = independent

\_\_\_\_\_

**MOBILITY (ON LEVEL SURFACES)**

- 0 = immobile or < 50 yards
- 5 = wheelchair independent, including corners, > 50 yards
- 10 = walks with help of one person (verbal or physical) > 50 yards
- 15 = independent (but may use any aid; for example, stick) > 50 yards

\_\_\_\_\_

**STAIRS**

- 0 = unable
- 5 = needs help (verbal, physical, carrying aid)
- 10 = independent

\_\_\_\_\_

**TOTAL (0-100):** \_\_\_\_\_

## **The Barthel ADL Index: Guidelines**

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1. The index should be used as a record of what a patient does, not as a record of what a patient could do.
2. The main aim is to establish degree of independence from any help, physical or verbal, however minor and for whatever reason.
3. The need for supervision renders the patient not independent.
4. A patient's performance should be established using the best available evidence. Asking the patient, friends/relatives and nurses are the usual sources, but direct observation and common sense are also important. However direct testing is not needed.
5. Usually the patient's performance over the preceding 24-48 hours is important, but occasionally longer periods will be relevant.
6. Middle categories imply that the patient supplies over 50 per cent of the effort.
7. Use of aids to be independent is allowed.

## **References**

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*Maryland State Medical Journal* 1965;14:56-61. Used with permission.

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## **Appendix R: Mini Mental State Examination**

## Mini-Mental State Examination (MMSE)

Patient's Name: \_\_\_\_\_

Date: \_\_\_\_\_

**Instructions: Score one point for each correct response within each question or activity.**

Maximum Score	Patient's Score	Questions
5		"What is the year? Season? Date? Day? Month?"
5		"Where are we now? State? County? Town/city? Hospital? Floor?"
3		The examiner names three unrelated objects clearly and slowly, then the instructor asks the patient to name all three of them. The patient's response is used for scoring. The examiner repeats them until patient learns all of them, if possible.
5		"I would like you to count backward from 100 by sevens." (93, 86, 79, 72, 65, ...) Alternative: "Spell WORLD backwards." (D-L-R-O-W)
3		"Earlier I told you the names of three things. Can you tell me what those were?"
2		Show the patient two simple objects, such as a wristwatch and a pencil, and ask the patient to name them.
1		"Repeat the phrase: 'No ifs, ands, or buts.'"
3		"Take the paper in your right hand, fold it in half, and put it on the floor." (The examiner gives the patient a piece of blank paper.)
1		"Please read this and do what it says." (Written instruction is "Close your eyes.")
1		"Make up and write a sentence about anything." (This sentence must contain a noun and a verb.)
1		"Please copy this picture." (The examiner gives the patient a blank piece of paper and asks him/her to draw the symbol below. All 10 angles must be present and two must intersect.)  
30		TOTAL

**Interpretation of the MMSE:**

Method	Score	Interpretation
Single Cutoff	<24	Abnormal
Range	<21	Increased odds of dementia
	>25	Decreased odds of dementia
Education	21	Abnormal for 8 <sup>th</sup> grade education
	<23	Abnormal for high school education
	<24	Abnormal for college education
Severity	24-30	No cognitive impairment
	18-23	Mild cognitive impairment
	0-17	Severe cognitive impairment

**Interpretation of MMSE Scores:**

Score	Degree of Impairment	Formal Psychometric Assessment	Day-to-Day Functioning
25-30	Questionably significant	If clinical signs of cognitive impairment are present, formal assessment of cognition may be valuable.	May have clinically significant but mild deficits. Likely to affect only most demanding activities of daily living.
20-25	Mild	Formal assessment may be helpful to better determine pattern and extent of deficits.	Significant effect. May require some supervision, support and assistance.
10-20	Moderate	Formal assessment may be helpful if there are specific clinical indications.	Clear impairment. May require 24-hour supervision.
0-10	Severe	Patient not likely to be testable.	Marked impairment. Likely to require 24-hour supervision and assistance with ADL.

**Source:**

- Folstein MF, Folstein SE, McHugh PR: "Mini-mental state: A practical method for grading the cognitive state of patients for the clinician." *J Psychiatr Res* 1975;12:189-198.

**Appendix S: Cognitive Incapacity and Behaviour Assessment**

# Initial Dementia Assessment

## Attachment 6—Cognitive Incapacity & Problem Behaviours Assessment

A primary caregiver is the family member or friend who gives the most help to someone with a health problem. Primary caregivers may help with personal care (e.g., bathing, dressing), instrumental daily activities (e.g., housekeeping, laundry, shopping), or health related decisions (e.g., when to seek care, what types of treatments to select). Because of this help, caregivers can give important information about possible symptoms that may not be noticed during a visit to the doctor or other care provider.

Please indicate the best response for each behaviour listed using the following scale. There are no right or wrong answers.

- Most or all of the time = 3
- Often = 2
- Sometimes = 1
- None of the time = 0

How often in the past four weeks did the patient:

1. \_\_\_ act confused?
2. \_\_\_ talk or mumble to him/herself?
3. \_\_\_ repeat the same thing over and over?
4. \_\_\_ hear or see things that were not there?
5. \_\_\_ forget the names of his/her family or close friends?
6. \_\_\_ forget the right words to use?
7. \_\_\_ yell or swear at people?
8. \_\_\_ interfere or offer unwanted advice?
9. \_\_\_ act restless or agitated?
10. \_\_\_ act fearful without good reason?
11. \_\_\_ complain about or criticize things?
12. \_\_\_ show inappropriate sexual behaviour?
13. \_\_\_ wander outside the house?
14. \_\_\_ refuse to be left alone?

Cognitive Score \_\_\_\_\_ (Sum of items 1–6)

Behavior Score \_\_\_\_\_ (Sum of items 7–14)

No exact cutting points for heightened caregiver risk have been determined for this tool. However, cognitive symptom scores greater than 7 may indicate heightened risk of caregiving problems and may warrant further clinical investigation. The presence of any behavior symptoms may warrant further investigation, with values greater than 2 indicating heightened risk.

Source:

Bass, D. M., M. J. McClendon, G. T. Deimling, and S. Mukherjee. 1994. "The Influence of Diagnosed Mental Impairment on Family Caregiver Strain." *Journals of Gerontology* 49:S146–55. Used by permission of the Margaret Blenkner Research Center at The Benjamin Rose Institute.  
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