A narrative inquiry into the family dynamics of a newly admitted person into long-term care

By

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A dissertation submitted in Partial fulfillment of the Masters in Systemic Family Psychotherapy

July 2023

Institute of Family Therapy - Malta

AUTHOR'S DECLARATION

I, the undersigned, hereby declare that this dissertation entitled 'A narrative inquiry into the family dynamics of a newly admitted person to a long-term care residence' is an original study carried out by myself and the conclusions drawn herein are a result of my own work, unless otherwise acknowledged by citation.

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Abstract

The aim of this study was to explore if and how family dynamics are influenced when an older person is admitted to a long-term care institution. A narrative approach to answer this research question was used.

Data was collected using semi-structured interviews with open ended questions. Three families who had one of their significant others admitted to a nursing home within the past year were recruited. In-depth interviews were carried out with the older person and their significant others. An ethnodrama approach was used to analyse the data.

Themes were identified from the interviews, and these were then used to develop a script of how the older person and the family lived the admission as well as family interactions and relationship dynamics, which this transition brought about.

The family relations were impacted by the admission of a loved one into a long-term care residence and the institution culture influenced the relations. The results are limited due to small sample size, but they shed light on the need to systemically look at the needs of older people and their families.

Acknowledgements

I would firstly like to express my gratitude to my supervisor, Ms. Helen Attard Micallef. She provided me with constant support, care and reflexivity all throughout this project. I am sure that without her constant support and guidance alongside her expertise, knowledge and experience in the field, this dissertation would not have been possible. Her dedication, motivation and exceptional eye for detail have continued to push me to work harder. Her kindness, gentleness and availability to help will be carried in my heart and encourage me to keep aspiring to be more like her whilst embracing who I am. She has made this experience a truly enriching one.

My heart is full of gratitude and thankfulness for my husband Karl. He has been my beacon of light in this long journey. Not only was he my personal supervisor whilst he completed his doctorate but he was my husband, lover and friend. I thank him for being there when I was doubtful of my abilities, helping me to see through the fog. He was my pillar of support, holding me up when I needed reinforcement and for supplying me with time to work in my studies taking on new roles. My endless thanks goes to our little girl, Eve. She has sacrificed time of play and fun from her mother whilst providing me with opportunities to work. With her resilience and innocence, she has been a wonderful supporter, cheering me on till the finish line.

I would also like to thank my parents, Raymond and Pauline who planted in the me the seeds of love for education and personal growth. They encouraged me every step of the way, believing in me since childhood. Their support has grown with me throughout my time in this life. They have set an example of how a couple can reciprocally and mutually build each other whilst nurturing each other. They continue to amaze me through showing me what perseverance, sacrifice and love have the power to do in this lifetime. I thank my best friends since early years, my sisters Elaine and Maria who believe in me no matter what happens, wishing real well wishes onto me every day, helping me laugh and reminding me to breathe and take a break whilst on this adventure.

I have been very blessed with amazing in-laws. Thanks goes to Cettina and Alfred for babysitting so I can rest when I needed and to my wonderful sister in-law Elaine for making me laugh when times were a bit dull.

Special thanks goes in particular to the participants of this study whose generous availability and personal stories were priceless to this dissertation. I doubt that I will ever be able to convey my gratitude fully, but I owe them endless appreciation for their contributions. Special prayers to a special lady who went to meet with the Lord whilst I was carrying out this research.

My gratitude also goes to all the tutors at IFT-Malta, who each have provided me with a unique opportunity and experience of growth. My admiration goes to them for striving to provide me with the support, teaching and expertise and giving me a chance to show my abilities in this new profession.

Thanks goes to my peer colleagues who have made this journey a special experience, by providing containment, companionship, and friendship.

Finally, I would like to give thanks and honour to my almighty God who made all this possible. He who blessed me with all these people in my life and He who gave me the strength not only physical, but also spiritual and emotional to embark on this journey of self-discovery.

Dedication

I dedicate this work to my family.

To my amazing husband Karl. May you be gifted with a long life full of love, health and adventure.

To my beautiful girl Eve. May you continue to grow in wisdom, beauty, and grace.

To my best friends and sisters Elaine and Maria. May we share endless laughter, hugs and memories.

To my devoted parents. May you be blessed with strength, health, and a long life together.

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Introduction

1. Introduction

This study is about stories of residents in long term care and their families, living in Malta during their transition to institutionalization. This was obtained through interviewing three families and their significant others conjointly, utilizing narrative analysis, to co-construct their stories of their management and meaning making process of their family dynamics in the Maltese context.

a) Biographical precis

Throughout the sixteen years of my professional career as a physiotherapist, I am appreciative of the fact that I have had the privilege to work in a vast number of different settings and entities across Malta and Gozo. Following rotations within different entities, in 2011, I was permanently transferred to a long-term care residence upon my personal request. Working withing the geriatric setting, in a long-term care residence, my passion for geriatrics and gerontology only grew. I feel very privileged to have been able to accompany so many people transitioning into long-term care. Being witness to so many emotions, thoughts and behaviours has encouraged me to want to learn more about this population. As my experience in the field grew, I noticed that it is not only the patient we relate to during work, but a lot of time and energy is spent communicating goals, problems, and accomplishment to the family of the resident. Customer care complaints were not only received from the residents, but a large proportion were by the family. This continued to encourage me to recognize the involvement of the family in this transition in life. In this present day, my curiosity shifted to how the process of institutionalization is lived by the entire family and how if any did it effect the already established family dynamics. The later invited me to want to know and learn more about the dynamics present in the environment I attend and make part of every day.

b) Rationale

Older persons are relocated from the community to residential care for either short term respite, or on a permanent basis. Working in a long-term care institution has presented me with different realities. Transfer into long-term care varies in meaning for the individual. Older adults

can experience this step as one to ensure safety, forming part of the culturally expected planning process for their later years of life. For others, the prospect that they can no longer manage to live independently at home is experienced as upheaval. This resonates with the greatest fear that I witness my own grandmother having at this present day, narrating stories about losing her purpose of being, becoming a burden on the family and suffering physical dependency. Irrespective of the way this transition is experienced by the individual it is a change. In this transition, family patterns of relating can emerge due to the stress imposed by the change.

Preliminary literature search yielded no local studies contributing to psychotherapy and old age. It is an understatement to say that there is a shortage of material on psychotherapy with the older population (Vassallo, 1995). Iain Gardner comments that "the field displays a gross lack of literature available for use by practitioners searching for guidance" (Chapman, 1993, pg 17).

It is hoped that this study contributes to address such a gap. The study aims to explore the different discourse and co-construction of the meaning within the family when the older person is admitted to a long-term care institution. It is hoped to shed light how systemic therapists could turn their attention to the issues that confront the aged. Locally family therapists might often be employed in agencies that focus on younger groups. Services providing care for older people might marginalize the need for psychotherapy, unless there are mental health issues, let alone systemic psychotherapy.

The dominant discourse is that older adults do not experience the same psychological problems as the rest of the population, but most problems are attributed to the additional burden of the ageing process. Programs and policies promoting positive resident outcomes are needed to shift this dominant discourse. This can be done only through incorporating and building of the relationships among staff, families, and residents beyond the traditional residential home environment (Gaugler, 2005).

2. Aim of the study

The study aims at shedding light on how family members make sense of this admission individually and between themselves, on how they mutually and reciprocally they co-construct their story as well as how their family dynamics may be reshaped. Gaining insight of how families remain involved in the lives of institutionalized older adults can help direct the design

and implementation of facility and family-level interventions that preserve family involvement (Maas et al., 2000; Pillemer. et al, 1998).

a) Research Agenda

I find myself alienated from the objectivist stance to research, that which has been common in my time as an academic and medical profession. Given the potential for intrusion in the lives of the research participants, I wished for the research to find meaning in undertaking research in a way that seems to be connecting to the experience. I find narrative as a research stance to help me become more aware and more reflective. I found this approach intuitively and immediately more powerful. My hope is that I will intrigue the readers enough to want to explore my dissertation further.

My story will have a narrative arc; it will demonstrate my goals and intentions, the ways in which I will carry the action forward by making connections between events, showing the influence of the passage of time, and recounting the personal meaning of the experience (Coulter and Smith, 2009).

3. Conceptual Frameworks

a) Narrative

Viewing narrative as an everyday activity may be helpful in thinking about narrative as a research methodology that we are all familiar with to some extent. Whether oral or textual, narratives are a distinct genre that I know and use, telling stories that construct a coherent plot about my/his/her life with a beginning, middle and end. Whether told only to oneself or to others, a narrative provides a robust way of integrating experience into meaningful learning, locating oneself and others in the account, and foreshadowing the future.

Narratives incorporate temporality, a social context, complicating events, and an evaluative conclusion that together make a coherent story. Most important, the narrator or protagonist is an active agent not a dupe in the account (Elliott, 2005). Thus, narratives provide a window into the process of identity construction (Riessman, 2008). Through the construction and recounting of narratives, individuals form and reform who they have been, presently are and who they hope to become. As narratives offer long-term reference points to replicate, live up to or overcome (Sfard

and Prusak, 2005), these stories can continue to influence how the narrator views him/herself and makes decisions to act (Holley and Colyar, 2009). Of great interest I find how, narratives, when told to others, may influence how others see the 'storyteller.'

Stories are appropriate when studying older persons (Phoenix et al, 2010; Fredman, 2010). Old people have an array of experiences and the complexity of how they construct their reality (Ellis, 2010) could be understood better by them narrating their story (Phoenix et al, 2010) around institutionalization.

b) Social Constructionist Approach

A social constructionist epistemology was used to interpret the families' narrative experiences during their transition to long-term care. This philosophical framework, fits within a systemic perspective and invites us to contextualize individuals and families in their social and cultural referents, through the mediation of language (Slovik and Griffith, 1992). This shift from viewing individuals as fixed objective identities to subjective views (McNamee and Gergen, 1992), focuses on the self as a relationship, which is conversationally created and constructed discursively, thus denotes the self as a narrative or relational self (Anderson, 1997).

I focused on the interactions, the talking amongst the residents and their significant others and their stories. Social constructionism views knowledge as mediated through my own subjectivity as an observer and researcher, referred to as epistemic relativism (Willig, 1998), as well as in line with collaborative language theory (Anderson, Goolishian and Winderman, 1986), in which I as a narrator attempt to make sense through my own perceptions of the couples' stories.

Maltese context shows institutional older care as more popular than in other European member states. In a special Euro-barometer the Maltese were two and a half times as likely as the EU27 average to express the opinion that dependent older people should move to a nursing home (European commission, 2007). This opinion may reflect dominant discourses of the government and Church homes for the elderly and the desire, in a close-knit community, to retain the independence of the nuclear family. Social constructionism has shown the Maltese context to believe that children should visit their parents and help them at home, with the subjugated discourse that parents should not live with their children. This belief system may represent the context of shorter distances prevailing in Malta, where it is relatively easy to visit one's parents

wherever they live. To note, the Maltese were far less likely to believe in home-based care by public or private providers, perhaps believing that context of residential care is fully comprehensive. In fact Maltese expressed the belief that professional care for dependent elderly people was excellent (84%) and that nursing homes offer insufficient standards of care (19%) (Pace, 2016).

When respondents were asked what care they themselves would prefer, should they need, respondents expressed a preference to be cared for in the home of a close family member but think this is unlikely. They neither predict, nor prefer, the prospect of receiving professional care in their home. The proportion of Maltese respondents preferring institutional care was, again, double that of the EU27 countries. The Maltese expressed the sixth highest opinion that they will have to pay for their care themselves (Pace et al, 2016).

4. Layout of the study

After presenting a brief introduction, the next chapter features available studies incorporating statistical and systemic literature, to ground this research. Chapter 3 discusses the methodology adopted, the steps used for the narrative inquiry, sampling, ethical procedures, and data analytical strategies used. The findings were presented in chapter 4, highlighting the co-construction of the narratives and the creation of the script written by myself. Finally, the discussion was presented together with the script and stories in context of the available studies and literature. The conclusion suggested clinical and future implications, as well as limitations.

Literature review

This chapter provides an overview of the literature pertaining to family and long-term care. The first section reviews the literature on family and old age and presents a working definition of family dynamics to be used in this dissertation. The next section reviews the literature on long-term care and how these impacts individuals being admitted in an institution. The final section of the chapter presents literature using a systemized literature search on family dynamics and institutionalization.

1. The family in old age

As a system moving through time, families are different from all other systems because they incorporate new members by birth, adoption, commitment, marriage, and members can leave through divorce and by death (Mc.Goldrick, 2000). She emphasizes that from a life cycle perspective, there is an intermingling of the generations, and events at one level that have a powerful effect on relationships at each other level. (Mc.Goldrick, 2000).

While one generation is moving towards old age, the next is contending with late middle age, caregiving or the empty nest while perhaps concurrently dealing with possible transitions of their parents' caregiving needs. The next generations cope with establishing careers and intimate peer adult relationships, having and raising children, and adolescents, while the youngest generations are focused on growing up as part of the system (McGoldrick, 2000). The important impact of events and relationships in the grandparental generation is routinely overlooked by researchers and therapists who focus majorly on the nuclear family. Indeed, human beings are unique for the role grandparents play in parenting (Bateson, 2010).

The ageing process brings with it an arising of crisis which come about in clusters of issues, relating to the process of getting old. A few from the long list of inventories would be the death of a spouse, low prognostic illness, loss of friends, lowered income, cessation of productive working experience, diminution of status, and decreasing physical, isolation and mental capacities. Ironically, these "insults" occur at a time when the individual is likely to be less able to cope with the changes in his life.

In the family, the parent would have most times promoted maturational growth of dependence progressing to independence to their children (McGoldrick, 1988). Roles were likely to be reversed when the parent ages, and the adult child, would ideally be able to accept and meet the increased dependency of his parent and assume a caring and quasi-parental role to his own parent (Bateson, 2010). If we give the metaphor of a scale or a balance to responsibility, we can say that the balance of responsibility is shifted, a new equilibrium is sought. The family can often mobilize to meet and deal with these demands and find a new balance. This capacity to achieve a new equilibrium through inner resources and community resources to plan constructively permits the accomplishment of this life-task (Brody, 1966).

For families though, the demands to achieve this equilibrium may be too big while for others perhaps they might not be in a position to respond to such requirements (Mills, 2003). The additional stress and demands of this phase of life is intensified according to the dynamics of the relationship, family conflicts, chronic pathologies, and co-morbidities. The older person would be more likely to become the focus of irrational feelings, or the identified person. The manifested problems of the older family member often overshadow and exacerbate relationship problems of the total family. The non-achievement to equilibrium may be an overwhelming experience and could lead to institutionalization of the older person.

2. The context of institutionalization and old age

Older persons relocate to residential care facilities for numerous reasons, including declining health, for support, or after crisis such as bereavement. Long-term institutional care is becoming an alternative to the family care model, and the rate of older adults who are opting to move to a Long-Term Care is gradually increasing (Chien et al., 2022). Our older adults face a completely new life pattern, which is a major life change that requires attention and support (Chien et al., 2022). Regardless if the older person used to live independently prior to admission to a long-term care or whether the individual was in a frail condition, consideration of institutional placement carries along with it the preoccupations and thoughts of the permanent separation from the older person's family and loved ones by death as well as other losses such as that of that of an autonomous life and community life. If the older person is considered as an individual and as a family member throughout the entire process of institutionalization, both in

discourse and in practice, the older person verifies and reasserts one's worth and dignity (Brody et al., 1996).

a) Institutionalisation and cultural context

Brownie et al. (2004) reviewed studies on the impact of cultural factors on their older population living in long-term care. In the United States, the American older adult was better than the Egyptian older adult in their readiness to move, and adaptability (Brownie,2004). The knowing that settling into a new environment takes some time (Tracy, 2004) as well as the residents believing they were in control of their outlook on the move was a key factor (Keister, 2006) whilst some thrived of the social environment in the residence and accepted the move as a solution to the higher level of care they required (Walker, 2007). In Japan, the resident was found to reflect on their living conditions after being admitted to a long-term care; reflect and go through the process of repeated thinking, finding meaning, and developing skills in response to their life in the long-term care (Komatsu et al., 2007). In Taiwan, home was the most anticipated residence for the older adults. In Taiwanese context and culture, 56% of the population of the older adults wish to live with their children, hoping to have family happiness living among their children and grandchildren, yearning for a life of peaceful old age (Chien et al., 2022). Studies in the Maltese context were however lacking, and not found in the literature search. In the United Kingdom, residents described how ill-health made the transition more difficult and the loss of continuity of roles impacted their self-worth. In Ireland, most older adults felt uninvolved and leaving home would evoke sadness and loneliness.

b) The transition into long-term care

Admission of an older relative to a long-term care facility involves integration into a new and frequently foreign social environment and requires the establishment of new and meaningful relationships. This is so not only for residents of the long-term care facility but also for members of their families (Ross et al, 2001). For many, family relationships continue, albeit in a different form and setting.

Observational research has highlighted that residents were seated in a communal lounge for breakfast and for extended periods (Victor,1994). This may be reflected by residents' own description of the experience as 'sitting around doing nothing in particular' and many older people consequently viewing residential care as a 'last resort' (Chien, 2022), reflecting loss of

utility in their lives. Contrastingly, positive experiences were reported by other older people including feeling less loneliness, more financial stability and safer (Edwards et al., 2003).

Indeed, moving to residential care was considered one of the most pervasive sources of anxiety marking later life depression, fear, and stress for older people. This can be described as an overwhelming life change for the older person (Chien et al., 2022). It has been given a name in order to define the transition resulting from moving into a new environment; "the Relocation Stress Syndrome" (Iwasiw, 2003). This means that they have to face the process of adaptation, usually happening within the first year which may be hindered by low self-esteem, grief, unknown territory, insecurity, and withdrawal (Costlow et al., 2019). The ageing process brings with it changes that could be resulting in a disability. The more coping ability they need to adjust to the transition, coupled with any loss of function they may have, the more would be the stress that could be added, and the more would be the need of their original coping ability. This pattern would hinder their adjustment process. Further contributors could be the poor attitudes of professionals and staff in the long-term care, poor regulations and the high level of dependency of the residents (Tuominen et al., 2016). Residents with visiting relatives and feel emotionally supported favour easier adjustments and adaptation of the resident into the long-term care (Lee, 2014).

Literature describing the experiences of the resident or his family in the first year at the long-term care is sparse and no literature could be found. Most residents did not consider the long-term care as their new home, believing that life there was beyond their control and where autonomy was limited (Johnson et al., 2014). Tsai (2020) showed residents hoping the burden on them would be decreased but were hoping for more contact with loved ones. They recognized the difficulty of the adaptation process whilst they appreciated individualized care.

3. Institution and the family

To identify literature about family and long term care a systemic literature search was carried out using PubMed and PsyInfo, together with a search in the grey literature using GoogleScholar. A search strategy was developed to identify articles with the terms family and long term care (Table 1). The search identified 8325 articles, which when filtered using the

below criteria were found to be relevant to the area being studied. The final number of articles to be discussed in this section was 18.

Family	family [MeSH Major Topic] family [Title/Abstract]
Long-term care	Long-Term Care [MeSH Major Topic] Long-Term Care [Title/Abstract]
Joint	((Long-Term Care[MeSH Major Topic]) OR (Long-Term Care[Title/Abstract])) AND ((family[MeSH Major Topic]) OR (family[Title/Abstract]))

Table 1 Systematic literature search for PubMed

Since this research aims to explore the family dynamics of a newly admitted residents to SVPR, I sought a definition of family dynamics as

> *"... the scheme of family members' relations and interactions including many prerequisite elements (family arrangements, hierarchies, rules, and patterns of family interactions). Each family is unique in its characteristics; having several helpful and unhelpful dynamics." (Gerhardt, 2017, pg. 4)*

In using this definition literature on the topic of family was considered relevant if the family was the participant, rather than the older person. In long-term care, the inquiry should not only be with the identified client but with the family as a whole and each of its members. Whether or not admission happens, involvement of the family should not be viewed solely as a means of facilitating a solution for the aged member. This is because the potential placement of a family member in an institution has major implications for the complex network of relationships. This goes in parallel with Gaugler et al, (2005) where the potential effects of family involvement on resident outcomes such as psychosocial status, discharge, or mortality were discussed.

Noelker and Harel (1978) identified predictors of well-being and increased mortality as a result of family involvement in long-term care and family members roles' extended beyond the provision of personal and instrumental care to encompass assistance that was designed to preserve the identity and quality of life of loved ones (Maas and Tripp- Reimer, 1999; Rowles and High, 1996).

Institutionalization in itself is a separation process. Following institutionalization, if the family is actively involved in the life of the older adult, an opportunity for emerging problems to be resolved constructively was likely to be created. Bowlby's attachment theory presents us with information that when an adult child works through the crisis of separation from a parent such as when being admitted to an institution, this moves forward one's own maturational process (Bowlby, 1979). In Mc Goldrick's (1988) family life cycle, separation of the son/daughter from their parents has been described as facilitating the son/daughter's own separation from the own children as well as a different separation from their own parent through death (Mc.Goldrick, 1988). In contrast to this, when a parent is institutionalized and separated from his adult child, it could present a process that might free the adult child from symbiotic or Minunchin's scapegoating situations in his own parental subsystem and enable him to find new meaning in his relationship with marital partner on the marital system and their own children (Ellison, 2017).

It has been documented that the very crisis which precipitates in the family to request causes the family patterns to stand out (Brody, 1966). Whilst the problems presented on admission may appear to be acute and to relate specifically to the necessity of a placement; sometimes, institutionalization as the process evolves, family patterns are revealed. Emphasis is made on the vigilance necessary upon request for admission because whilst admission may be a valid solution to a reality problem, it may also be a symptom onto which relational family difficulties are projected (Brody, 1966). Interestingly much of the research on family caregiving has focused on care in the home. Less is known about the experience of family members who continue to provide care following admission of an elderly relative to a long- term care facility (Ross et al, 2001).

a) <u>Attachment among children and their institutionalized parent</u>

Recent literature about attachment patterns in institutions was not identified when using the systematic search highlighting a literature gap in the area. Other research indicates that adult children maintain contact with institutionalized parent/s, however, much less is known about the quality of these relationships. Attachment theory offers a conceptual framework that can help explain the persistence of the parent-child relationship long after nursing home placement (Pruncho,1994). Bowlby (1980) extended his original theory of attachment saying that the child's attachment to the parent does not end in childhood or adolescence but persists throughout

life. Although as mentioned, separation from the parent is an inevitable part of the normal developmental sequence as the child moves out into the world, the need for closeness, communication, and physical contact continues and is reflected in parent-child behaviours in adulthood.

Most children report feelings of affectional closeness to their parents in adulthood and experience grief at the loss of a parent (Jarrett, 1985). Literature regarding the extent to which attachment wanes as parents become frailer, however, is inconclusive. Jarrett (1985) has stated that closeness dissipates when the adult child is under the strain of providing care, with resulting psychological distancing from the parent accompanied by guilt and despair. Empirical studies which have addressed this question, however, have brought mixed results with some indicating that a decline in the parent's health was associated with a decline in the adult child's positive feeling toward the parent (Pruncho, 1994). Blieszner et al. (1989) provided us with different observations where affection remained strong despite frailty. Applying the perspective of attachment theory to the latter, the parent was able to fulfil the adult child's need for emotional security. Branching off from this, Cicirelli (1991) speculates that if parents become too frail to offer psychological or emotional security to the child, the basis for maintaining attachment is gone. On the other hand, Horowitz and Shindelman (1983) found increased dependency of the older person to change the nature of the affective relationship despite having less enjoyable activities to be shared. Theoretical models were developed which predicted that a secure attachment pattern would still be shared with a parent who despite being ill, is able to maintain a positive mood Horowitz and Shindelman (1983). Hence, even when frail, cognitive ability was found to be a determining factor for the likelihood of a strong attachment with the parent despite frailty. Attachment may also need to be seen in light of the other family members and their support to the reality of the relationship between the older-parent and their adult child. This may perhaps provide a more systemic view of attachment inter-relationships.

b) <u>Meaning-making process in relationships after institutionalization</u>

Individuals and families transform, and need to transform, their relationships as they evolve, to adapt to changing circumstances over the life course. Moving to a new phase requires a change of the system itself (McGoldrick, 2015). Members of the family must change their roles and rules of relating as they move to a new phase. Most of these phases pertain to entries and

exits of family members or to changes in the nature of family members, relationships, role functioning, and status in relation to each other. All families must renegotiate their relationships with each other many times as they move through life. When families cannot adapt to individual and systemic changes as their life cycle phases require, they become stuck and their healthy development is subverted (McGoldrick, 2015).

Ross et al (2001) expressed the need for more research about the relationship between institutionalization and family relationships as much of the research on family caregiving has focused on care in the home. Less is known about the experience of family members who continue to provide care following admission of an older relative to a long-term care facility despite longitudinal studies implying family members remain involved in the lives of their institutionalized loved ones for long periods of time (Gaugler, 2003).

Families whose relationships were seen to be improved after institutionalization have experienced close ties throughout their lives. Such families would have often reported strains in their relationships prior to institutionalization, strains that were often accompanied by the increased disability of the parent and increased pressures on adult children who felt they could not meet their parents' needs. When the institution provided the support service, and took over the aspects of care, these children ceased feeling that all responsibility for care depended on them. They were then able to resume interactions with their parents and as will be described further on, changes their roles (Cooke et al, 2002).

Families that experienced deterioration in their relationships after institutionalization had a history of frequent contact and involvement but, on the contrary, they indicated ambivalence in their motivations. Following institutionalization, contact continued, but children were accompanied by guilt for their parent for being in an institution because they believed they could have done more for them. This highlights the major impact of the belief systems and social construction of care for older adults have on family members to make sense, and negotiate this transition. This encouraged the parent to feel anger towards their health and circumstances which gave more negative feelings among them, and the more this happened the guiltier the adult children felt (Gladstone, 2005).

Pruncho (1994) explains through the attachment theory that attachment is a precursor to caregiving behaviour, suggesting that it is because adult children want to preserve the bonds with

their parents that they embrace the caregiving role in an attempt to protect the parent from destruction. It is possible that once the parent enters a long-term care facility and the adult child is no longer responsible for day-to-day care of the parent, attachment to the parent ceases to be a motivator for caregiving behaviour and instead becomes an end of its own.

c) Family involvement following institutionalisation

It is becomes evident that the more family members remain involved in the lives of their older ones, the greater the likelihood of improved relational dynamics (Maas et al., 2000). Family caregivers reported their own expectations, such as to be involved and have shared responsibility for of the resident (Shnepp et al, 2018). More effectively targeted family-level interventions can be planned, such as family-staff partnership agreements, family councils, support groups that assist formal providers to maintain appropriate involvement.

Nurturing of relationships of the family members enriches the life of the residents at their new long-term home, and aids with the transition experienced by the family (Tsai et al, 2010). Developing relationships inside the facility increases the meaningful social interactions and provides them with opportunities to talk about their feelings and experiences (Brownie, 2014) and enjoy life at a long-term care (Newberry et al, 2015). In Iwasiw (2003) found that family contact in the first year had continued throughout the study itself with no noticeable change in visit frequency and quality. Family rituals were being continued along the time of study, including tea outings with the family, holidays as well as playing cards.

Families place a very high value on visiting their older family member living in a long-term care facility and derive great satisfaction when they feel useful, particularly through providing social and instrumental care to them. Relatives have said that good communication and being keen to visit their relative in the long-term care was key to the upkeep of good family dynamics (Iwasiw, 2003). Most said that when they keep their relationships strong, it made the long-term care feeling like living at home. Whilst both relatives and residents emphasize the joy and happiness being with their family brings. When the older member was seen able to have a relationship with good dynamics with relatives, studies saw a beneficial impact on families because it left the members with a feeling that the visit had a purpose (Gaugler et al, 2003). Nevertheless, what exactly constitutes this strong relationship may shed more light to what helps maintain these positive relationships. However, both relatives and residents felt that visiting was

a duty of filial piety. This was because visits were believed to maintain the family relationship with the older adults and the visitors, ensuring the quality of care provided by the long-term care, and allowing family members to express their emotional support for the older adults (Tsai et al., 2012). This contrasts with earlier research in the 70's where families "dumped" their relatives in long-term care resulting in isolation and thus a positive social relationship is absent.

d) Visitation and family relationships

A handful of studies have examined the role of institutional policies as potential factors themselves that influence family involvement. Facilities that are smaller, non-profit, and encourage visits and family input in care decisions, were more likely to facilitate visits from family members (Gaugler, 2003). Other studies have examined long-term care visits and found that many relatives visit weekly or more, soon after admission (Gaugler, 2003) and twice a week in the first 18 months (Gladstone, 2005). As longitudinal studies imply, many family members remain involved in the lives of their institutionalized loved ones for long periods of time (Gaugler, 2003) and continue to be of support to their relatives following the move to a long-term care facility (Gladstone, 2015). In contrast to this, there have been documentations of some relationships to have weakened and this was associated with less visits at the long-term residence. This was mostly attributed to emotional difficulty with the relative during the visit, a reduction in feelings of the guilt, and also other demands in the life cycle. Guilt begins to wane away once the family starts to feel more confident about the level of care of the staff as well as feeling of comfort about the facility start to grow (Gladstone, 2015).

Nevertheless, families continue to be involved through continuation in visiting and providing a range of support. (Gladstone et al., 2005). This continued involvement has been named 'caregiving career'', characterized by a trajectory of experiences that takes shape over time (Aneshensel et al., 1995).

Relatives' involvement in the older adult's life following admission was affected by primary stressors originating directly from the patient like challenges or problems that were embedded in the caregiving situation (Gaugler, 2003), and from secondary stressors such as family conflict or socioemotional support and the family member's own health and geographical location (Hünteler et al, 2020; Syse et al, 2022; Wolff, 2017).

Within this conceptual context, the domains of the stress process are hypothesized to influence frequency of family visits over time. Caregivers who suffer from less stressors were more likely to visit over time, while caregivers who report greater socioemotional support were more likely to remain involved with institutionalized relatives. Studies show that residents who had lived at the facility the longest received less frequent visits (Gaugler, 2003).

Gladstone et al. (2005) describes how there was limited research about the longitudinal patterns of involvement of the family with their older person. The same was identified in this literature search where lack of research was identified that have examined how frequency of visits changes over time, or what predicts such changes.

Family involvement may mean more than visitation frequency or the degree to which instrumental tasks are carried out. Some claimed this provides a skewed view of family members' benefaction and the meaning of the visits for both families and residents (Whitaker, 2009; Cooke et al., 2022). Whitaker (2009) explored the family involvement in Swedish care homes attending to the relational dynamics in which the visits were embedded. He highlights how family visits presuppose relational representation and nurture relationships beyond the residential home, ritualize continuity, and coherence through daily routines, and maintain their relative's identity and dignity. The COVID-19 pandemic had its toll contributing to deterioration of resident health, well-being, and emotional distress of both visitors and residents following restrictions in visitations at long-term care institutions during this period (Giebel et al, 2022). This resulted in less engagement of the residents and families (Ickert et al, 2021) especially at residents' end of life (Parks et al, 2021).

e) <u>The roles of the family after institutionalization.</u>

A reduction in role overload and captivity has been documented following admission into long-term care. The emotional strain of caregiving often continues following institutionalization (Aneshensel et al., 1995). Caregiving was found to be of a greater strain on women than men, to be greater on spouses than adult children, on those of a more advanced age and with less experience as a caregiver. This may continue to shed light that the social construction of psychological and practical expectation of caregiving to older adults maybe gender based. Research suggests that spousal caregivers were the most intensely involved in care (Gladstone, 2005), yet most times they too were old and may be living their own challenges, such as a health

and physical conditions. Over time this may impact on how they can live their role of caring for their spouse.

A small body of literature was identified to have examined the way that family members define their roles in long-term care settings. The majority of wives in Ross et al. (1997) study indicated that visiting their husbands and providing companionship and emotional support were the most important perceived caregiving activities. Bowers (1988) found that family members thought the essential purpose of their roles was maintaining their relative's dignity and sense of identity whilst in other studies, family members saw much value in their experiences as caregivers of their older family member prior to admission into the institution and were motivated in sharing their insights about their relative's care with staff in the facility (Duncan et al, 1994). This is consistent with studies who shared that visiting family meant instrumental, emotional, and social care; monitoring staff; and acting as advocates for their relatives (Gladstone, 2005). Once relatives became more comfortable with the facility and with the care provided, a ''regular visitor'' role was usually taken, relinquishing most if not all the care to the staff in the institution whilst changing the focus onto their own life goals and well-being (Dupuis et al.,2001).

Following admission, the majority of family members did not see themselves in the role of a caregiver anymore, mostly because they were not assisting with physical help. Instead, family members gave more voice to their roles as daughters, sons, spouses or other, whilst ensuring that staff performed their functions safely and effectively. Family members were available as a source of emotional and social support to their relatives when needed. Nonetheless, a minority of family members do consider themselves to have both roles of family as well as that of caregiver (Gladstone, 2005). Caregiving roles in long-term care were described as direct; having a hands-on approach like grooming, feeding and indirect; advocating, planning (Ross, 2001) rather than encapsulating the psychological aspect of emotional support. Of interest was that family members have also shared that participation and contribution to a diverse range of activities was an important process through which family members have succeeded in finding meaning in their changing roles (Gladstone, 2005).

These new roles, however, are not permanent and are still subject to change. Crisis situations in the residence have often forced the relatives to redefine their newfound roles and

find new resources and strategies to be able to adapt to some changing circumstances. An example of this would be when a resident is acutely ill, and the staff compliment was not seen as enough by the family to meet the needs of the patient. These dynamics may result in an increase in the visitation of the older adult. Another example would be the pandemic period where the nature of visits had to be altered and limited increasing distance and isolation.

f) Staff Relationships.

Relationships can also be built with the staff of the long-term care. Iwasiw (2003) showed that this is built along time, with some residents saying they are being treated like one of the family, yet it was noted that the nurses were referred to as collectively and not by name. As time in the institution went by the relationship being built with the nurses was seen as fundamental, mostly because they were the source of care (O'Neill et al, 2020). In these regards the Maltese context alerts for more updated studies due to the significant change in the caregivers. As there is a shift to a multicultural nature of the carers, which in some cases imposes even communication barriers with the old persons and their families.

Other studies identified the importance of relationships with people providing care in the nursing home (Baxter et al., 2020). These relationships were reported to be contributors to thriving in a nursing home in several ways, including having the ability to choose who, and to what extent, the individual wants to socially engage with (Baxter, 2019).

The most significant contribution of nurses, who encounter older adults and their families in their practice, education, and/or research, is to invite more adaptive and loving interactions that have the potential for softening the suffering of all family members. The focus on relationships with their accompanying repetitive patterns of interaction emerges from a systemic perspective about family functioning for health professionals (Bell, 2016; Rolland, 2018; Rolland and Walsh, 2005; Wright and Bell, 2009; Wright and Leahey, 2013).

g) Family therapy in institutions

The study of outcome in family therapy was found to be problematic in research as documented by Benbow et al (1997) where controls and outcome measures are not well established especially when dealing with chronic illnesses. When instruments where used, they were blunt and open to observer bias and when families were asked to rate the effectiveness of

therapy, this was difficult to interpret because for example ‘considerably helped’ would at times mean, the expectations hoped out of therapy were not met. Such an example would be where a relative wants an older adult to live with them but through therapy opts for long-term care admission (Benbow, 1997).

Residential care homes are complex systems, and staff often care for very dependent, distressed, and frail residents with little or no training in how to relate to people’s emotional and psychological needs (Curtis, 2015). Staff attitudes, their morale, the physical environment, the organizational structure of the unit, the style of management, communication between members of staff may impact on the quality of care provided (Jeffery, 1986). The application of systemic ideas in such settings therefore seems highly appropriate (Street, 1981).

Systemic consultation responds to referrals by focusing on the system rather than on the individual resident (Milton and Martin, 2003). By facilitating discussion, drawing out different perspectives from the staff group, and by using a reflecting team approach. They encourage a different analysis of the problem and an emphasis on relationships both between staff, residents and between staff members. Systemic therapy aims to draw on the resources within the staff team to move forward.

Denial of problems may be one way of coping that can result in misunderstandings and conflict. Fredman’s (1997) work on contexts for knowing and telling about death and dying was found relevant to this. She argues from a social constructionist perspective that what may be ‘known’ or ‘told’ about one’s experience will change over time, in different environments and in the company of different people (Curtis and Dixon, 2003).

Texts in family therapy chapters are now present on intervention and therapy with older people (Curtis 2005; Gilliard, 1996; Pearce, 2002, 2003; Qualls, 1996), and review articles introduce family therapy and systemic practice to a wider crowd (Curtis 2005; Benbow and Marriott, 1997; Jones, 2001; Marriott, 2001; Qualls, 1999).

However, this development is not reflected within dominant systemic literature. Recent family therapy texts continue to largely overpass later life, ageing and grandparenthood (Curtis 2005, Carr, 2000; Rivett and Street, 2003). Alike, content reviews of family therapy literature point out that late life family issues have not been significant themes of concern to family therapists (Curtis 2005; Rivett, 2003).

In addition, there is lack of empirical research into family therapy with late life families (Roper-Hall, 2008; Curtis 2005; Jones, 2001; Qualls, 2000). One possible explanation is that despite all the evolution, the number of family therapists practising work with older people is still modest, and access to family therapy for late life families remains confined. Fewer people are available with whom to be involved or to conduct the necessary research (Roper-Hall, 2008; Curtis 2005). It is perhaps those working in this area are obliged to find creative research methodologies to enable progress to be made (Qualls, 2000; Curtis 2005).

The rich and elaborate experiences of this client group require family therapists to assimilate a range of ideas and rationale, whilst being mindful of the cultural context and the personal resonances of therapy. Older people are a growing section of the community, and all systemic practitioners need to confront both their own internalized ageism and ageist practice within services (Curtis, 2005).

4. Conclusions

Overall literature sheds lights on segregated stories, kept in the dark, voiceless, and less considered which perhaps motivates me even further to privilege the stories to come. Overall, research highlights that family members maintaining quality contact both with older adult as well as forming a positive reciprocal relationship with staff members and other patients ameliorates the wellbeing of families and the persons in long-term care. This chapter adjoins to the following chapter which is the methodology and methods chapter by identifying the aims and objectives of this dissertation.

Methodology

This chapter identifies highlights the aims and objectives of this dissertation. Each approach to the research project requires a justification, and these need to be set at the outset (Crotty, 2015). The approach brings with it assumptions about reality and the way knowledge can be created. The research project needs to be defined in terms of ontology, epistemology, methodology, and methods (Crotty, 2015). These guide the way knowledge was developed in answering the below research questions and address the aims of the study.

1. The research question and aims

The research question for the study was:

Does admission into a long-term care institution influence family dynamics?

The aims of the study were to:

- Explore how family members make sense of the admission individually and between themselves.
- Explore how they mutually and reciprocally co-construct their story.
- Explore how their family dynamics may be reshaped.

2. Research design

A social constructionist epistemology is based on a relativism ontology. According to this view, all meaningful reality is constructed through and between human beings and transmitted within society (Crotty, 2015). Crotty, (2015) outlined that social constructionism is different from subjectivism in that it focuses on the interaction between people and the object, not the meaning imposed by subjects on objects. The relativism ontology alleges that there are multiple realities which exist, even if some of them are shared amongst individuals or cultures (Teddlie and Tashakkori, 2009). All knowledge created is value-laden, value free knowledge is not possible (Creswell and Poth, 2017; Scotland, 2012). Knowledge is constructed together with participants, with the aim of understanding their experience (Greene, 2012).

In using a social constructionist approach research assumptions were made about how knowledge can be created. This epistemological approach believed that multiple realities exist

(Creswell and Poth, 2017; Scotland, 2012). The way participants construct their reality is based on their own interpretation. The knowledge developed is value laden and context specific (Creswell and Poth, 2017; Greene, 2012; Scotland, 2012). As the participants' reality is based on their interpretation the world they experience and knowledge are not independent for each other (Scotland, 2012). They are interlinked. As a consequence of this assumptions value free knowledge is not possible (Scotland, 2012). Social constructionist develop knowledge through inductive logic (Creswell and Poth, 2017; Scotland, 2012). Meaning that knowledge is developed from specific context can later be used for broader context.

This study used a narrative approach to gather experiences on older persons admission in long-term care home and their family dynamics (Creswell and Poth, 2017). Narrative methodology has many forms and can take different perspectives depending on the researcher's preference (Andrew *et al*., 2013; Creswell and Poth, 2017). There is no single definition of narrative (Riessman, 2008). It focuses on the experience and lived experience told by individuals (Webster and Mertova, 2007). When telling stories people talk about their social interactions (Riessman, 2008). People tend to tell stories all the time, as narration is an elementary form of human communication (Bauer and Gaskell, 2003). During a narrative interview people recall their experiences, put them in sequence, find possible explanations, and re-play the chain of events. Story telling is performed by members of all classes of education (Anderson, Kirkpatrick and Anderson, 2016). This makes it ideal to research participants from different educational backgrounds, which the study set out to do. At the same time stories limit the research to what the interviewer chooses to say and what is most important to the participant (Webster and Mertova, 2007; Anderson, Kirkpatrick and Anderson, 2016). When the participants were narrating their stories, each of them had their own interpretation and experience of the home admission. Based on this and on what they considered most important and feel comfortable sharing the narrated their story. Table 2 present how the research process was guided.

Ontology	Relativist
Epistemology	Social Constructionist
Methodology	Narrative inquiry
Sampling	Quota
Tool	Interview
Type of Data	Qualitative
Analysis	Ethnodrama

Table 2 Research process

3. Methods

This section described the method used in the study based on the philosophical underpinning of the research. To reach the aim of the study the method was guided by narrative methodology. Semi-structured interviews were used to collect data using a narrative approach. Questions used were open ended and prompted the participants to narrate their own experiences. An ethnodrama approach was then used to analyze the data.

a) Sampling

A narrative approach focuses on collecting rich data on the participants' experience rather than a large number of participants. Taking this into consideration and time limitations. Purposive quota sampling was used to recruit participants (Onwuegbuzie and Collins, 2007). The sample size was set at three participants and their significant others with good quality interviews. The quality of the interview was based on the depth of the shared experience, truthfulness, and the sharing of the stories of the lived experience by the participants Terry et al. (2017). The inclusion criteria for the interview were participants who were admitted to the long-term care institution within the last year (2021-2022) and their identified significant others. A long-term care home with frequent admissions was contacted to carry out the study within their institution. A request was sent via email (Appendix 4) to the home director which provided clearance to contact potential participants through a gatekeeper. Three wards within the home were selected as the gatekeeper was familiar with the wards. These all had a recent influx of new admission in the previous year. The gatekeeper then contacted older people within the ward and asked them if they were willing to participate in the study. The participants had to meet the inclusion criteria set presented below.

b) Tools

The study took a social constructionist approach and the interview was used to identify how participants created meaning through their social interaction. Participants were prompted to use stories throughout their interview. Questions were developed by myself guided by Habermas framework (Baur, 2012) and a prior systemized literature review. The questions developed were discussed with the supervisor. As the participants were likely to be Maltese speaking, based on my own professional experience working in a residential home, the questions were developed in Maltese and then translated into English to ensuring that the translation did not lose linguistic sense. The developed questions were then piloted with an older person resident within the long-term care institution who was not part of the study sample and with his/her respective significant others. This interview was audio recorded and partially transcribed for practice. The recorded interview was listened to with the supervisor to ensure that questioning was neutral and non-judgmental. The transcription process was reviewed with the supervisor to check the amount of detail required. After the pilot some rewording of the interview questions was done (Appendix 7). The pilot study was not included as part of the study.

c) Interview

After obtaining clearance from the home management, three potential wards were identified from where the sample of participants was to be taken. Recruitment of participants was done through a gate keeper (Appendix 6), who provided the information letter (Appendix 1, Appendix 2) to potential participants. Once the participants accepted, a meeting was set with myself. On the first encounter I explained the information letter to the participants and answered any questions. After, an appointment convenient for them and their significant others was set. The interviews were carried out in the language of their choice, Maltese or English, and in a place of their preference. On the interview date, all the participants were provided with a consent form (Appendix 3, Appendix 4) which had to be signed prior to the start of interview. The participants were re-assured that their identity will be not disclosed, and the information provided as part of the write will not enable other people to identify them. No names were recorded as part of the transcript and avoidance of mentioning names in the audio recording. The interviews were audio recorded. During the interview, participants were informed that notes were still taken to assist in transcription and data analysis. To assist in my reflexivity, process a

reflective diary was kept. Before and after each interview reflection were noted on the interview, personal perspectives, potential biases and first impressions.

d) Data analysis

The data analysis process was guided by the ethnodramatic analysis approach described by Cannon (2012) which was based in Saldaña (2009) ethnodrama approach. This approach to data analysis was used to transform an interview or observation data into scripts which can be performed to capture the stories of the participants in a scripted manner. Saldaña (2009) proposed this method to engage people emotionally and be able to spread the findings to a wider audience base; in so doing, increasing the potential impact of the findings. In line with using a narrative methodological approach, ethnodrama provided a medium how the shared experiences were reauthored by the researcher to provide a perspective of how the family relationships and dynamics were lived by the family members going through the admission into long-term care. Being a researcher with prior knowledge and experience within the subject could have influenced my interpretation of their stories. When collecting the data, the participants might try to depict a positive picture of their family relationships and highlight experience which they believe I was interested in. This was avoided by building a rapport with the participants. They were met more than once, when introducing the research and later for the interview. Time was dedicated to make the participants feel comfortable and at ease with the research to have a honest and trusting relationship.

The data analysis process was divided into three parts:

- Data familiarization
- Transcription
- Ethnodrama analysis

- Data familiarization

Data familiarization initiates from the interview process up to transcibing and re-reading the data. The fact that participants were encouraged to narrate their story helped the researcher familiarize with their story.

- Transcription

The next step was transcription of the interviews. As the way the stories were narrated was important for the data analysis, the transcription included notes about pauses, reactions, sighs, pace, tone, relationship dynamics, exchanges, absences, and other details which could be used to gain a deeper understanding of how the participants constructed their story emotionally and relationally (Kowal and Connell, 2021). This level of detail was suggested when using a narrative approach (Cigdem, Mastoureh and Squire, 2013). The transcription process was aided by notes written during the data collection included in the reflective diary. All transcriptions were carried out by the researcher to gain data familiarization. The transcription process started with the interviews being heard and handwritten in draft format. They were then re-written including behaviour annotations and a third listening through the audio was done in conjunction with the interview notes to fully annotate the transcripts.

- Ethnodrama analysis

Interview were analysed in the original language the interviews were carried out not to lose cultural expressions (Flick, Resch and Enzenhofer, 2018). The script was written in English as it was my interpretation of the social actions and not what the participants' shared. When I was confident with the data, the first step was to identify codes. The codes developed were based on how the families constructed meaning with their new situation. After the initial set of codes, a second round of coding was done. This was done to aid in joining the codes into categories which were patterns of social action that could be used to narrate the story. Going through the data for the third-round themes were developed. These were used as the basis for the ethnodrama.

Based on the themes developed I developed characters and dialogue to bring the themes to life. The scene and dialogues created were guided by the experience shared during the interviews. The participants narrated their story of how they were admitted into the home and how they experienced this. Using this together with my experience of working in the setting I developed the scenes. The dialogues were then guided by actual verbatim quotes from the interviews which were used to justify the development of the categories. The quote had to be translated and modified to fit within the script play. This process development was used to develop the script.

The next step in developing the script was to rehearse and refine it by attempting to capture the relational dynamics of the participants and their stories. This was a guided by expert review. The script was narrated to two professionals working in the same setting to check that the message being conveyed was truthful to the themes identified. This created a sense of a stable third (Cooper and Vetere, 2005). The script discussed did not include any identifying information or interview extracts. This step is suggested by Cannon (2012) to ensure that the written script can be understood by the general audience. After finalizing the script and discussing it with the supervisor, members checking was carried out. The script was read to one of the participants who was interested in the findings. After reading the script it was checked that the participants identified with the script written. After this, a final discussion with the supervisor was carried out and script finalized. The below Figure 1 uses a flowchart to describe the data analysis process.

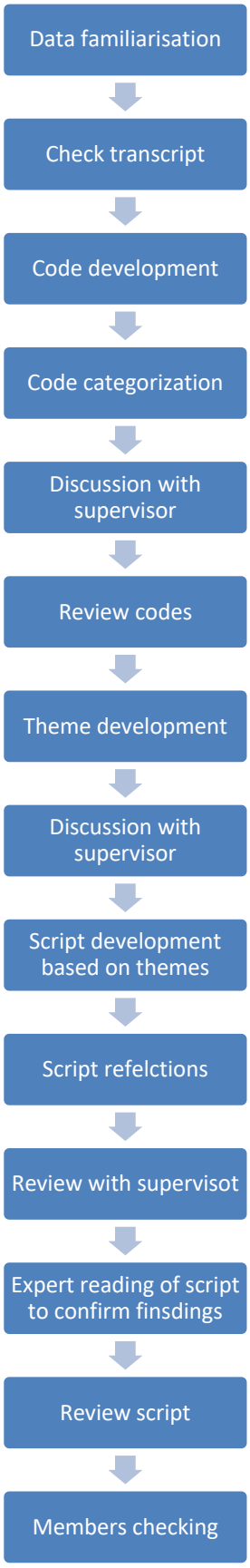


Figure 1 Data Analysis process

e) Study rigour

Rigour in qualitative research validity and reliability are described as credibility, transferability, dependability, and confirmability. Two possible approaches were discussed with the supervisor on approaching rigour in the study. A criteriological approach such as Tracy's (2010) big eight criteria or a guiding principle approach (Loh, 2013). Tracy's criteria approach defines how all qualitative research should be checked for rigour. Loh (2013) argues that all qualitative research is different as it is based on different philosophical assumption. Therefore it was decided not to use a criteriological approach as this has been criticised by qualitative researchers as it considers all qualitative approach as one (Smith and Mcgannon, 2018). A guiding principle approach was used towards rigour of this study as this was based on its epistemological under pinning (Loh, 2013; Levitt et al., 2017).

The study used a social constructionist epistemology based on a relativist ontology, which meant that there were multi-realities, which were developed through the social interactions that the participants experienced.

Credibility referred to the truthful representation of data. Transcripts were checked by another researcher to ensure they reflected the recording. Peer debriefing was used, with data analysis being discussed with the supervisor. Results were discussed with experienced professionals to ensure that the script was able to portray my interpretation of the participants' shared stories. The student took time to build a rapport with the participants, so they felt comfortable sharing their experience.

Transferability was obtained by providing a thick description of the participants experience. To vividly share the participants' stories a script was written highlighting the initial admission process. Using a script allows the readers to identify who the participants were and develop an understanding of their stories.

Dependability was assured by keeping an audit trail of the research. An audit trail was kept for the interviews, the reflexive diary, and the way the analysis developed.

Confirmability of the study was established by the analysis being grounded in the data. A reflective journal of the research process was kept. Members checking by providing the transcript to ensure conformity with what participant's would not have ensured further rigour

(Birt et al., 2016), the transcripts were checked by another researcher to ensure conformity with the recording. Members checking was used by providing one participant with the script and asked if they were able to relate to the story.

f) Ethical Procedures

Ethics application was submitted to the Institute of Family therapy Ethical Board and later approved. Prior to submitting ethical approval, the study was discussed with the residential home management to ensure support was provided. Family/significant others was considered an important part of the residents' system and verbal support for the dissertation was provided. Conditional approval was obtained to carry out the study based on ethics board outcome. Consent was obtained from the participants prior to the study by providing them with a letter of consent which ensured confidentiality as well as specifying the professionals which would have access to their information. During the interviews, participants shared stories of their lived experiences (Cigdem, Mastoureh and Squire, 2013). Participants recruited for the interview were presented with the information sheet prior to the participants signing the consent form. Participants were comfortable with the interview being recorded. During the interview process, as people started narrating their stories in a conversational way which easily allowed me to observe and include their relational dynamics.

Personal data was not collected to safeguard participants anonymity, confidentiality, and data security to meeting GDPR requirement (Gov.mt, 2020). Data were stored and backed-up on Onedrive with no identifying information. All data were kept on the online revisory to ensure safety of data. Confidentiality was kept when developing the scripts and presenting quotation to ensure that the participants were not identifiable through the story. Participants were also ensured that all data will be destroyed after the correction of the thesis.

4. Summary

This chapter provided an overview of the methodology and method employed in this study. A social constructionist epistemology was used, guiding the narrative approach. The tools used to collect data was semi-structured interviews using open ended questions. Quota sampling was used to recruit participants. Data was analysed using ethnodrama. Ethical issues for the study

were presented in the end of this section. The following chapter presents the study findings based on the methods discussed above.

Findings

This chapter presents the results of the data analysis through my understanding of the family's stories, as co-constructed with the resident and their significant others.

The narratives and voices of all family members are dramatized in this ethnodrama, which permitted me to produce a script whereby I attempted to be as true to the residents' stories and to the Maltese transcripts as possible. Following codifying and categorizing the following themes were identified as dominant to their stories, yet other possible subjugated stories are also intertwined throughout. The themes identified were:

- The abrupt change
- The construction of the family reality
- The silenced reality
- Blended family emotions
- The prospect of best outlook

Acknowledging my privileged position as the author may have led me to be biased and privilege stories over others based on my own reality of which themes are most pronounced. My daily exposure and contribution to the above themes in long-term care may have also contributed to the identification of the above themes. Throughout the interviews the family members may have experienced multiple emotions while relating and recounting their stories of transitioning between lifeworld and system. Themes are analysed by making use of a Habermasian theoretical framework, in attempt to be as truthful and close to as experienced by the client and family members, as well as my understanding and interpretation of these stories. These themes are weaved throughout the script in different scenes to give voice to different contexts.

1. Script

a) Setting the Scene

"Our Hearts" is a long-term care residence set in the rural areas of northern Malta. It is a large institution catering for 1000 residents. A team approach is the focus of this residence, taking pride in a holistic approach encompassing entire care of the self and working to balance

the pillars of health. The interviews consisted of three residents and their significant others yet for the purpose of the analysis I utilized one family attempting to capture all the themes identified. The characters in our ethnodrama shall now be introduced using pseudonyms.

Mr. Albert Lewis is a 76-year-old gentleman, has two children and is a grandfather. He is happily married to Mrs. Angela Lewis, who is 78 years old. He enjoys going out with his family and Angela is very happy spending time with her loved ones. They need some minimal help with certain work at home. Jim is the younger sibling, 44 years old, single and works as a bank manager. Bianca their daughter is 58 years old and is separated. She works as a hairdresser and has a 22-year-old daughter, Sarah. Sarah has a close relationship with her grandparents and is a University Student, studying Ethics.

b) <u>The admission</u>

i. Scene 1: The collapse

She looks at Albert, as he calmly signals, he was parking in the spot he found in front of the restaurant. His face was beaming proudly.

***Mr. Lewis*:** Not only am I so lucky to have you as my wife, but we also found a parking spot right in front of the restaurant.

Mrs. Lewis: 60 years lucky we are.

She puts her hand on his as he shifts the gear lever.

Mrs. Lewis: We have grown old together Albert.

Mr. Lewis smiles. Sarah comes up to the car and opens the car door for her grandmother. Mr. Lewis climbs out of the car and pops open the trunk to get the walking frame. Mrs. Lewis puts both feet on the pavement and one hand on the frame standing up. Bianca her daughter and Sarah walked beside her towards the restaurant's door. Mr. Lewis waits as Jim, their son pulls up his car.

Sarah: Happy Anniversary grandma.

Mrs. Lewis: Thank you sweetheart.

Mrs. Lewis puts her frame in front and takes two steps. She repeats the pattern a few more times and then stops. She turns her head and searches for her husband. Sarah is still standing beside her.

Sarah: Gran are you OK?

Mrs. Lewis: Can you get me a chair please? I need to sit.

Her face becomes pale, and her breathing picks up pace. Beneath her red lipstick her lips start turning blue.

Sarah: Someone get a chair quick!

Bianca: Jim! Come! Quick!

Mr. Lewis: what happened?

ii. Scene 2: The acute setting

Mrs Lewis' eyes were still closed but she could hear their voices close-by and that gave her comfort. There was one that she didn't recognize though. She managed to catch a glimpse of her husband looking very concerned. Bianca is crying and her brother is holding her. Sarah is there too, speaking to the doctor. Albert sits down. Mrs. Lewis cannot make out what they are saying. She needs to rest. They will take care of her. She closes her eyes.

Mr.Lewis*:* can you explain what's happening?

Sarah*:* Gran had a blood clot in her lung grandpa. She's ok but she's weak. She'll have to stay here for a couple of days for observation. Let's go get her clothes from home.

Mr.Lewis*:* Yes. Right. Let's go.

iii. Scene 3: Discharged where?

Three days later…

Mr. Lewis sits in the blue uncomfortable armchair next to Antonia's bed, listening to what she was saying. She seemed to be getting better, talking and eating even. Her colour was still a bit pale but she was as persistent as ever. He looked at her in admiration.

The doctor enters the room together with his team of medical students who gather around Mrs.Lewis' bed. They have Mrs.Lewis' medical file and all speak in hushed voices

whilst glancing at Mrs. Lewis. The consultant approaches the couple. Mr.Lewis holds onto the bed rail and stands up.

Dr.Brown: Well, Mrs. Lewis. Medically you are totally fine. Your blood results show there is not more threat to your health and you are discharged. We will follow you up at medical outpatients in three months.

Mr.Lewis: But doctor, she is not strong enough yet. She hasn't even walked. She hasn't even gone to the bathroom on her own yet. How can she come home like this? I'm old myself. How can I take care of her? Can she stay here a bit more, until she recovers?

Dr.Brown*:* I'm sorry but this is an acute hospital. Best I can do is give you one more day to make your preparations. If it were me, I'd look into a nursing home.

Mr.Lewis*:* A nursing home?

Dr.Brown: As you are saying, you are both only getting older, your wife is still physically weak. I think you should weigh your options. Going back home will be very hard, for both of you. Just let the nursing officer know where she will be going, and she'll let me know herself.

Mr.Lewis: ok….thank you

The medical team start talking about the next patient on their list and move away. Mr.Lewis slowly lowers himself back on the armchair and turns towards his wife.

Mrs.Lewis: We don't have any option love; I'll go in a nursing home. You can come see me there. I'll be ok.

Mr.Lewis: No Angela, I want you back home, where you belong. I want you with me.

Mrs.Lewis: Remember Albert, we made that promise for a reason. I love you very much and that is why I don't want to take you down with me. This is the exact reason why we made that promise when we were both healthy. We discussed this already, it's already planned and decided.

Mr.Lewis*:* But can't we try see if we manage at home?

Mrs.Lewis: and then what? Hurt you as well and we both go in the nursing home together?

Mr.Lewis: it wouldn't be a bad idea.

Mrs.Lewis: Darling, you have the house, the kids, and your birds. You will still have me. I'll just be in another place. And if I get stronger, I can always come back.

Mr.Lewis*:* Right. I'll call the kids. See what they think.

Mrs.Lewis*:* The kids work, they have their families. I don't want to be a burden on anyone. Please. We had said, when one of us gives out, we go to a home. You can visit me, right?

Mr.Lewis*:* Every day I promise.

Mrs Lewis*:* Then it's set. Call the nurse sweetheart.

Mr.Lewis: Cannot believe in five days, our life has turned upside down.

c) <u>The new reality</u>

iv. Scene 4: Waking up

Angela was awake in bed looking at the photograph of her family on her bedside table. Two voices were approaching, talking very quickly in a language she couldn't understand. One of them opened the small cupboard and quickly grabbed a skirt from the pile of neatly folded clothes. Another skirt fell out, which they hastily put back in as she said a loud good morning to Angela. Next, she chose a blouse once again, misplacing several other jumpers in the process.

Mrs.Lewis: Please be careful. My daughter folded them yesterday and I can hear very well, no need to shout.

Carer*:* Goodmorning Mrs Lewis. Ready for bath?

Mrs.Lewis: May I have some tea first? And the outfit you chose for me doesn't match.

Carer: Tea? Oh yes, she is coming. Wash first. How sweet, you really like dress don't you!

Mrs.Lewis: You always say this, and I have to wait a whole other hour for tea. I always have tea and biscuits at home before I shower.

Carer: Grannie this no home! We won't make it on time if we don't wash now.

The other carer smiles and doesn't take part in the conversation. The carers speak to each other in a language that is foreign to Angela whilst they started undressing her.

Mrs.Lewis: Aren't we going in the shower today?

Carer: Sorry Granny, we have to do it quick today as we are little staff. Don't worry, will still wash you well. Your husband will find you nice and clean don't worry.

The carer translates to the other carer, and they laugh loudly. After Angela is dressed in the clothes picked out for her, she takes her walking frame and takes a few steps to her wheelchair. She sits and waits whilst the carers do her bed.

Carer: Sweety, its better you get a small bedspread. This is single bed not double. I'll tell your daughter to take this back home.

Mrs.Lewis: We love that quilt. It's from our bed at home, very soft.

Carer*:* yas madam yas

Rose: I can take her out of her room.

Carer*:* Fine by me Gran.

Rose*:* Have no idea why she thinks I'm her grandmother.

v. Scene 5: New friends

Rose pushes Angela's wheelchair out in the dining area next to the table where the five roomates spend most of their time. Two are playing rummy, Josephine is reading and Rose sits down next to Angela.

Angela: You got me out just in time. Why don't they understand that the quilt means a lot to me? It's how I feel my husband next to me at night. I miss him so much and it's not getting any better.

Rose: It will get better Angela, it's just until you get used to it. We have everything we need here, doctors, medicine, food, xrays, everything.

Angela: I need my life back. I miss my family. It's like I'm locked in prison here. I'd give anything to go outside again.

Rose: But doesn't your husband take you outside now when he comes?

Angela: Yes but just in this yard and we're never alone. I cannot say what I want in privacy.

Rose: Your business is everyone's business here. They have to know everything so they can take care of us. I like that I'm comfortable and I'm not lonely like this.

Angela: I do feel lonely, I can only see my family on visiting hours. Sometimes I wonder if we made the right choice. I'm lucky enough to have been put in the same room with you four. At least I found good friends.

Josephine: Of course you have, and you are lucky enough to have your family come see you. Some of us don't. I once had Bernard with me here but ever since he died, I just look out the window hoping to see him walking over here. I hope we will meet again soon. I have nothing else left here.

The nurse approaches their table, and the carer places a bowl of cereal in front of each of them together with a cup of tea.

Nurse: Good morning ladies. Here are your pills Josephine, Angela. Here you go.

Angela: what's this blue one?

Nurse: that's to help you feel less sad.

Angela: but since when?

Nurse: your daughter and son were very concerned about your mood lately. So they spoke with the doctor and he agreed we should try this and see how you feel.

Angela: but i feel fine. No one told me anything. Isn't it normal to be sad if this isn't home?

Nurse: Sweetie, speak with your children. I'm just doing my job. Take your pill.

Angela shakes her head and takes the pill.

vi. Scene 6: Afternoon tea

Later in the afternoon, Angela sits by the window in the terrace as usual. Bridget, her other roommate is sitting on a comfortable looking sofa, reading a book with a cup of tea next to her.

Bridget: Looks like your children aren't coming are they?

Angela: They were supposed to come. If they said they'd come, they will .

Bridget: Mine started out like that too.

Angela: Bianca never missed one day, only when she's sick. She used to come over with the shopping every day before I came here and she still does. Jim has to work so he cannot come so frequently.

Bridget: Doesn't Bianca work too?

Angela: Yes but she still comes. She has to wash my clothes too. I cannot wash them myself here. Bianca used to help me out a lot. She got my groceries cause some are too heavy for us. She washed my floors cause we couldnt reach under some furniture and cleaned the high up places and the curtains. She also checked my medication every day and fixed my medical appointments cause Albert tends to mess them up somehow. She always came with me to the doctor too. She keeps track of everything. She's a great listener,always listens to my worries too.

Bridget: What about Jim? Did he used to do anything?

Angela: Jim has work, he doesn't have time.

Bridget: What about his wife? Couldn't she help you with the house?

Angela: She's sweet but she's not my daughter. I don't expect that from her.

Bridget: Sounds to me like your daughter got a break with you in here.

Angela: That's not nice to say.

Bridget: The truth hurts darling.

Half an hour passes when Bianca and Sarah walk in the ward carrying one small bag each. By that time most of the residents had gathered in the terrace, seated around three small tables, some having tea, some chatting and some doing nothing, seemingly waiting.

Angela: There you are! I thought you weren't coming.

Bianca: You know we always keep our word mum. We were raised well.

Bianca winks at her mother. Angela's lips curved into a smile.

Angela: Those were the days. I was so strong.

Bianca: Come on mum don't be like that! Come on! Look what we got you.

Sarah handed her grandmother a rikotta cheesecake and Angela takes it. The women sitting at the table all look at her.

Sarah: and we got you a pea one too.

Bianca: we have enough for everyone. Look, we can have a party!

The other women chuckled and nearly all helped themselves to one of the maltese delicacy.

Rose: After tea, we can cut the cake my children got me for my birthday. Hey maybe the nurses would like a piece as well.

Angela: Yes of course, Sarah sweety, why don't you go give them some cheesecakes.

Sarah: Mum already did! We got them a lot, don't worry. Our little thank you for taking care of you.

d) <u>The best we can do</u>

vii. Scene 7: Happy birthday.

Albert approached the counter and the young lady behind the counter gave him a warm smile.

Elaine: What can I help you with Mr.Lewis?

Mr.Lewis: Good morning Elaine, I would like a birthday card please.

Elaine: Sure thing. Who is it for Mr.Lewis?

Mr.Lewis: For the missus, it's her birthday tomorrow and I want to have everything ready.

Elaine: How sweet. I haven't seen her in a while. How is she?

Mr.Lewis: She's ok, she's at "Our hearts" home.

Elaine: Oh poor Mrs.Lewis. She's that bad? I'm so sorry. Give her my regards.

Mr.Lewis: She's doing ok.

She hands him the card and answers the telephone that was ringing, smiling politely at Mr.Lewis.

Mr.Lewis steps out of the elevator and walks towards the ward door, holding onto his stick with one hand and a paper bag in the other.

Mr Lewis: (internal dialogue) The door seems to be heavier since six months ago. I hope she likes my tie and the card. I hope we will find somewhere private so I can spend some time alone with her. I don't like being some sort of entertainment for the rest of them to see telling us how cute we are.

Nurse: Would you look at that! Mr.Lewis, where are you going so smart?

Carer 1: It's his wife's birthday! How cute! He came all dressed up for her. She's been waiting for you. She's in the dining area Mr.Lewis.

Carer 2: Angela, look who is coming to see you! It's your love. How sweet. Look at the poor man, he came all smart for you.

Mr.Lewis nods his good morning to the residents seated next to his wife. He hesitates and takes a seat next to Angela.

Mr.Lewis: Happy birthday Angie (low voice).

Mrs.Lewis: Thank you darling.

Mr.Lewis: Would you like to go sit outside for a bit?

Mrs.Lewis: I cannot, I'm waiting for them to take some blood tests.

Mr.Lewis: I really miss our alone time love. Last night, no one woke me up when I dozed off on the sofa. I woke up very stiff in the middle of the night. I have no-one to laugh with, or argue with.

Mrs.Lewis: Somehow we argue less here right?

Mr.Lewis: Of course we do. There's nothing to argue about anymore. And how can we argue in front of everyone.

Mrs.Lewis: You have the kids though right?

Mr.Lewis: The kids are not you. They only come once a week now anyways. And they are not you.

Mrs. Lewis: once a week? How are you coping with the shopping and the washing? And what are you eating?

Mr.Lewis: oh, Bianca cooks for me. She brings me portions and I freeze it. The rest of the days, I can cook some basics myself.

Mrs.Lewis: I can see that (laughs gently). Your shirt has a stain. Did you wash that?

Mr.Lewis: hmmm….yes I did. I didn't want to bother Bianca with the spaghetti sauce. She had just got me the fresh laundry. She has enough errands to run.

Mrs.Lewis: Of course. And she does have her own family other than us two.

Mr.Lewis: Haven't seen her yet this week. Used to see her almost every day.

Mrs.Lewis: Mondays, Tuesdays and Fridays she comes here so maybe you'll see her tomorrow? Jim comes here in the weekend.

Mr.Lewis: I haven't seen Jim in more than two weeks.

Mrs.Lewis: I bet he's busy with work. He works very hard. But they should both come here today they said.

Mr.Lewis: Just like the good old days.

Later on that same day, Bianca and Sarah did come to visit Angela and brought a cake for the residents. Jim called and said he would come later on.

Sarah: Mum, you cannot just give anyone a slice, we have to check with the nurse. Not everyone can have cake.

Bianca: oh, poor patients, can't they enjoy what is left in this lifetime?

Angela: No Bianca, you really have to ask them first.

Bianca: Fine, let me ask.

As Bianca was returning from the nurses' station, Albert was making her way towards her.

Mr.Lewis: Bianca, what do you think about speaking to someone and getting your mother back home?

Bianca: we've been through this dad, don't make it any harder. They all said that she's not good enough to come home. Don't you think I want her home?

Mr. Lewis: I want her home more than anyone. I am alone. I have no one with me. We were fine a few months ago.

Bianca: We're barely getting by as is dad. I have my own family, I have you and I have to come here for mum. Cannot just have her here and expect everyone to do our job. They are not her children anyway.

Mr.Lewis: I am getting by but I'm not happy and I don't think she is either. Is there anyone we can speak to?

Bianca: it's not about speaking to someone dad, it's managing at home that's the problem. Everyone here told us you won't manage.

Mr.Lewis: yes but how do you know? They don't live with us.

Bianca: because they are the experts dad not us.

The gentleman and his daughter walked back towards Mrs.Lewis, each of them thinking.

Mr.Lewis: This is how I shall remember my wife. In a home, and from here there is only one way out apparently and that is not home. Maybe I should come here too. I am an extra piece of work for the kids, and I am alone. If I come here I'll be safe, and I can be closer to her somehow. I can come here and be next to her easier. I'll make everyone's life easier.

Bianca: My poor mother. She's another year older. Shouldn't she be home celebrating her birthday? I shall speak to Jim about what dad said. He'll say it's up to me anyway. Will mum be happier? She's only getting older and I want to do everything possible to see her happy. She did so much for us growing up. Did we make the right choice? Is there really nothing more we can do to get her back?

The End

2. Behind the Scenes

a) Scene 1 – 3: The admission

These scenes introduce the Family Lewis as the protagonists. Mr and Mrs.Lewis share close relationships as a couple and on a transgenerational level. Celebration as a family of special life cycle moments like their anniversary, words of praise and appreciation and instrumental and emotional acts of service show how this family makes meaning from their close ties. The sudden and unforseen complications of old age are highlighted in these scenes. They are followed by the immediate hospitalization, together with the uncertainties, worries, fears, and negotiations that have to be made by the family whilst being constrained by time, power and loyalties.

This is a relational process where in this case the patient admits and the husband resists to the idea. We see the negotiation of their love and their practical needs. These scenes shed light onto promises and compromises made in couplehood as portrayed by decision making in circumstances the family never preempted. This moment was a more advanced process in this difficult decision making as the couple had already discussed this moment before, perhaps suggesting that families may require earlier interventions to prepare them even discursively and emotionally for this moment. Decision making is also being seen to extend to the filial system following the couple's negotiation process.

In the interview process, Family A shared with me that decision making was made at an earlier stage when both were physically independent. Admiration for the couple was very strong from my end, especially for being able to share a conversation where they were able to negotiate and plan the unforeseen even though it is not an easy decision to make. When the decision had to be taken, I felt there was the option of renegotiation and found myself questioning how this was not explored. Out of respect for their decision and perhaps also fearing this would fuel regrets about their decision I refrained from asking yet it may have enriched the story if I did.

Family C's admission decision was done differently but loyalty was still pertinent in the process. When the husband could no longer have his needs met in the community, he moved to this residential home. I felt comfortable asking around this decision perhaps because I was captivated by the romanticized story being told and my strong beliefs around love and sacrifice. His wife showed me she had strong transgenerational gender defined roles and felt that she

belongs with him, keeping her role of carer despite the professional caring role and despite being institutionalized herself, sacrificing her own freedom to fulfil her perceived marital duties.

Family B did not have much say in the admission process. Health complications resulted in admission of the older adult to hospital, and it was the health system itself that urged her for long term care, heavily influencing the admission process. I was not surprised by this perhaps because I have witnessed this at my place of work, when reading the history of admission in the medical files. Despite this, as a researcher I may have operated from the knowing position and was less curious, not exploring how this decision making was lived by the resident and her significant other; her niece who was her legal guardian and was with us in the interview.

Thus, decision making was lived very differently in all families; whilst one family processed the admission process well prior to its occurrence, the other 2 families reflected the process as more of a response to the circumstance.

i. My personal and professional positioning.

Qualitative in scope, my research grows from a place of concern and passion for my vocation. Thus, I felt guided throughout by My professional experience of being part of the admission team at my workplace has exposed me to the many stories told by the residents which resulted in their admission to long-term care yet positioned myself to be open and curious to these stories. This facilitated the details of history and sharpness for 'the collapse' that led to the patient's admission. My close relationships with my living grandmother and my experiences with all my deceased grandparents, have gifted me with the ability to provide detail to the first scene where movement and expressions of the older adults were described in detail.

Having had experience in working in Malta's acute general hospital in several wards for a good period, I was witness, as a professional and constructed my own meaning of what an acute admission was lived as. Furthermore, my own admission at hospital as a patient myself, co-constructed meaning to my initial interpretation. I wonder if during the interviews I more recipient to the preferred story of problem saturated descriptions of the fast-paced and non-empathic setting of the 'acute setting' was.

b) Scenes 4-6: The New Reality

These scenes are an attempt at creating a snippet of what life in a residential home is like, as recounted by the participating families as well as from my own personal observations and biases. Mrs. Lewis shows us a part of her new daily routine, struggling to make new patterns whilst battling social constructionism and dominant discourse portraying age and institutionalization. Scene 4 portrays the unspokeness of familiarity, of personal and familiar care as opposed to this new mechanical care which fits the structure and dehumanizes the person. Mrs Lewis and her needs felt fading away whilst the home's needs took privileged. This might add on to the confusion rather than aid towards integration and care giving us incongruent stories of what the institution needs rather than of love and care the person needs. The tea in the morning, the personal quilt, and the nicknames of grandmother all make her unacknowledged; just seen.

There is subtle ageism surrounding sexuality in old age and preferred stories and construction of meaning of being old and having an increase in dependence and need of professional care. The quilt was an attempt to be heard, to say it was a connection to her husband. Taking it with her shows that older people still find solace in their attachment figurines and their symbolic representation of them, suggesting that we need to intervene to acknowledge what is meaningful to them. Losing her privacy and freedom, friends try to give her solace, sharing their private stories into public stories. Mrs.Lewis even shares her losses with new friends such as the feeling of prison and that life is public. This scene also shows the discourse around pills and the physical needs rather than the emotional shown by the functional carers "I'm just doing my job

The multivoicedness of the older adult was shown through the participation of other residents where they recount justification for less privacy, visitation frequency and decision making in institutions. Doubt of the family's original closeness becomes alive when loyalties become questioned by some residents and gender ascribes roles and expectations are discussed amongst different residents too. Here we see the loss of basic functions like washing the clothes and the exemptions from filial roles by gender with stories featuring gender role differences in filial role of caregiving. There is also the realizing of a burden an old adult may be 'your daughter's relief with you coming here'. The scene also shows that the Childrens' female loyalty

towards the older parents are embedded in the Maltese context. When the relatives enter the scenes again, they show that care and involvement is ongoing and paves the pathway to explore instrumental vs emotional support. Bianca also refers to the attachment patterns and reciprocity towards her parents. Her understanding at appreciating and strengthening the relationship between the family and the nursing staff, supports societal discourse that family and staff relationships translates to access to, and level of care provided, pointing towards the power shared.

Family B strongly voiced their disappointment towards the attitude of the staff and the dominant discourse in a long-term care institution. The fact this was experienced in my place of work and in the resident's previous experiences at other homes made me realise how big a problem this was to the residents, and how adjusted society became to this new reality and discourse. This is congruent with my emotion I feel regularly during work as frustration and anger at the mechanical care and dehumanization explicitly shown by some members of staff. I didn't share my anger with the family regarding this situation as I didn't want to solidify their truths furthermore. I may have however allotted the family more time than required during these questions in the interview in order to feel heard and understood and found myself unable to stop their sharing of stories with unmet expectations and disappointments.

In contrast to this Family C only had stories of great expectations being met, great level of care provided and exceptional services, grounds, and amenities. I found myself perplexed as a researcher and health practitioner as I wondered how at peace and satisfied this family seems with their choice of residence. What stayed with me during speaking with this family was the contradiction that expectations from the family members were unmet as regards visitation, gender roles, parental and filial duties, and responsibilities. They were not congruent with my own beliefs, and I struggled to push back my biases in such moments. I found myself at some points tempted to defend the position of the eldest daughter. Upon reflection this may have been because of my same sibling position in my family of origin.

Family A also brought to the interview may positively experiences of adjustment to living in long-term care. When the granddaughter spoke with pride at her accomplishment in using her social connections to get her grandmother admitted into this long-term care, I felt that the granddaughter deserves to be given credit for the efforts she made to have her grandmother

provided with a safe place to live. The grandmother reciprocated this and with warmth in her eyes and worry in her tone of voice, she showed emphasis that her granddaughter had given up all hobbies and social life to look after her and now needed to find purpose in her life and regain her role as a granddaughter and not a carer.

The goals of the residential home and needs of their residents were also lived differently. Whilst Family B experienced living in the institution as a disappointment and delusion from their expectations, families A and C had described it as the epitome fulfilment of their stage in life.

ii. My personal and professional positioning.

My positioning as a researcher was influenced both by my personal life and by my being a member of staff at this institution. Throughout this research, since I have an identity represented by my place of work, I realise that I may have been influenced by split loyalties and so acknowledge my biases as I have affinity and loyalty to this institution. I was the researcher who knew the policies and the daily routine procedures and was myself a part of the multidisciplinary team at the institution. This privileged me as a researcher by decreasing initial communication barriers and making me feel more comfortable in the data collection stage where communication especially with the staff regarding timing was concerned. I was very accommodated by my colleagues and was advised to come after dinner time for successful collection of data and was also given a private office to carry out the interviews.

Being a staff member, I had the circumscribed social role of a professional where most patients recognized who I was, despite not wearing my uniform and this may have influenced the relatives and the residents to be collaborative. I not only had power as a researcher but also as a professional, one that was accompanied with established therapeutic trust.

I had an established identity with the ward life; I was present doing my work as a physiotherapist every other day, so this privileged me in being familiar and able to identify the detail in their stories that I already knew existed. This same existent familiarization may have helped me into constructing the themes and giving vivid detail to the script.

c) Scene 7: The Best We Can Do

The negative discourse about being in a home shown throughout this scene decreases hope and induces guilt. It presents stories of contrast, on one hand there is Mr.Lewis' enthusiasm to

make it special for his wife and on the other, the guilt evoking discourse from the lady behind the counter. This final scene shows Mr.Lewis purchasing a birthday card for his wife and here we have the recounting of being in a long-term care facility and the social constructionism with problem saturated descriptions that accompany a story of institutionalization and old age.

This scene shows Mr.Lewis' internal dialogue where he hints at his decline in physical health as well as recounts his hope at preserving the couple's intimacy, pleasing his wife, whilst she eagerly waits for him. This explains and displays to us that our need to feel loved does not subside with age and that celebrating special occasions may remain meaningful. Missing intimate time with each other also shows us that they have a unique role, place, and space in each other's heart. Ironically, the more this need is made explicit in the script such as privacy for the couple, looking attractive, and satisfying each other, the more the subtle ridicule about intimacy is experienced from the system.

This final scene highlights the change in the couple's patterns of conflict and decision making. The reciprocal rules of relating between parent and filial system are displayed through the weight of being a burden to the children to a point of considering institutionalization despite not needing professional help. In contrast to this we also witness the guilt felt by the daughter who starts to consider other options whilst in reverence to the medical professionals' opinion. The script ends with Mr.Lewis doubting and rethinking the decision for Mrs.Lewis to live in a home, when his daughter grounds him, keeping a firmer position. This is when loneliness kicks in, fearing his last memories of his wife in a home and envisaging the last stage towards end of life, getting in touch with it and making it more real.

A strong theme that emerged with Family A was the lack of intimacy and the dominant discourse that in old age, intimacy is unneeded and often unspoken of. As the husband clutched the hand of his wife and uttered the words in between tears "I miss you in bed", I felt my heart clench. The reciprocity from his wife was witnessed as well as she patted his thigh and whispered, "I love you". At that moment I viewed this reality as very unfair for couple hood and I felt the need to acknowledge this and empathize with the couple for living this ongoing loss of what is theirs. I did this and this opened up to more stories about how their intimacy changed following institutionalization.

The husband was not hesitant to express the fear and grief he had lived when his wife was being admitted into long-term care. He spoke very bluntly and seemed very sure his wife would never come out alive from the residence. His sudden bursting into tears helped me appreciate the grandiosity of how scary this must have been for him. I found myself very comfortable with the silence in the room and because of this I also could understand better the open communication he had with his wife, when she assured him all with be ok, and did not dismiss his crying but rather gave him mutual time.

Family B refers to the slow but evident regression in health of the wife. The resident speaks about her physical deterioration as a matter of fact and emphasised the expectations she had from her daughter because of the transgenerational scripts of her family of being a female and also fulfilling her caring role. Her voice was so set and uncompromising with her daughter, almost punitive at one point, that I decided to take a one down position and stop from pursuing this further in the interview. It felt like this was a prohibited area to explore and the daughters' non-verbal signalled to me to not challenge this. In fact, when I attempted to do this, the patient told me "I think I told you all you need to hear, there is no more to discuss about this." This changed my perspective of this female resident and left me wondering what was encouraging her to keep this position and if these beliefs where the reason for her choices including being admitted with her sick husband to follow her script. The daughter repeatedly said she felt trapped with guilt and often questions the need for her mother to remain in the home once her father has now passed away. Still though, I could feel the entrapment she finds herself in when she helplessly looks at the sky and said it was worthless discussing it with her brother cause all the filial duties will be up to her anyway.

Family C, was quite passive about the decision to come into institutional care, explaining that following the death of her husband, she felt alone, forgotten and of no purpose. This reality was also lived by the niece who was the significant other. Despite having her niece very present in her life, the older lady felt it was appropriate and timely that she enters institutional care. I felt pity for the lady for being let down and abandoned by her community, her social system. Somehow, she was encouraged by her system that this was 'normal' and a due stage in the life cycle. I did deconstruct this during the interview and the more the former encouraged this reality the more solidified the reality became for both resident and niece.

Family B and C are seen to understand the admission as the best option in dealing with the consequence of ill health and as part of the ageing process whereas Family A made meaning of it as a certain end to life, one that was lived in great fear.

iii. My personal and professional position

This scene was the one that resonated with my personal life the most. I feel I influenced the creation of this scene inspired by the fear I have of having similar unforeseen complications arise to my 86-year-old grandmother. She is a very important figure in my life, one that I have great respect and love towards. I have become more mindful of how time waits for no one and how old she is becoming. I see myself negotiating the justification and the greater good of the societal discourse; that of when one becomes too old to care for oneself, one goes to a residential home. I have come to realise what a crossroad would be ahead of me, and my family should my grandmother ever deteriorate in her health. The more I dig deeper into this study, the more I realise this and the more I realise this, the deeper I dig.

As a health professional and now a researcher, I feel honoured to be able to be a part of this stage of the life cycle of the residents at SVP. Through this dissertation I aimed to be able to give voice to that honour and privilege that I have been given by the residents. As a researcher, I aimed to give voice to my choice I make every day to stand by their side and be a witness to their lives through the writing of this script. In Saldaña's (2003) "Dramatizing Data: A Primer," I am reminded that the author touched upon the issue of ethnodramatists casting themselves in their own work. I attempt a reflection on my desire to keep my presence in the script: whilst carrying out the interviews I became more mindful of certain positions I take with the residents that mean differently to the patient despite my benevolent original intent. I found this very insightful and hence included parts of myself in the script.

3. Summary

The concepts identified through the data analysis were narrated as a script of a resident and her significant others. The script was used to highlight the family dynamics as presented during

the interviews of newly admitted residents in a long-term care residence. These results are discussed in the following chapter.

Discussion

This Chapter presents the discussion by highlighting the family stories and dynamics as presented during the interviews of newly admitted residents in a long-term care residence and comparing this with the literature available on the topic within the conceptual frameworks highlighted earlier. Discussion is presented as concept identified as dominant to their stories.

1. The abrupt change

The family expressed narrations about the relocation to be a stressful and a major change, similar to Costlow et al., (2019) and Ross (2001). This was identified across different phases through their transition. Within the script, stories were dominated by discourse of helplessness, concern, worry, uncertainty which were used to describe this change.

Mr.Lewis: Cannot believe in five days, our life has turned upside down.

This is in line with my direct daily experience in my work in the wards where I witness stories unfold. Being part of this transition through being their physiotherapist, assessing their physical aspect and try and establish short- and long-term goals as they start this new part of their lives makes me feel honoured and privileged. A new life pattern is needed suddenly (Chien, 2022).

Rose: It's just until you get used to it.

Iwasiw (2003) described this as an 'overwhelming' event. Alike, the husband spent time differently at home, including house duties whilst the wife tried to adjust to the new routine on the ward. Reflecting, I see this change as concurrent, mutual, and reciprocal effecting both partners' separately yet concurrently yielding adjustment and loss.

Older adults preferred a residential home as compared to a relative's home when professional care was needed. The opposite was the preferred choice for healthy ageing that did not require professional care (Pace, 2016). Throughout the script, this dominant discourse was also that of professionals and relatives themselves.

Dr.Brown: Going back home will be very hard

2. The construction of family reality

Consideration of the older person as a stakeholder throughout the process of institutionalization discourse and in practice, verifies and reasserts worth and dignity (Brody et al, 1996). In contract, inclusion of the resident was observed to be lacking in the study in different contexts; the staff, the other residents, and the family members themselves.

> *Mrs.Lewis: Please be careful. My daughter folded them yesterday and I can hear very well, no need to shout.*
>
> *Carer: Sorry Granny, we have to do it quick today as we are little staff.*

This reflects that consideration is constructed in the local context of the institution itself and larger context of how policies are drawn locally, needing to work harder towards fostering and privileging the dignity of old people and their families.

The construction of the reality of the transition was found to be affected by cultural factors and embedded in the lived experience of the move (Brownie, 2004). I interpreted the drastic and quick change of culture one lives in with their family to be a big contributor to the family's settling in, whilst concurrently creating new stories. Settling in was found to be a reciprocal process dependent on the family being knowledgeable that it takes time (Tracy, 2004) and being mindful of the resident's own meaning making of the move (Keister, 2006). These were highlighted in the findings where stories that questioned the choice to be admitted, were reciprocated with disregard to autonomy and made sense of the move as a justification to decrease the burden on the family.

The Maltese contexts presented data where the families represent stories of continuation, rather than termination – enfolding into a new chapter in the life cycle. Improved relational dynamics between the resident and family enriches the life of the residents and facilitates the transition of the entire family (Maas, 2000). I do think that in this study, the narrated improved relational dynamics were influenced by the fact that all participating residents were able to communicate well, perhaps also influencing willingness of the family to be involved (Iwasiw, 2003). Gaining insight of how families remain involved in the lives of institutionalized older adults over long periods can help direct the design and implementation of facility and family-level interventions that preserve family involvement (Maas et al., 2000; Pillemer., et al, 1998). Gladstone et al (2005) documents that during the first two years post admission, families visit

frequently and show involvement through visitation and support. Comparatively, this study investigated *recent* admission to a long-term care institution and disengagement in visitation was already commented on by the participants. Long term, some families showed continued involvement whilst other relationships waned away possibly due to other life cycle commitments, such as Jim's work and decreasing guilt perhaps nourished by the good level of care of the home. Changes in emotional connection in the family were expressed in the script.

Bridget: Mine started out like that too.

In other shared experiences, the community-dwelling spouse notes a shift in the family dynamics where visitation to the community-dwelling spouse was less following the admission of the partner.

Mr.Lewis: Haven't seen her yet this week. Used to see her almost every day.

Through these stories as sustained by Tsai (2012) and Gladstone (2005), the continuation and maintenance of the relationship post admission seems to be located in the larger context whereby roles of care are mostly understood to be the filial duty as well as that of the spouse, or perhaps even more based on gender differences when it comes to role expectations: perhaps a female daughter is more expected to do her filial duty to visit her parent/s rather than her male sibling.

Mrs.Lewis: Jim has work, he doesn't have time.

Mrs.Lewis: She's sweet but she's not my daughter. I don't expect that from her.

During the interview, being a female in the Maltese context, this sparked anger in me. I later reflected this could be related to me being the eldest out of three girls and brought up in a family with feminist ideas of equality was never exposed to such justified gender constructs nor expectations. This may have positioned me to be less curious and more cautious, asking less around it during the interview, in order to keep my emotions and thoughts unrevealed. Yet it would have benefitted to elicit more meaning perhaps if I did.

Residents whose relatives visit and are also emotionally involved not only experience an easier transition into long-term care (Lee, 2014) but also an increased identity and perceived quality to their life (Maas, 2006). The long-term care is often not experienced as a new home by residents and their families (Johnson, 2014). Reciprocal and mutual benefits were hoped for by

the resident; that whilst the burden would decrease on their family, contact time would as a result increase, creating new roles and expectations.

Mrs.Lewis: They were supposed to come.

Meanwhile, Pruncho (1994) through attachment theory, explains how the parental child attachment pattern persists following admission in a nursing home, which resonated to Bianca when she voiced that they are close because they were raised right.

Bianca: You know we always keep our word mum. We were raised well.

The meaning of involvement by means of provision of care following admission is not well studied (Ross, 2001) however in this Maltese context this was felt to be strongly present in various ways, like practical help for the spouse living at home and advocacy with the medical staff.

Mr.Lewis : She has enough errands to run and work to do.

I recognize that moving to this new phase requires a change of the system itself as well as shift in roles (McGoldrick, 2015). Members of the family must change their roles such as carer versus daughter's role and rules of relating such as conflict patterns as they move to a new phase (Cooke, 2002).

O'Neill (2020) also highlights the importance of building a good relationship with the nursing staff since they provide and give access to care. The multicultural shifts in Malta have brought an increase in employment of foreign nurses and carers. From my own professional experience I witness this relationship in difficulty of being built. A relationship barrier perhaps through language as most never learn Maltese, expectations from our older Maltese patients not being attuned with their own cultural ones and learnt behaviour towards our older patients through their own meaning making of institutionalization is externalized strongly in the script.

Voices were approaching, talking very quickly in a language she couldn't understand.

3. The silenced reality

Societal discourse presents later life bringing with it colourful experiences for the family some of which includes dealing with everyday functioning,

opens the car door for her grandmother

pops open the trunk to get the walking frame

but also, unforeseen complications accompanying old age together with the ability to make decisions, face losses and changes.

Mrs.Lewis: Then it's set. Call the nurse sweetheart

These include familial and social roles encompassed with respect for the wisdom and experience of the older adult (Wright and Leahey, 2013). This respect was observed to initiate before the unforeseen institutionalization of Mrs. Lewis, thus ongoing shifting identity roles in both the old person and their respective significant others. Perhaps an internalized voice of the entire family may be that admission to long term care, carries with it the weight of possibilities of the permanent separation from the loved ones by death (Chien, 2022).

Mr.Lewis: That's the end of my wife

This captures other parts of the stories that are felt yet not uttered or is lived or perceived yet not voiced. It makes me wonder about how families would benefit from being encouraged to talk about this to make sense together of such lived silence or perhaps not.

Societal discourse may also encourage problem saturated discourse associated with old age such as that ageing lowers productivity, depletes cognition, encourages dependence, and invites death. Sometimes I think this may easily influence the care system as well in the attitudes and approach the staff members themselves present to the older adult, the belief systems of the professionals as well as the policies implemented by the institution itself.

Dr.Brown: I'd look into a nursing home. You are both only getting older

Once a resident, most of the day s/he spends idle time with little scope (Victor 1994; Chien, 2022) although Edwards (2003) reports increased safety and security. I reflect upon how the system feeds positively into this feedback loop of demand-provide pattern. Professionals may want to have more independent and motivated patients, yet perhaps with all the safety and security demands, they then provide and then may be prompting further dependence which may need further assistance, ending up with a paradoxical intervention. All these were outlined in the findings.

...some having tea, some chatting and some doing nothing, seemingly waiting.

Your business is everyone's business here. They have to know everything so they can take care of us.

4. The Caring Role

Once safety and security are attained by the family, when they feel that proper care is being offered, thus can actually rely on the carers and the home in general, literature shows that the family may even relinquish most of their caring role to the professionals (Dupuis, 2001) and redirect their energy at their roles like mother and wife in the case of Bianca.

Bianca: I still have to do my other jobs.

Even though caregiving continues (Aneshensel, 1995), the caregiving roles of family Lewis following admission in the institution was observed to be of a more hands on approach (Ross, 2001). Once the physical part of caregiving was done by the healthcare workers, the family would plan and advocate, but the emotional indirect way of caregiving was not observed in the findings and I wonder what meaning was made of their new found roles as they seemed to be perhaps unsure as to what they could now do or not yet mindful that they can fulfill emotional needs.

Bianca: I shall speak to Jim about what dad said.

Brody (1996) mentions that family patterns are revealed after admission and Jim may have been an example of this as he seemed less involved in the process of the transition. This is something I question at work; do the family dynamics presented after institutionalization match the previous family patterns lived as a family before a member becomes a resident? Going back to Tsai (2012), emphasis is made on visitation and involvement is often considered as a filial duty. I became more mindful about how my understanding of this is perpetuated onto the family-physiotherapist relationship sometimes finding myself judgemental of the lack of physical presence or involvement of the relatives.

Previously mentioned was the importance of the relationship, despite the challenges, that is built between family and staff. A barrier to this potential relationship to me was the dominant discourse among the staff about the residents being less able and less cognitive, almost infantilized. Demeaning discourse thus may dominate stories that transcend from caregivers which perpetuate further dependence and perhaps may make patients feeling even less useful.

Carers: Don't worry, will still wash you well.

This was brought up later by Mr. Lewis himself when he visits his wife and the renegotiation of intimacy in old age was somewhat recounted as a preferred story.

Carers: How cute! He came all dressed up for her.

This dominant discourse in the residential setting was also picked up by the husband himself. and I wonder how the couple's intimate relationship is lived in context of this discourse. Couples may for instance feel more observed and thus their intimacy may be deprived of privacy.

Mr.Lewis: being some sort of entertainment

Tuominen (2016), adds on to these experiences linking poor attitude of the staff to further contribute to the adjustment process of this transition. This highlights the caregivers role as having a vital impact in the family experience of admission and living experience. It is like an extension of the family system, where the family's well-being in the process is largely dependent and in response to the caregiving system. This poses a new dimension to the story where family members are co-constructing simultaneously and separately a new relationship with the caregivers as a new yet needed extension to their family.

5. Blended family emotions

As discussed, the unsaid by the entire family as regards permanent separation from the loved ones following admission to an institution, brings with it emotions highly composed of worry and uncertainty (Chien, 2022). Different family members carry this, shown in the data by the resident, the daughter and the husband. Thus making sense is a process which entails guilt and doubt about the decision itself at different periods of the admission. It is not one fixed story but an evolving one encompassing an interplay between the patients' wellbeing, the staff's quality of response and service and the reassurance it provides or absence of it. This sheds light on what is required during therapeutic interventions, including processing loss, guilt, eliciting the unsaid and provision of ongoing reassurance. One may also need to include the staff or encourage the family members how to approach the staff/management to better the relationship.

Angela: I wonder if we made the right choice

Bianca: Did we make the right choice? Is there really nothing more we can do to get her back

Mr.Lewis: That's the end of my wife, she's never gonna come back home

From my experience any form of hospitalization is a threat to the continuity of family life, and in my workplace, the societal discourse among both patients and staff is that a residential home is the final stage of life with rare return to their previous family community-based life. Contrastingly, if the parental relationship was one that scapegoats the subsystem, institutionalization may perhaps bring freedom that enables new meanings in other relationships. Perhaps this would renegotiate the meaning making for the family member; for instance, the older person might live this transition as a punitive experience, whilst others like daughters or spouse who might have been previously living a very burdening and hard emotional and physical experience taking care of that person, this might represent a sense of relief for instance, therefore concurrently living oppositional emotions during this process. It makes me wonder if family members would benefit to make sense of these polarized emotions, perhaps normalizing them, to help them make sense of this process.

From my experience, relatives would expect to be involved in the care of their relative at the home (Shnepp,2018) and this is often lifelong (Gaugler, 2003). Descriptions that come to mind are seeing their loved one is getting the best treatment possible; their needs are being met and to be informed in any change in treatment plan. I for one, like to see the relatives being interested and following the care plan of their older relative, however there is often a fine line how this is interpreted. An example from my professional experience would be that sometimes the relatives insist on working on mobility for the resident when the resident clearly has no wish for this, positioning me in where I have to make a choice between these multiple voices. Sometimes this can rob the resident of one's own agency and autonomy. The script from the data illustrates this where power was passed onto the relatives without the involvement of the resident and this was then further augmented and defended by the nurses in the system, following obvious disappointment from the resident. Circularly, I do see the feedback loop as being a demand and withdraw pattern which could hinder the communication process going on in the family.

Nurse: they spoke with the doctor and he agreed we should try this

This perhaps is shedding light on how we need to intervene better to make this process a more collaborative one to all family members to support them co-construct their new roles and share common understanding of their involvement, fostering autonomy and respect towards the older person as well as giving the proper acknowledgment and voice to family members. This may be calling for more specific policies and procedures as to how to foster such practice as an

integral part of the transition and daily practice of the homes where proper questions help elicit such plan, ensure collaborate and clarity of roles, where everyone feels heard, involved, and acknowledged in a transparent and clear way.

Family involvement through instrumental care and visitation may bring different meanings to each family member. This transition into long term care may need to get into play the renegotiation of the meaning making of involvement for the members (Cooke et al 2022.; Whitaker et al, 2009). The main characters do offer instrumental care and visitation, but I felt this lacks the relational aspect of communication. Of particular interest to me was how Mr and Mrs. Lewis had planned from earlier on that they do not wish to ever be a burdened it physical or emotional on their children.

> *Mrs. Lewis: we made that promise for a reason. I don't want to be a burden on anyone*

I note the meaning of burden to be a prime reason of many older adults admitted in my place of work. This is often followed by hope and expectations of more frequent contact with their loved ones which I see as an expectation of reciprocity; they choose admission to be a less of a burden but in return, more contact is hoped for. Without a doubt this was very effected throughout the pandemic years. Being a frontliner, I was witness to the helplessness and the fear reigning in the wards for a long time. It was heart-breaking to watch and listen to the longing of both relatives and residents to be able to be united yet for that same longing, being unable to. This highlights further that patients and family members both yearn to maintain contact and privilege this relationship. Mrs Lewis makes it very heard that she sees her family members as very important to her life.

> *Angela: I need my life back. I miss my family.*

She makes this explicit several times and increases doubts regarding the choice to live in a long-term care. In agreement with this, relatives expressed good communication is key and willingness to visit their relative in the long-term care is key to the upkeep of good family dynamics (Iwasiw, 2003). Conforming to the script, strong relationships encourage the long-term care to feel like living at home whilst both relatives and residents emphasize the joy and happiness being with their family brings (Gaugler, 2003). This helps us reflect on the importance of maintaining and sustaining this relationship as a central part of the emotional and

psychological wellbeing of all family members. Thus, policies and procedures have to keep this at the centre of their planning.

6. The Prospect of Best Outlook

Research shows that if the resident has the knowledge that this unknown reality has some known to it, the transition can be easier, and this would positively feed into the construction of the meaning that the choice was the best one possible. Such an example is the normalization that the transition will need its time (Tracy, 1994) whilst also taking on the mutual and reciprocal responsibility that the resident is directly in control of the perception of this outlook (Keister, 2006). The transition as a meaning-making process needing its own time was expressed by the other residents who experienced it.

Rose: it's just until you get used to it

However, the individual ownership of the perceived outlook was not explored in this study. I have become more mindful that the time needed for this transition is a process not only for the resident but for their significant others as well, as well as the caring system.

Bianca: We're barely getting by as is dad

Reflecting about the long-term care I work in, this is lived daily by older adults having the prospect of best outlook to offload their perceived burden on the relatives and the relatives having the same prospect because the medical team see the resident as unable to live in the community. The family thus accepts the move as a solution to the higher level of care required (Walker, 2007). Iwasiw (2003) continues to consolidate the idea that the renegotiation of the family continues to grow inside the institution especially since no significant changes in family contact are observed throughout the first year and together with Gaugler (2003) 'home' can be maintained if a strong family relationship is alive. On the other hand, I see the prospect of best outlook to be challenged when the patterns of relating between the staff and family as framed by the Habermas' theory are not functioning well. Mr.Lewis challenges the choice they made and also speaks about his needs.

Mr.Lewis : I want her home more than anyone. Is there anyone we can speak to?

This then triggers doubt and a plan of action for the daughter where she questions if the best choice has truly been made for her ageing mother and for the entire family.

7. Summary

This chapter discussed the findings in relation to the literature identified in the literature review. The main finding was that the relationship between the patient, the family and the caring system was seen as central to the wellbeing of the family transitioning to the long-term care facility. The next chapter presents the conclusion which provides an overview of the strengths and limitations of this dissertation, and study recommendations.

Conclusion

The main findings of this dissertation were:

- The relationships between the institutionalized resident and the family have remained strong when the family maintains contact that is regular and of good quality. Through a good quality contact, it was understood that the family not only has physical connection such as visitation but also an emotional one such as meaningful conversations.
- A sense of amelioration and well-being was found to be influenced by the usefulness and functioning of the resident within the institution. This positive sensation was also transmitted to the resident's significant others when witnessing the patient being well taken care of and having relationships with other fellow residents.
- The children or the partner who did not experience guilt and felt involved in the care process when at the residential home, were found to positively influence the care process in the home.
- A meaningful relationship prior to admission is likely to result in a meaningful relationship post institutionalization.
- The relationship may experience movement of roles when a person enters institutionalization.
- The family dynamics and relationships with significant others may continue to grow after institutionalization. The caring team becomes an extension of the care and support system and previous may continue to flourish following this transition.

1. Limitations

One of the limitations in this study was that all older adults had no problem or deficit with verbal communication. Perhaps it would have been interesting to experience other families where the older adult is less verbal or not verbal at all, adding more diversity and a wider context to study family dynamics. The research design of this study was cross-sectional and did not allow me to observe family dynamics across time but only in a specific present time. The study having been carried out in the immediate post-covid era may have also influenced the quality of

the data however this opportunity may be used as a comparison should a similar study be carried out in the future.

When carrying out the systemic literature search and after reviewing the available literature, it was identified that research does not may portray stories of hope and repair and following this study literature should feature reparative and strength-based stories where older parents and children may reconnect following institutionalisation and set a better tone towards closure. Literature in this area is yet again limited by its emphasis on an instant of the family involvement at one point in time following institutionalization, with minimal studies analysing patterns of involvement. This opens up room for further studies. Furthermore, literature about the Maltese Islands and the family dynamics following institutionalisation in our community is sparse.

2. Strengths

Throughout this research process the findings were ongoingly discussed with my supervisor and a stable third to ensure validity and an audit trail was recorded. The interviews were carried out with the residents together with their significant other which was more enriching and carried a greater opportunity to be a witness and privileged to the family dynamics. In preparation for the study, I was able to build a rapport with the families and this may have made it easier for the participants to be honest and transparent when narrating their stories. A reflective journal was kept and made it easier for me to connect with the participants and be mindful or my contribution to the process during the interview. The script, presented as the findings, gives the ability for it to be reproduced effectively and efficiently and be understood by a wide variety of audience, ranging from professionals, management, families, residents, significant others, students and more. This makes is an easy and accessible tool for educational and information purposes. With thus study it is hoped to provide a contribution to the scarce research in this area both locally and abroad, so as to start privileging more stories of older adults and their families which is also a very important part of the life cycle which deserves more acknowledgement both in research and in literature to better our understanding as to how we can provide better services and support to families at this time of life.

3. Future studies

As indicated by the limitations, the understanding of the nature of continued family involvement in the long-term care setting remains quite limited in longitudinal patterns of involvement of the family with their older person. Recommendation is for research to examine how dynamics change over time, or what predicts such changes.

Future research may also focus on other families where the older adult portrays different ability levels of communication, for example receptive or expressive deficits adding more diversity and a wider context to study family dynamics following institutionalization.

4. Service recommendations

This research sheds light on how the institutionalization system needs to intervene better to make this transition a more collaborative one with all family members, to support them co-construct their new roles and share common understanding of their involvement, fostering autonomy and respect towards the older person as well as giving the proper acknowledgment and voice to all family members. This maybe calling for more specific policies and procedures as to how to foster such practice as an integral part of the transition and daily practice of the homes where proper questions help elicit such plan, ensure collaborate and clarity of roles, where everyone feels heard, involved, and acknowledged in a transparent and clear way.

Family caregivers reported their own expectations, such as to be involved and have shared responsibility for the resident (Shnepp et al, 2018). More effectively targeted family-level interventions can be planned, such as family-staff partnership agreements, family councils and support groups that assist formal providers to maintain appropriate involvement. Support to the significant others where their belief and meaning of care for the family resulted in guilt for not fulfilling their roles till the end.

5. Preunderstanding and post understanding.

My understanding of the dynamics of a family following the admission of their significant other into long term care has been refreshed and enriched. The most salient and powerful reality I understood and became more mindful of now was that in which some couples and families process the idea of institutionalization before the life situation is encountered showing me more a

advanced process in this difficult decision making. This is in contrast to other families who have shown their decision making as a process that is as a reaction according to the situation in that moment in time.

I found this research project to be a great privilege and honour; to be a witness to the very core experience of the family in the context of institutionalization. It has been a very humbling and enlightening journey to me, both as a researcher and as a physiotherapist.

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Appendix 1

Recruitment Letter (English version) Letter of invitation

A narrative inquiry into the family dynamics of a newly admitted person to a long-term care residence.

Dear Participant,

I am currently a student at the Institute of Family Therapy and this research is going to be conducted in part fulfilment of my Master Degree in Systemic Family Therapy. This research has been approved by the ethics committee and I have been assigned a tutor from the above-mentioned institute who will guide me throughout the process.

I would like to invite you to participate in this study which sets out to explore the family dynamics of a newly admitted person to a long-term care facility. This research will be carried out through interviews with the resident and the family of the resident.

The interview will take place and recorded at your convenient location. You will be asked to sign a consent form before the interview. Confidentiality and anonymity will be ensured and only the tutor and I will handle your data. Data protection measures will be ensured as names will be falsified and information will be anonymous. All the recordings will be destroyed once research is completed. A copy of the final research will be made available to the participants upon request.

Participation is voluntary and no incentives will be given. The participants have the right to withdraw from the research at any point in time and ask for their data to be destroyed. You will not be required to disclose an explanation to the researcher.

Following the interview, participants will have the opportunity to share their experience of being part of this research project, together with any positive or negative emotions which might have been elicited. At this point you will be provided by a contact number and given information of available psychological support in the community. Your involvement would be of great value and importance to this field of study. I will gladly answer all your questions and offer additional information and clarifications. Kindly make contact on 79337147 should you decide to take part in this research study.

Thank you for your attention.

Kind Regards,

_____

Claire Spiteri
Student
Claire.dimech@gmail.com

Appendix 2

Recruitment Letter (Maltese Version) Ittra ta' Invit

In-narrativa tad- dinamika tal-familja ta' persuna ġdida residenti ġo residenza għal żmien fit-tul

Għażiż parteċipant,

Din ir-riċerka hija parti mill-istudji tiegħi fil- insitute ta' terapija għall-familja, taħrig offrut parzjalemnt għall- Masters Systemic Family Therapy. Il-proposta għal din ir-riċerka ġiet approvata mill-Bord tal-Etika ta' l- istess Istitut u ġejt assenjata 'tutor' li ġentilment ser jigwidani u jsegwini tul l-investigazzjoni kollha.

Nixtieq nistedinkhom biex tieħdu sehem f'din ir-riċerka li l-għan tagħha huwa li tesplora n-narrativa tad- dinamika tal-familja ta' persuna ġdida resident ġo residenza għal żmien fit-tul.

L-intervista ser tiġi rrekordjata permezz ta' reġistratur u użatha fil-partijiet sussegwenti tar-riċerka. Qabel ma tibda l-intervista l-parteċipant ser jiġi mitlub jiffirma ittra ta' kunsens, li fiha ser ikun hemm miġbur l-informazzjoni li qed tiġi mogħtija permezz ta' din l-ittra. Kemm il-kunfidenzjalita' u l-anonimita' ser jiġu rrispettati u mħarsa, u jiena u t-tutur biss ser ikollna aċċess għall-informazzjoni provduta minnkhom. Wara li din ir-riċerka tiġi konkluża, l-informazzjoni kollha tagħkhom, ser jiġu meqruda b'mod responsabbli. Kopja tar- riċerka finali ser tkun disponibli għal dawk il-parteċipanti interessati.

Il-parteċipazzjoni tagħkhom f'din ir-riċerka hija kompletament volontarja u l-ebda tip ta' benefiċċju qiegħed jiġi offrut. Intom għandkhom dritt li tirtiraw il-parteċipazzjoni tagħkhom f'kull stadju ta' l-istudju mingħajr ma toffru spjegazzjoni. Tistgħu wkoll issaqsu biex l-informazzjoni diġa' miġburha ma tiġiex użatha iżda tiġi meqruda b'mod responsabbli.

Wara li nispiċċaw l-intervista, ser ikollkhom l-opportunita' taqsmu l-esperjenza tagħkhom bħala parteċipant, flimkien ma xi emozjonjiet u ħsibijiet kemm pozittivi u/jew negativi li setghu ġew imqanqla. Qabel ma nitilqu lil xulxin, inti ser tiġi mfakkar fil-modijiet differenti li bihom tista' tagħmel kuntatt u fis-servizzi ta' sapport psikoloġiku li huma offruti fiċ-ċentri tas-saħħa mentali fil-kommunita'. L- involviment u l-kontribuzzjoni tiegħek hija ta' valur kbir. Jiena disponibli biex nirrispondi l-mistoqsijiet tagħkhom u anke biex noffri iktar informazzjoni. Inti ġentilment mitlub tagħmel kuntatt miegħi fuq in-numru 79337147 jekk tixtieq tipparteċipa.

Nirringrazjakhom ta' l-attenzjoni tagħkhom. Tislijiet,

Claire Spiteri
Studenta
Claire.dimech@gmail.com

Appendix 3

Consent form (English version)

A narrative inquiry into the family dynamics of a newly admitted person to a long-term care residence.

Please answer the following questions by ticking the response that applies

	YES	NO
I have read the Information Sheet for this study and any questions about the study have been answered to my satisfaction.	☐	☐
I am aware that I can ask questions about the study at any time.	☐	☐
I understand that I am free to withdraw from the study up till 3 weeks following the interview, without giving a reason for my withdrawal or to decline to answer any particular questions in the study without any consequences.	☐	☐
I agree to provide information to the researchers for the duration of 5 years following the interview, under the conditions of confidentiality set out in the Information Sheet.	☐	☐
I wish to participate in the study voluntarily.	☐	☐
I consent to the interview being audio recorded and transcribed verbatim.	☐	☐
I consent to the information collected for the purposes of this research study, once anonymised (so that I cannot be identified), to be used for any other research purposes.	☐	☐

Participant's Signature: _____ _____ Date: _____
Participant's Name: _____
Contact details: _____
Researcher's Name: Claire Spiteri_____
Researcher's Signature: _____
Researcher's contact details:
Claire Spiteri
79337147
Claire.dimech@gov.mt

Please keep your copy of the consent form and the information sheet together.

Appendix 4

Consent form (Maltese version)

In-narrativa tad- dinamika tal-familja ta' persuna ġdida residenti ġo residenza għal żmien fit-tul

Qabel tieħu sehem fl-istudju int mitlub timla l-formola tal-kunsens. Ġentilment wieġeb "iva" jew "le" għal kull stqarrija, dan huwa meħtieġ biex tkun ċert li int taħt il-parteċipazzjoni tiegħek.

	Iva	**Le**
1. Qrajt il-Karta ta 'Informazzjoni għal dan l-istudju u kwalunkwe mistoqsija dwar l-istudju ġiet imwieġba għas-sodisfazzjon tiegħi.	☐	☐
2. Jien konxju li nista 'nistaqsi mistoqsijiet dwar l-istudju fi kwalunkwe ħin.	☐	☐
3. Jiena nifhem li jien liberu li nirtira mill-istudju sa wara tlett ġimgħat mingħajr ma nagħti raġuni għall-irtirar tiegħi jew li nirrifjuta li nwieġeb kwalunkwe mistoqsija partikolari fl-istudju mingħajr ebda konsegwenza.	☐	☐
4. Jiena naqbel li nipprovdi informazzjoni lir-riċerkaturi għat-tul ta 5 snin wara l-intervju, taħt il-kundizzjonijiet tal-kunfidenzjalità stabbiliti fil-Folja ta' Informazzjoni.	☐	☐
5. Nixtieq nipparteċipa fl-istudju volontarjament.	☐	☐
6. Jiena naqbel għall-informazzjoni miġbura għall-finijiet ta 'dan l-istudju ta' riċerka, ladarba anonimizzat (biex ma nkunx nista 'nkun identifikat), biex jintuża għal kwalunkwe skop ieħor ta' riċerka.	☐	☐
7. Jiena naqbel li l-intervista tkun awdjo rrekordjata u traskressa verbatim.	☐	☐

Firma tal-Parteċipant: _____ Data_____

Isem tal-Parteċipant: _____

Isem tar-Riċerkatur: Claire Spiteri

Firma tar- Riċerkatur: _____

Dettalji tal-kuntatt tar-Riċerkatur:
Claire Spiteri
79337147
Claire.dimech@gov.mt

Jekk jogħġbok żomm il-kopja tiegħek tal-formola tal-kunsens u l-folja ta 'informazzjoni flimkien

Appendix 5

RE: Letter of Permission (Physiotherapy SVP)

Fiorentino Ronald at SVP

Thu 14/04/2022 01:29

To: Dimech Claire at MFCS-SVPR <claire.dimech@gov.mt>; Cutajar Josianne at SVP <josianne.cutajar@gov.mt>;

Cc: Briffa Valerie at SVP <valerie.briffa@gov.mt>;

2 attachments (43 KB)

Consent Form English and Maltese.docx; recruitment letter English and Maltese.docx;

Ms Dimech,

Thank you for choosing SVP as part of your Master's field-work. There is no objection for this research, subject to the approval by the Institute's Board of Ethics.
You are kindly being requested to submit a copy of the acceptance letter by the Institute's .ethics board (once approved).
I wish you all the best for your studies and hope that your research would continue to enhance our knowledge of Geriatrics.

Regards

Dr Ronald Fiorentino MD
Director Svpr
Med. Supt. Office
St Vincent de Paul Long Term Care Facility

t +356 21224461 e ronald.fiorentino@gov.mt
[www.family.gov.mt]www.family.gov.mt |
[www.publicservice.gov.mt]www.publicservice.gov.mt |
fb.com/servizzpubbliku

MINISTRY FOR THE FAMILY, CHILDREN'S RIGHTS AND SOCIAL SOLIDARITY

ST VINCENT DE PAUL LONG TERM CARE FACILITY, FLORENCE NIGHTINGALE ROAD,
LUQA, MALTA

Kindly consider your environmental responsibility before printing this e-mail

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From: Dimech Claire at MFCS-SVPR <claire.dimech@gov.mt>
Sent: 04 April 2022 21:25
To: Cutajar Josianne at SVP <josianne.cutajar@gov.mt>
Cc: Fiorentino Ronald at SVP <ronald.fiorentino@gov.mt>; Briffa Valerie at SVP <valerie.briffa@gov.mt>
Subject: Re: Letter of Permission (Physiotherapy SVP)

Thank you Dr.Cutajar.

Kind Regards

Claire

From: Cutajar Josianne at MSCA-SVP
Sent: 02 April 2022 18:29:18
To: Dimech Claire at MFCS-SVPR
Cc: Fiorentino Ronald at MSCA-SVP; Briffa Manuel at MSCA-SVP
Subject: FW: Letter of Permission (Physiotherapy SVP)

Dear Claire
well done in continuing your studies and thank you for including SVP.

kindly coordinate with Dr Florentino and Ms Briffa for ethical and data protection approval within SVP. you have my full support on their greenlight.
Jos

Josianne Cutajar
Chief Executive Officer
Ceo Office
St Vincent de Paul Long Term Care Facility

t +356 22912400 e josianne.cutajar@gov.mt
[www.gov.mt]www.gov.mt |
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fb.com/servizzpubbliku

MINISTRY FOR SENIOR CITIZENS
AND ACTIVE AGEING

ST VINCENT DE PAUL LONG TERM CARE FACILITY,
FLORENCE NIGHTINGALE ROAD,
LUQA, MALTA

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From: Dimech Claire at MSCA-SVP <claire.dimech@gov.mt>
Sent: Friday, 01 April 2022 13:41
To: Cutajar Josianne at MSCA-SVP <josianne.cutajar@gov.mt>
Subject: Letter of Permission (Physiotherapy SVP)

Dear Dr. Cutajar,

I am a Physiotherapist working at SVP and I am currently reading for a Masters Degree in Systemic Family Psychotherapy at the Institute of Family Therapy. As part of my studies, I am required to conduct a research study. My study is titled:

"A narrative inquiry into the family dynamics of a newly admitted person to a long-term care residence."

The study is being carried out under the supervision of Ms. Helen Attard Micallef. It aims to explore the different stories of family members and how they mutually and reciprocally co-construct meanings to make sense of the admission of their significant older person to a long-term care institution. The number of participants is aimed to be between 3-5 residents and their respective family members/significant others. The targeted population in this study will be that of older adults (over the age of 60) who are residents at St Vincent de Paul and who have been residing in the residence for not more than a year, so as to capture the recency of the formed stories. Data collection will be through an interview at SVDP or at a location convenience for the family.

The interview sessions with the participants will be audio-recorded. Confidentiality and anonymity will be maintained throughout the study and the identity and personal information of the participants will not be revealed in any publications, reports or presentations arising from this research. All data collected will be pseudonymised and no personal information will be kept. Any identifiable date would not be used to ensure confidentiality at all times. This data may only be accessed by the researcher, the academic supervisor and the examiner(s) for

assessment purposes. The audio recordings and transcripts will be stored on the researcher`s personal computer in an encrypted format and password protected folder. Any material in hard-copy form will be placed in a locked cupboard, till the research is completed and corrected.

In the event any of the participants would feel distressed due to participation in the interview, the service of a healthcare professional will be available and if necessary the interview process will be stopped to safeguard the mental health of participants at any point in time during the interview process. Participation in this study is completely voluntary and participants are free to accept or refuse to take part without giving a reason. Participants also have the right to withdraw and terminate their participation from the study without giving a reason, even after the interview would have been terminated. Once the study is completed and the results are published, all data collected will be erased.

I would like to seek your approval in order to perform this study at St. Vincent de Paul and to identify and invite residents through an intermediary person whom you deem appropriate to participate in the study.

Kindly note that permission and approval to conduct this study is also being sought from the IFT Malta Ethics Boards.

Should you wish any further information or clarification about the proposed study, please contact me on +356 79337147 or by email Claire.dimech@gov.mt or my supervisor; helenattardmicallef@gmail.com

Attached with this communication please find:

Patient information letter and consent form both in English and Maltese for your information.

I thank you in advance,

Kind Regards,

Claire Spiteri
Student Researcher

Appendix 6

Re: gatekeeper

Camilleri Oliver 1 at SVP

Mon 16/05/2022 20:02

To: Dimech Claire at MFCS-SVPR <claire.dimech@gov.mt>;

Dear Ms Spiteri,

From my end, I find no issues with this study and would be glad to act as a gatekeeper.

Kind Regards,

Oliver Camilleri
Senior Physiotherapist SVP

Get Outlook for Android

From: Dimech Claire at MFCS-SVPR <claire.dimech@gov.mt>
Sent: Monday, May 16, 2022 4:47:58 PM
To: Camilleri Oliver 1 at SVP <oliver.camilleri.1@gov.mt>
Subject: gatekeeper

Dear Mr. Camilleri,
I am a Physiotherapist currently reading for a Masters in Systemic Family Therapy with the Institute of Family Therapy.
As part of my studies, I am required to conduct a research study. My study is entitled
"A narrative inquiry into the family dynamics of a newly admitted person to a long-term care Residence."
The study is being carried out under the supervision of Ms.Helen Attard Micallef. The objective of this study is to capture the stories of families who have recently undergone admission of their older significant person to long term care. It aims at shedding light on how family members make sense of this admission individually and between themselves to shed light on how they mutually and reciprocally co-construct their story as well as how their family dynamics may be reshaped.
Older adults (over the age of 60) who are residents in a long-term institution, St Vincent de Paul who have been residing in the residence for not more than a year and their family members/significant others.
Respondents will be recruited via gatekeepers through the use of purpose sampling. They have to be residents within St Vincent de Paul residence for not more than 1 year to capture the recency effect of the admission process. They need to be able to carry out a conversation and not identified as having a cognitive impairment for the purposes of providing a coherent story as required specifically by this study. Participants need to be willing to participate in the study. They need to speak the Maltese or English language. All admissions within SVP take place through an admission ward. A physiotherapist within the ward will be asked to be a gatekeeper for the study. Residents who meet the inclusion criteria will be approached by the gate keeper and provided with the information letter. If the resident would be willing to participate in the study the researcher will set an appointment with him/her and answer any questions regarding the study, identifying a place at their convenience. The potential participants will be asked to invite any 'family' members/significant others who he considers as such. These will be provided with the information letter as well. If they are interested to participate the researcher will approach them and explain any question. If they agree, a date and time for the interview is set with all the family members. On the interview date all participants will be requested to sign the attached consent form which would need to be signed by all for the interview to take place. Once the study is completed and the results are published, all data collected will be erased.
Your approval is being sought to act as the intermediary person in order to circulate the information sheet and seek consent from participants, patients and healthcare workers. Thank you for your time and consideration.
Attached please find the research proposal. Should you have any questions or concerns do not hesitate to contact me on 79337147 or by e-mail claire-dimech@iftmalta.com

I thank you in advance,
Kind Regards,
Claire Spiteri

Appendix 7

Demographic Data

- Length/duration in the home
- Age
- Status
- Reasons for referral/admission. – age, health, by choice/forced
- Most involved significant others and their relationship to the person

Can you tell me a bit about your experience of being admitted to this home, how did it come about, by whom was the decision taken and in what way are you making sense of this experience? (and all the family members will contribute in a dialogue possibly)

What sense do you think your relative makes out of this experience?

What sense do you think the 'elderly person' is making out of this experience) – x'jahsbu dwar xulxin

How did you manage your relationship upon this transition? How is it similar or different to how it was prior to your admission?

What did you find helpful and least helpful during and after this transition?

What would you like to have more of and less of now and in the future?

Do you think your reciprocal and mutual role/s changed following this admission? and how do you see this contributing to your relationship?

xi thossu li nbidel mir-rwoli taghkom li kontu taghmlu qabel ma dhalt il-home? Taraw xi tibdil fir-relazzjoni taghkom li gabu maghhom dan it-tibdil fir-rwoli?

Did you observe any differences or similarities in decision making before or after this shift? If yes what is your understanding about what may have contributed to this change?

How would you describe your relationship before coming here? How did you manage conflicts if any and do you observe any differences or similarities now? If yes what is your understanding about what may have contributed to this change?

How do you feel about staying here and how do you think your relatives feel about your stay here?

How do you feel about other residents here? Did your experience here contribute to how you used to view residents prior to your admission – similarities or differences

What would you suggest to the home/staff as to what you have liked to be more helpful to assist in your transition and to sustain your relationship to your significant others

What would you suggest to your significant others as to what you have liked to be more helpful to assist in your transition and to sustain your relationship with them and what would you (sig others) would like similarly or differently from your loved one to help you smoothen the transition and the relationship?

Would you like to add anything that you may feel important to include in my results?