The Perceived Impact of Caregiving on the Couple Relationship, When an Adult Child has a Severe Mental Illness

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Author Note

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Abstract

This study explores the impact on the couple relationship when providing care for adult children with severe mental illness. To explore such a phenomenon, interpretative phenomenological analysis (IPA) was used as a methodology, using a multi-perspective design. In-depth individual and dyadic semi-structured interviews were conducted with three female and three male spouses from three heterosexual couples, whose adult children have a mental illness and reside in the same house as the couple. Participants were recruited through mental health NGOs and the public Mental Health Services. The results captured the individual burden of being a caregiver, and its impact on the other spouse, indicating some gender differences. The participants' accounts reflected that the role of caregiving emphasised their individual differences, leading to couple discord. Caregiving also limited the couples' time alone. The impact of caregiving was perceived to influence other family members too. The results indicated that the participants' similar views, and commitment as a couple, supported by professional and spiritual support, aided their experience as caregivers, and helped in their sons' wellbeing and future independence. The implications for clinical practice and proposals for policy making drawn from this research suggest that couples and their families require adequate practical, professional, and therapeutic support to aid them process and live through their role as caregivers. Recommendations for future research were also noted.

Key words: impact on couple relationship, caregiving, adult children, severe mental illness, interpretative phenomenological analysis

Dedication

To all those who provide care for their loved ones with mental illness.

Your dedication, perseverance, and love are truly commendable.

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Introduction

Preamble

I have always been sensitive to caregivers and interested in the topic for several reasons. Throughout my past work experiences as a learning support assistant, and with a local NGO offering community rehabilitation services for people with mental health problems, I often reflected on the parents' perspectives when caring for their children, both young, and adults, with mental health difficulties.

Particularly when working with Sam, a young person with psychosis, I recall the situation of her mother, Susan[1], who was her full-time caregiver, as well as a wife to Sergio, and mother to another adult son. Concerned about her daughter's health and safety, Susan had decided that Sam would sleep in her parents' bedroom. Learning about this led me to reflect about the couple's relationship whilst coping with such arrangements. In addition, Sergio regarded his wife's determination for their daughter's recovery as useless, because he seemed to struggle to accept her illness. Consequently, Susan carried out most caregiving responsibilities alone. I could recall countless other couple issues observed throughout my rather short work experience in mental health rehabilitation.

However, perhaps the most salient and sensitive position of myself as a researcher is that of my own experience of having a family member with mental health problems. This involvement led me to being sensitive to caregivers, quite possibly, because I saw myself in their experiences, and recognized similarities between theirs and my own family member's suffering. This seemed to fuel my interest in pursuing a profession in the psychology field.

Subsequently, my experiences spurred my interest in exploring the influence of caregiving on the main informal carer, as well as its impact on the whole family system,

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[1] All names have been changed to preserve anonymity

particularly the couple. When researching family and couple dynamics as impacted by caregiving, I found a dearth of research on such a topic (Granek, Danan, Bersudsky & Osher, 2016; Penning & Wu, 2019; Schulz & Eden, 2016), especially when compared to the large quantities of studies done on the physical, emotional, and socioeconomic effects of caregiving on the individual (Miller, Sukhera, Lynch, & Wardrop, 2017; Savage & Bailey, 2004; Pristavec, 2018; Schulz & Eden, 2016; Turcotte, 2013). This lack of research encouraged me to investigate the systemic impact, particularly on the couple relationship.

An Introduction to Mental Illness and Caregiving

Mental illness is a growing public health concern (Mental Health Foundation, 2016) affecting around 25% of the population, globally (World Health Organisation [WHO], 2015). It is estimated that around 1 in 6 people have common mental health problems such as anxiety and depression (McManus, Bebbington, Jenkins & Brugha, 2016). The Global Burden of Disease study by Whiteford et al. (2013) noted that the major mental health conditions worldwide are depressive disorders, followed by anxiety, schizophrenia, and bipolar disorder.

When young adults experience mental illness, it is often their parents who become their informal caregivers (Kaufman, 1998; Kaufman, Scogin, MacNeil, Leeper, & Wimberly, 2010; Robinson, Rodgers, & Butterworth, 2008). Around 8.4 million citizens in America provide care to an adult with an emotional or mental health issue, with nearly half caring for an adult son or daughter (The National Alliance for Caregiving, 2016). Similarly, in the UK, close to seven million are carers, 13% of these caring for someone with a mental illness (Carers UK, 2018).

European informal caregivers were found to spend an average of 22 hours a week directly supporting a relative with a mental illness (Vermeulen et al., 2015a). Local (Abela et al., 2016; Vermeulen et al, 2015b), and overseas studies (Copeland & Heilemann, 2011; The National Alliance for Caregiving, 2016) reported that most caregivers tend to be female.

Caregiving is associated with negative consequences faced by caregivers, including physical and mental health problems, employment and financial burdens (Abela, Farrugia, Vella, & DeGiovanni, 2016; Fenech & Scerri, 2014; Mental Health Foundation, 2016; Turcotte, 2013; Schulz & Eden, 2016) and other challenges like stigma and lack of support by staff or services (Vermeulen et al., 2015b). Stigma was also associated with limiting caregivers' personal relationships and weakening their quality of life (Park & Seo, 2016). Studies have also looked into caregiving as being a source of fulfilment (Schwartz & Gidron, 2002). It has been described as a twofold experience, such as being a source of achievement, besides being tough and burdensome (Lemoine, Lavoie, Poulin, Poirer, & Fournier, 2005; Pristavec, 2018).

Relevance of the Current Study

Historically, research and health services have focused on the individual caregiver or care receiver (Racher, 2003), with little focus given to how caregiving is shared among other relatives or the couple subsystem within the family (Magliano et al., 1999; Schulz & Eden, 2016), nor on interpersonal relationships of people with mental illness and their families (Gilligan, Suitor, Rurka, Con, & Pillemer, 2017; Granek et al., 2016). The onset and chronic course of a patient's illness may coincide with or disrupt other family transitions or inducing new and unexpected transitions within the family life cycle and/or individual and couple phases (Rolland, 2012). The significance and impact of the informal caregiver's role on their wellbeing, relationships, and health, is often overlooked (Family Caregiver Alliance, 2006).

Although extensive research had been done specifically on the experience of parents providing care for their adult children with mental health problems (eg: Godress, Ozgul, Owen, & Foley-Evans, 2005; Kaufman, 1998; Kaufman et al., 2010; Pickett, Cook, & Solomon, 1995); only a few report on the marital effects of couples as caregivers, particularly in the field of anorexia (McCormack & McCann, 2015; Smalley, Dallos, & McKenzie, 2017).

I have not come across any qualitative studies focusing solely on the couple's perspective. Whereas studies on the relationship between caregiver and relative suffering from a chronic illness have been done, such as spouse to spouse (Granek et al., 2016; Tranvåg & Kristoffersen, 2008), parent to child (Amirkhanyan & Wolf, 2006), and child to parent (Bookwala, 2009), no specific research was found to have been carried out on the impact of caregiving on the couple relationship when the adult child has a mental illness. There is also a lack of literature on older couples' marital functioning (Papp, 2018), suggesting a lacuna in research and awareness about the possible impact on older couples when caregiving their adult children.

Research on the Couple Relationship when the Children become Adults

Although the factors that impact young couple relationships have been widely researched (Driver, Tabares, Shapiro & Gottman, 2012; Parker & Commerford, 2014), families and couples in later life, particularly older couples' marital functioning, have been largely understudied (Margelisch, Schneewind, Violette, & Perrig-Chiello, 2017; Papp, 2018).

Caregiving for an adult child most often takes place at a time when most parents are launching their children towards independence and autonomy (Kaufman et al., 2010), and coming to terms with the notion of the parental system returning as a dyad (McGoldrick, Garcia-Preto, & Carter, 2016). Apart from such difficulties, caregiving one's adult children may come at a stage in life when the caregiver is struggling to deal with one's own challenges related to their own aging (Gilligan et al., 2017; Kaufman et al., 2010). This stage may also be an expectant time for older couples to become grandparents (McGoldrick et al., 2016), a phase which, due to the nature of the adult child's mental illness, may not come about.

Rolland (2012) noted that when a young adult is affected by an illness, he or she may require a return to the family of origin, possibly "derail[ing] a family's momentum" (p. 468). As described above, such a derailment could also be depicted as a need for adaptability, as caregivers of adult children adapt to changing their roles and to the adoption of new responsibilities (Edwards, Higgins, Gray, Zmijewski, & Kingston, 2008).

Although frameworks pertaining to the family life cycle and family systems theory have shed light on how stages and systems intersect, influence, and are influenced by each other (McGoldrick et al., 2016), less is known about the "the constellation of problems across generations" and how such difficulties influence older adults (Fingerman, Huo, Graham, Kim, & Birditt, 2018, p. 1054). Therefore, in my study I aim at portraying both the impact on the individual, as well as that on the couple, thus presenting the "we-ness," or couple identity (Eisikovits & Koren, 2010, p. 1645) in caregiving.

Research Question and Aims of this Study

My study aims at answering the following research question: "What is the perceived impact of caregiving on the couple relationship, when an adult child has a severe mental illness?" This study aims at broadening the literature on family caregiving, particularly by looking into:

- the experience of caregiving an adult child on the individual partner
- the experience of caregiving, and its impact, on the couple relationship
- how such an experience may impact other family members (eg: siblings)

Theoretical Framework

The theoretical framework of this study is based on Bronfenbrenner’s ecological systems theory (Bronfenbrenner, 1979), family systems theory (Dallos & Draper, 2010), the family life cycle perspective (Carter & McGoldrick, 1989) and the individual and family resilience perspective (Masten, 2014; Walsh, 2012a). These theories provided a structured method to help me, as the researcher, understand the situation as a whole, looking into the individual and interconnected relationships and stages between couple and family subsystems.

Bronfenbrenner’s ecological systems theory. Bronfenbrenner’s (1979) theory is based on the notion of human developmental outcome as emerging from its environmental interactions. Compared to “Russian dolls” packed within each other (1979, p. 3), the ecological environment is described as being formed of different levels, from the immediate and closest system of the individual, such as family, to the widest level of the environment, such as culture and society. A person’s development is therefore viewed as influencing, and being influenced by, the environment (Rosa & Tudge, 2013). This theory guides this research as it aids in understanding the dynamic interaction between my participants’ and their adult children’s multiple environments, as well as the way in which they are part of each other’s systems, and therefore, interact with each other’s development.

Family systems theory. As one of the earliest pioneers of this theoretical framework, Ludwig von Bertalanffy (1968, p.37) described systems theory as “a general science of *wholeness*”. This later came to be explained as the interdependence and influence of patterns and actions emerging and evolving within the family (Bateson, 1972; Dallos & Draper, 2010). To understand a system, one must consider the individual, interpersonal, and macrosystemic relationships of the same system (Stanton & Welsh, 2012). Therefore, this theory supports my research because it widens the prevalent individualistic model of caregiving to the experience and contribution of the couple and family (Walsh, 2012b).

Family life cycle perspective. As the family evolves and functions in relation to its broader ecological and sociocultural context, so does its life cycle. The family life cycle perspective (Carter & McGoldrick, 1989) is based on the notion that families follow similar stages which are shaped by the cultural and social norms of any given society. However, in our rapidly changing world, the definition of a family life cycle is not a straightforward one (Carter & McGoldrick, 1989; McGoldrick & Shibusawa, 2012). As clinicians and researchers, we are encouraged to discard outdated norms and delve into the broader spectrum of contemporary family life (McGoldrick & Shibusawa, 2012). Therefore, the family life cycle perspective will support me as a researcher as I explore the participants' and their families' own life cycles, in relation to their caregiving and parenting roles in older age, which may also present a challenge to their traditional view of the family life course (Gower & Dowling, 2008).

Resilience framework. The family resilience theoretical perspective (Masten, 2014; Walsh, 2012a) outlines the process in which families, when experiencing challenging life events, may come to bounce back, recover, and flourish. Although some families may experience disruptions in their life transitions and be deeply influenced by crisis, many of these vulnerable families emerge empowered and skilled. As I explore the couples' experiences of caregiving, the resilience framework provides a perspective of looking at my participants' strengths in response to their family's difficulties. This perspective is grounded in the belief that families all have the potential to recover and grow positively in the face of adversity (Walsh, 2012a).

Ontological and Epistemological Stance

"*What is real? How is one to know?* These are among the most ancient questions not only of philosophical inquiry proper, but of human thought as such" (Berger & Luckmann, 1966/1991, p.13). I adopted the social constructionist perspective for this study as I aim at understanding the couples' experiences as created within *their* context, and embedded within historical, cultural settings, dialogues, and values, as they continuously take place in the world (Wang, 2016). Social constructionism also relates to my study as it gives importance to relationships, as personal experiences are influenced by people's interactions with the social context (Wang, 2016; Ponterotto; 2005; Richardson, 2012). Families co-construct and co-author each other's lives, such as that children co-construct their parents' lives as much as parents co-construct their children's development (Richardson, 2012). In light of this, social constructionism supports me as I delve into the couples' experiences of caregiving their children, and how such an experience may impact their relationship.

Working Definitions

Caregiver. The term 'caregiver' is a broad definition referring to, usually, a relative or friend, who has a significant relationship with, and provides a broad range of support to, another person with a chronic illness or disabling condition (Family Caregiver Alliance, 2005). In my research, the term 'caregiver' refers to informal caregiving, done without a virtue of a contract nor as voluntary work (UK Care Act, 2014). Although carers may be secondary caregivers living away from the care-recipient, my research will focus on parents, living with, and providing care for their adult children with mental illness.

Care-recipient. In this study, the term 'care-recipient' refers to an adult with mental illness, receiving informal care by his parents, such as ongoing and daily practical and psychological support in various matters. Particularly in my research, since all the adult children were male, I will be referring to the care-recipients mostly with the use of their pseudonyms or as “the participant’s son/adult child”.

Mental illness. The title of the study emphasises that the adult children of the participants must be diagnosed with a severe mental illness. The term ‘severe mental illness’ is often referred to a diagnosable chronic illness, characterized by significant and chronic impairment to a person’s cognition, emotion regulation, or behaviour. This would reflect a dysfunction in the psychological, biological, or developmental processes of the person’s mental functioning in relationships, work, and other activities (American Psychiatric Association, 2013; Vermeulen et al., 2015a).

I reflect that using the term ‘mental health problem’, rather than ‘severe mental illness’, encompasses mental health on a continuum, and possibly minimises stigma. I would have personally preferred using the term ‘mental health problem’ when referring to mental ill-health. However, in view of ensuring a fair degree of homogeneity (Smith, Flowers, & Larkin, 2009), it was deemed necessary to set such a criterion. Throughout the study, the term ‘condition’ will also be used when referring to mental ill-health.

Overview of the Study

Following this introductory chapter, I will be presenting a review of literature on caregiving and the couple experience. I will be then discussing the methodology and research design implemented in this study. Consequently, I will be presenting the major themes which emerged from my participants’ interviews in the Results section. This will be followed by the Discussion chapter, where the results of this study will be discussed, substantiated with other literature and my reflections. To conclude, I will be presenting a summary of the research findings, including limitations of the study, and recommendations and implications emerging from this research.

Literature Review

Introduction

In this chapter, I will present an overview of literature in relation to the experience of mental health caregiving, and experiences of parenting and providing care to adult children. I will also refer to research pertaining to couple relationships, particularly in middle-age. Prior to this, I will set the scene by providing an overview of caregiving in the Maltese context. A review of the process of the literature search is first presented below.

Literature Search

To begin my research and identify relevant articles, a number of online databases, such as *Oxford Academic*, *SAGE Journals, SpringerLink, Taylor & Francis Online,* and *Wiley Online Library*, were searched through the University of Malta *HyDi* library, using the keywords ‘couple’, ‘couple relationship’, ‘parents’, ‘adult child/children’, ‘mental illness’, ‘impact’, in combination with the word ‘caregiving’. Further research articles and books were identified from the initial search and journals found. Secondary sources and grey literature pertinent to my research were also referred to and included.

Caregiving in the Maltese Context

Informal caregiving plays a significant role in Malta due to the traditional role that the family holds within the European community (European Commission, 2016; Fokkema, ter Bekke, & Dykstra, 2008), which seems to be also influenced by culture and religious teachings of the Catholic church in Malta (Abela, 2016). Families tend to be the primary caregiving resource for individuals with serious mental illness, even in countries like Australia, United States, and Taiwan (Hsiao & Van Riper, 2009; Kaufman, 1998; Edwards et al., 2008). Due to deinstitutionalisation, the role of the family as informal caregivers has been increasing substantially, globally (Cook, Cohler, Pickett, & Beeler, 1997; Copeland & Heilemann, 2011; Hsiao & Van Riper, 2009; Robinson et al., 2008).

According to a report by the European Commission (2016), informal caregivers in Malta are entitled to a combination of financial benefits and care leave, respite, and other benefits via community services. Although the right for carers to receive treatment is highlighted in the Mental Health Act (Buttigieg, 2012; Mental Health Act, 2012), locally, support for caregivers of relatives with mental health problems and dementia (Abela et al., 2016; Fenech & Scerri, 2014; Innes, Abela, & Scerri, 2011), still seems to be lacking.

It seems that a few local non-governmental organisations, such as Richmond Foundation, Mental Health Association, St Jeanne Antide Foundation, and Be Positive – Bipolar Self Help, offer support specifically to mental health informal carers. The office of the CEO of the Mental Health Services in Malta noted that one off support groups for caregivers take place at Centru Tommaso Chetcuti (CTC), an outpatient service department at Mount Carmel Hospital, Malta's psychiatric hospital. The local Mental Health Services also offer 'GP services' for those who require counselling, without the need of a psychiatric referral. Another service noted was that of the Acute Response Team (ART) which provides support to families and relatives of patients who are admitted to Mount Carmel Hospital and Karen Grech Rehabilitation Hospital (C. Bonnici, December 3, 2018, personal communication; J. Camilleri, 2018, personal communication, December 7, 2018). Therefore, although some support seems to be available, family caregivers in Malta have inadequate services to make use of (Gauci, 2016; Fenech & Scerri; 2014; Abela et al., 2016). The Mental Health Strategy for Malta noted that such resources need to be further developed (Ministry of Health, 2018).

In addition to this, local research on the experiences of the Maltese caregiver are only a handful (eg: Abela et al., 2016; Fenech & Scerri, 2014; Innes et al., 2008; Scerri, et al., 2018; Vermeulen et al., 2015b). Similar to international findings, Maltese caregivers experience a range of emotional and physical difficulties when caring for a relative with a mental illness. All the studies above noted the need for improving caregiver help and support in the local context.

Caregivers' Rights in the Maltese and European Context

One of the objectives in the European Mental Health Action Plan 2013-2020 (WHO, 2015) proposes that mental health services are to be easily available, competent and affordable, and that "family capacity and needs [should be] assessed periodically, and training and support provided" (p. 7). The local Mental Health Act (2012) states that carers of 'mental healthcare users' shall be informed of the patient's rights and are to have access to receive guidance and support, and also participate in the formulation of the patient's multidisciplinary care plan.

In the United Kingdom, a Care Act (2014) was specifically set up to reform the law relating to care and support given to adults, as well as support for carers. A significant reform is also that of assessing the carer's needs for physical, psychological and financial support. Such a reform is not yet present within the local legislation.

The Experience of Caregiving

Caregivers face detrimental consequences due to their responsibilities, including physical, emotional, and mental health problems, employment and financial burdens, and other challenges (Abela et al., 2016; Fenech & Scerri, 2014; Miller et al., 2017; Pristavec, 2018; Turcotte, 2013; Schulz & Eden, 2016). Physical effects of caregiving were also found to be present, specifically increasing the risk for autoimmune disorders (Koutentaki et al., 2014) independently of depression, sleeping difficulties, and anxiety. In addition to this, caregiving may also lead to family members losing social ties, roles, faith, competence, routines and control, whilst also experiencing financial difficulties (Richardson, Cobham, McDermott, & Murray, 2013).

Although the risk of caregivers experiencing mental health difficulties is higher in the initial years of caring (Marks, Lambert, & Choi, 2002; Scerri, Saliba, Saliba, Scerri, & Camilleri, 2018; Steele, Maruyama, Galynker, 2010), depressive symptoms and anxiety experienced by caregivers of relatives with dementia were found to persist with similar severities, even when the relative moved to a long-term residence (Schulz et al., 2004). This reflects that caregiving burdens could persevere. In addition, chronic stress due to the caregiving role does not necessarily manifest in depressive symptoms, but may induce other changes, such as increased anxiety, anger, and abusive behaviour towards the care recipients (Robinson et al. 2008; Zarit, 2008). Individuals may also renounce their caregiving role due to such stress (Kaufman et al., 2010; Zarit, 2018).

Many parents also experience grief when their child experiences a mental illness, as they mourn the loss of the person they knew before the illness prevailed, and the loss of aspirations, disruption to family life, relationships, and future aspirations (Berman & Heru, 2013; Godress et al., 2005). Due to the chronic nature of their adult child's illness, parents may experience an enduring grief, which may alter the representation of the losses being experienced (Ozgul, 2004).

Benefits of caregiving. As mentioned previously, although most research focuses on the burden of caregiving, studies have also looked into caregiving as being a source of fulfilment (Schwartz & Gidron, 2002), leading to beneficial effects on positive dimensions of psychological well-being (Marks et al., 2002). Researchers indicated that the caregiving experience is not one-dimensional; and that it can be burdensome, yet, at the same time, a satisfying experience (Lemoine et al. 2005; Pristavec, 2018). A positive finding by Hsiao and Van Riper (2009) was that when family caregivers had an optimistic interpretation of family caregiving, lower levels of family caregiver burden were reported. In the face of adversity and stress, while some families may lose their communal strength, others may ‘pull together’ and flourish (Robinson et al., 2008).

The Couple Relationship

Ainsworth conceived of couple attachments as an integration of the sexual, attachment, and caregiving systems, which come to provide the foundation for caring for offspring (Ainsworth 1989; George, 2009). As research on relationships develops, the notion of relationship quality as unidimensional is being revised, and is now highlighting the implications of both positive and negative dimensions of relationships (Birditt, 2017; Bookwala, 2016). An individual’s interests, behaviours, and feelings, both positive and negative, within a couple relationship, influence not only their own personal marital experience, but also that of their partner (Hsieh & Hawkley, 2018). In fact, interdependency was found to have significant life-giving benefits (Gottman & Gottman, 2015). A study by the National Centre for Family Research (2017) noted that irrespective of whether the couples in their study were happy or distressed, most were facing, or had previously experienced, major life challenges such as chronic illnesses or work-related difficulties within their families. It was noted that it was the *interaction* between the couple, and whether respect, trust, and love were being communicated, which supported the couples in managing these life challenges.

In longitudinal couple studies by John Gottman and his assistant Janice Driver, they discovered that “the smallest moments” in the couples’ bids for communication “told an important story” (p. 5) of how their marriages would proceed long-term. The communication patterns of couples forged their strength and indicated how conflict and life stressors were managed in a relationship (Gottman & Gottman, 2015). Indeed, wives and husbands in conflict, married longer than 10 years, reported higher levels of depressive symptoms (Whisman, Robustelli, Beach, Snyder, & Harper, 2015). In light of these findings, I reflect whether couples with older children experiencing difficulties of their own come to be influenced by such stressors within their relationships, and how possible daily interactions come to support, or negate, their marital connection.

Parenting adult children. Research shows that parents continue to be a significant source of support when their children enter adulthood (Bucx, Van Wel, & Knijn, 2012; Furstenberg, 2010). As children age, parents experience the challenge of providing flexible yet firm boundaries, without instilling complete control (McGoldrick & Shibusawa, 2012). Although minimally researched, the impact of parental styles on children reaching adulthood seems to last (Steele & Mckinney, 2018). As the child grows into an adult, the parent-child interactions tend to shift, emphasising the relationship dynamic, as the grown child begins to make choices without the parents' involvement (Steele & Mckinney, 2018). However, such an opportunity may come into question if the adult child is experiencing mental health difficulties. This is where the parent may be required to play a vital role in their adult child's life (Gerten & Hensley, 2014) and regain the active parenting role that they would have otherwise transitioned out of (Cook et al., 1997).

Caregivers of Adult Children

As mentioned previously, parents of adult children with mental health problems experience several emotional hardships, including loss and grief (Godress et al., 2005; Ozgul, 2004). When children do not achieve societal expectations of normal adult development, parents may express both solidarity towards the child, while concurrently mourning their adult child's missed opportunities, and disappointment about their future (Pillemer, Munsch, Fuller-Rowell, Riffin, & Suitor, 2012).

In addition to this, parents who are caregivers expect their son or daughter to live longer than them (Kaufman et al., 2010), which may foster foreseeable concern, as they worry about their adult child’s future needs, once they are no longer able to care for them (Chou, Pu, Lee, Lin, & Kröger, 2009; Marsack, 2016).

Research indicates that grief experienced by the parents due to their adult child’s mental illness may negatively influence their relationship with their child (Richardson et al., 2013). Caring for adult children may also coincide with personal health and other challenging factors related to aging (Kaufman et al., 2010) which could come to be unidentified or avoided due to their responsibilities towards the care-recipient (Robinson et al., 2008), particularly by female caregivers (Gilligan et al., 2017). If not addressed, such difficulties could pose negative consequences on the caregiver, and possibly on the couple’s relationship, due to the interdependence of couples (Hsieh & Hawkley, 2018). Godress et al. (2005) noted that grief experienced by parents of adult children with mental illness seemed to be related to a lowered psychological wellbeing. In my study, I seek to explore such possible experiences of grief, and psychological wellbeing, in relation to the couple relationship and their relationship satisfaction.

The Couple Relationship when the Children Become Adults

As highlighted in the introduction, families with emergent adults are in a sensitive period where the individual member in the family and the other members come to intersect, influence, and be influenced by each other (McGoldrick et al., 2016). The risk of marital problems in later life may directly intersect with, and be influenced by, important life cycle transitions in family contexts (Papp, 2018; Wickrama, O’Neal, & Lorenz, 2013). Research on older couples however suggested that marital satisfaction is higher, when compared to middle-aged and younger couples (Carstensen, Gottman, & Levenson,1995; Henry, Berg, Smith, & Florsheim, 2007). T. W. Smith et al. (2009) argued that older and more satisfied couples tended to discount their spouse’s negative behaviours or actions, which led to a higher indication in marital satisfaction, with Papp (2018) noting that couples who have ‘emptied the nest’ also reported less disagreements.

The quality of the couple relationship is also characterised by the joint effects of positive and negative experiences (Hsieh & Hawkley, 2018). As couples age, their marital quality comes to play a significant role as they may become reliant on one another, as social connections lessen with age (Margelisch et al., 2017). Such high co-reliance was reported to create adversity in some couples (Hsieh & Hawkley, 2018). This could potentially be further influenced when caring for an adult child, as other demands and strains come into play.

Relationship satisfaction. Long-term marital satisfaction has been outlined by six vital contributors, these being caring, commitment, communication, conflict, compromise, and ‘contract’, referring to the couple’s expectations of each other and of their marriage (Cheung, 2005). Maltese couples noted that struggling with work, having children, and experiencing financial difficulties put an augmented strain on relationships (National Centre for Family Research, 2017). A lack of time and diminished communication was noted by participants to spur the couple to take each other for granted, leading to a lack of intimacy, and thus another major contributor to relationship distress. In their study, Hsieh and Hawkley (2018) found that indifference within a couple relationship potentially indicates a lack of engagement in, or withdrawal from, the marital relationship Such experiences may be further enhanced when caring for young children, as well as older adults, whose demands may require more time and attention.

In relation to this, Cheung (2005) noted that when couples have more flexible gender roles within their marital relationship, they felt higher satisfaction. Relationship satisfaction is also related to a person’s own mental health as well as that of their partner (Robinson et al., 2008). As mentioned previously, because of the several emotional consequences of caregiving on the individual’s mental health (Kaufman et al., 2010), relationship satisfaction may come to be influenced by this, although a few studies have questioned the marital quality of their participants in light of their caregiving experience (Bookwala, 2009; McCormack & McCann, 2015). Wiener et al. (2016) fittingly noted that, although an individual is ‘married’ or ‘partnered’ with someone, a parent caregiving a child with a severe illness may still feel alone when caregiving. Similarly, a caregiver who is ‘single’ may still receive considerable support when caregiving a child. This is substantiated with findings by de Jong Gierveld, van Groenou, Hoogendoorn and Smit (2009), who noted that loneliness can also be found in marriages. Older married adults who were provided with more active support, especially emotional support, had less incidence of emotional loneliness.

Sexual intimacy. As couples age, intimacy and sexuality remain an activity related to couples’ emotional health and life satisfaction, and may also protect against the several physical and mental health problems that individuals experience as they grow older (Bitzer, 2011). Sexual activity in middle-aged and older couples was found to be associated with better relationship quality (Orr, Layte, & O’Leary, 2017). The sexuality of midlife couples is patterned and driven by their past, as much as by their biological drive (Berman & Wohlsifer, 2013). Although noted to commonly continue throughout midlife, some couples discontinue sexual behaviour without obvious marital problems, whilst other individuals, fatigued by life circumstances or difficult marriages, cease sexual intimacy with their partner (Berman & Wohlsifer, 2013).

Caregiving and Couple Dynamics

As previously noted, few studies have explored the influence of caregiving on the marital quality of participants in light of their caregiving experience (Bookwala, 2009; McCormack & McCann, 2015; Penning & Wu, 2019). In Bookwala’s study of adults caring for their frail older parents, the researcher found that experienced caregivers reported significantly lower marital role satisfaction, and higher hostility within their marital relationship than recent caregivers. Similarly, Aschbrenner, Greenberg, and Seltzer (2009) also found that parents of adults with serious mental illness were at an increased risk for marital disruption. A study with caregivers of relatives with Huntington's disease noted that the need for care could cause conflicts between maintaining the role as a family member and family caregiver (Røthing, Malterud, & Frich, 2014), similarly reflecting the dilemma of adaptability that caregiving parents face (Edwards et al., 2008).

Caregivers also reported that arguments with their spouses regarding management of their child's eating patterns were impacting their marital relationship, as well as the home atmosphere (McCormack & McCann, 2015). In relation to this, Birditt (2017) noted that coping among spouses is often symbiotic, and couples often do not experience stress individually but as a dyad. These findings encouraged me to research the impact of caregiving on parents whose children have a mental illness, and whether marital satisfaction, among other issues, is influenced.

Interpersonal difficulties within the family. Ozgul (2004) noted that "the onset of the illness means the family system is irrevocably changed" (p. 183), where symptoms, change and loss of function, and possible demands and change in roles, could halt a family's natural momentum (Rolland, 2012). In relation to this, life-course perspectives, age of family members, and onset of illness should also be considered when studying the impact of caregiving (Cook et al., 1997). It is in this moment where family resilience is accentuated, where through the use of its strengths and skills, some families adapt due to the demands and stressful life events (Hsiao & Van Riper, 2009).

In a local study, caregivers noted that mental illness impacted their other family members, such as the young children of women who required inpatient treatment (Gauci, 2016). The Australian Institute of Family Studies (Edwards et al., 2008) noted that partners and children of caregivers were two to five times more likely to experience a depressive episode when the carer had also experienced a depressive episode of 6 months or more since they started caring. This is in line with Amirkhanyan and Wolf (2006), who noted that distress may be experienced by the non-caregiver too, within the family.

Impact on siblings. A young person experiencing mental health difficulties may stress the resources of parents and their grandparents, and attention on their siblings may lessen (Berman & Heru, 2013). Wolfe, Song, Greenberg, and Mailick's (2014) research noted that individuals whose sibling had a mental illness evidenced a divergent pattern of adult development, such as completing fewer years of education than their counterparts where no siblings had mental illness, and being less likely to be employed in the early years of midlife. The authors of the study also noted that the onset of the mental illness influenced a change in the sibling relationship. This is in tune with findings by Berman and Heru (2013), who noted that the ability of families to maintain a warm emotional environment seems to be influenced by the difficulties and unhappiness of any family member. Furthermore, siblings may also be the ones to whom caregiving responsibilities of the adult child's needs fall on, when parents age and pass away (Cook et al., 1997; Leith, Jewel, & Stein, 2018).

These findings further evoke questions into my research, as I aim at looking into how the dyad and individual members of the couple relationship could be impacted by the experience of caregiving, as well as any possible influences on their relationships with other children (without mental illness) in the family.

Mothers of Adult Children with Mental Illness

As highlighted in the introduction, most caregivers tend to be female (Abela et al., 2016; Copeland & Heilemann, 2011; The National Alliance for Caregiving, 2016; Vermeulen et al, 2015a). Research in gender differences on the effects of caregiving has furnished inconsistent results across diverse studies, however the majority of evidence suggests that women tend to experience more burden and psychological stress in their roles as caregivers than men, apart from taking on more caregiving responsibilities (Yee & Schulz, 2000). Apart from motherhood, women seem to accommodate more, and they also instigate more change in relationships to counteract the inequality reported in marriages (Cheung, 2005).

The mother's role can become disrupted when the child experiences a mental illness (Gerten & Hensley, 2014). Such a role may not only be influenced by personal choice, but also shaped by societal expectations (Cheung, 2005; Dallos & Draper, 2010). In relation to this, mothers providing care to their adult daughters with mental illness reported to feel ambivalent towards wanting to protect their child, yet wanting them to be independent (Copeland & Heilemann, 2011).

Similarly, Smith's (2015) findings with mothers of adult children with psychological or financial difficulties noted that the participants described their caregiving experience as being a violation of their motherhood, whilst also experiencing self-blame and guilt, reflecting an ambivalent perspective. Interestingly however, due to the maternal role, women may come to report less negative feelings, and more positive ones, towards their adult children (Pillemer et al., 2012). Gilligan et al.'s (2017) findings substantiate these views by noting that, due to the high levels of emotional and instrumental support by mothers to their adult children with mental illness, mothers are at greater risk of experiencing health difficulties, and practicing less self-care.

Fathers of Adult Children

Men’s roles in families are also changing (Gorell-Barnes, 2018; McGoldrick et al., 2016), with increased active roles in parenting and homemaking, although still unequal to women’s family obligations (Walsh, 2012b). Fathers reported higher levels of ambivalence towards their adult children, particularly when their children were not married or had lower educational achievements (Pillemer, et al., 2012). Such findings may also be compared to the losses experienced by fathers in their expectations of their adult children’s future, due to their mental illness (Wiens & Daniluk, 2009).

A European study by the Netherlands Interdisciplinary Demographic Institute (Fokkema et al., 2008) on solidarity between parents and their adult children reported that fathers provided more financial assistance towards their grown children, rather than help in kind, as mothers did. Although fathers seemed to have less contact with their daughters and sons in general, nevertheless, the fathers’ sense of family care obligation was no less than the mothers’.

Support and Coping

Psychosocial and active support can be of benefit for caregivers (Scerri et al., 2018; Sörensen, Pinquart, & Dubertstein, 2002). Indeed, sharing one’s difficulties with other caregivers and professionals was reported to be a way of coping (Gauci, 2016; Kaufman, 1998). Participants in the local study by Fenech and Scerri (2014) noted the importance of being made aware of long-term residential services for their relatives with mental illness, whilst in a study led by the European Federation of Associations of Families of People with Mental Illness (EUFAMI) (Vermeulen et al., 2015b), Maltese caregivers noted their dissatisfaction at the ease of receiving support from staff.

Researchers Sörensen et al. (2002) noted that when carers maintained social relationships, these appeared to provide a pivotal area of well-being and connectedness. As caregivers advance in age, their social networks may become smaller, thus increasing the possible risk for isolation (Sörensen et al., 2002). Family caregivers with higher perceived community support reported lower burden due to caregiving (Hsiao & Van Riper, 2009).

Martin, Ridley, and Gillieatt (2017) suggested that mental health policies should view care recipients and their families as “co-existing and interdependent” (p. 484), while acknowledging that each have their own personal needs and experiences. When caregivers are provided with the right support and a space for dialogue, care-recipients and their families are empowered to use their capabilities, experiences, and resources for recovery and progress (Ozgul, 2004; Richardson et al., 2013; Seikkula, Alakareb, & Aaltonena, 2011). In line with this, Scerri et al. (2018) noted an association between higher scores of psychoeducation with less emotional impacts and lower perceived consequences for caregivers, highlighting the significance of caregiver professional support.

In addition, Kaufman (1998) noted that religious and cultural factors seem to play a vital role in providing coping strategies to parents providing care to their adult children. It is interesting to keep in mind such factors within the Maltese context and caregiving, particularly in relation to couple relationships.

Conclusion

The literature above provided us with a comprehensive outlook of the outcomes experienced through caregiving, complimented with research on individual and couple relationships when the children become adults. As family members age, the systems within the family experience interdependent transitions (McGoldrick et al., 2016), which may come to be disrupted due to major life stressors such as illness and caregiving needs (Ozgul, 2004;

Rolland, 2012). However, the impact of caregiving on the couple and family systems and older couple’s marital functioning remain research gaps (Papp, 2018; Penning & Wu, 2019; Schulz & Eden, 2016). The literature provided us with reflections about the possible experiences that couples in later life face when their adult children are experiencing difficulties of their own. In the following chapter, I will be presenting the methodology used for my study.

Methodology

Introduction

In this chapter, I will be presenting the research design and methodology used in this study to explore the experience of caregiving an adult child with a mental illness and its impact on the couple relationship. The rationale for the choice of methodology and philosophical underpinnings will also be discussed, as well as information pertaining to the process of participant selection, the interview process, and data analysis. I will also be presenting my own reflections as a researcher and the ethical considerations pertaining to the study.

Research Rationale

The aim of my research is to delve into the perceived impact of caregiving on the couple relationship, when an adult child has a mental illness, thus addressing the scarcity of literature in the area of family and couple dynamics when caregiving (Schulz & Eden, 2016; Penning & Wu, 2019), particularly older couples' marital functioning (Papp, 2018).

The need for a qualitative study. Whilst I came across abundant amounts of quantitative research on the individual experience of caregiving (eg: Chou et al., 2009; Hsiao, & Van Riper, 2009; Pristavec, 2018; Vermeulen et al., 2015a), to my knowledge, no previous study to date has explored the experience of caregiving adult children with mental illness from the couple's perspective, nor its perceived impact on their relationship. The research question required a design which would bring forth the in-depth experiences and meaning-making process of my participants, both as individuals and as a couple. For this reason, I chose a qualitative research method to enable my participants to voice the complexities and descriptions of their meaning-making (Coyle, 2007). Furthermore, qualitative studies uncover the understanding and analysis of how participants make sense of their experience in relation to social, historical, cultural, and theoretical processes (Creswell & Poth, 2018; Larkin, Watts, & Clifton, 2006). Consequently, a qualitative design, using Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009) as the chosen methodology, was deemed ideal. A multi-perspective dyad design was employed (Larkin, Shaw, & Flowers, 2019), since the research is concerned with shared and distinctive features of the perceptions of both spouses, within their couple system, as spouses and caregivers.

Epistemological Reflexivity, and Underlying Philosophical Tenets of IPA

The philosophical underpinnings of qualitative research shape the researcher's formulation of the research question (Ponterotto, 2005), and aid the reader in understanding the author's frame of mind (Creswell & Poth 2018).

Ontology. As noted earlier, in assuming a social constructionist lens, this study explores the nature of the participants' reality as created within their own experience, context, and interactions (Mavhandu-Mudzusi, 2018; Richardson, 2012; Wang, 2016). It acknowledges that "multiple realities" co-exist among my participants' lives, experiences, and relationships (Berger & Luckmann, 1966/1991, p. 35). Through a constructivist perspective, as a researcher, I address the relations among individuals, referred to as *verstehen* in German, which translates to the "act of understanding" of human interaction (Heidegger, 1962, p. 120). Therefore, I am required to be an active facilitator in addressing, and then making sense of, the participants' lived experience (Larkin et al., 2006; Smith et al., 2009), supported by underlying philosophical frameworks, as described below.

Epistemology and methodology. IPA (Smith et al., 2009) was deemed to be the ideal methodology for this study, as its theoretical frameworks of phenomenology, hermeneutics, and idiography support the aim of this research to explore the in-depth experiences of the participants, as caregivers, and as spouses. Hence, the study's 'epistemology', which refers to the variations and validities of human knowledge about the world (Langdridge & Hagger-

Johnson, 2009), is a phenomenological one, as applied through IPA. Using a multi-perspective design, I retain IPA’s concepts, whilst also illuminating interactions and contrasts, through the inclusion of multiple perspectives (Larkin et al., 2019) within a couple relationship.

Although IPA’s development in the mid-1990s is rather recent, its philosophical concepts have longer histories (Smith et al., 2009). IPA’s approach in inquiry is rooted in transcendental phenomenology, which refers to the wholeness of an experience and adheres to what can be exposed “through reflection on subjective acts and their objective correlates” (Moustakas, 1994, p. 45). In other words, phenomenology examines the human perceptions of the world (Langdridge & Hagger-Johnson, 2009; Smith et al., 2009).

Edmund Husserl is considered to be the pioneer of such a philosophical approach (Kakkori, 2009; Moustakas, 1994; Yahalom, 2013). Husserl emphasized that we must step out of our own consciousness and assumptions, and back towards the essence of the participants’ knowledge of a given phenomenon, in order to make sense of it (Smith et al., 2009). Such a proposition was described as ‘epoché’, or ‘bracketing’ one’s beliefs, so that pure phenomenological knowledge can be obtained, without any presumptions or preconceived ideas (Langdrigdge & Hagger-Johnson, 2009). This allows the experiences and phenomena to speak for themselves (Pietkiewicz & Smith, 2012). However, unlike transcendental phenomenologists like Edmond Husserl, other philosophers such as Heidegger, Merleau-Ponty, and Gadamer, to name a few, postulate that as researchers we cannot completely set aside our reflections or biases (Creswell & Poth, 2018; Larkin et al., 2006), which brings us to the next underlying tenet of IPA: hermeneutics.

Whilst phenomenology studies the essence, hermeneutics is often described as the theory and process of interpretation (Smith et al., 2009; Kakkori, 2009), of which Martin

Heidegger (1962) is a notable figure. To investigate meaning in his work ‘Being and Time’, Heidegger developed the concept of *Dasein,* which translates to “any kind of *Being* or existence” (1962, p. 28). This refers to the experiential engagements to the world and one’s relationships with others (Larkin & Thomson, 2012; Smith et al., 2009). However, as we seek to understand, we inevitably interpret (Schwandt (2000). Therefore, Heidegger linked phenomenology to hermeneutics because the examination of a phenomenon, previously latent, takes place through the eyes of the researcher’s own pre-suppositions and prior experiences (Creswell & Poth, 2018). As the participants’ attempt to make sense of their experience, so does the researcher, involving a double hermeneutic (Smith & Osborn, 2003). This requires the necessity of self-reflexivity (Kakkori, 2009) which ultimately relates to the existence of others, the ‘*being* with’. Heidegger goes on to emphasize the significance of gaining self-awareness when interpreting, in order to give priority to the phenomenon being interpreted, rather than one’s own fore-conceptions (Creswell & Poth, 2018).

When using dyadic interviews, a ‘triple hermeneutics’ (Mavhandu-Mudzusi, 2018) occurs, as a third interpretation takes place between the researcher and each member’s attempt at interpreting one another’s lived experience.

Lastly, IPA’s strength also lies in its idiographical approach. Idiography places emphasis on the particular; on grasping the meaning of experience of a particular participant (Smith et al., 2009). Larkin et al. (2008) noted that idiography may also be used as a term to refer to a *specific situation or event* as being lived by the participant. This approach supports the value of utilizing small, intentionally selected samples, or even single case studies, as participants (Smith et al., 2009).

The Participants

Sample criteria. For a homogenous sample (Smith et al., 2009), participants in the study were required to be heterosexual married couples who were caregivers of adult children experiencing severe mental illness.

The couples were required to be living in the same household as their adult child. The adult children and their parents were required to be in contact with mental health professionals at the time of the study. For this reason, I liaised with gatekeepers. Initially, one of the criteria recommended that the ages of the participants' adult children would be between 18 to 30 years of age. However, due to the difficulty in recruiting participants whose adult children fell under that criteria, the age range was extended.

In line with literature, the main caregiver within the couple system was initially required to be the wife. This was requested since both locally (Abela et al., 2016), and overseas (The National Alliance for Caregiving, 2016), caregivers tended to be female. However, as recruitment and interviews took place, it transpired that the participants in my study were equally involved in the caregiving responsibilities. The title of my study was consequently amended.[2]

Due to my previous work experience with Richmond Foundation, I specified that no past clients, or their relatives, could be participants in my study (as specified in the letter of recruitment, see Appendix A). This measure will be further discussed in the section pertaining to ethical considerations.

Recruiting the participants. Participant recruitment and data collection took place between December 2018 and April 2019. Initially, the non-governmental associations

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[2] The title of the research study was initially the following: "The perceived impact of ***maternal*** caregiving on the couple relationship on when an adult child has a severe mental illness." The word ***maternal*** was consequently removed after data collection and analysis took place.

(NGOs) Richmond Foundation and St Jeanne Antide Foundation (SJAF) were informed of my study and their consent to be gatekeepers was sought. A copy of the request for participant recruitment can be found in Appendix A. After obtaining their approval (see Appendices B and C respectively), I met with the managers from the NGOs to discuss my study and requirements in further depth. Due to limitations in reaching the sample size, approval to have Mental Health Services as an added gatekeeper was also sought and received (See Appendices D and E respectively).

Staff members from the corresponding gatekeepers identified interested service-users or their family members, and provided them with information sheets regarding the study. The interested participants were invited to contact me, as the researcher, through phone or e-mail, should they be interested in participating.

It is of note that, shortly after meeting the gatekeepers, I was informed by SJAF that although 17 couples had been informed of the study, they all disagreed to participate. Prior to this, during the initial meeting, a staff member from SJAF had informed me that the families they worked with encountered many difficulties to get their relative to seek treatment. SJAF mostly work with families who are still in the very early and raw stages of dealing with mental illness. For this reason, due to the very nature of their children's condition, the staff member informed me that the families might not be in a position to participate. I was also aware that recruiting participants in the month of December would be problematic, since, as informed by SJAF, this tended to be a very busy month for them, where many families sought assistance due to their caregiving distress and the sensitive Christmas season.

This challenge in participant recruitment led me to reflect further on the idiographical experience of each couple and individual who has a caregiver role. I wondered whether the couple's relationship was further burdened by the multiple stressors influencing their current state, and seemingly their interest in the study. Factors such as the time of year, their adult child’s diagnosis and prognosis, the support being received, the couple’s financial situation, the family members’ coping mechanisms, and personality, are only some of the many issues which couples could be facing when dealing with a relative with a mental illness.

Introducing the Participants

A brief introduction of the three participating couples is presented in Table 1. Some brief information about their adult children was also included to better understand the family structure. To safeguard anonymity, pseudonyms for all participants and their family members were assigned. For coherence, the couples were identified as Couples A, B, and C, respectively, and their pseudonyms correspond to the designated letter of each couple, namely Anna and Anton (Couple A), Berta and Brian (Couple B), and Catherine and Charles (Couple C). It is worthy to note that all the couples seemed to be from middle-class to upper-class households.

Table 1

Participants' and their families' basic details

Couple A			**Brief Description**
	Female Participant	**Male Participant**	Anna and Anton have been married for 30 years, and work together in a family business. Their son, Nathaniel, was diagnosed with psychosis around 7 years ago. Their daughter Nadine lives out of the country. Nathaniel spends most of his days at the family business. During the course of caregiving, around two years ago, Anna experienced a depressive episode.
Names	Anna	Anton	
Ages	52	58	
Adult child	Nathaniel		
Age	25		
Diagnosis	Psychosis		
Other children	Nadine		
Ages	24		
Couple B			Berta and Brian have been married for 43 years. Their grown children Ian and Adriana live with the couple. Their other son Tony is married and has two children. Berta is a housewife and Brian has retired from a managerial position. Ian has been diagnosed with OCD for over 10 years. Ian attends a work-training scheme during the day. The couple remarked that Berta has traits of OCD, however she has never been diagnosed nor assessed.
Names	Berta	Brian	
Ages	70	70	
Adult Child	Ian		
Age	34		
Diagnosis	Obsessive Compulsive Disorder (OCD)		
Other children	Adriana	Tony	
Age	44	41	
Couple C			Catherine and Charles have been married for 43 years. Their son David lives with his parents, whilst Danica has her own apartment, however she visits her parents often. David has been diagnosed with severe anxiety and depression for over 10 years. During the caregiving process, particularly when Ian resigned from work, Catherine experienced a depressive episode. Charles has retired from an administrative job, and Catherine is a house-wife.
Names	Catherine	Charles	
Ages	68	72	
Adult Child	David		
Age	43		
Diagnosis	Generalized Anxiety Disorder and Depression		
Other children	Danica		
Age	38		

Data Collection

While, initially, the aim of the study was to conduct conjoint couple interviews with 6 to 8 couples, difficulties in recruiting a large number of interested participants required an amendment. It was decided that individual and conjoint semi-structured interviews would be employed with three participating couples. Ethics Approval of this alteration was sought and approved (See Appendix F). In hindsight, this change proved to be highly beneficial to delve deeper in the idiosyncrasies of each participant, whilst seeing their shared meanings as a couple, as will be described in more depth further on.

A note on individual and couple interviews. As noted, the data was gathered using individual and conjoint semi-structured interviews. Therefore, each participant was interviewed twice; once alone, and another time with their spouse. In employing a multi-perspective design, I developed an in-depth and multifaceted perspective of the phenomena of caregiving from the perspectives of husbands and wives, and its impact on their couple relationship (Larkin et al., 2019; Smith e al., 2009).

Whilst in-depth individual interviews provided a facilitative and safe space for my participants to share their story from their own perspective (Eisikovits & Koren, 2010), couple interviews aided me, as the researcher, on observing overlapping and contrasting couple perspectives on various levels (Eisikovits & Koren, 2010), which continued as I analysed and processed their joint interview transcripts (Mavhandu-Mudzusi, 2018). The joint interviews were also deemed to be ideal to observe the unspoken interactions between the spouses (Polak & Green, 2016; Racher, Kaufert, & Havens, 2000; Taylor & de Vocht, 2011). The interviews evoked discussions and disagreements, but also provided me with rich information about the couples’ synergy and attunement.

As noted by Taylor and de Vocht (2011), combining individual and couple perspectives provided broader truth and authenticity towards understanding of phenomena, thus linked to Heidegger’s *Dasein*. Combing both approaches aids in eliciting the individual’s perspective, and their shared meanings (Butt & Chesla, 2007). Interviewing couples together also meant that the participants were seen in the social context being studied, that of their couple relationship (Eisikovits & Koren, 2010; Taylor & de Vocht, 2011).

Interview schedule. I devised semi-structured interview guides in the English and Maltese languages, to support me during the interviews, and to facilitate a conversation whereby the participants feel comfortable to share a detailed account of their experience (Smith et al., 2009). Although the individual (Appendices G and H) and couple interview guides (Appendices I and J) are similar, some questions pertaining to the couple relationship were added to the conjoint interview schedule, particularly after the pilot study was held.

The guides were first drafted using literature and personal queries I wished to explore with my participants. I was careful to devise questions that can be answered by both participants, and also aware that one question from my guide can yield different responses from both my participants. Since qualitative work follows an inductive and emergent logic, starting from a phenomenon or idea, rather than a theory (Creswell & Poth, 2018), the semi-structured interview schedules were drawn for the needs of understanding my research problem. The questions were used as guides, whilst open-ended probes facilitated the conversation.

Conducting the interviews. Upon identifying interested couples, I set appointments with the participants through phone calls and e-mail exchanges. The individual interviews were held first, followed by the joint interviews, which were held on a different day. The couples were informed that the interviews could take place wherever they deemed appropriate. Whilst some interviews took place at the participants' homes, others were held at the participants' place of work, at the Richmond Foundation offices, and at the University of Malta. The interviews lasted around 60 to 90 minutes each, with the couple interviews naturally taking longer than the individual ones.

In most cases, the adult children's presence seemed to determine the location of the interview. On two separate occasions, Anna and Anton's adult son had to be asked to leave the place where the interviews were taking place. Similarly, Catherine and Charles requested that their interviews be held at university due to their son's presence at home. I perceived issues of limited privacy and flexibility from the couples' point of view, and wondered whether this was reproduced in their everyday lives. Despite this, all the participants, both in their individual and couple interviews, seemed comfortable and at ease.

During the interviews, I was aware to bracket my own biases or intuitions, and intervene minimally and only when required (Creswell & Poth, 2018; Smith et al., 2009). I was aware of any possible patriarchal or hierarchical positions the participants have in society and in the research (Etherington, 2007; Turnbull, 2018). Although the advantages of couple interviewing are plentiful, a possible weakness is the impact of inequality as a participant within the couple may silence the other member's account (Mavhandu-Mudzusi, 2018). Therefore, I was sensitive to strike a balance for both individuals to participate, and to avoid 'siding' with one partner, especially when my personal and professional views were consistent with that of the interviewee (Taylor & de Vocht, 2011). By weaving my role as a researcher with my clinical training, through empathic and non-judgmental interactions, I fostered a safe working alliance with my participants (Sammut, Abela, & Scerri, 2012).

At the end of each interview, I dedicated time to debrief the participants and thanked them for sharing their experiences with me. I informed them that they would be invited to give me feedback on the results emerging from the individual and conjoint interviews, once data analysis is complete.

Pilot Study

The first sets of interviews were conducted as pilot studies, to familiarize myself with the interview guide and assess how it was received by the participants. It also shed light on certain prompts and further questions to be added to refine the interview guide (Creswell & Poth, 2018). No major changes in the individual interview guide were needed, so this pilot study was included in the data analysis.

However, the conjoint pilot interview, conducted with another couple, was not included because they seemed not to fit the criteria. As I conducted their individual interviews, I noted that, because their adult child's diagnosis included an intellectual disability from birth, the couples' experiences seemed to differ drastically from the other participants' accounts, whose children were diagnosed with a mental illness in their adolescence or early adulthood. Therefore, because I wished to focus specifically on the area of mental health caregiving, rather than intellectual disability, after discussion with my supervisor, and for the sake of homogeneity (Smith et al., 2009), their interviews were not analyzed nor included. However, the couple interview which was carried out with them served as a pilot study. I noted that further questions pertaining to the couple's experiences in view of their caregiving roles, identities, and future, were required. These were added in the couple interview guide and marked in bold (see Appendices I and J).

Data Analysis

Interviews were recorded electronically and transcribed verbatim by myself. Although an arduous process, this stage was extremely beneficial as it helped me gain more familiarity with the participants' accounts and paved the way to an in-depth analysis of the data. The data was analyzed using IPA (Smith et al., 2009) whilst referring to the stepped approaches as described by Langdridge & Hagger-Johnson (2009) and Smith et al. (2009). However, since IPA is described as more of an approach, rather than a methodology, the researcher is flexible to develop one's own ways of conducting a study, whilst still being true to the principles of IPA (Larkin et al., 2008; Smith & Eatough, 2008; Smith et al., 2012).

After transcriptions were complete, the next step of data analysis was that of reading and re-reading each transcript. For ease of analysis, the transcription was edited into three columns on a Word document: the main interview text positioned in the middle section, whilst the first set of notes, reflections, and observations of the researcher done on the left-hand side. Excerpts of an individual and conjoint analysed transcripts can be found in Appendices K and L respectively.

After the initial stages of getting as near to the participants' experiences as possible, by producing informed descriptions and my own reflections, an interpretative analysis ensued. This encouraged me, as the researcher, to interpret what *it* means for the participants who have expressed their experience about the *particular* situation (Larkin et al., 2006).

Subsequently, I then identified themes by drawing out patterns from each single transcript, organizing emergent themes as they occur. Since a multi-perspective design was employed, each participant was first treated and analysed as an individual case at an idiographic level (Larkin et al., 2019). As suggested by R. Shaw (personal communication, April 29, 2019), similarities and differences were then drawn between the female's and male's individual accounts. The couples' accounts were analysed as units, and comparisons were made within and between the couples.

When moving on to a next transcript, I was aware to 'bracket' any previous reflections or ideas from the previous ones, consistent with the frameworks of IPA. As I engaged with the emergent themes by printing each one on different slips of paper, as suggested by Smith et al. (2009), I moved them around and attempted to group them into "clusters and hierarchies of meaning", when appropriate (Langdridge & Hagger-Johnson, 2009, p. 399). Once recurrent themes were identified, a number of super-ordinate themes were developed, which each super-ordinate theme having a number of sub-themes. This was repeated for each individual, and consequently for each couple interview. This process required a constant negotiation between moving focus from the shared experiences of different individuals and couples, to the individuality of each participant (Smith et al., 2009), or couple system (R. Shaw, personal communication, 29 April 2019). I was also aware to follow IPA's hermeneutic framework whilst processing their own experiences and my own.

After discussing the findings with my supervisor, two final tables were developed, as represented in Table 2 and Table 3 in the Results Chapter. Following this stage, the results were discussed in light of extant literature, whilst noting novel findings emerging from this study, together with reflexive inquiry. This is presented in the Discussion chapter.

Credibility and Trustworthiness

Creswell and Poth (2018) suggested engaging in at least two, out of the ten validation strategies for qualitative research. Throughout the whole process of my research, I sought an external check through my supervisor, who, as a peer reviewer, encouraged me to reflect, and be aware of the methods, interpretations, results, and meanings emerging from the participants' accounts. As I bracketed my own presumptions to allow the genuine phenomena to emerge (Pietkiewicz & Smith, 2012), I gained awareness of my own possible involvement in interpretation (Smith et al., 2009). This also helped align the power imbalance between researcher and interviewee (Creswell & Poth, 2018; Etherington, 2004), thus ensuring a cooperative, credible, and nonexploitative relationship (Creswell & Poth, 2018).

To ensure that the data collected and interpreted by me was valid to the interviewees' experiences, I shared with them the results emerging from each of their own individual and couple interviews. One spouse from each couple replied and agreed to the resultant themes. No changes were therefore needed to be done. When replying via e-mail to me, the participants, Anna, Brian, and Charles, noted their appreciation for having been contacted, and for having participated.

Reflexivity

Reflexivity is an important part of the research process (Fleet, Burton, Reeves, & Dasgupta, 2016), and indispensable in qualitative work (Langdridge & Hagger-Johnson, 2009). Reflexivity also addresses the researcher's inevitable subjectivity on the research (Creswell & Poth, 2018; Turnbull, 2018). My research topic was not a mere coincidence: as mentioned previously, the area of 'caregiving' has been of great interest to me, both personally and as a professional. Therefore, by being aware of this, I make my values and beliefs transparent (Etherington, 2007). Further reflexive thought helps me 'bracket' my own experiences and knowledge of caregiving, so as to abstract the participants' idiographical phenomenon as lived by them (Smith et al., 2009). This also assures ethical practice towards my research and my participants (Guillemin & Gillam, 2004).

I was also aware to reflect on any possible influences that my age and gender could have on the participants, since such characteristics may influence the interview process and interview outcome (Mavhandu-Mudzusi, 2018). Nevertheless, I perceived that my participants were at ease and also answered in-depth, honestly, and genuinely. I was grateful to perceive that they felt comfortable with me, particularly whilst sharing sensitive accounts, or during the couple interviews, where instances of the spouses being playful, or in discord, emerged.

In keeping aware of, and processing my involvement as a researcher, I kept a journal in which I jotted down my reactions and reflections throughout (Fleet et al., 2016). As Macfarlane (2009) suggested, reflexivity in research should be an ongoing process. In relation to this, as suggested by Bond (2004), since the interviews included sensitive disclosures, my supervisor supported me through regular and ongoing supervision. This also helped me to avoid focusing solely on the descriptive outcomes of the research (Larkin et al., 2006).Therefore, exploring such reflections and disclosures with my tutor was further useful in making sense of, and processing, my reflections and notes, as well as reducing the risk of harm to the participants and to the researcher (Bond, 2004; Larkin & Thompson, 2012; Mitchell & Irvine, 2008).

Ethical Considerations

To carry out this research, ethical approval was sought from and obtained through the University of Malta Faculty Research Ethics Committee (FREC) (see Appendix M). As mentioned previously, approval of recruiting participants from local gatekeepers was sought and approved (See Appendices A - E). Once approval was granted and the rigorous inquiry on the research area was done, the gatekeepers were briefed about the study and the recruitment of participants was initiated through the use of the information sheets provided in the English (Appendix N) and Maltese languages (Appendix O).

The information sheet highlighted the caregivers' voluntary participation, their right to withdraw at any point of the study, and the assurance of their anonymity. The information sheet informed the participants that, should they be willing to participate, they could contact me via phone or e-mail.

An ethical consideration I emphasized in the participant recruitment letter was that none of the participants or their children could be my ex-clients from my previous work experience at Richmond Foundation. This was done to ensure that I would not know any of the participants beforehand, as the nature of our past therapeutic relationship may raise further complex ethical dilemmas and biases when doing research (Gabriel, 2005). This would also ensure that participants would be choosing to participate freely, rather than feeling obliged to accept due to our past relationships.

Once eligible and interested participants were identified and contact was made, the interview appointments were set to their discretion. The information sheet was again presented to the participants, whilst written consent of their partaking was obtained from every participant. A copy of the consent forms in English and Maltese can be found in Appendices P and Q respectively.

It is important to note that the adult children, thus, the third-party participants, were also given the same information sheet and asked for consent, as seen in Appendices R and S. This was done in order to preserve, respect, and empower the adult children’s self-determination and right to consent, or dissent, the sharing of their experiences (Amer, 2013; Lambert & Glacken, 2011), through their parents’ participation in my research. Giving the third-party participants the choice of consent also fostered integrity and transparency within the research, and within the couples.

The procedure to recruit participants through gatekeepers was established as the preferred recruitment method for several reasons. Firstly, it ensured that the participants in the study would be supported by mental health professionals prior, as well as after, the interviews took place, ensuring their protection and wellbeing (Bond, 2004). Although the recalling of the caregivers’ narratives may have elicited discomfort, I took great care to ensure that any possible burden that the participants may have experienced due to the interviews was no greater than that to which they have been exposed to through the experience of caregiving. Nevertheless, in ensuring that the possible benefits and implications of the research outweigh the risk to participants (Bond, 2004; Creswell & Poth, 2018; Emanuel, Wendler, & Grady, 2000), recruiting participants through gatekeepers ensured support to my participants, should it be required.

As mentioned previously, throughout the process of the interviews, I was aware to practice sensitively, through the use of self-reflexivity and by using both research and clinical skills (Sammut Scerri et al., 2012). In hindsight, apart from ensuring credibility, exchanging the results with my participants strengthened an ethical practice, whilst ensuring that the participants were pleased to have their experiences being represented (Smith et al., 2009).

Conclusion

This chapter provided the reader with an in-depth overview of the epistemological underpinnings, methodology, and ethical considerations undertaken in my research. I also informed the reader of the reflexivity behind my study, which also comes to support the credibility of the research. In the following chapter, I will be presenting the results obtained from the interviews through interpretative phenomenological analysis.

Results

In this chapter, I will be presenting the data which emerged from the participants' accounts through clustered superordinate and subordinate themes. Although the experiences of each participant are pertinent to their unique and personal narratives, similar themes were extracted through the analysis of data. Since some of the themes were observed through the perspective of gender, for illustrative purposes and to facilitate sense-making, the table of themes emerging from the individual interviews states whether certain themes were shared among both female and male participants, or inherent to one gender only.

The second part of the results chapter will present an overview of the superordinate and subordinate themes which emerged from the couples' dyadic interviews in the form of a table followed by a detailed review of the findings. To avoid repetition, I will not be including themes which have already emerged through the individual interviews. Nevertheless, I noted the significance of illustrating some subthemes again in this section, because they captured rich moments of the couple's interactions. These instances included moments where the participants finished off each other's sentences, or when they had conflicting opinions. I decided to adopt this way of presenting the findings following correspondence with Professor Rachel Shaw (personal communication, April 29, 2019).

Throughout the chapter, direct quotes from my participants' accounts will be supplemented in italics in the Maltese language, followed by an English translation. English was mostly spoken during Anna's and Anton's interviews so minimal translation was required. Line numbers from the transcripts are included for reference alongside each quote.

Table 2

Superordinate and Subordinate Themes Emerging from the Individual Interviews

Themes Shared Among Female and Male Participants	
Superordinate Themes	**Subordinate Themes**
1. The Experience of Having an Adult Son with a Severe Mental Illness	1. Defining ‘caregiving’: a process requiring empathy, care and dedication [Anna, Berta, Catherine, Anton, Brian, Charles] 2. A struggle to accept son’s condition and grieve his capabilities and future [Anna, Berta, Catherine, Anton, Brian, Charles] 3. Acknowledging spouse’s experience of caregiving and other responsibilities [Anna, Berta, Catherine, Anton, Brian, Charles] 4. Fearing for son’s future care and independence [Berta, Catherine, Brian, Anton, Charles] **Subordinate themes shared among the female participants** 5. Being accommodating and offering reassurance to son’s needs [Anna, Berta, Catherine] 6. Exasperation and frustration towards son’s symptoms; leading to retaliating, and ultimately regret [Anna, Berta, Catherine] **Subordinate themes shared among the male participants** 7. Acknowledging and empathising with son’s experience of mental illness [Anton, Charles, Brian] 8. Frustration towards son’s idleness and lack of skills [Anton, Brian]
Themes Shared Among Female and Male Participants	
2. Individual Differences and Common Stresses between Spouses Create Strain	1. Differences in engaging and encouraging son’s independence lead to couple discord [Anna, Catherine, Brian vs Anton, Charles, Berta] 2. Adult son’s close attachment with wife fuels helplessness in husband [Berta, Brian] 3. Refusing adult son’s attendance to rehabilitation or respite services [Anna, Catherine, Anton, Berta – as noted by Brian] **Subordinate theme shared among the female participants** 4. The mother’s sensitivity vs the father’s confrontation towards adult child leads to discord and criticism [Anna, Berta] **Subordinate theme shared among the male participants**

	5. Being cautious and intuitive towards son's needs or escalations [Anton, Charles] 6. Avoiding couple discord escalating by being patient and calm [Brian, Charles]
Themes Shared Among Female and Male Participants	
3. Caregiving as an Added Strain to the Couple Relationship and the Need for Attunement	1. Caregiving adds on existing challenges in the couple relationship [Anna, Anton, Charles] Decline in affection due to multiple stressors [Anna, Anton, Catherine] 2. Couple time and affection are limited due to son's presence, needs, or crises [Anna, Anton, Charles] 3. Feeling guilty at leaving son at home for couple activities [Anna, Anton, Berta] 4. The avoidance of couple discord due to son's anxiety [Berta, Brian] 5. Normalising couple discord [Catherine, Berta, Anton, Brian, Charles] 6. The benefits of attuning to each other's perspectives [Anna, Charles]
Superordinate Theme shared among the Female Participants	
4. Experiencing Mental Health Problems in their Roles as Caregivers	1. The impact of experiencing a depressive episode due to the caregiving role [Anna, Catherine] 2. Acknowledging husband's reaction to their wife's depressive episode [Anna, Catherine] 3. Acknowledging one's own traits of OCD, and questioning responsibility on son's condition [Berta] 4. Accumulated stress due to dealing with other life responsibilities, other than son's condition [Anna, Catherine]
Superordinate Theme Shared among the Male Participants	
5. The Husbands' Experience of Wives' Mental Health Problem	1. Acknowledging wife's experience of mental health problems [Brian, Charles]
Themes Shared Among Female and Male Participants	
6. Impact of Adult Son's Illness on Siblings	1. Stress and frustration experienced due to brother's symptoms [Brian, Catherine, Anna, Anton]

	2. Acknowledging that siblings received less attention from parents [Berta, Catherine, Anton] 3. Siblings as future caregivers? [Catherine, Berta, Brian, Charles] **Subordinate theme shared among the female participants** 4. Mother split into two to provide attention to all her children [Anna, Berta, Catherine]
Themes Shared Among Female and Male Participants	
7. Accepting the Situation and Moving Forward	1. Accepting son’s condition and limited prospects of recovery [Anton, Brian, Berta, Charles] 2. A united couple despite the odds [Anna, Anton, Catherine, Charles] The benefits of having a solid foundation as a couple before the illness strikes [Catherine, Charles] 3. Gaining new perspectives and positive outcomes through the caregiving experience [all women + Charles] 4. The benefits of professional and familial support [Anna, Catherine, Charles, Brian, Berta] **Subordinate theme shared among the female participants** 5. Spiritual dimension as a channel of support, hope and gratefulness [Anna, Berta, Catherine, Charles]

Note: The names in the square brackets correspond to the participants whose accounts captured the corresponding subtheme.

Theme 1: The Experience of Having an Adult Son with a Severe Mental Illness

This first superordinate theme revolves around the experiences of participants as parents and caregivers of adult children with mental illness. As participants defined ‘caregiving’ from both its practical and psychological aspects, they also recalled their struggles at accepting their son’s condition, whilst grieving his abilities and fearing for his future care and independence.

Defining ‘caregiving’: a process requiring empathy, care and dedication. All the participants described ‘caregiving’ as a process requiring patience, empathy, and understanding towards their son's symptoms and needs, including overseeing their sons' psychiatric treatment. This is illustrated in Catherine's account:

> *…nipprova nagħmel mill-aħjar li nista' biex immur għall-problemi tiegħu […] u nipprova nkun konxja… u fl-istess ħin inkun qed ngħinu, fej' xi haġa ma toġgħobnix, ħa ngħidlu… inħossha dik hi l-kura… barra l-kura tal-pinnoli, hija l-kura ta' kuljum, tad-dar* (Catherine:8-10)
>
> …I try to do my best to understand his problems […] and try to be conscious… and at the same time, I help him by letting him know when certain behaviour is worrying to me… that is what caring means to me… apart from overseeing medication, and the everyday care at home (Catherine:8-10)

Anna emphasised that caregiving requires prioritising her son's problems over her own: "[…] his problems obviously come before your frustrations and things, otherwise… you would have lost the battle…" (Anna:7-8)

A struggle to accept son's condition and grieve his capabilities and future. Most of the participants shared the painful struggle of accepting their son's condition and the losses that he had to face due to his experience. Anna's account vividly describes her feelings:

> ah it entails a lot, obviously, it entails a lot of perseverance... it entails... a lot of heartache... [becomes tearful] especially when up to the age of eighteen… he was… not like this... (Anna:24-25)

Berta stated that she wished she did not need to be a caregiver, as she yearns for her son's 'normality', whilst also aware of the subjectivity of the term. She is uncertain of whether she has accepted her son's condition of OCD as of yet:

> *ma ridtx inniżżilha, ma stajtx inniżżilha, ma stajtx nammettiha… […] ma tixtiqhiex… għax… l-uliedek kulħadd jixtieqhom… hekk imsejjaħ 'sewwa'…* […] *domt, domt, m'accettajtha… u naħseb, lanqas… ma nafx, accettajtha?... u… ma nafx… ma nistax infisser lili nniffsi…* (Berta:59-82)

> I refused to accept it, I could not accept it, I could not admit it… […] no one wishes it… because, everyone wishes their children to be… referred to as 'okay'… […] it took long for me to accept [his condition]… and I think… I haven't accepted it yet… I don't know… I can't explain myself… (Berta:59-82)

Similarly, Catherine experienced shock and grief when her son gave up his job due to experiencing anxiety and depression. She grieved her son's future as she compared him to young people his age who, unlike him, were progressing. Anton mourned his adult son's teenage years and prospects of having a family of his own.

Acknowledging spouse's experience of caregiving and handling other responsibilities. Most participants recognised how caregiving is experienced by their spouse. Charles noted his wife's sensitivity in the caregiving process, whilst acknowledging that experiencing an illness within the family is never a pleasure:

> *imbagħad affetwat ħafna, mhux għax m'affetwatx lili ta, jiġifieri, affetwat lil Catherine […] għax hi iktar toħodhom bi kbar l-affarijiet, toħodhom bi kbar għax biex […] kif tgħid… fuq il-mard, ma jieħu ħadd pjaċir bih jiġifieri…* (Charles:62-68)

> and then…. It was very distressing to… it's not because it did not affect me… but, it really affected Catherine […] because she blows issues out of proportion… she blows them out of proportion… […] how do you say it… nobody enjoys having to deal with illness… (Charles:62-68)

Berta acknowledged that her role as a caregiver sometimes led her to retaliate towards her husband, who would have just arrived from a day's work. She was aware that his work commitments were added responsibilities for him too.

Fearing for son's future care and independence. A deep sense of anxiety and fear towards their son's future care emerged strongly among the participants, as illustrated by Anton's comment:

> the problem is, how he's going to cope when we're not around, that's another one… […] I don't know **how** he's going to cope… *iġifieri* (so)… *fhimt* (do you understand)… […] he needs money to live, he needs a place to live, he needs somebody to take care of him *iġifieri* (so)… these are all things you… you can't leave it until the end… *iġifieri* (so), you have to start from now… (Anton:1088-1099)

Catherine noted that, she and her husband Charles often think about their son's future care when they can no longer be his caregivers. Catherine reflected on her husband's suggestion to move into a residential care home together with their son:

> *ir-raġel jgħidli, [chuckles] "nidħlu f''home' u niħduh magħna"; ngħidlu, "vera!" aħna forsi, inkunu tal-eta', ħa, jekk il-Bambin iħallina ħajjin… fuq is-70, 80 sena, imma hu… jkun għadu zgħir… mhux se ddaħlu 'home' miegħek uw? Meta inti ma tkunx kapaci tagħmel daw' l-affarijiet* (Catherine:352-354)

> my husband tells me, [chuckles] "we should get into a residential care home and take him with us", and I tell him, "we should!" we'll be of age, let's say, if God willing we'll still be alive, we'll be in our 70s, or 80s… but he… he will still be young… you're not going to take him into a residential care home with you, ay? When you are not able to do these [caregiving] duties (Catherine:352-354)

Brian's concern towards his son's future care is further impacted due to his distant relationship with his son. Brian fears the consequences if his wife had to pass away. He fears his son would get highly anxious and he would know how to help him.

Being accommodating and offering reassurance to son's needs. All the female participants referred to instances of providing comfort or reassurance to their adult son; Anna's daily routine involves going to work in the morning and driving back home to collect her son to join them at work when he wakes up. Catherine noted that, when strangers are at home, such as handymen, her son's anxiety leads him to isolate himself in his room. Catherine comforts her son by taking his lunch in his room:

> *jekk jista' jkun, noħodlu l-ikel hemm… għax… ma jagħmilx kuntatt ma dawk in-nies li jiġu, ma… sakemm… ma jkunx xi ħadd tal-familja…* (Catherine:500)
>
> if I can, I take his food there… because, he doesn't make any contact with people who come, unless… they're family members… (Catherine:500)

Berta explained that during dinner, her son seems distraught with obsessional thinking while she serves the food at table. He repeatedly asks whether she will be eating, and requires their portion sizes to be the same. Berta's comment captures this:

> *ġieli, jekk insaħħan pizza u ma jkunux bħal ta' xulxin, tiegħu u tiegħi, taf li jkolli naqsam nofs u nofs, biex nieħu bhalu!* (Berta:1104)
>
> sometimes, if I would have heated up some pizza, and they're not the same, his and mine, you know that I would have to cut them both in half, so that I would eat like him! (Berta:1104)

Exasperation and frustration towards son's symptoms; leading to retaliating, and ultimately regret. All the female participants recalled moments of exasperation towards their son's behaviours. Catherine experienced guilty emotions when reacting to her son when she used to find him asleep during the day:

> *dik, jiena wkoll, tgħatni rabja kbira! Ngħidlu, "is-sodda qedha hemm biex norqdu bil-lejl, u forsi wara nofsinhar biex nistriehu naqa'… imma matul il-ġurnata ma rridekx fis-sodda" u ġieli qlibtlu s-sodda b'kollox, ngħidlu, "ħa nżarmawha, ma rridekx toqgħod"… forsi dak iż-żmien, kont inkun naqra aggressiva, għax, kif għidtlek, biex aċċettajt il-ħaga… forsi minflok ġid, kont qed nagħmillu deni… ma nafx…* (Catherine:506-513)
>
> Catherine: that too, really angered me! I would tell him, "the bed is there to sleep in it at night, and maybe in the afternoon to rest… but I don't want you in bed during the day" and I would sometimes hurl the bed with everything, telling him, "we're going to dismantle it, I don't want you in bed"… maybe at the time, I was a little aggressive, because, as I told you, I struggled to accept it… and maybe instead of being helpful, I was causing more damage… I don't know… (Catherine:506-513)

Similarly, Berta remarked that she sometimes retaliated at her son's obsessions. This would then lead her to feel guilty due to the possibly of reinforcing his obsessions further.

Acknowledging son's experience of mental illness. All the men acknowledged the difficulties, and empathised with their sons' experience. Charles' understanding is portrayed through this excerpt:

> *it-tifel għandu ċertu diffikultajiet, diffikultajiet serji […] il-kundizzjoni tiegħu nafu kemm jgħaddi min inkwiet anke li ma jidhirx… imma tarah iġifieri, ċertu tensjoni, anzjeta'* (Charles:5-8)
>
> our son has certain difficulties, severe difficulties […] we know how much his condition leads him to experience worries that don't show to others… but you can see him, a certain tension, anxiety... (Charles:5-8)

Likewise, Anton and Brian noted that their sons must experience discomforting thoughts and anxieties, due to their mental health conditions.

Frustration towards son's idleness and lack of skills. Anton and Brian shared their frustrations towards their son's lack of motivation. Brian questioned how it was possible for his adult son to have forgotten how to use a bus, doubting his son's credibility:

> *allura dana wkoll… l-memorja qedha tmur? Jew, jew qiegħed jgħid hekk, biex jeħles? Għax hu, jħobb jagħmel daw' l-affarijiet… "ma nafx, ma nafx", tgħidlu, x'tgħidlu… ma jafx... u naf li jkun jaf... […] ħeqq… inħossni… ngħid… bejn qalbi, "u dan x'iġifieri ma jafx?!"* (Brian:322-324)
>
> so, is he losing his memory too? Or, or is he saying this to shirk his duties? Because he likes doing these things… "I don't know, I don't know", whatever you tell him… he doesn't know… […] eh… I feel… deep down, I say, "how can this be, how can he not know!" (Brian:322-324)

Anton's frustrations emerge through this illustration, as he compared the productivity of another employee with mental health problems working with their family business, with his son's idleness:

> *tagħna xej', xej', qas irid imiss, xej' ma jrid jagħmel… iġifieri, tagħmillu, x'tagħmillu…* he doesn't even… help himself *iġifieri…* (Anton:1463)
>
> our son does nothing, nothing, he doesn't want to touch, he doesn't do anything… so, whatever you do for him, he doesn't even… help himself, you know… (Anton:1463)

Theme 2: Individual Differences and Common Stresses between Spouses Create Strain

This theme explores the differences and commonalities that are emphasised through the participants' roles as caregivers, which often lead to couple discord.

Differences in engaging and encouraging son's independence lead to couple discord. Whilst Anna, Catherine, and Brian all emphasised the importance of their sons being encouraged to work on their independent living skills, Anton, Charles, and Berta seemed to be more lenient in this regard. This difference leads to couple discord, as illustrated in the extract below, as Brian shared his frustration at his wife's lack of input of encouraging their son to go to the bank. Instead Brian went with his daughter to manage their son's finances:

> *mhux aħjar kieku ġie hu, u jara kif jiddaħħal il-PIN number u x'għandu jagħmel? "Darb'oħra ngħidulu…", hi tgħidlek. Imma mhux darb'oħra, għaliex mhux illum?! Qiegħed hemm id-dar…* why wait till tomorrow? (Brian:589-591)
>
> wouldn't it have been better if he came too, to see how to put in a PIN number, and what he has to do? "next time, we'll tell him", she says. But why, next time! Why not today?! He's just there, at home… why wait till tomorrow? (Brian:589-591)

Catherine and her husband Charles both noted that, despite having minimal disagreements, when they did occur, they were often due to such differences. Whilst Catherine would instruct her son to do some house chores, Charles would tell her not to annoy him because he did not like arguments. Catherine noted with frustration that she wanted to involve her son for his own good to gain independent skills for the future.

Similarly, Anton described the consequences of such disagreements on their relationship, and on their son too:

> the relationship starts getting, *ifhem* (well)… you say one thing, she says another, *iġifieri* (so)… and he… acts more… because then, there's not a confronted front, basically… (Anton:270-271)

Adult son's close attachment with wife fuels helplessness in husband. In their individual interviews, both Berta and Brian acknowledged that their son's close attachment to his mother caused difficulties and helplessness. Both participants recalled that, in the past, their son would refer to his father, Brian, as "*Dak ir-raġel t'ommi...*" "my mother's husband" (Brian:24) or *"ir-raġel tiegħek"* "your husband" (Berta:567) which puzzled them.

Berta acknowledged her husband's helplessness:

> *imma illitikajna, imħabba fih, vera! Għax jien jidhirli, irridu jagħti kasu, iktar... u... hu, kien jgħidli, "Ma tarahx li lejk l-iktar li hu? X'se nagħmel jien?"* (Berta:581)
>
> but we argued because of him, it's true! Because I would think that I'd want him to give him more attention… and he, he would say, "can't you see that he's closer to you? What can I do?" (Berta:581)

Refusing adult son's attendance to rehabilitation or respite services. Anna, Anton, Catherine and Berta remarked that their adult son would not benefit from attending a rehabilitation programme, either due to their sons' sensitivity, or due to the risk of their son engaging with other service users who may be experiencing more severe conditions.

Catherine recalled that, although she highly respected the service, her son was becoming highly anxious when attending. She noted that he would get influenced when seeing and being around other service users. For this reason, his community programme was terminated.

On the other hand, Brian noted his dismay towards his wife's refusal of their son's attendance to the residential programme, as illustrated below:

> *il-mara… kienet topponi li dana jagħmel eh… live-in il… jew [mental health rehabilitation service]… għax it-tifel ma jridx, naturalment huwx… imma jien naħseb li kieku zfurzajnih…li dana, jagħmel dan il-pass […] li jmur… joqgħod għar-rasu… ċertu żmien… kienet tkun 'beneficial' għalih ħafna… imma il-mara ma riditx… bl-ebda mod… u naturalment lanqas hu ma ried…* (Brian:912-918)

> my wife refused that our son attends the live-in, or… the [mental health rehabilitation service] …our son didn't want to go, obviously… but if only we had encouraged him to… make that step […] and go… live alone… for some time… it would have been really beneficial for him… but my wife definitely did not agree… and obviously, so did he… (Brian:912-918)

The mother's sensitivity vs the father's confrontation towards adult child leads to discord and criticism. Anna and Berta both recalled instances when their husband's confrontational exchanges with their sons caused discord within the couple. Anna warns her husband not to demean their son in front of others. She explained:

> but my husband sometimes, loses it a bit more than me. So, I tend to, totally disagree on that… and tell him, "no, that's no"… that's it, really… […] and then we end up arguing ay! … we end up arguing… (Anna:297-300)

Berta shared her frustration towards her husband's abruptness towards their son, which then leads her to reprimand him, by telling him that he should have "bit his tongue" (*mank gdimt ilsienek!* Berta:953). She recalled that Brian would question what he had done wrong. He often disagreed with her on the matter.

In the case of Catherine and Charles however, it seems that Charles was the one to be more cautious, and less confrontational, towards their adult son.

Being cautious and intuitive towards son's needs or escalations. Anton and Charles noted that they tended to be more intuitive than their spouses, when their son's behaviour was escalating. Charles shared an example of a routine, whereby they attend mass every morning. Upon seeing their son still in pyjamas when it's time to leave, his wife tends to impulsively rush him to hurry, which may then trigger their son's anxiety. Charles seemed to hesitate before he shared this, seemingly nervous that he was revealing an undesirable behaviour of his wife:

> *Kultant… Catherine… mhux… b'daqshekk… [hesitates]… imma kultant tgħidlu "ejja, qum minn hemm!"… jien le... ngħidlu, "illum ġej? għax ara ħa nilbes jien", speċi… iġifieri… imma mingħajr ma' ngħidlu iġifieri… "ilbes int ukoll"* (Charles:621-624)
>
> sometimes… Catherine… well…this isn't… [hesitates]… but sometimes she tells him, "come on, get on with it!"… I don't… I tell him, "are you coming? Because look, I'm getting dressed", so… like… without telling him… "get dressed too" (Charles:621-624)

Anton's intuition towards their son's escalating behaviour, when at a social event, leads him to encourage his wife and son to leave, to avoid potential crises. Anton often feels apprehensive at social gatherings. He says: "I can't really be at ease and enjoy it… *fhimt*... (you know…) without wanting… he's always at the back of your mind…" (Anton:975)

In the individual interview, Anna also noted her husband's intuition. Although she often disagreed on having to leave a party, she was aware that Anton would be right in saying so, and would comply to his suggestion.

Avoiding couple discord escalating by being patient and calm. Brian and Charles acknowledged their patience, which helped to avoid disagreements with their spouses from escalating. Brian reflected on the relationship with his wife being a good one, despite some arguments, as illustrated through this quote:

> *inħobbu lil xulxin u dan, imma, meta tgħid ċertu argumenti… miegħi, kif għidtlek… nieqaf… inħalliha tikkwieta, u… jekk aħna ġġielidna issa, sa siegħa, sagħtejn oħra, qisu ma ġara' xejn [chuckles]* (Brian:464-466)

> we love each other and all this… but, when she disagrees with me, as I said… I stop… and I let her calm down, and… if we are fighting now, in about an hour or two, it would be like nothing happened [chuckles] (Brian:464-466)

Theme 3: Caregiving as an Added Strain to the Couple Relationship and the Need for Attunement

This theme explores the individual participants' experiences of the impact of caregiving on the couple, exploring issues such as multiple stressors, and limited couple time and affection. This theme also explores the participants' accounts of normalising couple discord within a relationship, and the process of attuning to each other's perspectives.

Caregiving adds on existing challenges in the couple relationship. Some of the participants noted that, apart from their role as a caregiver, they were also dealing with other daily responsibilities, which could influence their stress burden.

The below illustration from Anna's interview describes the challenge of dealing with multiple responsibilities:

> I'm stretched out between my mother now, my son, work, ay… I mean… so you become more stretched out… more responsibilities… certain things I inherited, property… I have to deal with that too… […] which I end up… so that's more stress on me, my husband as well, more stressed… the older he grows… he started suffering from blood, high blood pressure… so… you know! The situation doesn't help, when you have a son like this… (Anna:218-225)

Charles noted that, as a couple, they were also tense due to their adult daughter's (healthy child) behaviour, due to experiencing stress at work, which then led her to be irritable with her parents.

Decline in affection due to multiple stressors. Anton reflected that their intimacy as a couple may have suffered due to his wife's multiple responsibilities, and not due to their son. He shares his thought:

> she has a lot of things on her mind as well *iġifieri* (so)… when her father passed away, a lot of things came on her… her mother, eh… *allura* (so) it's not just one thing… […] as we were saying before… she'll be tired, always tired, always with headaches [laughs] (Anton:653-658)

Catherine reflected that her intimate relationship with her husband was influenced negatively by her role as a caregiver, and also by her own depressive episode. As she describes it, "*qisu, tkun, m'intix fsiktek għal kollox… […] ċertu affarijiet ma jkollokx aptit.*" (Catherine:1028)

> "you wouldn't be completely yourself… […] you wouldn't feel like certain things…" (Catherine:1028)

Couple time and affection are limited due to son's presence, needs, or crises. Some of the participants noted that their son's presence has limited their time with their spouses, including moments of intimacy. Anton's description explicates his view on the matter:

> …everything we do, he's always with us *iġifieri* (so)… so, basically, there's always a third person in the middle… that is life now *iġifieri, fhimt?* (so, you know?) before… we were… two, we were, he's still our child, *imma*, (but) there was time for two, now it's always…. By three basically… (Anton:82-88)

Anna also noted that, due to their son's crises, sometimes family activities needed to be suspended. She also added that the time spent together as a couple is second priority, after her son's needs: "the first priority is my son's needs… and then, if we have time to be together alone, yes, if not, it won't be that way" (Anna:172-173).

Light-heartedly, Charles reflected that their son's scrupulous and conservatist nature may have impacted the intimacy and affection between himself and his wife.

> *forsi jien naf il-… eh minħabba fih iġifieri li kien kontinwament id-dar u hekk ma kienx forsi… insibu ħin, eh… Jien naf… forsi iktar konna… [chuckles]… ninnammraw iktar...* (Charles:477-479)
>
> maybe, I don't know… eh because of him, because he's always at home… we couldn't find time eh… I don't know… maybe we could have… [chuckles] flirt with each other more… (Charles:477-479)

Feeling guilty at leaving son at home for couple activities. Anna and Berta noted that they would feel guilty leaving their son at home while they go out, or go abroad with their husbands. Berta explained that she and her husband rarely go out alone as a couple. She noted that she would pity her son, knowing he is home alone, when he could be accompanying the couple else-where.

On the other hand, Anton remarked that they could not leave their son behind when going abroad, because he would not stay, and also due to the responsibility that he entailed:

> Even going abroad… we're not going abroad, we're not going alone… he's coming with us… We can't leave him behind… *mhux se ngħidlu* (I'm not going to tell him), "stay here"… he won't stay, *iġifieri* (so)… and we're not going to give that responsibility to other persons… to… keep him for… […] basically… if he can't do it… we don't do it, that's it… it's always him first… then… we come second, basically…. (Anton:114-119)

The avoidance of couple discord due to son's anxiety. Due to their son's anxious state, both Charles and Catherine, in their separate interviews, noted that they often avoided any disagreements in the presence of their son. Catherine explained:

> *jekk jarana nargumentaw f'xi ħaġa, jinkwieta u jinkwieta… anki ħabba fih aħna, qas nistgħu nagħmlu! [chuckles] qas ikollna niġġieldu, ħabba fih… [chuckles] għax jinkwieta ħafna, jibda jibża'…*

> Interviewer: *iġifieri ġieli ħassejt li bqajt lura milli tgħid xi ħaġa lir-raġel?*
>
> Catherine: *eħe! Ħabba fih ukoll! Għax ngħid li hu se jinkwieta, u jinkwieta vera!* (Catherine:1302-1308)

> if he sees us arguing because of something, he worries and worries… so even because of him, we can't do it! [chuckles] we can't argue, because of him… [chuckles] because he worries a lot, he gets anxious…
>
> Interviewer: so have you ever restrained yourself from telling something to your husband?
>
> Catherine: yes! Because of him too! Because I'd think that he would worry, and he really would! (Catherine:1302-1308)

Charles also added that he was aware of his mannerisms towards wife after an argument took place, in order to show his adult son David that their relationship was fine, despite the quarrel.

Normalising couple discord. Most of the participants remarked that despite having arguments with their spouses, disagreements occurring within a couple were normal. Berta remarked that, although their son's condition had itself caused many disagreements with her husband, she noted that some couple dissonance would have still taken place regardless:

> *ikun hemm ċertu ċirkostanzi, tilletika naqra… għax, erm… u qas kieku m'għandix din il-biċċa tax-xogħol, għax ukoll, bħal ma'diġa għidna, tilletika, ħin jew ieħor… xi ħaġa, xi ħaġa ħa tgħid…* (Berta:1041-1043)
>
> Berta: "there are certain circumstances, when you quarrel a little… because, erm… and even if we didn't have this situation, because, as well, like we said before, you quarrel, at one point or another… there's always something to say… (Berta:1041-1043)

The benefits of attuning to each other's perspectives. Two of the participants, Anna and Charles, remarked that being well-attuned to their spouse's perspectives or intuitions lessens the stress between the couple. Anna noted that, although she and her husband had many disagreements due to their different perceptions as caregivers, they are becoming more attuned to each other now:

> we're sort of… reaching more or less the same wavelength you know […] on the way, it's calmer… on the way… we have accepted it, obviously, and we're trying to work around our son's behaviour to the best of all the three of us… (Anna:311-324)

Charles recalled how being bonded as a couple helped them get through their moments of crises together:

> *dawn il-mumenti ta' kriżi li kellna jiġifieri Allaħares ma kinitx dil-bond, haw' speċi, li servitna biex naħdmu għal ġid tiegħu…* (Charles:96)

> in these moments of crises that we had, God forbid we did not have this bond, here, like, because it helped us work together for his own good… (Charles:96)

Theme 4: Experiencing Mental Health Problems in their Roles as Caregivers

In this theme, the female participants' experiences of mental health problems are explored. Whilst Anna and Catherine experienced a depressive episode related to their caregiving role, Berta acknowledged her traits of OCD.

The impact of experiencing a depressive episode due to the caregiving role. In the following excerpt, Anna discusses the process of experiencing a depressive episode as a result of her caregiving role and other stressors occurring in her life:

> the summer before… I literally got a breakdown! Which I never thought I would in my life… […] it was beyond me… erm… okay, obviously, it was a result of all the tension and stress that I had, plus other things which then were the cherry on the cake… (Anna: 422-429)

As mentioned earlier, Catherine was very shocked when her son terminated his employment. This led to her experiencing a depression. She noted that she got to a stage where she would not know what or how to cook, or how to wash the clothes. She noted she sometimes felt guilty when her daughter returned home from school, eager to share her day's stories, but found her in bed.

Acknowledging husband's reaction to their wife's depressive episode. Both participants noted how their husbands experienced their depressive episode. Catherine noted that her husband was definitely confused in seeing his wife depressed. She explained:

> *ma kienx kuntent, żgur, żgur, żgur, kien imħawwad ħafna… għax kien jiġi, jsibni fis-sodda… u hekk kont ngħid, f'qalbi, "mela barra l-problema tat-tifel, inqalet il-problema tiegħi" […] kont narah li huwa… kkonfondut… u "x'nagħmel?" qas jaf x'ħa jaqbad jagħmel… "inċempel lit-tabib, inċempel lil ħutek, jew xi ħaġa?"* (Catherine:861-867)

> he wasn't happy, for sure, for sure, for sure, he was very confused… because he used to come home and find me in bed… and I used to tell myself, "apart from our son's problem, my problem too showed up!" […] I used to see him… confused… and "what do I do?" he didn't know what to do… "do I call the doctor, do I call your siblings, or something?" (Catherine:861-867)

Anna was apprehensive regarding her husband's reaction of her depression, because to him, she was the optimistic spouse. She worried her distress would affect him. Anna recalled how her husband coped with her depressive episode: "then he realized, my husband… you know, that… I'm not the invincible Wonder Woman which I thought I was and he probably thought I was…" (Anna:433).

Acknowledging one's own traits of OCD, and questioning responsibility on son's condition. Berta's experience of having similar compulsions to her son led her to question whether she was to blame for her son's condition:

> *għax għidtlek, hu jaħsel idejh, jien naħsilhom, vera, għandi qiegħda dik… naf… allura, nibda ngħid, "ħtija tiegħi ġiet is-sitwazzjoni?" Ma nafx… tħoss sens ta' ħtija qisek naqra… kulħadd jgħidli, "le, insiha dik…" imma inti tħossok li… "tgħid tajtu jien, il-protezzjoni żejda?... li tajtu…"* (Berta:98-101)

> I told you, he washes his hands, I wash them, true, it's in me too, that… I know… so, I say, "is this situation my fault?" I don't know… you kind of feel a sense of guilt… everyone tells you, "no, forget that…" but you feel… "did I overprotect him?" did I give him… (Berta:98-101)

Accumulated stress due to dealing with other life responsibilities, other than son's condition. Most of the participants mentioned other life responsibilities which accumulated further stress. Catherine recalled that at the time of her depressive episode, her brother had a terminal cancer and died at the age of 42. She experienced anxiety and avoided visiting him because she had intrusive thoughts of also being diagnosed with cancer herself. Catherine also acknowledged her husband's multiple stressors in dealing with his son's and wife's mental health, and his employment:

> *għax kien żmien diffiċli… u bil-problema tiegħi, il-problema ta' David… ir-raġel hu… mhux xi ħaga… bil-fors hu… u jrid imur għax-xogħol hu, anki x-xogħol hu, fih it-tbatija tiegħu, kien jiġi, imkisser, mhux imbilli skrivan… kont nifhmu jiena hu…* (Catherine:889-891)
>
> it was a difficult time… and with my problem, the problem of David… my husband, ay… it's not something… inevitably… and he had to go work, ay, even work, it's strenuous, he would come back, feeling exhausted, even though he's a clerk, but still… I sympathised with him, you know… (Catherine:889-891)

Theme 5: The Husbands' Experience of Wives' Mental Health Problem

This theme presents the experiences of the male participants, in living through their wives' mental health problems.

Acknowledging wife's experience of mental health problems. Brian and Charles empathised with their wife's difficulties. Charles added that in upholding his duty as a husband and a father, he supported his wife as much as he could, including learning new skills, such as washing the floors or grocery shopping. This is illustrated in this excerpt:

> *jien għalija kienet xi ħaga… jiġifieri… normali… normali… mhux, is-sitwazzjoni ma kinitx normali… imma jiena, dħalt, jiġifieri, għamilt commitment, jiġifieri, familja, jiġifieri r-raġel u l-missier jiġifieri li jkun hemm bżonn inmidd idejja jiġifieri kont immur…* (Charles:567-569)

> Charles: "to me the situation was… what I mean... normal… normal… no, it wasn't a normal situation… but, I went in, I committed myself, to my family, I mean, as a husband and a father, so, I did what needed to be done… I would go… (Charles:567-569)

On the other hand, Brian understood that his wife might experience anxiety due to her compulsions, however he struggled with her behaviours, and throughout the interview, often expressed his frustrations on the matter, particularly when his wife demanded that he washes his hands frequently. He often gave in to her requests to avoid disputes.

Theme 6: Impact of Adult Son's Illness on Siblings

All the participants stated that, some way or another, their adult son's siblings were impacted due to their parents' roles as caregivers.

Stress and frustration experienced due to brother's symptoms. Most participants noted that due to their adult son's symptoms, their 'healthy children' experienced stressful moments at home. The following excerpt portrays Anna's thoughts about her daughter's experience and subsequent move out of the country:

> she used to feel a lot of stress, as well, with the situation… and she's abroad… partly because she always wanted to travel… partly as well… because… she's two years younger, and used to have a lot of erm…. Commotion in the house… and she needed her space as well I guess, so… (Anna:225-228)

Catherine noted that her adult son's poor communication caused her daughter sorrow. She pondered whether the lack of communication between her two adult children, led her daughter to feel as though she did not have a brother. Catherine was sure that her son's condition impacted her daughter:

> *allura, impatt negattiv… kellu fuqha, żgur, żgur, żgur, u għada ġġorru s'issa… għada, iġġorru s'issa…* (Catherine:1249)
>
> so, it must have had a negative impact on her, for sure, for sure, for sure, and she's still burdened till now… she's still… burdened till now… (Catherine:1249)

Acknowledging that siblings received less attention from parents. Some participants recognized that their caregiving responsibilities led them to diminish their attention towards their other children. Anton noted that their time was consumed by their adult son's needs when his condition was in the acute stage. Catherine's experience was similar. Her account describes her thoughts on the matter:

> *kont inħossha li hi… naqra hekk, tinġibed xi ftit… dak iż-żmien kienet għada id-dar, qed tistudja wkoll… erm… li, hi… peress li ġara hekk, qed tarana lilna t-tnejn, qed natuh ħafna attenzjoni… imma kellu bżonnha… kienet tifhimha… kienet intelliġenti, jiġifieri… kienet tifhimha* (Catherine:1229-1231)
>
> I would notice that she… feels a little, she would withdraw… at that time she was still living at home, she was studying too… erm… that she… because this happened, she would see us both giving him a lot of attention… but he needed it… she used to understand it… she was intelligent, so, she understood (Catherine:1229-1231)

Siblings as future caregivers? Most participants discussed their worries concerning their son's future care, particularly their own and their other children's ambivalence towards being the possible caregivers for their brother. Charles recalled a short conversation with his daughter, who told him she was concerned about her brother's future:

> *u qaltli "Din ta' David problema ta!" qaltli "Veru ma nafx x'jiġri meta tiġu neqsin intom* (Charles:817)
>
> she told me, "This thing of David is a problem", she said, "I don't know what's going to happen when you both pass away" (Charles:817)

Berta's concern lied at the prospect of her other children being responsible for her adult son as caregivers. Although her children reassured her that they would take care of their brother, Berta wished her son could be independent and take care of himself. She noted that she feels troubled to have to leave her adult son as an added responsibility for her other children.

Mother split into two to provide attention to all her children. Most of the female participants were aware that they wished to dedicate time and attention to all their children. Anna shared an instance when her adult son was disappointed when Anna and her daughter went abroad, after he had been discharged from a psychiatric admission. Anna recalls the experience:

> I told, I tell him, "I have two children, Nathaniel!" I knew you were in safe hands, and" erm…. […] I mean… I had responsibilities for my daughter too… (Anna:534-538)

In Catherine's experience, she had been told by her daughter that she had been overprotecting her son. She was aware not to overlook her daughter's needs:

> *jien qatt ma ħallejtha, erm, tara li qed nitraskuraha, jekk tgħidli, "ejja noħorġu, nimxu ftit", ngħidilha "imxi noħorġu nimxu ftit"* (Catherine:1237)
>
> I never let her, erm, see me overlook her, if she tells me, "let's go out for a walk", I tell her, "come on, let's go for a walk" (Catherine:1237)

Theme 7: Accepting the Situation and Moving Forward

This final theme explored the participants' perspectives of acceptance and prospects of the future, whilst noting the benefits of receiving support. All the participants recalled the significance of having a secure relationship with their spouses whilst facing the challenges of life.

Accepting son's condition and limited prospects of recovery. Most of the participants noted that despite being a struggle, one must come to terms with accepting their son's condition and abilities. The following illustrates Brian's experience:

> *il-kundizzjoni tiegħu hi li hi… u trid taċċcetta… dak li għandu... tipprova tgħinu meta tista'… jekk hu jikkopera wkoll hu… għax inutli tgħidlu, "għamel hekk, u għamel hekk" ma jagħtix kas…* (Brian:706-708)

> his condition is what it is… and you have to accept… what he has… you try and help him when you can… and hopefully he cooperates too… because it's useless telling him, "do this, and do that" he doesn't give any notice… (Brian:706-708)

Anton also shares a similar acceptance, whilst reflecting on the possibility that their son's illness might "[go] away as it came, *minjaf!* (who knows!") (Anton:134-135). He noted that despite there being chances that he might recover, the probabilities seemed low.

A united couple despite the odds. Most participants noted that despite their roles as caregivers, they have remained united as a couple. Charles reflected that the experience helped them to bond further together as a couple.

> *din il-problema iktar serviet biex tibbondjana, 'you know'… erm jiġifieri hemm… mhux il-pożittiv imma, imma… hu, huwa pożittiv ukoll li ir-relazzjoni tikber u ma titkissirx… għax hemm relazzjonijiet meta jinqala' l-għawġ… titkisser… jiġifieri…* (Charles: 98-100)

> Charles: this difficulty we have helped us bond even more, you know… erm so…. There's… not positive, but, but… well it's still positive that our relationship grew and didn't break down… because there are some relationships which break up when passing through difficulties, so… (Charles:98-100)

Similarly, Anton also shared his thoughts on the couple relationship, which, despite the hardships, endured:

> we're still here, we didn't fight and move… our separate ways… because we had a child… *ifhem* (you know)… so some people do… okay sometimes it does get tiring, *jiġifieri, ifhem,* (you know, so) it does get to you, but… (Anton: 151-153)

The benefits of having a solid foundation as a couple before the illness strikes. Catherine and Charles emphasised that having a secure and safe relationship before their son's condition emerged, was a great source of support. Catherine's illustration describes this theme further:

> *lanqas qabel jiġifieri… għalhekk ukoll, dal-fatt, meta ġiet din il-problema kbira, ma kellniex 'clashes', qed tifhem? Għax kellna diġa bażi, qisa tajba, ħa ngħidlek… […] konna qisna, lesti għal kollox* (Catherine:786-791)
>
> Catherine: not even before, so… that's why, when this happened, when this big problem occurred, we didn't have any clashes, you know? Because we had a foundation, a good one, let's say… […] we were ready to face it all (Catherine:786-791)

Gaining new perspectives and positive outcomes through the caregiving experience. All the female participants, and Charles, noted that the experience of being a caregiver also provided them with positive outcomes. On the other hand, when asked whether their roles as caregivers strengthen them, Anton and Brian struggled to find any.

In Berta's case, she become more empathic and understanding towards the needs of others, despite people experiencing different problems: *tibda tifhmu naqra iktar il-bniedem… […] tifhem naqra, tgħid, tgħid, "minn xiex ikun għaddej il-bniedem"* (Berta:1016)

> you start understanding people more… […] you become understanding, you say you wonder, "what that person is going through"

Anna reflected that as a couple they also gained strengths in handling certain problems:

> we can… deal with certain problems, which maybe, for other people, would be, big problems… […] if you know, what I mean… for us, certain problems are trivial […] that certain people seem to have a mountain (Anna:491-495)

The benefits of professional and familial support. All the participants mentioned that having familial and professional support, such as having a supportive psychiatrist, or attending talks, was very beneficial for them as individuals and as a couple. Berta noted:

> *tolqtok ħaga zgħira… u li jirnexxielek tagħmilha u jirnexxielha taħdem… […] u forsi jekk ngħid xi ħaġa jien, mill-esperjenza ta' ieħor… għax m'hemmx formula li taħdem… dritta, għal kulħadd… kulħadd isib… in-niċċa tiegħu…* (Berta:1193-1199)
>
> something small strikes you… and you manage to do it, and it works… […] and maybe, if I say something, from other people's experience… because there isn't an exact formula… for everybody… everyone tries… to find their own approach… (Berta:1193-1199)

Spiritual dimension as a channel of support, hope and gratefulness. Anna, Berta, Catherine, and Charles referred to God and prayer as a source of support and hope for the future. Anna hoped that her son would recover, saying: "I wish it changes, but it's up to the Above to decide…" (Anna:515)

Both Catherine and Charles remarked that spirituality and prayer were a significant form of comfort for them as individuals and as a couple, since they felt supported by God's presence. Catherine was grateful to God, because despite their difficulties, their marriage was a success:

> *le, le, bħala familja, għal grazzja t'Alla, mill-bidu nett jien ngħid, "iż-żwieġ tiegħi irnexxa, 'hundred percent', minkejja d-diffikultajiet…* (Catherine:775-776)
>
> Catherine: no, no, as a family, thank God, from the very beginning, I say, "our marriage was a success, one hundred percent, despite the difficulties… (Catherine775-776)

Following this section, the results emerging from the couple interviews will be now presented.

Table 3

Superordinate and Subordinate Themes Emerging from the Conjoint Interviews

Superordinate Themes	**Subordinate Themes**
1. Disagreements and Dilemmas due to Caregiving Role	1. Normalising couple discord and daily conflicting opinions [All couples] 2. Struggling to find cause and acceptance of son's illness [All couple] 3. Differences on managing son's independence causes conflict [Couple A, B]
2. The Adversities Experienced as a Couple	1. Acknowledging the difficulties endured as a couple [Couple A, C] 2. Limited couple spontaneity due to son's needs [Couple A, B] 3. Coping with distasteful or conflicting comments from professionals [Couple A, C] 4. The process of registering their sons' disability considered as impacting negatively on their identity [Couple A, B]
3. The United Couple: Living Through the Process Together	1. Acknowledging that commitment and love for the family binds the couple together [All couples] 2. Appreciating the little time together as a couple [Couple A, C] 3. Acknowledging the difficulties of other caregivers with even greater care burden [All couples] 4. Appreciating the benefits of receiving support [All couples]
4 Worries and Concerns for the Future	1. Enrolling their son in a mental health rehabilitation programme is of concern [All, except Brian] 2. Thinking ahead and planning for son's future [All couples] 3. Uncertainties about son's future caregivers [All couples] 4. Coming to terms with their son's loss of a family of his own [Couple B, C]

Note: The identified couples in the square brackets correspond to the couples whose accounts captured the corresponding subtheme.

Theme 1: Disagreements and Dilemmas due to Caregiving Role

All the couples recalled that the role of caregivers caused dilemmas, as they struggled to accept their son's illness, and manage his symptoms and independent skills.

Normalising couple discord and daily conflicting opinions. All the couples noted that couple disagreements were normal to occur and experienced by most couples. Berta and Brian amusingly agreed that since Brian's retirement, they have been quarrelling more, with Berta describing the couple as *"qisna kelb u qattus!"* [chuckles] (we're like "cat-and-dog!") (Couple B:189).

Anna and Anton noted that they had always been opposites and never agreed on anything.

Struggling to find cause and acceptance of son's illness. As the couples learnt about their sons' conditions, they struggled to understand its cause and to accept it. Catherine and Charles' excerpt illustrates the initial thoughts they experienced as a couple when they learnt of their son's condition:

> Charles: *"infissduh iżżejjed?" jew…*
>
> Catherine: *ehe tibda' tgħid, "x'ġara'?" ehe, dik ġieli għidniha! "X'ġara' ħazin? X'għamilna ħażin aħna?"*
>
> Charles: *ehe dak il-perjodu…*
>
> Catherine: *"X'għamilna ħażin?"* … *"X'għamilna ħażin?"* (Couple C:737-771)

> Charles: "are we overprotecting him too much?" or…
>
> Catherine: yes, you start thinking, "what happened?", yes, we've said this! "what went wrong? What did we do wrong?"
>
> Charles: yes, during that time…
>
> Catherine: "what did we do wrong?" … "what did we do wrong?" (Couple C:737-771)

Differences in managing son's independence causes conflict. Two of the couples disagreed as they discussed their views on how to manage their sons' behaviour and independence. Brian and Berta had several discussions during the dyad interview due to their differences towards their son's independence. While Brian insisted on their son being more engaged, Berta noted that their son needed support while he learnt a certain skill, and that he would benefit from examples. The following conversation illustrates this subtheme:

> Berta: *tgħinu, mela, tgħinu! Biex turih li… għax ma jafx, ma jafx!*
> Brian: *tgħinu mod, u tagħmel l-affarijiet għalih, mod ieħor!*
> Berta: *imma int qed tgħidli… "tgħid lil ħaddieħor biex jgħinu!"*
> Brian: *imma mhux tgħinu biss trid, tgħinu biex jagħmel l-affarijiet għal-rasu!*
> Berta: *tgħinu biex jitgħallem jagħmilhom!*
> Brian: *imma, dana, inti, ma taccettahx!*
> Berta: *ajma ma! Mulej! [breathes out]* (Couple B:1044-1050)
>
> Berta: yes, we should help him, of course! To show him, because he doesn't know!
> Brian: helping him is one thing, but doing things for him is another!
> Berta: but you said, "you tell others to help him!"
> Brian: but you shouldn't just help him, you have to help him do things himself!
> Berta: you help him learn how to do them!
> Brian: but you don't accept this!
> Berta: oh, God! [breathes out] (Couple B:1044-1050)

Anna and Anton had similar disagreements; whilst Anna insisted that their son Nathaniel gains independence by trying different skills, Anton disliked the fact that he was not doing them well.

Theme 2: The Adversities Experienced as a Couple

All the couples recognised several difficulties and constraints occurring due to their caregiving role. Two of the couples also experienced adverse situations due to the mental health professionals' input.

Acknowledging the difficulties endured as a couple. All the couples recognized that their experience as caregivers was a tough experience. As Catherine and Charles processed their reflections, they noted that, despite their son's condition not causing a radical change in the couple or in their lives, they acknowledged that it did leave its impact, especially as they struggled to accept it. Charles's remark encapsulates the couple's reflective process:

> *hekk, u tgħid, speci ... "ara x'kellu jiġrilna" 'in a way' hekk...* (Couple C:695)
>
> well… you say, "look what had to happen to us" in a way…" (Couple C:695)

Similarly, Anna and Anton recalled several examples of tense moments occurring as a result of their caregiving role. As they discussed this, Anna recalled that there were instances when Anna and Anton told each other that they could not take it anymore. However, as presented further down, their commitment and love for the family helped them get through their hardships.

Limited couple spontaneity due to son's needs. Most of the couples noted that, unlike other people their age, they were restricted in engaging in certain activities, like booking a spontaneous holiday, due to their son being dependent on them. This is illustrated through Brian and Berta's exchange:

> Brian: *forsi…. koppji oħra... ikunu waħedhom… iħobbu jsiefru, 'l haw' u 'l hemm… u aħna le… jew għalinqas, inti toqgħod tgħidli, "hemmek ma morniex" "hemmek…"*
>
> Berta: *[chuckles] għax ngħidlu, "ara, hemmek!"*
>
> Brian: *[chuckles] toqgħod tara r-riklami! Tgħidli, "inti qatt ma toħodni mkien!"* (Couple B:1372-1375)

> Brian: maybe… other couples… are alone… so they can go abroad, here and there… and we can't… or if anything, she tells me, "we've never been there!"
>
> Berta: [chuckles] because I tell him, "look at that place!"
>
> Brian: [chuckles] she'd be watching adverts! And she tells me, "you never take me anywhere!" (Couple B:1372-1375)

Anna and Anton noted similar limitations. Anton added that their spontaneity was also restricted due to having their business, which they could not hand over to their children to run, whilst they were on holiday.

Coping with distasteful or conflicting comments from professionals. Two of the couples recalled instances when mental health professionals either caused conflict within the couple due to their suggestions, or made offensive comments on their son.

Anna and Anton's experience with a family therapist caused discord between the couple due to the professional's advice to ignore their son's smoking. In another instance, upon visiting a mental health professional, the couple were put off by unpleasant and blunt remarks on their son's behaviour, as Anton described. They were told that, "he was one of the worst characters that you can ever have […] and he would be violent and would be… always stubborn…". Anna added: "and up to mischief, and "I pity you as parents!" [chuckles] […] Jesus!" (Couple A:319-324).

Catherine and Charles recalled an upsetting experience when their son had gone to a medical board due to social security reasons. The couple noted that the psychiatrist's comment was upsetting, particularly because they had been striving to help their son get better:

> Charles: *kien hemm psikjatra… haw'… qalilna, qalilna, "da' da' għażżien, da'… da' għazz għandu fuqu…"*
>
> Catherine: *eh, qalilna "dan għadu marbut maż-żokkra t'ommu" xi ħaġa… "mal-umbilical cord", qal, "dan għadu", u vera, eqq, weġġħatni lili!* (Couple C:757-759)

> Charles: there was this psychiatrist… he told us… "this guy… he's lazy! He's just lazy…"
>
> Catherine: eh, he told us, "he is still stuck with his mother's belly button", something like that… "with the umbilical cord", he said, "he is still", and it really, eh, it offended me!" (Couple C:757-759)

The process of registering their sons' disability considered as impacting negatively on their identity. The couples struggled to accept that their son had to be given a 'label' for his mental illness, and for this reason, Anna and Anton initially refused to apply for their son's social benefits. They were encouraged to do so by a psychiatrist.

Similarly, Berta refused to accept that their son had to register for a 'Disability Card'. However, Brian struggled to understand her reasoning and urged her to understand its benefits. Brian also remarked that Berta seemed to be influenced by the meaning of 'disability' as referring to physical conditions. The following illustrates this process:

> Brian: *morna Ħal-Far darba, biex... qalulna, "trid tirreġistrah bħala 'disabled'"*
>
> Berta: *għidtlu, "imxi, ma rrid nirreġistra xejn"*
>
> Brian: *ma riditx... mill-ewwel*
>
> […]
>
> Brian: *għax ma riditx taċċettaha din, li dana għandu, li, għandu diżabilita'* (Couple B:802-808)

> Brian: we went to Hal-Far once, to… because they told us do you want to register him as "disabled"
>
> Berta: I told him, "let's go, I don't want to register him"
>
> Brian: She didn't want… instantly
>
> […]
>
> Brian: because she doesn't want to accept… that he has, he has a disability (Couple B:802-808)

When their son was recommended to attend a local service, which catered for physical and learning disabilities, Berta did not agree because she felt their son did not have the same disability as the other service-users.

Theme 3: The United Couple: Living Through the Process Together

This theme explores the couples' recognition and appreciation towards their spouses and families, which helped them live through the process together.

Acknowledging that commitment and love for the family binds the couple together. All the couples recognised their bond as a couple and love for their family helped them face and manage their sons' situation. When asked what helped Anna and Anton get through moments when they wanted to give up, this is what they said:

> Anna: with me, it's the love of my family aye, and, and… your responsibility and commitment…
>
> Anton: basically you're committed to the marriage… and you just don't give up… […] you do what you can, the best you can… and you continue going, move forward… (Couple A:787-789)

Investing in the little time they have as a couple. Most of the couples recalled their attempt at spending some time alone, without their son. Anna and Anton noted that, although they got used to having their son around, they appreciated their time alone as a couple while their son is out for a coffee or before he wakes up.

Catherine and Charles were encouraged by their psychiatrist to spend some time alone. They noted that they try attending cultural walks from time to time, although Charles noted that their son is always at the back of their mind. The following illustrates this theme:

> Charles: *jiġifieri konna… konna nippruvaw insibu biex da'… dejjem 'at the back of your mind' jiġifieri… imma… konna nippruvaw… għal ġid tagħna jiġifieri*
>
> Catherine: *tirrilekksja b'xi ħaġa li tħobb tagħmel flimkien!* (Couple C:830-832)

> Charles: so we tried finding some time to… he was always at the back of our mind though, but we try, for our own good
>
> Catherine: you relax with something you like doing together! (Couple C:830-832)

On the other hand, when asked about their activities as a couple, Berta replied with an astonished expression that a family therapist had asked them the same question, and had seemed to encourage the couple to do activities together. The following excerpt illustrates this:

> Berta: *ommi, kulħadd hekk! Anki t-terapista tal-familja kien qalli!*
>
> Brian: *ma tantx [nagħmlu attivitatijiet bħala koppja]... għax iżjed tkun trid, mat-tfal...*
>
> Berta: *hekk nieħu pjaċir! Inkunu familja! Taf kemm nieħu pjaċir! [...] Għax hekk trabbejt, dak l-ambjent!* (Couple B:1079-1082)

> Berta: oh my, everyone asks me this! Even our family therapist had told me!
>
> Brian: we don't really [do activities as a couple]… because she prefers having the children come too…
>
> Berta: that's what I enjoy! When we're a family! I really enjoy it! […] that's how I was raised, in that environment! (Couple B:1079-1082)

Acknowledging the difficulties of other caregivers with even greater care burden. Whilst talking about the difficulties they endured, all the couples empathised with the suffering of other caregivers, whose children have greater burdens, such as physical disabilities. Anna and Anton added that certain caregivers might also incur financial struggles due to resources needed for their child.

Catherine and Charles reflected on other people's difficulties due to physical disability, compared to their own experience. Their conversation below illustrates this theme further:

> Catherine: *għax meta, imbagħad, ara, meta nibda nara hekk, ngħid, "ara naqra!" ikun haw' wieħed l-knisja, jiġi l-quddies magħna, nibda narah hekk, miskin, hekk, ngħid, "ara jiena, da' m'għandu xejn qiegħed ħdejja, ħdej' dak, ara xi sforz qed tagħmel il-mama' tiegħu"… u nipprova… eqq, eqq, inġaħġaħha hekk…*
>
> Charles: *le, għax imbagħad, meta tara s-sitwazzjoni tal-oħrajn… tibda' tgħid…*
>
> Catherine: *tirrealizza…*
>
> Charles: *tirrealizza….*
>
> Catherine: *kemm qed nagħmel għaġeb… mix-xej'!* (Couple C:898-905)

> Catherine: when I see certain things, then I say, "look at that!" there's a man who comes to our church, and when I see him, poor man, I say, "look at me, my son is beside me and has nothing compared to that man… his mother must work so hard to help him", and I try, eh, to console myself like that…
>
> Charles: because when you see other people's situations, you start saying…
>
> Catherine: you realise…
>
> Charles: you realise…
>
> Catherine: what a big fuss I'm making… out of nothing! (Couple C:898-905)

Appreciating the benefits of receiving support. All the couples noted the benefits of support for their son's improvement in health and independence, as well as for their own benefit as caregivers. Anna and Anton noted the significance of a teacher's support for their son when he was still at secondary school. It was thanks to her that she identified that their son had certain difficulties and suggested further assessment. Anna and Anton also appreciated their friends' understanding and support. To encourage the couple to attend an event, Nathaniel was always invited too, even when other couples' children were not.

Although Berta was initially hesitant of acquiring professional support for their son, the couple acknowledged that it was this support that helped their son's health improve. Berta and Brian's observations are illustrated below:

> Brian: *ħeqq, issa aħna kieku lil Ian, ma għamilniex daw' l-affarijiet... ħadnih 'l haw', u ħadnih 'l hemm…*

Berta: *le, għamel avvanz kbir! Għamel avvanz kbir! Il-verita', il-verita'!*

Brian: *x'kundizzjoni kien ikun?* (Couple B:886-889)

Brian: had we not done this for Ian, taken him here and there…

Berta: no, it's true, he improved a lot! He improved a lot! It's the truth, it's the truth!

Brian: what condition would he be in? (Couple B:886-889)

Catherine and Charles noted similar benefits of receiving support from professionals, whilst also appreciating the small but significant improvements observed in their son. It was thanks to a professional's suggestion that encouraged the couple to plan for their son's future financial savings.

Theme 4: Worries and Concerns for the Future

This last superordinate theme encompasses the participants' concerns about their sons' future wellbeing and care, whilst also coming to terms with their sons' limitations.

Enrolling their son in a mental health rehabilitation programme is of concern. All the couples, except Brian, noted that, for different reasons, their son would not benefit from enrolling in a residential mental health rehabilitation programme. Anna and Anton both agreed on not sending their adult son to such a service because they were concerned that he would befriend other individuals who could influence their son, Nathaniel, due to their own difficulties. The following excerpt illustrates their reasoning:

Anton: at the end, *minn hu zopp, ma jistax jagħmilha… fhimt x'qed ngħidlek?*

(the blind can't lead… you know what I'm saying?)

Anna: he needs someone to guide him, not someone...

Anton: somebody better than him… to walk forward with…

Anna: to guide him ay…

[…]

> Anna: this is like, this is like… you have a blind person, and you expect another blind person to lead him… (Couple A:1225-1231/1233)

Catherine and Charles recalled that, although they were grateful for the service's support which encouraged their son to practise certain independent living skills such as grocery shopping, the environment caused too much anxiety and tension for their son. This resulted in a joint decision for him to stop attending.

In Berta and Brian's case, although their son had attended the service during its day programme, Berta agreed with their son, Ian, not to enrol him in the residential programme. Brian disagreed with this, as he felt that their son could have gained independent skills from residing within the rehabilitation community.

Thinking ahead and planning for son's future. All the couples remarked that they were aware of their sons' future needs. Anna and Anton, and Catherine and Charles, both commented that they were putting money aside for their son's future financial needs. The following illustrates Charles' and Catherine's conversation on the matter:

> Charles: *[…] irridu naraw li jkollu bażi finanzjarja, għax forsi… jidħol f' 'home' jew hekk*
>
> Catherine: *u hu m'għandux idea ta' flus, lanqas isaqsi, "imma jien kemm għandi flus?" jew, xejn xejn…*
>
> Charles: *imma anke… kieku kellu idea, xorta… hu mhux kundizzjoni li jakkumula somma li jista' dan… allura, irridu naħsbu għaliha wkoll… per eżempju, l-'allowance' ma mmisshielux…*
>
> Catherine: *le, dik tiegħu, daqshekk* (Couple C:1117-1124)

> Charles: […] we have to plan for him to be financially stable, maybe he'll enrol in a residential care home or something similar
>
> Catherine: and he doesn't understand the value of money, he never asks, "how much money do I have?" or, never…

> Charles: and even if he did have an idea, he is not in the condition to accumulate enough money to… so, we have to plan ahead for him, too, for example, I don't touch his allowance
>
> Catherine: no, that's his, that's it (Couple C:1117-1124)

Although Berta and Brian noted that they were aware that their children would not force their son Ian out of their house, they wanted to be sure that their accommodation would remain Ian's to reside in, when they pass away.

Uncertainties about son's future caregivers. All the couples discussed their worries about their sons' future due to the lack of independence. They were all concerned that, although their other children could be their sons' future caregivers, they did not want to burden them with such a responsibility.

When discussing Nathaniel's finances, Anna suggested that their daughter could manage their son's assets. However, Anton felt that it would not be fair on her to have such a responsibility. The following illustrates the couples' concern:

> Anton: You can't think… what she's– she has her own life
>
> Anna: *hekk hu* (that's true)
>
> Anton: and she does whatever she wants
>
> Anna: aha
>
> Anton: *imbagħad* (and then) if she wants to help, it's good for her, at the end, and good for Nathaniel but…
>
> Anna: *hekk hu*… (that's it…)
>
> Anton: You can't tie her down… tell her, "he's your responsibility" either
>
> Anna: of course not (Couple A:1073-1080)

Coming to terms with their son's loss of a family of his own. Two of the couples reflected that their son's condition limited him from getting married and having children of his own. Charles and Catherine remarked on certain expectations they had on their son's future, which were now long gone. Catherine's comment below captures these feelings:

> Catherine: *... li m'għandniex, m'għandniex neputijiet! [chuckles] għax nara ħuti inkwetati bin-neputijiet... u hekk... dik forsi tħossha, għax ngħid, "ara, kieku David kiber, iżżewweġ, għandu t-tfal"... allura dik tħossha, mingħajr ma trid, hux vera...* (Couple C:923-925)
>
> Catherine: … the fact that we don't have any grandchildren! [chuckles] because I see my siblings worried with their grandchildren, and so on… and I am, sort of affected by it, because I say, "David could have gotten married, had children"… so it affects you, without wanting it to, you know… (Couple C:923-925)

Similarly, Berta and Brian noted that, although they do not mind having their son residing with them, perhaps, if he had not had this condition, he could have met a partner and be in a stable relationship.

Conclusion

This chapter presented the superordinate and subordinate themes emerging from the individual and dyad interviews. The results capture the individual burden of being a caregiver, and indicated some gender differences. The participants' accounts reflected that the role of caregiving could cause a strain on the couple relationship and seemed to emphasise the couples' differences, which could lead to couple discord. The results indicated that the participants' similarities, agreements and commitment, as a couple, supported by professional or spiritual support, aided towards their sons' wellbeing and future independence.

The following chapter will be discussing the above results in relation to extant literature presented in the literature review, and other new research referred to as a result to my emerging findings.

Discussion

This chapter aims at discussing the salient findings emerging from the participants' individual and joint interviews. I will be referring to existing literature and to the theoretical frameworks underpinning this research. My experience as a clinical trainee and qualitative researcher throughout my research process will interlace with the discussion, whilst instantiating a double hermeneutic (Smith et al., 2009), as I make sense of my participants' accounts.

The Emerging Couple Identity vis-à-vis their Caregiving Roles

I feel honoured to have been entrusted with each individual's and couple's account of their experiences of caregiving, which conveyed palpable experiences of heartaches, constraints, discord, frustrations, commitment, and resilience. Although the study yielded rich experiences reflecting a shared meaning among the individuals and couples, I wish to present briefly the salient characteristics emerging from each couple's "we-ness" or couple identity (Eisikovits & Koren, 2010; Torgé, 2013). I am aware that certain issues are also pertinent to the other couples and I will therefore discuss them in more detail when moving on to present other perceptions shared among participants.

"We're totally opposites, you know!": Anna and Anton's experience. Particularly in Anna and Anton's case, the couple remarked on their numerous conflicting opinions. In the context of caregiving, their differences seemed to induce a systemic interaction where, Anton's discipline and impatience towards their son were regarded as insensitive, causing Anna to reprimand her husband, whilst Anton admonished her leniency and lack of intuition. Their differences seem to be associated with complications within their couple relationship, due to the lack of collaboration when dealing with stress (Birditt, 2017).

Unlike the other participants, Anna and Anton were both working full-time together by running a business. In fact, finding a suitable day and time for the couple interview proved to be a challenge due to their busy schedule. Considering that caregivers who were employed were found to have significantly higher levels of tension (Abela et al., 2016), their dual roles as spouses and business partners could have created more stress in their personal and professional life, as postulated by research on co-working couples (Santhosh & Kutty, 2012). I wonder whether this interaction of responsibilities burdened the couple further, thus fuelling their differences and tension. Anton had jokingly noted that, similar to being bothered by his son's constant presence, he sometimes would not want his wife around either, due to the amount of time spent together! Although said light-heartedly, it seems to reflect Anton's yearning for personal space and time alone, which, due to the responsibilities of caregiving for their son and running a business, seemed unattainable. This is in tune with findings by Genadek, Flood, and Moen (2019) who found that, although being with one spouse was associated with happiness and less stress, less time spent with one's spouse was associated with enhanced happiness, especially reported by working husbands.

Anna and Anton's experience relates to the dynamic interaction between the couple's myriad environments and responsibilities (Fraenkel & Capstick, 2012; Rosa & Tudge, 2013), as parents, spouses, caregivers, and employers, further influenced by their differing views on numerous issues.

Caregiving and living with OCD: Berta and Brian's experience. The experience of interviewing Berta and Brian led me to reflect further on the multiple layers pertaining to the couple; apart from being caregivers to their son, their marital relationship seemed to be influenced by Berta's compulsive traits. Her compulsive behaviour seemed to trigger stress and discord within the couple, possibly also increasing Brian's burden even further (Idstad, Ask, & Tambs, 2010).

Berta would often clean kitchen surfaces frequently and instruct her husband not to touch anything before washing his hands. She often complied with her son's request of cleaning his chair before sitting, possibly reinforcing their son's same condition (Whisman & Robustelli, 2016), although Berta remarked that she did so to avoid conflict with her son. The couple reflected whether Berta's traits and perinatal problems were associated with their son developing OCD (Kerig, Ludlow, & Wenar, 2012). As remarked by Brian, and as observed during the interviews, Brian questioned his wife's behaviour and tried to reason with her, however he noted that he would often accept her instructions and submit to her requests. Although with good intentions, Brian's compliance may alleviate Berta's distress momentarily and avoid couple discord (Abramowitz et al., 2013), it could lead to symptom severity and poorer marital relationship functioning (Boeding et al., 2013).

Unlike the other joint interviews, Berta spoke at length while Brian, who had actively participated in the individual interview, was quite reserved. I wonder whether this disparity in participation reflected an imbalance in power within their couple dynamic. It seems that this was reproduced in their caregiving decisions, such as their son's lack of participation in a residential rehabilitation programme, or on his poor independent skills, as had been strongly encouraged by Brian, yet disapproved by Berta.

The attuned and selfless couple – Catherine and Charles' experience. Although this subject emerging from my participants' views will be delved in more depth further on, I noted that attunement was a noticeable feature in Catherine and Charles' relationship. Even in their interactions during the interviews, I observed how each spouse prudently interjected their partner's conversation, and their sentences seemed to be finished off by each other in a harmonious and unspoken collaboration. As noted by the couple, their well-founded marital bond, maintained by their respectful and trustworthy interactions between them, seemed to support the couple in managing their multiple life challenges (National Centre for Family Research, 2017; Masten, 2014), one of them being their son's condition.

Through my observations and their relating behaviours, Catherine and Charles seemed to have a well-integrated attachment system (Ainsworth, 1989), involving valuable marital qualities of forgiveness, sacrifice, commitment, and emphasis on maintaining and regulating their relationship (Amato, 2007). Their ability to be reflexive also seemed to contribute to their resilience. The husband, Charles, also seemed to make use of humour frequently, including comments about their amorous exchanges. Such regulation within their interactions was indicated to be influenced by key factors of psychological resilience and personality traits (Margelisch et al., 2017), which Catherine and Charles seemed to possess.

Caregiving of Adult Children from a Couple Perspective

Although the individual outcomes of managing a family member's mental health have been thoroughly researched (Abela et al., 2016; Fenech & Scerri, 2014; Greenfield & Marks, 2006; Miller et al., 2017; Pristavec, 2018; Turcotte, 2013; Schulz & Eden, 2016), little seems to be known on its impact within the family (Magliano et al., 1999; Schulz & Eden, 2016), or on the marital stability of the caregiving couple (Penning & Wu, 2019).

A salient finding from my study indicated that the caregiving role seemed to accentuate the spouses' differing views, thus causing strain on their relationship. All the participants perceived that their differences of opinion on their sons' behaviour and on his engagement in daily independent skills led to conflict, in line with findings in McCormack and McCann's (2015) study with parents of adolescents with anorexia nervosa. My participants also remarked on their disagreements in sensitivity, confrontation, and intuition, when addressing their son's needs and condition.

Whilst a recent quantitative study by Penning and Wu (2019) found a significant association between caregiving and union instability in middle and later life, the issues potentially linking caregiving to union dissolution were not explored. Therefore, the current research sheds light on instances arising within couple relationships due to their caregiving roles, possibly inducing couple instability.

Furthermore, considering that marital conflict was found to be related to parent-adult children disagreements (Suitor & Pillemer, 1987), this study highlights the systemic impact that conflict between different systems has on the family. As experienced by my participants, frustrations towards their son's behaviour or retaliating at his idleness seemed to be associated with further conflict with their spouses. It is worthy to note that, despite existing research on parent-adult children relationships (eg: Birditt et al., 2019; Fingerman, Kim, Birditt, & Zarit, 2017), I did not come across any studies, except Suitor and Pillmer's (1987), which found an association between parent-adult child and parent-parent conflict.

Whilst parents, in general, seem to experience a challenge in providing flexible yet firm boundaries to their grown children (McGoldrick & Shibusawa, 2012), the findings from this study highlight the added challenges of caring for grown adults in the context of the couple system. Adding to Copeland and Heilemann's (2011) and Smith's (2012) qualitative findings, it seems that, apart from caregivers holding their own ambivalent feelings towards their adult children's autonomy, this study portrays how such dilemmas experienced by parents may fuel conflict within their couple relationship. In addition, when mental illness symptoms developed in their sons, underlying conflicts in the couple systems may have been evoked (Miklowitz, 2004). This highlights the significance of viewing mental illness and caregiving from a systemic approach.

Nevertheless, all the couples normalized their disagreements. Using a remarkably similar metaphor referred to by a Chinese female spouse in Cheung’s (2005) study, Berta had compared the couple’s disagreements to “cat-and-dog”. The couples in my research tried to manage couple conflict and life stressors as best as they could (Gottman & Gottman, 2015), seeming to succeed, with some better than others. Indeed, the process in which couples deal with conflict in their relationship is more important that the conflict itself (Coleman, 2011).

Perhaps the response that these couples had towards their son’s emerging illness fueled a commitment within their relationship, because presumably they had hope for the future, saw problems as solvable and loved one another (Amato, 2007). The issue of ‘commitment’ led me to reflect on the participants’ meaning when speaking about their couple unity, particularly Anton’s. His remarks on being “committed to the marriage…”, and not having split up despite their child’s illness, seemed to evoke an underlying feeling of moral commitment to the marriage. Despite being a construct of commitment, Amato (2007, p. 307) noted that staying in a relationship only to avoid feelings of guilt is not being “truly committed”. Catherine and Charles’ discourse was on a different wavelength. They explicitly noted that their son’s condition bonded the couple further. These differences between couples could also be associated with their communication patterns. As noted by Gottman and Gottman (2015), these indicate how conflict and life stressors are managed in relationships.

The systemic impact on siblings from the couple’s perspective. Within the couple context, it seems that for some of the participants, the consequences experienced by their (healthy) children caused further resentment or distress within the couple system. Whilst Anton resented their daughter’s departure, Anna reprimanded him for not keeping contact with her. On the other hand, Catherine and Charles’ daughter had told her mother that she had spoilt her brother, David. Indeed, most couples noted that in acute moments, their sons did gain more attention from the couple, than did their other children. This is in in tune with research (Berman & Heru, 2013; Gilligan et al., 2017; Edward et al., 2008). Nevertheless, to counteract this split, Anna and Catherine noted that they tried their best to provide equal attention to their daughters.

Grief was also briefly mentioned from the context of the adult sons' siblings. Some of the participants noted that their other children seemed to struggle to communicate with their brothers due to their reserved nature. Similarly, Anna and Anton's daughter experienced stressful moments at home during her brother's acute stage of mental illness. The experience of living in such commotion, according to the couple, led her to leave the country and live abroad. Catherine and Charles' daughter was highly concerned about her brother's future, whilst stressed with her own personal issues. This seems to reflect the distress being experienced by non-caregivers too within families (Amirkhanyan & Wolf, 2006; Pini et al., 2018). As postulated by Leith, Jewell, & Stein (2018), given that mental illness runs in families, one cannot assume that the "healthy" siblings do not in fact face their own mental health struggles. Whilst not explicitly caused by their brother's mental ill-health, two of the couples had briefly noted that their daughters had experienced some form of emotional distress, such as anxiety when abroad, or stress and seemingly burn-out due to work commitments.

The multi-faceted experience of caregiving. The research study brought me face to face with a heterogeneity of stressors faced by the participants, and all their adult children, including their siblings without mental illness (Fingerman et al., 2018). I came to make sense of my participants' interrelated patterns, in light of their multiple roles and stressors within the different subsystems of the family; as caregivers, spouses, parents, employers, volunteers, and numerous other responsibilities. Some examples of these are Anna having to look after her mother and dealing with extended family issues, Catherine dealing with her brother's terminal cancer and subsequent passing, or the male participants (some before having retired) and Anna facing work responsibilities, whilst all dealing with their other (healthy) children's needs.

This seemed to echo Fingerman et al.'s (2018) remark on the significance of understanding how constellations of issues within families are dealt with, and how they are associated with parents' mid-life wellbeing. Perceived through a systemic lens, the family dynamics are seen to be influenced through the simultaneous interactions of complex and multiple components (Bronfenbrenner, 1979; Dallos & Draper, 2010, Stanton & Welsh, 2012). This is once again reflective of the significance of addressing multiple levels of the family system when understanding and intervening with psychiatric disorders (Miklowitz, 2004).

Caregiving Dilemmas and the Parent-Adult Child Relationship

In Berta and Brian's relationship, Berta's overprotective nature with her son led to arguments between the couple due to his progress or lack of it. As Brian seemed to encourage their son's independence, Berta was unhurried about this and instead defended her son's needs. This could also indicate the reasons for the poor relationship between Brian and their son Ian. In line with Zemp, Milek, Cummings, and Bodenmann (2017), the main caregiving parent, usually the mother, like Berta, can have a major impact on Brian's access and involvement in his relationship with his son, and his role as caregiver. If the mother blocks the father's view, a vicious cycle is set in motion, which triggers helplessness in Brian because he knows that his son disregards his involvement. The more criticism by Berta, the more the lack of engagement from Brian.

Studies with families of adolescents with eating disorders noted that the parent–child relationship may present with more tension and distress than that found in families without mental health problems (Latzer, Lavee, & Gal, 2009). Among my participants, Anton and

Anna also remarked heightened tension between father and son, although Anton noted that their son sought comfort with him when in a crisis. This portrays the significance of approaching caregiving from the context of a systemic perspective (Rolland, 2012), since the influence of mental illness shapes the experience of the entire family (Utz, Berg, & Butner, 2017).

In addition, although this study does not explicitly explore this area, the participants' disagreements and protective behaviour led me to wonder whether this was associated with the development of their sons' conditions. Research postulates that distorted demands and requirements towards a child may pose a risk towards his mental health (Sluzki, 2007). As feared by Berta herself, a parents' overprotective caregiving at an early age may fuel vigilance and anxiety in one's children (DeKlyen & Greenberg, 2016).

Grieving the Losses Resulting from the Adult Sons' Chronic Illness

In line with the literature, the participants seemed to simultaneously express solidarity with their sons' difficulties, yet mourn and fear for their adult son's future life (Muhlbauer, 2002; Pillemer et al., 2012; Wiens, & Daniluk, 2009). In the context of the couple relationship, some participants referred to their expected stage in the family's life course (McGoldrick et al., 2016) as they remarked on their sons' limited prospects of getting married and having children. This is in line with Gower and Dowling (2008) who noted that caregiving and parenting in older age may present a challenge to the traditional view of the family life course. The couples' fears were also related to their son's future care, once he outlives the couple, as noted in previous research (Chou et al., 2009; Kaufman et al., 2010; Marsack, 2016). Although anxious, the couples reflected on possibilities for their children's future care, including their siblings as possible caregivers. Nevertheless, this finding suggests the importance for policy providers to support aging parental caregivers who require some form of lifelong reliance (Marsack, 2016).

The difficulty in perceiving their son's identity as tainted by 'mental illness'. Some couples noted their dilemmas in making a decision on whether to register their son for a disability allowance, to avoid the 'label'. Although the couples' reasoning seemed to refer to stigma, which is indeed experienced by caregivers (Park & Seo, 2016; Vermeulen et al., 2015b), and may lead to abstaining from mental health services to avoid such 'labels' (Turner & Liew, 2010), this seemed to have a deeper meaning from a social constructionist perspective.

This particularly emerged with Berta, who, whilst yearning for her son's recovery, used the term 'normal', and consequently discussed what 'normality' really meant. Her husband Brian replied, comfortingly, that everyone seemed to have a 'disability', one way or the other. I wondered whether Brian's comment was one he truly believed in, or whether he said so to relieve his wife's preoccupations. Adhering to a social constructionist framework, it seems that the couple created an understanding of their son's condition and life (Wang, 2016) as constructed by language (Berger & Luckmann, 1966/1991). The participants' struggles of registering their son's disability seems to portray a resistance to changing discourse (Richardson, 2012). As a qualitative researcher, I take this a step further to make sense of the participants' hesitation towards their sons' changing identity as possibly threatening their own "stable and socially recognized identity" (Berger & Luckmann, 1966, p. 188), as parents and as a couple.

In addition to this, whilst members within the couples had differing views on the levels of engagement for their sons' independent skills, all the participants, except Brian, unanimously refused to engage their sons in a residential rehabilitation programme. Although some participants were fearful of having been overprotective over their sons when younger, they remarked on the significance of encouraging their son's independence, noting their frustration towards their idleness. Nevertheless, the participants' covert concerns and behaviours seemed to restrict their sons' independence and limit their prospects of recovery, thus seemingly indicating a certain level of ambivalence (Copeland & Heilemann, 2011; Pillemer et al., 2012; Smith, 2015).

I am aware that my position on this aspect is influenced by my previous work experience at a mental health rehabilitation community and my current psychology training. However, literature also highlighted how social networking and environmental resources are beneficial for mental health recovery (Wood & Alsawy, 2018). Although in Catherine and Charles' case, their son's attendance at a rehabilitation service was terminated due to him feeling highly anxious at the centre, Anna and Anton had explicitly remarked that they did not want their son to mix with other service-users who were perceived to be doing 'worse' than him. I perceived a sense of entitlement, possibly due to the family's middle/upper social class background (Piff, 2014). In Anna and Anton's case, their resources and work flexibility possibly aided in supporting their son, although they both voiced their concern towards his recovery. Swartz (2008) warned that private support may reinforce social inequalities while systemic solutions to collective societal problems (such as community mental health rehabilitation!) are discouraged. This would be an interesting area to explore within the local field, considering that, from my experience, few care-recipients from upper class backgrounds made use of the rehabilitation program. Researching such individuals and their families' reasons and resources could unearth certain important findings which could help develop such services better.

The Emotional Distress Experienced by the Female Spouse

Anna and Catherine both had depressive episodes which they associated with their caregiving role, possibly due to their high levels of emotional support towards their adult children, and lack of self-care (Gilligan et al., 2017). All the women in my study noted their sensitivity and heartache towards their sons' illness. Their dilemmas resulting from accommodating their adult children yet being exasperated by their behaviours, as noted in other research (Copeland & Heilemann, 2011; Smith, 2012; Smith, 2015), could have further triggered their depressive episodes. Their sons' illness seemed to challenge their family's traditional life cycle outlook (Carter & McGoldrick, 1989; McGoldrick & Shibusawa, 2012). In fact, Catherine noted that her depressive episode was triggered when her son decided to leave his employment, which then resulted in their son's heightened anxiety at seeing his mother unwell, and Charles' apprehension of dealing with the complex situation.

Moreover, as previously noted, Anna and Catherine were also experiencing other family stressors and responsibilities, reflecting how caregiving overlaps with other responsibilities in caregivers' lives (Shulz & Eden, 2016). Research on gender differences in caregiving suggests that females suffer more problematic consequences than men, including greater feelings of burden, stress, and depression (Bookwala, 2009; Yee & Schulz, 2000), as seemed to be the case for the females in my study.

The husbands' experience of facing their wives' distress. As previously mentioned, a partner's stress is often experienced within the couple system (Bateson, 1972; Birditt, 2017). Brian and Charles acknowledged their wives' mental health difficulties and their behaviours to accommodate their wives. Although Anton did not mention his wife's depressive episode during the interview, Anna recalled her trepidation towards informing him of her ill-health, since she feared he would not cope well. Similarly, Catherine noted her husband's confusion at having to deal with their son's and his wife's illness. This reflects how the onset of illness influenced the family system (Ozcul, 2004; Rolland, 2012). In line with Altschuler (2005), the participants' coping within their couple system involved a running process, where each person's welfare seemed to be dependent on the other.

Although the caregiving responsibilities appeared equal between the couples, the women seemed to be providing their sons with the most psychological care (Abela et al., 2016; Copeland & Heilemann, 2011; The National Alliance for Caregiving, 2016; Vermeulen et al, 2015a), whilst the husbands provided more financial and practical assistance (Fokkema et al., 2008). This could also shed light on the psychological impact that caregiving had on the mothers, and its consequent impact on their husbands.

The Unsaid: The Parental System Not Returning to a Dyad

Although not clearly reported, I reflected whether the couples perceived their son's condition as unsettling their family's and couple's momentum, as Rolland (2012) noted. Although only Anton, Anna, and Charles explicitly remarked that their sons limited their couple time and affection, all my participants' accounts seemed to reflect that their adult son's presence was rather constant. It was mostly Anton who verbally emphasized that their son's company turned their couple relationship into a "threesome". In Berta and Brian's case, I wonder whether their adult son's presence served as a function for the couple (Dallos & Draper, 2010), particularly for Berta, who was surprised that I had asked the question about couple time, which had already been asked by a family therapist. I also noted that Brian remained silent, but then remarked that it was Berta who preferred having family outings. This could indicate that Brian yearned for more time and activities together with his wife, whilst Berta seemed to avoid such instances.

Interestingly, this was also observed as I came to hold the interviews: Anna and Anton's son Nathaniel initially interrupted the interviews since he was present at the office (Anna's interview) and at their home. In Berta and Brian's case, their son Ian was at the job placement during the couple interview but coincidentally arrived home when I was leaving. On the other hand, Catherine and Charles had specifically requested that their interviews would be held at university because of their son David's presence at home. Interestingly, however, I also “met” David by being shown a photo of their family. The fact that I met the participants’ adult children when I did not need to (although I was given their consent as third party participants), left me wondering on whether the couples were aware that developmentally, they were at the stage when usually couples were coming to terms with the notion of their system returning to a dyad (McGoldrick et al., 2016). This seemed to be only briefly observed by Berta and Brian as they spoke about a couple their age who now lived alone since all their children had moved out. They also noted, together with Anton and Anna, that, contrary to most couples their age, they seemed to be limited from spontaneously booking a holiday as this normally entailed some forward planning.

Multiple stressors and decreased sexual intimacy. Although not expressed as being a direct cause of their caregiving responsibilities, some participants noted that the couple’s intimacy had been influenced negatively by multiple stressors within the family system. However, Charles had amusingly suggested that their sons’ presence at home limited the couple’s affectionate and flirty exchanges. It seems that the couples’ decreased sexual intimacy was fatigued by life circumstances (Berman & Wohlsifer, 2013), rather than difficult marriages.

The Couples’ Attunement and Resilience in the Face of Adversity

The multi-perspective design provided the space for my participants to discuss their experience both in the presence of their spouse, and alone. Although rich insights were achieved through having both individual and dyadic interviews, I noted that no major exclusive themes were brought up when the spouses were individually interviewed. This could reflect that the couples seemed comfortable to disclose their views truthfully in front of their spouse (Eisikovits & Koren, 2010). The respectful and trustworthy interactions between them possibly supported the couples in managing their life challenges (Gottman & Gottman, 2015; National Centre for Family Research, 2017). From my observations, the couples seemed to practice constructive strategies during conflict resolution, such as regulated communication, demonstrations of support and affection, and attempts at problem solving and finding resolutions (Papp, 2018). This, of course, could have been influenced by my presence as a researcher during the interviews.

The joint interviews were also pivotal to observe the processes and interactions between the spouses (Polak & Green, 2016; Racher, Kaufert, & Havens, 2000; Taylor & de Vocht, 2011). The interviews evoked discussions and disagreements, but also provided me with information about the couples' playful and humorous exchanges. Despite recalling difficulties endured due to the caregiving role, among other stressors, all the participants resonated well-attuned marital relationships and attitudes of resilience. Their satisfaction within their marital relationship may have further motivated them to provide support and encouragement to each other, thus enhancing the happiness and well-being of the other (Margelisch et al., 2017).

The very fact that Anna, Anton, Berta, Brian, Catherine, and Charles agreed to participate could indicate their readiness to share their individual and couple stories with me. I reflected whether their choice to participate also distinguished their relationship from the numerous other couples who refused to take part.

Their participation could also reflect a sense of strength in response to their family crises, echoing the resilience theoretical framework (Masten, 2014; Walsh, 2012a). Similarly to findings from Cohen, Ferguson, Harms, Pooley, and Tomlinson (2011) and Muhlbauer (2012), in the face of caregiving for a family member with a mental illness, my participants sought support and acquired skills and knowledge about dealing with mental illness, and seemed to develop their communication skills with their spouses and sons. This appeared to ease the strain and help the participants to bounce back. Interestingly, the couples empathized with the suffering of other caregivers who had harder challenges to deal with. Possibly, this outlook consoled the couples, yet supported them further, as they viewed their difficulties in relation to other people's suffering.

The impact of professional support on the couple system. The couples remarked that their coping was supported by psychiatrists and other mental health professionals, in tune with other research (Gauci, 2016; Kaufman, 1998; Scerri et al., 2018; Sörensen et al., 2002). Unlike Vermeulen et al.'s (2015b) local findings, the participants seemed satisfied with the ease to get help and support from medical and care staff. However, considering that the couples were from a middle-class background could suggest that they were financially stable and could refer to private treatment when needing swift interventions.

Nevertheless, some couples noted distasteful comments from professionals in the past, which fueled a sense of guilt or shock among the dyad. This finding supports previous suggestions for the importance of educating medical professionals on interrelating skills (Wear, Aultman, Zarconi, & Varley, 2009), and on the damage that can be done when using derogatory and cynical comments with patients and their families.

The impact of prayer on the couple system. As similarly noted by Abela et al. (2016) and Rozario (2016), some of the participants noted that prayer was an important resource for coping. Religious and cultural factors provided my participants with coping strategies and optimistic views when caregiving their son (Kaufman, 1998). Indeed, most of the participants made linguistic reference to religious factors (eg: *God willing; it is up to the Above to decide; with God's support*), as they made sense of their family's situation or son's future.

Particularly in Catherine and Charles' experiences, their trust in God seemed influential for their enduring relationship, because they felt supported, particularly whilst dealing with their caregiving responsibilities. Their strong attunement as a couple could also be indicative of their faith, due to having a forgiving nature within their marriage (Fincham, 2014), possibly protecting the couple against risk factors within their relationship.

In conclusion, a systemic diagram in Figure 1 presents a brief summary of the findings of my research. The diagram portrays the impact of the adult son’s mental illness and the caregiving responsibilities on the individual participants, and its impact on the participants’ couple relationship. The impact on the siblings is also noted. The diagram includes other stressors, and protective factors, that influenced, both positively and negatively, the couple relationship.

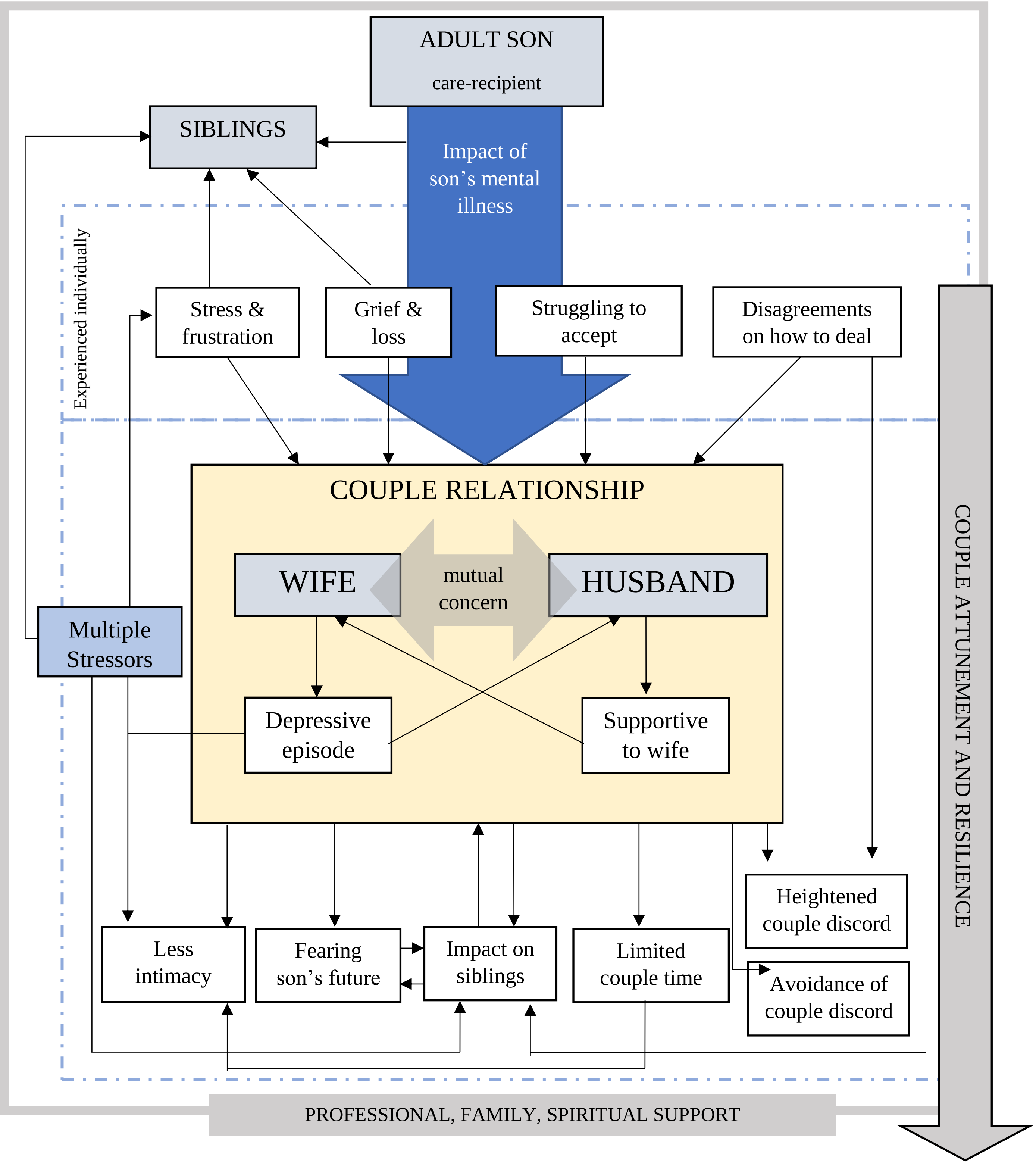

Figure 1. The diagram presents a systemic view of the impact of caregiving as perceived by the participants. The impact on the spouses, on their couple relationship, and on other members within the family is noted. Multiple challenges experienced by the family members further influence the system. The diagram includes the protective or supportive factors, in grey, that were highlighted by the participants.

Conclusion

This research provides new insight into the lives of middle-aged couples, their relationship, and their interactions, as influenced by their responsibilities of caregiving. It illustrates how caregiving can come to strain the couple relationship due to the unveiling of individual differences causing discord between the couple. Several adversities as individuals and as couples were experienced, such as struggling with accepting their son's illness, having limited couple time, and coping with multiple stressors. The research also shed light on protective factors, such as couple attunement, and professional and spiritual support, that seem to provide the participants with a resilient outlook to face their adverse circumstances together. The following and final chapter will provide the reader with an overview of the salient findings, followed by the studies' limitations, recommendations for future research, and implications for policy.

Conclusion

This final chapter will provide an overview of the salient findings emerging from the study, followed by its limitations. Recommendations for future research and proposals for policy will be presented.

Overview of the Main Findings

This research provided awareness on the previously overlooked subject of how caregiving is shared in the couple relationship (Magliano et al., 1999; Schulz & Eden, 2016). New insights on the experiences of couples, their relationship, and their interactions, as influenced by their responsibilities of caregiving, were highlighted. The findings noted that, apart from individual burden already underlined in literature, the process of caregiving may cause a strain on the couple relationship in a number of ways, such as accentuating the spouses' differences, increasing their multiple stressors, limiting couple time and affection, and instigating concern and dilemmas on their children's future.

The research also highlighted the systemic interaction and influences between an adult child's mental illness, the wife's mental health problem, and the husband's reaction towards such developments. The study also explored the impact of caregiving on the siblings, as perceived by the participants. The findings also shed light on mature couples' marital functioning, upon which there was also a gap in research (Papp, 2018). The couples' resilience seemed to be forged through their marital qualities of forgiveness, sacrifice, commitment, and emotional regulation (Amato, 2007). The couples' attunement and bond seemed to serve as a protective factor, which, together with professional and spiritual support, motivated them to sustain and encourage each other, and their son.

Limitations of the Study

The participants in my study were all white, Maltese, and heterosexual individuals, in secure and long-term married relationships. The couples were from middleclass backgrounds and financially stable, in their mid-life to older life stages. The couples were recruited through gatekeepers and were therefore in contact with mental health professionals. Although many couples were informed of the study, only a few agreed to participate. Therefore, couples who refused to participate, and couples who were not currently receiving any professional support could have provided novel results not shared by my participants. I reflected that the reasons of why some couples refused to partake in this study could very well be due to the nature of their marital relationship.

It is also significant to mention that my participants' stable financial backgrounds may have also limited the findings. My participants seemed to make good use of public and private professional services. Low income was found to be associated with increased caregiving burden for parents who provide care for children with disabilities (Essex & Hong, 2005). Therefore, low income couples may have had different stories to tell about their perceptions on the influence of caregiving on their relationship.

Clinical Implications

Holloway and Biley (2011, p. 974) described qualitative research as "the most humanistic and person-centred way of discovering and uncovering thoughts and action of human beings". After the interviews, three of the participants highlighted the benefits of sharing their perspectives through this process, with Catherine and Charles remarking that they had never had the opportunity to reflect on their own lived experience of being caregivers before. They were thankful for having been given the chance to do so.

This shed light on the importance for clinicians working in the mental health field to provide a safe space for caregiving couples to address these issues (Wiens & Daniluk, 2009). The findings also highlighted how individual issues of one spouse could influence the other, particularly issues such as care burden and mental health problems. Therfore, clinicians are encouraged to explore how both positive and negative issues influence one's own, and their partner's, marital experience (Hsieh & Hawkley, 2018).

The couples' experiences also highlighted the importance of receiving support, and the possible harm that can arise if professionals do not practise self-awareness and sensitivity. Further training on family systems and normative demands of various health problems over the life course of an illness should be included in the education of all health professionals (Rolland & Walsh, 2005), including psychiatric residence trainees (Berman & Heru, 2005; Rice, 2016).

My participants also remarked on their struggles of accepting and understanding their sons' difficulties. This seemed to impede certain parents from registering their sons for social benefits or community support. Clinicians are encouraged to explore caregivers' sense of coherence, since the latter may be an indicator of psychological distress, potentially leading to high levels of anxiety and depression (Del-Pino-Casado, Espinosa-Medina, López-Martínez, & Orgeta, 2019).

Proposal for Policy

Although the couples in my research noted positive remarks on the assistance they were receiving, support for caregivers remains inadequate locally (Gauci, 2016; Fenech & Scerri; 2014; Abela et al., 2016) and needs to be further developed (Ministry of Health, 2018). Keeping in mind that two of the female participants had experienced a depressive episode due to their caregiving role, whilst Berta also had mental health problems of her own, highlights the necessity of identifying caregivers who are at risk for emotional distress (Zauszniewski & Bekhet, 2014), and providing the appropriate services.

Ideally, local health services should support caregivers by lessening the burden that caring can have on their health (Savage & Bailey, 2004). This could be further reinforced through the development of a local ‘Care Act’, similar to the one enacted in the United Kingdom. The UK’s Care Act (C23, 2014) emphasizes that caregivers are to be assessed on their ability, interest, and willingness to care for a care-recipient.

As mentioned previously, the participants’ concerns on their sons’ future care highlights the significance of the development of more long-term supported accommodation for adults with mental illness. Finally, more resources of family therapists and psychologists are to be provided within the local services to reach out to more families (Abela et al., 2016).

Suggestions for Further Research

Concurrent with suggestions by Penning and Wu (2019), my research findings recommend that the focus on physical and psychological implications of caregiving should move beyond and address its influence on other outcomes within family subsystems. Being an under researched area, further studies could explore the systemic impact of ‘caregiving’. Including couples from different social classes and different life stages would be beneficial. Longitudinal research for couples’ affinity (Butt & Chesla, 2007) and different family typologies (Fingerman et al., 2018; Penning & Wu, 2019), is needed to identify risk factors and understand whether patterns of relationships and family problems change and arise over time.

Conclusion

Despite the stated limitations, this research provided new insights into the lives of middle-aged couples, their relationship, and their interactions, as influenced by their responsibilities of caregiving. As I conclude this study, my thoughts go back to my participants, and towards all the couples I have had contact with through my work experiences.

I cannot help but think of Susan and Sergio, the couple I referred to briefly in my introduction. I wonder whether professional couple support could have aided them in exploring their incongruencies towards accepting and dealing with their daughter’s condition, thus uplifting some of Susan’s burden, whilst also providing a safe space for her reserved husband Sergio to speak about his view. This study aimed at acknowledging such experiences, whilst encouraging further research and attention to be given to the informal caregivers’ wellbeing vis-à-vis their relationships and health, which are sadly often overlooked (Family Caregiver Alliance, 2006).

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Appendix A

Letter for Request for Approval for Access to Participants Sent to Gatekeepers via E-Mail

Request for Approval for Access to Participants

Paula Caruana
10, Papillon,
E.H. Furse street
Msida
MSD 1621

[Address of Gatekeeper]
Richmond Foundation
St Jean Antide Foundation
Mental Health Services

Dear [Gatekeeper],

I am contacting you to inform you about a dissertation study that I am proposing to conduct as partial fulfilment for the Masters of Psychology in Clinical Psychology, at the University of Malta, which requires approval for access to participants from [Gatekeeper].

The prospective research, supervised by Prof Angela Abela, is entitled, *The Perceived Impact of* ***Maternal***[3] *Caregiving on the Couple Relationship, when an Adult Child has a Severe Mental Illness.*

The study aims at broadening the literature on family caregiving, and the impact of maternal caregiving by addressing the perceived impact of such an experience on the couple relationship, when an adult child has a severe mental illness. This study could also shed light on the impact, role, and needs of caregivers and their spouses, and how role conflicts or changes in family life developing due

---

[3] NB: After the data analysis, the title was amended slightly and the word '**maternal**' was removed since through the interviews, it emerged that both spouses had similar caregiving roles and responsibilities with their adult sons.

to the illness within the family could be further supported through professional assessments and interventions.

I have contacted you to ask whether you would approve the recruitment of participants, specifically couples, to take place through *Richmond Foundation/St Jeanne Antide Foundation/Mental Health Services*. Should you agree, and should the University Research Ethics Committee approve of my study, I will be forwarding an information sheet / poster which would be given to caregivers with whom you are in contact with. The interested participants would be invited to participate in my study through the information sheet by contacting me directly through phone or e-mail. The information sheet would also highlight the caregivers' voluntary participation, anonymity, and their right to withdraw at any point of the study. Written consent will also be obtained from every participant.

This recruitment method ensures that the participants in the study would have been already supported by mental health professionals prior, as well as after, the interview takes place, although the level of possible burden or discomfort that the participants may experience due to the interviews will be no greater than that to which they have been exposed to through the experience of caregiving.

As mentioned, in order to proceed with the study, I require approval from the University Research Ethics Committee. To do so, I must present the approval from the institutions, such as *Richmond Foundation/St Jeanne Antide* Foundation*/Mental Health Services*, for access to participants. The dissertation proposal has been accepted by the Masters of Psychology Board of Studies.

Participants in the study will be required:

- To be heterosexual couples, where the female spouse is required to be the main caregiver of their adult child diagnosed with a mental illness. This particular requirement was noted, since studies done both locally (Abela et al., 2016[4]), and overseas (The National Alliance for Caregiving, 2016[5]), have shown that caregivers tend to be female.

- to be living in the same household as their adult child. The adult child requires to be followed by a mental health professional at the time of the study. No contact will be done with the child of the couple, however information about the study will be passed on, and consent will be also requested from the adult child.
- **Not** to be related to/or be ex-clients I have worked with closely in the past, in my role as mental health recovery officer with Richmond Foundation between 2015 and 2017.
- **The data will be gathered using conjoint interviews with the couples. Six to eight couples will be interviewed.**[6]
- The interviews will be audio-recorded and transcribed. All notes and digital recordings will be destroyed once the study is complete.
- Participants may choose to carry out the interview at their own home, or at a place they feel comfortable in.

Data collection is aimed to take place in January and February 2018.

Interested participants will be given an information sheet and consent form to read, sign, and keep a copy of. Both partners are required to give their consent. They will be free to disclose as much information as they would like, and also informed that they have a right not to respond to questions that they would not like to answer. Participants will have the right to withdraw from the study, even after giving consent.

---

[4] Abela, A., Farrugia, R., Vella, A. M., & DeGiovanni, K. (2016). Familialistic countries need a family-inclusive service when caring for people with mental health problems: The case of Malta. *Families, Relationships and Societies, 5*(2), 313-331. doi: 10.1332/204674315X14365326675064

[5] The National Alliance for Caregiving (2016). *On pins and needles: caregivers of adults with mental illness*. Retrieved from http://www.caregiving.org/wp-content/uploads/2016/02/NAC_Mental_Illness_Study_2016_FINAL_WEB.pdf

[6] NB: Originally, only conjoint interviews were going to be held with 6-8 couples. However, due to difficulty in recruiting participants, it was later decided to carry out individual and conjoint interviews with interested participants. Due to this change, three couples were then recruited. Ethics approval for this change was sought and received (See Appendix F).

Participation is voluntary and confidential at all times. All information, and audio recordings will be destroyed following the completion of the research.

Should you have any questions or require any further information, please do contact me. I am optimistic that this research may contribute to the field of mental health caregiving, particularly its impact on the family and couple system, which has been minimally researched in the caregiving literature (Schulz & Eden, 2016[7]).

Thank you for your time and consideration. I look forward to hearing from you.

Kind regards,

Paula Caruana
M. Psy Clinical Psychology trainee
University of Malta

E-mail address: paula.caruana.11@um.edu.mt
Mobile number: 79306039
Address: 10, Papillon, E. H. Furse street, Msida

Details of supervisor: Prof Angela Abela
Email address: angela.abela@um.edu.mt
Telephone number: 23403601

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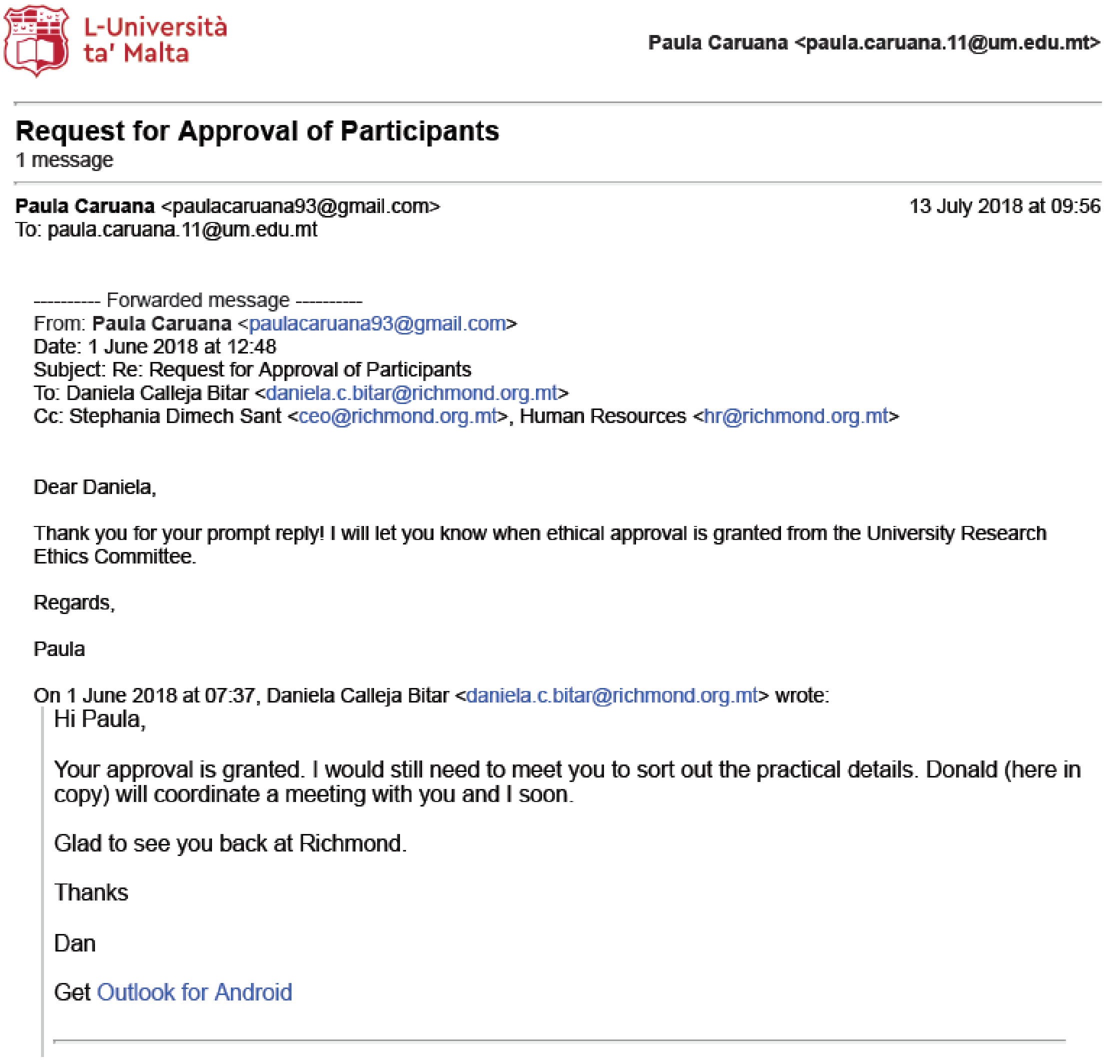
[7] Schulz, R. & Eden. J. (2016). *Families caring for an aging America. The national academies of sciences, engineering, and medicine.* Washington, DC: The National Academies. Retrieved from http://www.nap.edu/23606

Appendix B

Approval for Access to Participants – Richmond Foundation



L-Università ta' Malta

Paula Caruana <paula.caruana.11@um.edu.mt>

Request for Approval of Participants
1 message

Paula Caruana <paulacaruana93@gmail.com>
To: paula.caruana.11@um.edu.mt

13 July 2018 at 09:56

---------- Forwarded message ----------
From: **Paula Caruana** <paulacaruana93@gmail.com>
Date: 1 June 2018 at 12:48
Subject: Re: Request for Approval of Participants
To: Daniela Calleja Bitar <daniela.c.bitar@richmond.org.mt>
Cc: Stephania Dimech Sant <ceo@richmond.org.mt>, Human Resources <hr@richmond.org.mt>

Dear Daniela,

Thank you for your prompt reply! I will let you know when ethical approval is granted from the University Research Ethics Committee.

Regards,

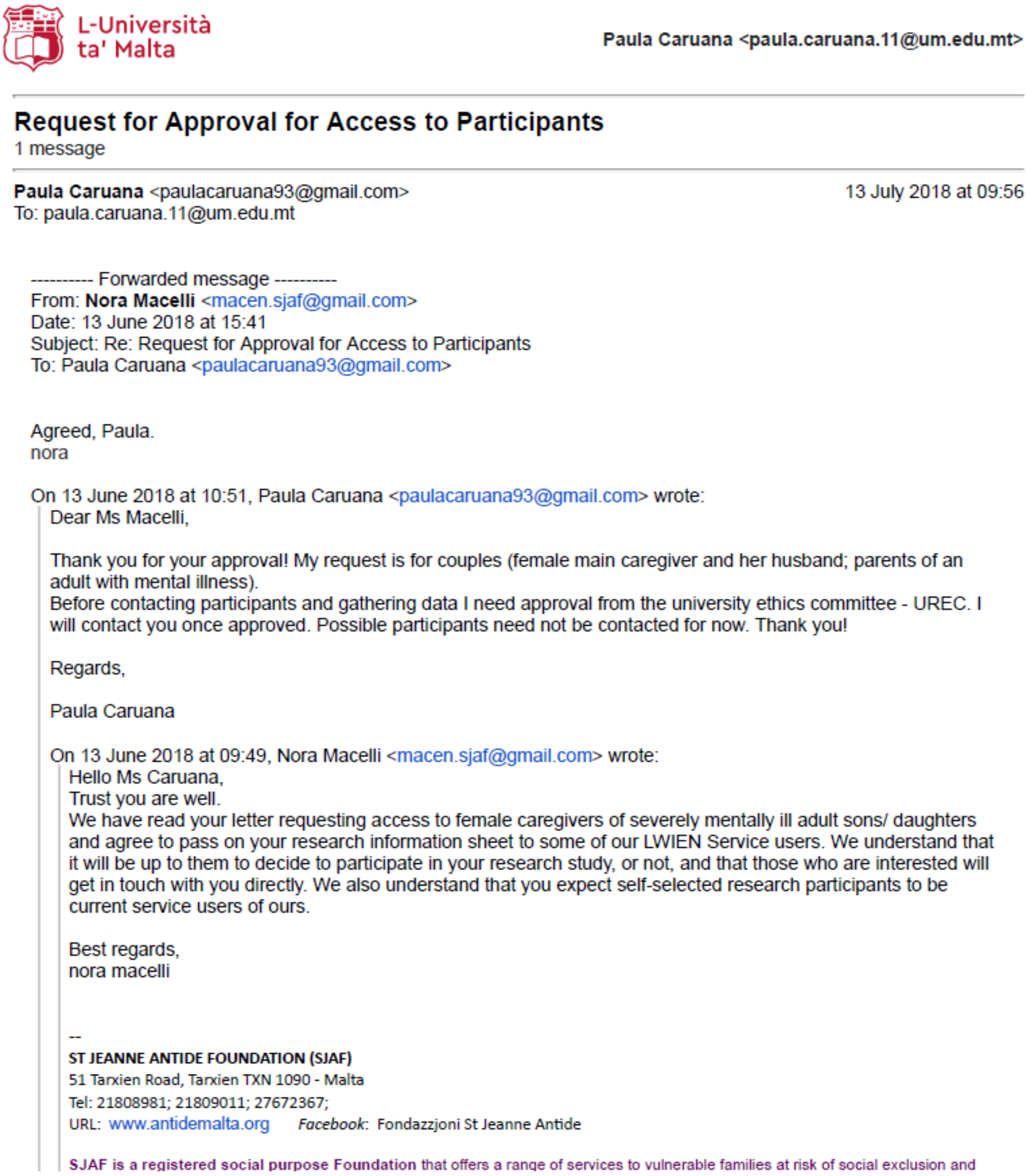
Paula

On 1 June 2018 at 07:37, Daniela Calleja Bitar <daniela.c.bitar@richmond.org.mt> wrote:

> Hi Paula,
>
> Your approval is granted. I would still need to meet you to sort out the practical details. Donald (here in copy) will coordinate a meeting with you and I soon.
>
> Glad to see you back at Richmond.
>
> Thanks
>
> Dan
>
> Get Outlook for Android

Appendix C

Approval for Access to Participants – St Jeanne Antide Foundation



L-Università ta' Malta

Paula Caruana <paula.caruana.11@um.edu.mt>

Request for Approval for Access to Participants
1 message

Paula Caruana <paulacaruana93@gmail.com>
To: paula.caruana.11@um.edu.mt

13 July 2018 at 09:56

---------- Forwarded message ----------
From: **Nora Macelli** <macen.sjaf@gmail.com>
Date: 13 June 2018 at 15:41
Subject: Re: Request for Approval for Access to Participants
To: Paula Caruana <paulacaruana93@gmail.com>

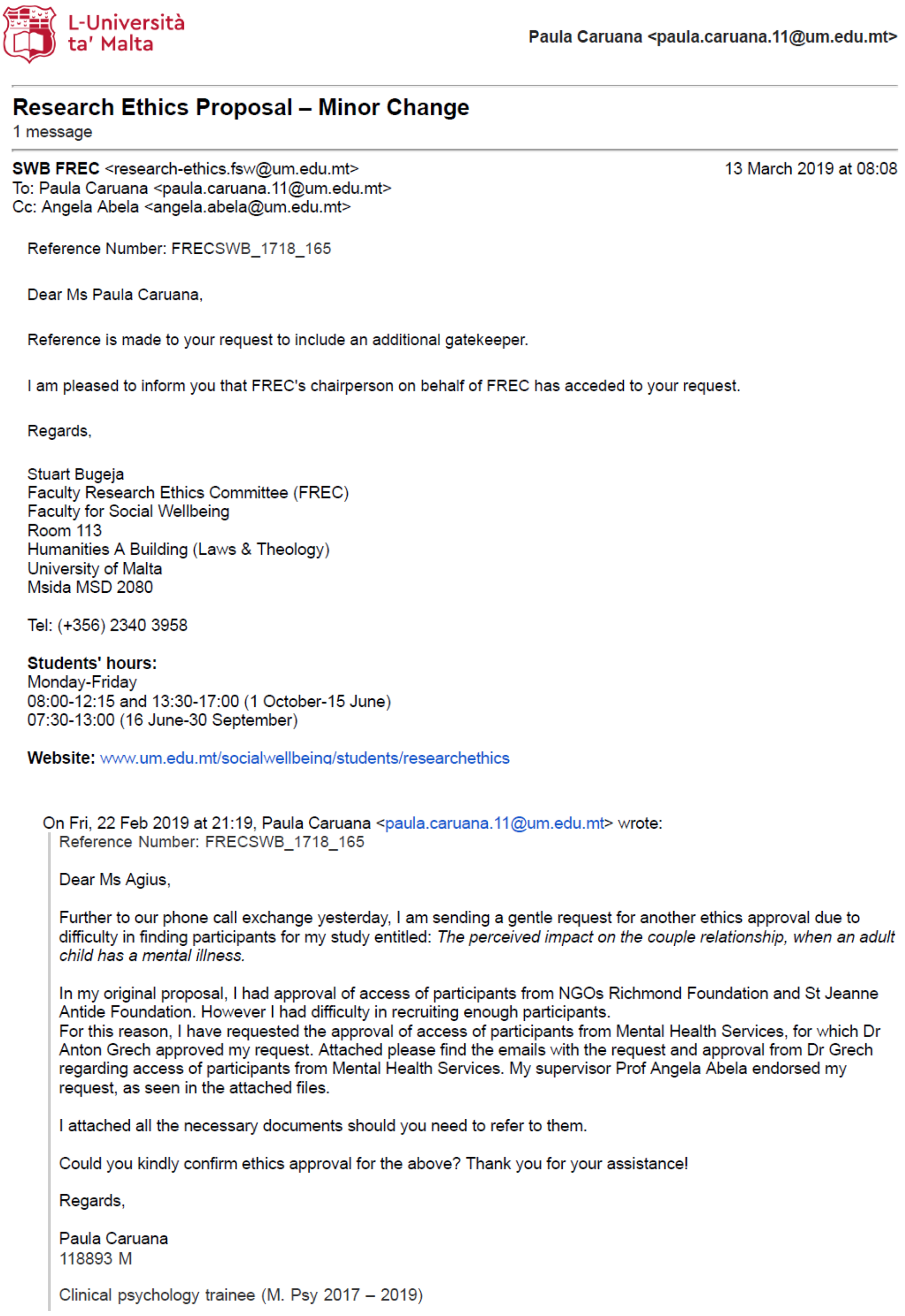
Agreed, Paula.
nora

On 13 June 2018 at 10:51, Paula Caruana <paulacaruana93@gmail.com> wrote:

> Dear Ms Macelli,
>
> Thank you for your approval! My request is for couples (female main caregiver and her husband; parents of an adult with mental illness).
> Before contacting participants and gathering data I need approval from the university ethics committee - UREC. I will contact you once approved. Possible participants need not be contacted for now. Thank you!
>
> Regards,
>
> Paula Caruana
>
> On 13 June 2018 at 09:49, Nora Macelli <macen.sjaf@gmail.com> wrote:
>
>> Hello Ms Caruana,
>> Trust you are well.
>> We have read your letter requesting access to female caregivers of severely mentally ill adult sons/ daughters and agree to pass on your research information sheet to some of our LWIEN Service users. We understand that it will be up to them to decide to participate in your research study, or not, and that those who are interested will get in touch with you directly. We also understand that you expect self-selected research participants to be current service users of ours.
>>
>> Best regards,
>> nora macelli
>>
>> --
>> **ST JEANNE ANTIDE FOUNDATION (SJAF)**
>> 51 Tarxien Road, Tarxien TXN 1090 - Malta
>> Tel: 21808981; 21809011; 27672367;
>> URL: www.antidemalta.org *Facebook*: Fondazzjoni St Jeanne Antide
>>
>> **SJAF is a registered social purpose Foundation** that offers a range of services to vulnerable families at risk of social exclusion and

Appendix D

Acceptance of Minor Change to include Mental Health Services as Additional Gatekeeper



L-Università ta' Malta

Paula Caruana <paula.caruana.11@um.edu.mt>

Research Ethics Proposal – Minor Change

1 message

SWB FREC <research-ethics.fsw@um.edu.mt> 13 March 2019 at 08:08
To: Paula Caruana <paula.caruana.11@um.edu.mt>
Cc: Angela Abela <angela.abela@um.edu.mt>

Reference Number: FRECSWB_1718_165

Dear Ms Paula Caruana,

Reference is made to your request to include an additional gatekeeper.

I am pleased to inform you that FREC's chairperson on behalf of FREC has acceded to your request.

Regards,

Stuart Bugeja
Faculty Research Ethics Committee (FREC)
Faculty for Social Wellbeing
Room 113
Humanities A Building (Laws & Theology)
University of Malta
Msida MSD 2080

Tel: (+356) 2340 3958

Students' hours:
Monday-Friday
08:00-12:15 and 13:30-17:00 (1 October-15 June)
07:30-13:00 (16 June-30 September)

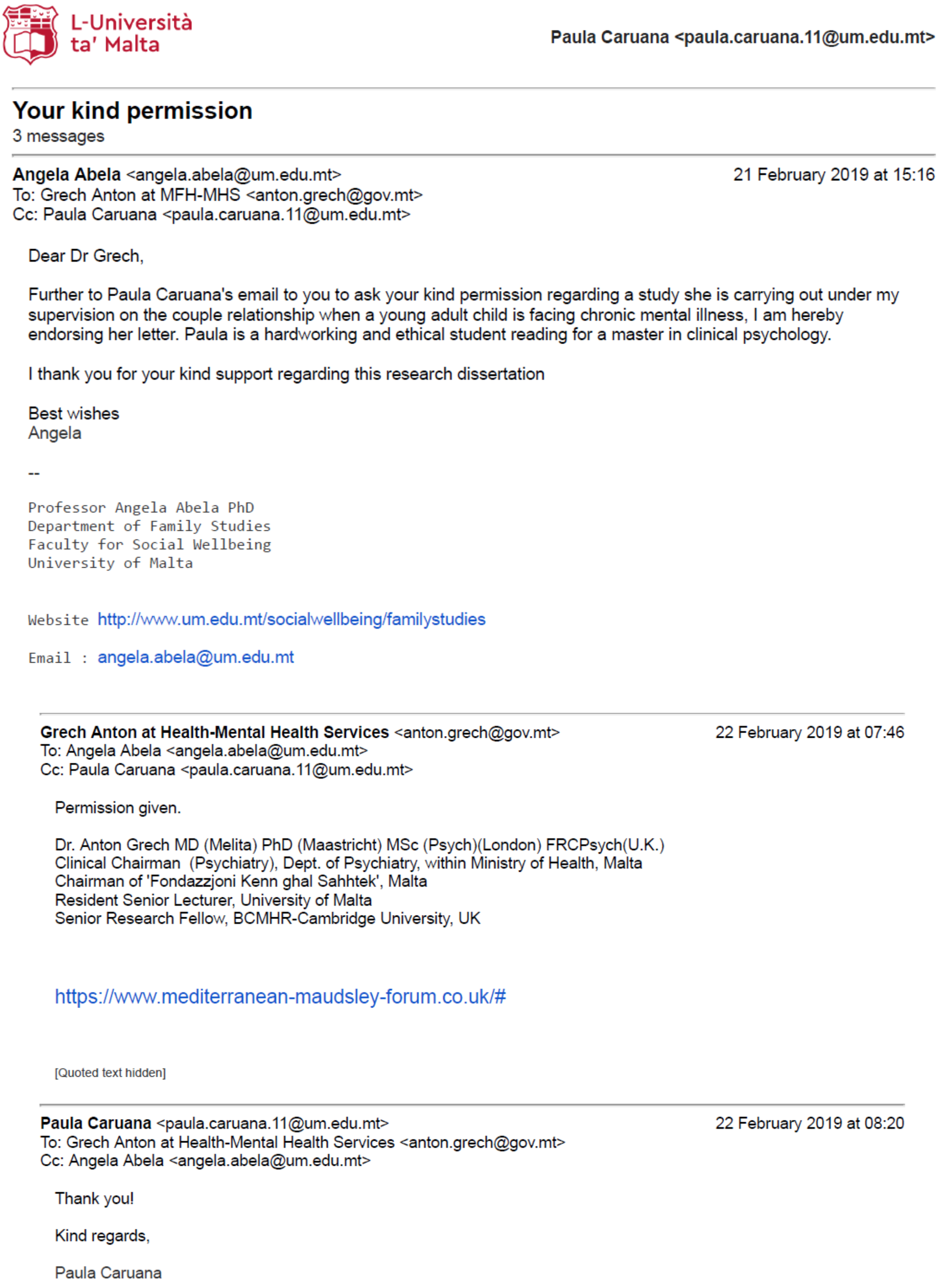
Website: www.um.edu.mt/socialwellbeing/students/researchethics

On Fri, 22 Feb 2019 at 21:19, Paula Caruana <paula.caruana.11@um.edu.mt> wrote:

> Reference Number: FRECSWB_1718_165
>
> Dear Ms Agius,
>
> Further to our phone call exchange yesterday, I am sending a gentle request for another ethics approval due to difficulty in finding participants for my study entitled: *The perceived impact on the couple relationship, when an adult child has a mental illness.*
>
> In my original proposal, I had approval of access of participants from NGOs Richmond Foundation and St Jeanne Antide Foundation. However I had difficulty in recruiting enough participants.
> For this reason, I have requested the approval of access of participants from Mental Health Services, for which Dr Anton Grech approved my request. Attached please find the emails with the request and approval from Dr Grech regarding access of participants from Mental Health Services. My supervisor Prof Angela Abela endorsed my request, as seen in the attached files.
>
> I attached all the necessary documents should you need to refer to them.
>
> Could you kindly confirm ethics approval for the above? Thank you for your assistance!
>
> Regards,
>
> Paula Caruana
> 118893 M
>
> Clinical psychology trainee (M. Psy 2017 – 2019)

Appendix E

Approval for Access to Participants – Mental Health Services



L-Università ta' Malta

Paula Caruana <paula.caruana.11@um.edu.mt>

Your kind permission
3 messages

Angela Abela <angela.abela@um.edu.mt> 21 February 2019 at 15:16
To: Grech Anton at MFH-MHS <anton.grech@gov.mt>
Cc: Paula Caruana <paula.caruana.11@um.edu.mt>

Dear Dr Grech,

Further to Paula Caruana's email to you to ask your kind permission regarding a study she is carrying out under my supervision on the couple relationship when a young adult child is facing chronic mental illness, I am hereby endorsing her letter. Paula is a hardworking and ethical student reading for a master in clinical psychology.

I thank you for your kind support regarding this research dissertation

Best wishes
Angela

--

Professor Angela Abela PhD
Department of Family Studies
Faculty for Social Wellbeing
University of Malta

Website http://www.um.edu.mt/socialwellbeing/familystudies

Email : angela.abela@um.edu.mt

Grech Anton at Health-Mental Health Services <anton.grech@gov.mt> 22 February 2019 at 07:46
To: Angela Abela <angela.abela@um.edu.mt>
Cc: Paula Caruana <paula.caruana.11@um.edu.mt>

Permission given.

Dr. Anton Grech MD (Melita) PhD (Maastricht) MSc (Psych)(London) FRCPsych(U.K.)
Clinical Chairman (Psychiatry), Dept. of Psychiatry, within Ministry of Health, Malta
Chairman of 'Fondazzjoni Kenn ghal Sahhtek', Malta
Resident Senior Lecturer, University of Malta
Senior Research Fellow, BCMHR-Cambridge University, UK

https://www.mediterranean-maudsley-forum.co.uk/#

[Quoted text hidden]

Paula Caruana <paula.caruana.11@um.edu.mt> 22 February 2019 at 08:20
To: Grech Anton at Health-Mental Health Services <anton.grech@gov.mt>
Cc: Angela Abela <angela.abela@um.edu.mt>

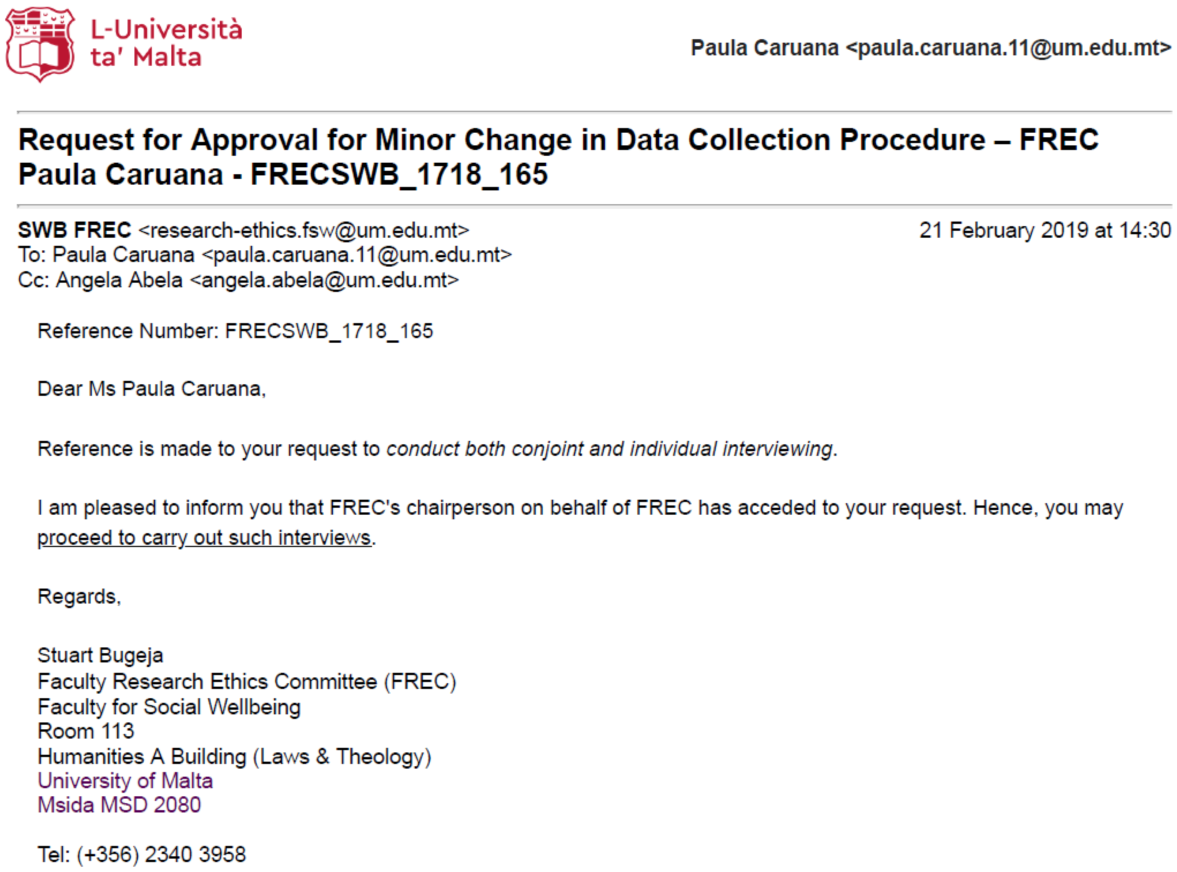
Thank you!

Kind regards,

Paula Caruana

Appendix F

FREC Approval for Request of Individual and Conjoint Couple Interviews



L-Università ta' Malta

Paula Caruana <paula.caruana.11@um.edu.mt>

Request for Approval for Minor Change in Data Collection Procedure – FREC Paula Caruana - FRECSWB_1718_165

SWB FREC <research-ethics.fsw@um.edu.mt> 21 February 2019 at 14:30
To: Paula Caruana <paula.caruana.11@um.edu.mt>
Cc: Angela Abela <angela.abela@um.edu.mt>

Reference Number: FRECSWB_1718_165

Dear Ms Paula Caruana,

Reference is made to your request to *conduct both conjoint and individual interviewing*.

I am pleased to inform you that FREC's chairperson on behalf of FREC has acceded to your request. Hence, you may proceed to carry out such interviews.

Regards,

Stuart Bugeja
Faculty Research Ethics Committee (FREC)
Faculty for Social Wellbeing
Room 113
Humanities A Building (Laws & Theology)
University of Malta
Msida MSD 2080

Tel: (+356) 2340 3958

Appendix G

Semi-Structured Interview Guide for Individual Interviews– English Version

Individual Interview Guide

1. I am interested in hearing about your experience of caregiving your son / daughter.
    a. What does 'caregiving' mean to you?
    b. What is the experience like?
2. I wonder if you could tell me, what were your initial thoughts and feelings when you noticed that your son / daughter was experiencing mental health difficulties or was diagnosed with a mental illness?
    a. What did it mean for you to discover that your son / daughter has a mental health problem?
3. How would you describe your relationship with your partner before the onset of your son's/daughter's mental illness?
    a. Did the relationship change in any way after you took the caregiving role? If yes, in what way?
    b. How did this influence your relationship as a couple?
4. What impact did caregiving have on your relationship?
    a. Did this impact your life, in any way? If yes, how so?
        i. Where there any activities you used to do which changed, or stopped, due to being a caregiver?
        ii. Communication patterns / disagreements / arguments
        iii. Roles within the house
        iv. Time together / intimacy / affection
        v. Other social relationships / support
5. Can you tell me about how you are coping during this time? How do you think your partner perceives your coping?

6. Are there any strengths you think you may have developed or expanded as an outcome of your experience?
7. I wonder if you could talk about a typical day at home whilst caregiving for your son / daughter?
8. How is the relationship with your son / daughter like? Did you notice any changes from your relationship before and after the illness was diagnosed?
9. How is the relationship with your other children like? Did you notice any changes from your relationship before and after the illness was diagnosed?
10. Did the impact of your son's / daughter's illness have an effect on his/her siblings?
    a. If so, did this impact influence your relationship as a couple? How so?
11. Is there any support you find useful for yourself? If not, what kind of support would you like to receive?
12. We have reached the end of this interview, is there anything else that you would like to add or comment on? Is there anything you wished I asked you that I did not?

Appendix H

Semi-Structured Interview Guide – Maltese Version

Gwida għall-intervista Individwali

1. Jien interessata nisma' dwar l-esperjenza tiegħek li ta' tieħu ħsieb lil ibnek/bintek.
    a. Xi tfisser għalik li tagħti kura?
    b. Kif inhi din l-esperjenza għalik?
2. Nixtieqek kieku tgħidli, x'kienu l-ewwel ħsibijiet, u x'ħassejt, meta ndunajt li ibnek/bintek kien għaddej minn diffikultajiet ta' saħħa mentali / jew li kien qed isofri minn mard mentali?
    a. X'kien ifisser għalik meta sirt taf li ibnek/bintek għandu/għandha problema ta' saħħa mentali?
3. Kif tiddeskrivi r-relazzjoni mal-"partner" (mar-raġel/mara) tiegħek qabel feġġħet il-marda mentali ta' ibnek/bintek?
    a. Ir-relazzjoni nbidlet b'xi mod, wara li inti ħadt ir-rwol ta' "caregiver"? Jekk iva, b'liema mod?
    b. X'effett kellu dan fuq ir-relazzjoni tagħkom bħala koppja?
4. X'effett kellha l-għoti tal-għajnuna fuq ir-relazzjoni tagħkom?
    a. Din affettwatlek ħajtek, b'xi mod? Jekk iva, kif?
        i. Kien hemm xi attivitajiet li kont tagħmel li nbidlu, jew li waqfu, minħabba li kellek tagħti l-għajnuna?
        ii. Modi ta' komunikazzjoni / nuqqas ta'qbil / argumenti
        iii. Rwoli fid-dar
        iv. Ħin flimkien / intimita' / affezzjoni
        v. Relazzjonijiet soċjali oħrajn / sapport
5. Tista' tgħidli dwar kif qed tlaħħaq matul dan iż-żmien? Kif taħseb li l-"partner" (ir-raġel/mara) tiegħek qiegħed jipperċepixxi l-isforzi tiegħek?

6. Kien hemm xi kapaċitajiet li rawwimt fik jew li saħħaħt bħala riżultat tal-esperjenza tiegħek?
7. Tista' kieku tgħidli dwar ġurnata tipika d-dar, waqt li tkun qed tagħti l-għajnuna lil ibnek / bintek?
8. Kif inhi r-relazzjoni ma ibnek / bintek? Innutajt xi bidliet fir-relazzjoni minn qabel għal wara li feġġħet il-marda?
9. Kif inhi r-relazzjoni ma' l-ulied l-oħra? Innutajt xi bidliet fir-relazzjoni minn qabel għal wara li feġġħet il-marda?
10. Il-marda ta' ibnek / bintek kellha xi effett fuq ħutu / ħutha?
    a. Jekk iva, din kellha effett fuq ir-relazzjoni tagħkom bħala koppja? Kif?
11. Hemm xi sapport li ssibu utli għalikom? Jew inkella li tixtiequ li jkollkom?
12. Wasalna fl-aħħar ta' din l-intervista, hemm xi ħaġa oħra li tixtieq iżżid jew tikkummenta?

Appendix I

Semi-Structured Interview Guide for Couple Interview – English Version

Interview Guide

1. I am interested in hearing about your experiences of caregiving your son / daughter.
    a. What is the experience of ‘caregiving’ like as **a couple**?
2. What did it mean for you as **a couple** discover that your son / daughter has a mental health problem?
3. How would you describe your relationship before the onset of your son’s/daughter’s mental illness?
    a. Did the relationship change in any way after you took the caregiving role? If yes, in what way?
    b. How did this influence your relationship as a couple?
4. What impact did caregiving have on your relationship?
    a. Did this impact your life, in any way? If yes, how so?
        i. Where there any activities you used to do which changed, or stopped, due to being a caregiver?
        ii. Communication patterns / disagreements / arguments
        iii. Roles within the house
        iv. Time together / intimacy / affection
        v. Other social relationships / support
5. Can you tell me about how you are coping during this time? How do you think your partner perceives your coping?
6. Are there any strengths you think you may have developed or expanded as an outcome of your experience?
7. **Looking back at this experience, what helped you to get through this experience together?**

8. How is the relationship with your son /daughter like? Did you notice any changes from your relationship before and after the illness was diagnosed?
9. How is the relationship with your other children like? Did you notice any changes from your relationship before and after the illness was diagnosed?
10. Did the impact of your son's or daughter's illness have an effect on his or her siblings?
    a. If so, did this impact influence your relationship as a couple? How so?
11. Is there any support you find useful for yourself? If not, what kind of support would you like to receive?
12. **How do you see yourselves similar and different from other couples you know?**
13. **How do you see your future as a couple?**
14. We have reached the end of this interview, is there anything else that you would like to add or comment on? Is there anything you wished I asked you that I did not?

Appendix J

Semi-Structured Interview Guide for Couple Interview– Maltese Version

Gwida għall-intervista tal-Koppja

1. Jien interessata nisma’ dwar l-esperjenza tiegħek li ta’ tieħu ħsieb lil ibnek/bintek.
    a. Kif inhi din l-esperjenza għalikom **bħala koppja**?
2. X’kien ifisser għalikom **bħala koppja** meta sirtu taf li t-tifel/tifla għandu/għandha problema ta’ saħħa mentali?
3. Kif tiddeskrivu r-relazzjoni tagħkom qabel feġġħet il-marda mentali ta’ ibnek/bintek?
    a. Ir-relazzjoni nbidlet b’xi mod, wara li inti ħadt ir-rwol ta’ “caregiver”? Jekk iva, b’liema mod?
    b. X’effett kellu dan fuq ir-relazzjoni tagħkom bħala koppja?
4. X’effett kellha l-għoti tal-għajnuna fuq ir-relazzjoni tagħkom?
    a. Din affettwatlek ħajtek, b’xi mod? Jekk iva, kif?
        vi. Kien hemm xi attivitajiet li kont tagħmel li nbidlu, jew li waqfu, minħabba li kellek tagħti l-għajnuna?
        vii. Modi ta’ komunikazzjoni / nuqqas ta’qbil / argumenti
        viii. Rwoli fid-dar
        ix. Ħin flimkien / intimita’ / affezzjoni
        x. Relazzjonijiet soċjali oħrajn / sapport
5. Tista’ tgħidli dwar kif qed tlaħħaq matul dan iż-żmien? Kif taħseb li l-“partner” (ir-raġel/mara) tiegħek qiegħed jipperċepixxi l-isforzi tiegħek?
6. Kien hemm xi kapaċitajiet li rawwimt fik jew li saħħaħt bħala riżultat tal-esperjenza tiegħek?
7. **Meta tħarsu lura, x’għinkom taffrontaw din l-esperjenza flimkien?**
8. Kif inhi r-relazzjoni ma ibnek / bintek? Innutajt xi bidliet fir-relazzjoni minn qabel għal wara li feġġħet il-marda?

9. Kif inhi r-relazzjoni ma’ l-ulied l-oħra? Innutajt xi bidliet fir-relazzjoni minn qabel għal wara li feġġħet il-marda?
10. Il-marda ta’ ibnek / bintek kellha xi effett fuq ħutu / ħutha?
    a. Jekk iva, din kellha effett fuq ir-relazzjoni tagħkom bħala koppja? Kif?
11. Hemm xi sapport li ssibu utli għalikom? Jew inkella li tixtiequ li jkollkom?
12. **Kif taraw lilkom simili u differenti minn koppji oħrajn?**
13. **Kif taraw il-futur tagħkom bħala koppja?**
14. Wasalna fl-aħħar ta’ din l-intervista, hemm xi ħaġa oħra li tixtiequ iżżidu jew tikkummentaw fuqha?

Appendix K

Excerpt of Analysed Individual Transcript

Comments/Reflections	Anna's Individual Interview Transcript	Emergent Themes
	Interviewer: So, to start off, I'd like to know a bit about your experience of caregiving your son, if you had to define caregiving, what does it mean to you?	
	Anna: Caregiving... not with a child with problems, or caregiving in general?	
	I: Caregiving in general, but particularly in your experience of having a son with	
Describing caregiving: Mother's empathy – placing child first and foremost	A: ah! In my experience, caregiving would be, erm, first of all, you have to be very calm and try not to show your emotions, to a person, who's suffering from mental illness, and try to think, about, his problems first, rather than yours. His problems obviously come before your frustrations and things, otherwise… you would have lost the battle…	Caregiving means keeping calm and regulating one's emotions Caregiving means putting child's needs first
	I: mhm	
Mother talks about difficulty in caregiving and dealing with adult child with mental illness	A: …in dealing with a person like that... which is difficult obviously, coz sometimes without wanting to, you lose control, but basically… I would think that, as caregiving, that is the, the crux of trying to be with someone like that, when you try to put him first, his condition, try to put yourself in his mind, which is… sometimes… impossible. And then, you can start to care for that person, in that state... that...	Caregiving means that without wanting you, you lose control Caregiving means putting child's needs first Caregiving means being empathic
	I: seeing his, really seeing his, experience, kind of…	
Child experiencing difficulties due to psychotic symptoms – mother is aware that although hallucinations are not real, for the person, such symptoms are still very distressing	A: yes, erm, seeing what he suffers from, and although he would not be… you would know that it's not, real… what he's passing through, or what he's seeing... what he's passing through is real! But what he's imaging would not be real...	Caregiving means empathizing with and understanding child's symptoms
	I: mhm	

– and need empathy and understanding She does not want to deceive him. She empathises with the symptoms he experiences	A: it's different... it's very difficult to sort of... you're not gonna tell him, "yes I'm a seeing what you're seeing" coz you can't say that. But on the other hand, you can say "yes I know the condition that you are suffering from, and I know that you are seeing it that way, but it is not that way". I cannot lie and say "I'm seeing something" which I'm not... that's what I would… fhimt… A: mhm... and what's the experience like for you to be a caregiver?	Mother's difficulty to attend to child experiencing delusions and hallucinations Caregiving means be being truthful to child in a respectful and careful way
Mother starts crying when talking about experience of caregiving; this was a touching moment. The mother's heartache was evident…	I: ... ah it entails a lot, obviously, it entails a lot of perseverance... it entails... a lot of heartache... [tearful] … …. especially when up to the age of 18 he was… not like this... but, you have to face facts and live the best way possible... and obviously then it effects also, if you're married, your daughter... and... in my case my daughter, and my husband, everyone…	Caregiving means perseverance and heartache Caregiving means a process of grief and loss Caregiving means facing the facts and living the best way possible
Mother speaks about experience effecting all family members, her work life experience, "whole life"… [systemic effect?]	I: Mhm... in what way A: and friends and family, everything, …and work! It effects the whole life, basically… I: aha, I can imagine even thinking about the effects of it… is hard... it's difficult…	The illness effects on marriage, other children, social relationships, work everyone
Mother talks about issue becoming a difficulty when son hurt people outside of the family… at the same time she seemed ambivalent because she did not feel it is right to talk about her son's illness to outsiders… perhaps they would understand more? Why so? Stigma? Fear of hurting others?	A: aha, because when the person who is, who suffers from this condition hurts you or your husband, it's one thing, it's perceived in the family… but then when you see him hurting outsiders... at the same time, you're restricted to tell them exactly what he suffers from, maybe, coz then there's, you know, his personal, life... …and at the same time, he would be in an uncontrollable state sometimes, and that is the worst part, when he would be in an uncontrollable state in front of people. That… because at home… you stay at home. But when he's in front of people…	Facing the dilemma of protecting child's privacy and disclosing his condition to explain his behaviour to outsiders The symptoms can lead to the adult child hurting outsiders Preferring to stay home when child is unwell to avoid distress of having to manage him in front of outsiders

Appendix L

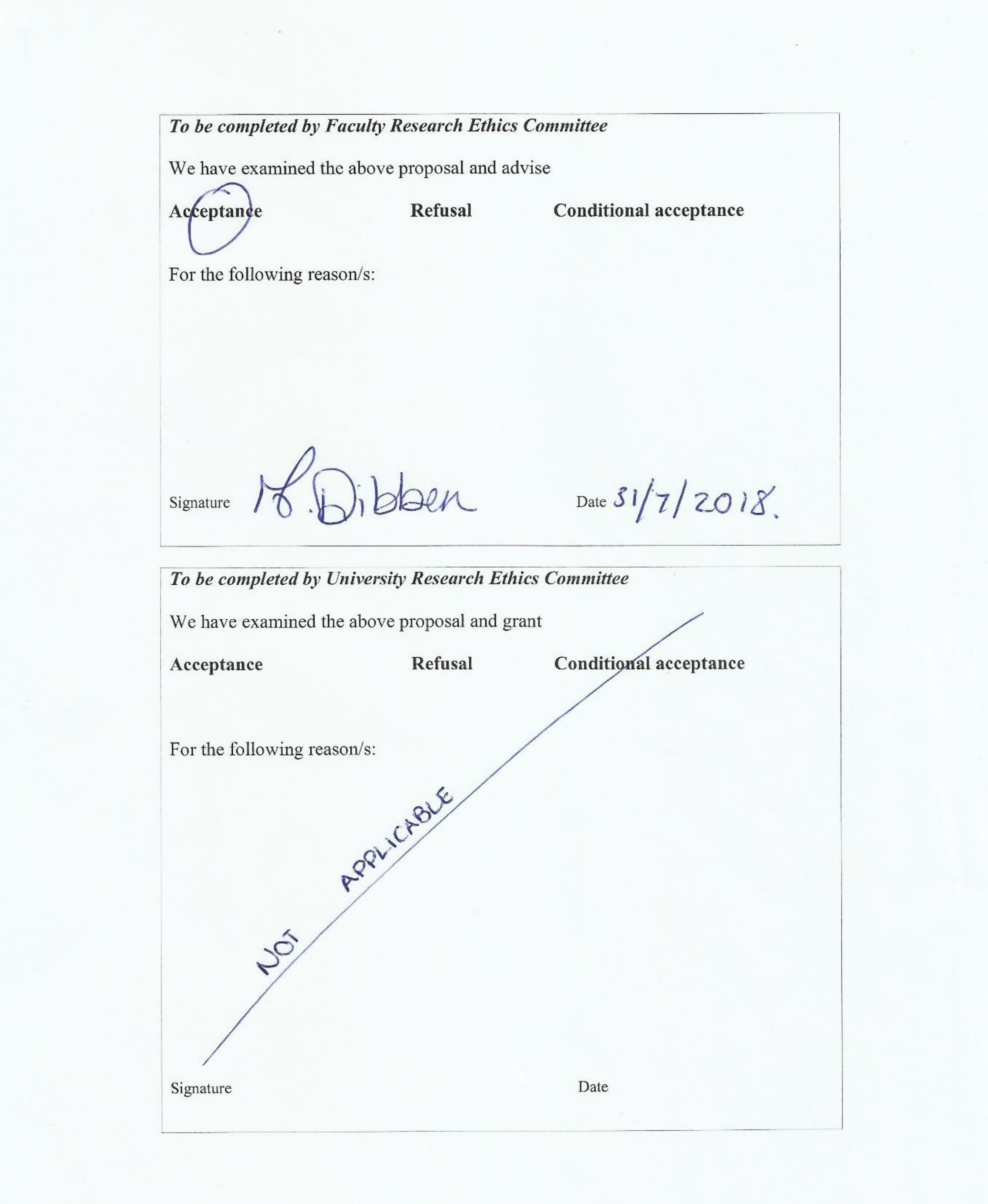
Excerpt of Analysed Couple Interview Transcript

Comments/Reflections	Anna and Anton’s Conjoint Interview Transcript	Emergent Themes
	Interviewer: looking back at this experience, what do you think helped you get through out together, as a couple… the difficult moments…	
Anton seems weary to reflect on his experiences; he seems more driven to keep on moving forward day by day….	Anton: I don’t know… You just continue… with life… basically… you go from one thing to the other… Alla hares you stay thinking about… what you pass through ghax kieku… you won’t	Husband acknowledging the importance of resilience rather than stopping to think
Anna speaks about the hardships they endured due to their son’s illness… her husband seemed aware to give himself time alone when in a tense situation (beyond his control), whilst dealing with a crisis concerning their son… Anna saw this as a positive trait…	Anna: u we passed through a lot! Uw, it’s not the first time Anton used to spark and leave and say, “ahjar I leave… go for a drive with the car… milli… I can’t handle the situation in here with Nathaniel, ahjar milli nisplodih” which is good u, if he can’t handle it anymore in a sensible way… ahjar you move out… probably… I don’t think I used to do it that much, I don’t know… qas naf…. Imma Anton’s way of handling it was that, when it was beyond his control…	Wife acknowledging the difficulty they endured as a couple Acknowledging husband’s way of handling son’s issue was to get away
	I: mhm mhm… so you saw it as kind of, “let’s move, let’s move from one thing to the next” because stopping to think for you, might have…	
Husband acknowledges that life is not easy, and if it wasn’t for Nathaniel’s issues, then other issues would occur too… (this seems to be a pessimistic view from Anton’s perspective, but realistic too!)	Anton: ifhem… it’s not an easy way, but life is not easy, anytime, igifieri, whatever it is… if it’s not Nathaniel, it’s something else	Husband acknowledging the difficulty in life and the other issues that can cause difficulties within a relationship
	I: aha ah	
Mother is aware that sometimes her husband and herself could not take the situation anymore....	Anna: imsomma it’s not the first time Anton used to tell me, “I don’t know if I can keep on going like this anymore”… and even me, at certain times, you say it… I used to tell him, “I’ve had enough of it”…sorry… you feel you want to get away…	Acknowledging couple’s moments of giving up from situation The commitment and responsibility towards the family encouraged the couple to carry on during son’s difficult moments
	I: aha, yes…	

but then she adds that she is aware that that would have meant giving up…	W: uh but that's running away from reality…	
	I: mhm mhm… so what helped in those moments do you think? When you…	
The wife's love for the family and her commitment helped her during those moments	Anna: with me, it's the love of my family aye, and, and… your responsibility and commitment…	Commitment and love towards family supported wife in difficult moments
	I: mhm	Husband's letting go of certain worries to carry on moving forward
Anton noted that being committed to a long marriage supported him during the difficult moments… he notes that if they wanted to leave/separate, there were many moments they could have… but they did not…	Anton: basically you're committed to the… marriage… and you… just don't give up… la, we're in our… what? 30th year now… of marriage igifieri… if we had wanted to leave, want to… there were many times that you could leave, igifieri… imma… I just…. Go on, continue… igifieri…	Husband acknowledging that issues happen in life and one must continue moving forward
	I: aha…	
Anton noted that he does the best he can, to move forward…	Anton: you do what you can, the best you can… and you continue going, move forward uw…	
	I: mhm…	
I'm unsure of husband here: is he speaking truthfully here? Or did he give up on his daughter ever coming back? The wife, in fact then makes a funny face and says that her husband has not yet accepted their daughter's departure to another country…	H: issa imbilli noqghodu nghidu, "ghax dik hemm, u dan hawn, u din hemm"… ah… she wants to get… [… omitted to protect anonymity] she wants to leave to [country out of Europe], she left! Eqq… m'hemmx x'taghmel igifieri… things happen in life uw… igifieri… heqq… you can't stop, because of things, you have to continue… I: mhm Anton: [looks at wife] xi gralek Anna? Anna: [chuckles] he hasn't accepted it, that she left, imma imsomma… eh…	Husband: accepting children's decisions and giving in to life challenges Husband's perseverance in the face of obstacles Husband's resentment of daughter's departure (according to wife)
Anton seems to say that it is 'useless' accepting the situation of not, because he has no control over it…	Anton: you have to accept it, you don't have to accept it, it's there… it's there [chuckles] so accept it or you don't!	Lack of control over daughter's decision
	I: aha…	

Appendix M

University of Malta Faculty Research Ethics Committees' (FREC) Approval



To be completed by Faculty Research Ethics Committee

We have examined the above proposal and advise

[✓ **Acceptance**] **Refusal** **Conditional acceptance**

For the following reason/s:

Signature M. Dibben Date 31/7/2018.

To be completed by University Research Ethics Committee

We have examined the above proposal and grant

Acceptance **Refusal** **Conditional acceptance**

For the following reason/s:

NOT APPLICABLE

Signature Date

Appendix N

Information Sheet for Participants – English Version

Dear participant,

Thank you for showing interest in my research study. This document will be providing you with the necessary information you may require before consenting to take part in my study.

Research title: The perceived impact of maternal caregiving on the couple relationship, when an adult child has a severe mental illness.

Brief description of the study

The purpose of this research is to explore the perceived impact of maternal caregiving on the couple relationship, when an adult child has the severe mental illness. This study is being carried out as partial fulfilment of a Masters in Clinical Psychology, at the University of Malta.

Participants

To make this research possible, I would like to interview heterosexual, married couples, who have an adult child with a severe mental illness. The couples will be recruited via organisations, such as Richmond Foundation, St Jeanne Antide Foundation, or Mental Health Services, to participate in this research study, by discussing a number of questions.

Adult Children

The children of the participants will not be interviewed, however, information about the study will be given to them, and approval about the study from the adult children will be required through a consent form.

Interviews

Each participant is being asked to take part in two interviews of around 60 to 90 minutes. One of these interviews shall be carried out individually, whereas another one shall be carried out as a couple. Both partners are required to give their consent to participate in the study. For data collection purposes, the interviews will be audio-recorded. The interviews can take place at your homes, or where you feel most comfortable.

I am very eager to hear your experiences. Nevertheless, you are free to disclose as much information as you would like, and you also have the right not to respond to questions that you would not like to answer. Participation is voluntary and confidential. You also have the right to withdraw at any point of the study. All information, and digital recordings will be destroyed following the completion of the research. Should you wish to participate and then receive a copy of the study, do let me know.

Your participation is highly valuable as it can shed light on the impact on couple relationships when caring for an adult child with a mental illness, which is an area which hasn't been researched yet. Your contribution can therefore help create more awareness on the experiences and impacts of caregiving on the couple relationship and quite possibly inform professionals on the needs of couples passing through similar experiences.

Should you be interested in participating in the study, please contact me on my mobile number, or send me an e-mail using the details below.

I look forward to hearing from you!

Regards,

______________________	______________________
Researcher - Paula Caruana	Tutor – Prof Angela Abela
M. Psy Clinical Psychology Trainee	
University of Malta	

E-mail address: paula.caruana.11@um.edu.mt
Mob no: 79306039
Address: 10, Papillon, E. H. Furse street, Msida

Appendix O

Information Sheet for Participants – Maltese Version

Paġna ta’ informazzjoni

Għażiż parteċipant,

Grazzi talli wrejt interess fl-istudju u r-riċerka tiegħi. Dan id-dokument ser jagħtik l-informazzjoni meħtieġa qabel tagħti l-kunsens tiegħek biex tieħu sehem fir-riċerka tiegħi.

Titlu tar-riċerka: Kif l-għoti tal-għajnuna mill-omm tidher li taffettwa r-relazzjoni tal-koppja, meta l-wild adult ikollu kundizzjoni ta’ saħħa mentali severa.

Spjegazzjoni qasira tal-istudju

L-għan ta’ din ir-riċerka hu li tinvestiga kif l-għoti tal-għajnuna mill-omm tidher li taffettwa r-relazzjoni tal-koppja, meta l-wild adult ikollu disabbilita mentali severa. Dan l-istudju qed isir bħala parti mir-rekwiżiti għal “Masters” fil-Psikologija Klinika, fl-Universita’ ta’Malta.

Parteċipanti

Biex din ir-riċerka tkun tista’ssir, nixtieq nintervista koppji miżżewġin eterosesswali li għandhom wild adult b’kundizzjoni ta’ saħħa mentali severa. Il-koppji ser jiġu avviċinati permezz ta’ organizzazzjonijiet, bħal “Richmond Foundation”, “St Jeanne Antide Foundation” jew “Mental Health Services”, biex jieħdu sehem f’din ir-riċerka, billi ssir diskussjoni fuq numru ta’ mistoqsijiet.

L-ulied tal-parteċipanti

L-ulied adulti tal-parteċipanti mhumiex ser jiġu intervistati. Għaldaqstant, l-ulied ser jingħatu l-informazzjoni dwar l-istudju, kif ukoll jkunu mitluba biex jagħtu l-kunsens tagħhom bhala terzi persuni (third-party) fl-istudju.

Intervisti

Kull parteċipant qed jiġi mitlub biex ikun intervistat darbtejn; darba waħdu, u darba f'intervista konġunta bħala koppja. Il-parteċipazzjoni tagħkom tkun tinvolvi ħin ta' madwar 60 - 90 minuta f'kull intervista. . Iż-żewġ partijiet ikunu meħtieġa li jagħtu l-kunsens tagħhom biex jieħdu sehem fl-istudju. Għal skopijiet ta' ġbir ta' informazzjoni, l-intervisti ser ikunu rrekordjati. L-intervisti jistgħu isiru fid-djar tagħkom, jew fejn tħossukom l-aktar komdi.

Għandi ħafna entużjażmu biex nisma' l-esperjenzi tagħkom. Madankollu, intom liberi tagħtu informazzjoni daqs u kemm tridu, u għandkom ukoll id-dritt li ma tirrispondux għal mistoqsijiet li ma tixtiqux twieġbu. Il-parteċipazzjoni hija volontarja u kunfidenzjali. Għandkom ukoll id-dritt li tirrevokaw il-kunsens tagħkom fi kwalunkwe stadju u ma tibqgħux tieħdu sehem fl-istudju. Kull informazzjoni, u r-"recordings" diġitali jiġu distrutti wara l-konklużjoni tar-riċerka Jekk tixtieq tipparteċipa u imbagħad tirċevi kopja ta' l-istudju, għidli.

Il-parteċipazzjoni tiegħek hija ta' valur kbir għax tista' titfa' dawl fuq kif l-għoti tal-għajnuna taffettwa r-relazzjoni tal-koppja, meta l-wild adult ikollu kundizzjoni ta' saħħa mentali severa, li hu suġġett li għadu ma ġiex riċerkat. Il-kontribuzzjoni tiegħek tista' allura tgħin biex jinħoloq iżjed għarfien dwar l-esperjenzi u l-effetti fuq ir-relazzjoni tal-koppja u possibilment tinforma lil professjonisti fuq il-bżonnijiet ta' koppji għaddejjin minn esperjenzi simili.

Jekk inti interessata li tipparteċipa fl-istudju, jekk jogħġbok ikkuntattjani bil-mowbajl, jew ibagħtli "e-mail" kif jidher hawn taħt.

Nistenna bil-ħerqa li nisma' minn għandek!

Inselli għalik,

Riċerkatriċi - Paula Caruana	Tutor – Prof Angela Abela
M. Psy Clinical Psychology Trainee	Faculty of Social Wellbeing
University of Malta	University of Malta

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Appendix P

Consent Form for Participants – English Version

Research title: The perceived impact of maternal caregiving on the couple relationship, when an adult child has a severe mental illness.

Dear participant,

Thank you for your interest in participating in this study concerning the perceived impact of maternal caregiving as experienced by the couple, when an adult child has a severe mental illness. In order to proceed to the interview process, you are kindly requested to grant your consent below:

I, here the undersigned, give my consent to participate in the above stated research being conducted by Paula Caruana, Masters of Clinical Psychology student within the University of Malta, and supervised by Prof Angela Abela.

I confirm that this research project has been explained to me, and I have read the Information Sheet about the research study whose title appears above. I have had the opportunity to consider the information and clarify all my concerns about my participation in the research.

I understand that agreeing to participate means that I am willing to be interviewed, individually, and with my partner, by the researcher; and allow the interviews to be audio-recorded digitally.

Data protection

I am aware that any information I provide is confidential and will be accessible only to the researcher, Paula Caruana, and the tutor of this study, Prof. Angela Abela.

I understand that this research will be submitted to the University of Malta.

No real names will be used during the interviews.

No identifiable personal data will be published and none of the identifiable data will be shared with any other organization.

I understand that no information that could lead to my identification will be disclosed in any reports on the research or to any other party.

The digital audio-recording will be erased after the research is complete.

Withdrawal from study

I understand that my participation is voluntary and I can withdraw from this study at any stage, without being disadvantaged in any way.

I have read the information sheet and consent form, and have been given a copy of both.

________________________	________________________
Participant’s signature	Participant’s signature
________________________	________________________
Researcher - Paula Caruana	Tutor – Prof Angela Abela

M. Psy Clinical Psychology Trainee
University of Malta

E-mail address: paula.caruana.11@um.edu.mt
Mob no: 79306039
Address: 10, Papillon, E. H. Furse street, Msida

Appendix Q

Consent Form for Participants – Maltese Version

Formola tal-Kunsens

Titlu tar-riċerka: Kif l-għoti tal-għajnuna mill-omm tidher li taffettwa r-relazzjoni tal-koppja, meta l-wild adult ikollu disabbilita mentali severa.

Għażiż parteċipant,
Grazzi ta' l-interess tiegħek li tieħu sehem f'dan l-istudju dwar kif l-għoti tal-għajnuna mill-omm tidher li taffettwa r-relazzjoni tal-koppja, meta l-wild adult ikollu kundizzjoni ta' saħħa mentali severa. Biex ikun jista jibda l-proċess tal-intervista, inti ġentilment mitlub/a tagħti l-kunsens tiegħek hawn taħt:

Jiena, hawn taħt iffermat/a, nagħti l-kunsens tiegħi biex nieħu sehem fir-riċerka msemmija hawn fuq li se'ssir minn Paula Caruana, studenta għal "Masters of Clinical Psychology" fl-Universita' ta' Malta, taħt it-tmexxija ta' Prof Angela Abela.

Nikkonferma li dan il-proġett ta' riċerka ġie spjegat lili, u li qrajt il-'Paġna ta' Informazzjoni' dwar l-istudju ta' riċerka li t-titlu tiegħu jidher hawn fuq. Kelli l-opportunità nirrefletti fuq l-informazzjoni u niċċara l-biżgħat kollha tiegħi dwar il-parteċipazzjoni tiegħi fir-riċerka. Nifhem li l-kunsens li nieħu sehem ifisser li jiena ppreparat/a li niġi intervistat/a waħdi, uflimkien mal-"partner" tiegħi, mir-riċerkatriċi; u nippermetti li l-intervistijiġi rrekordjati b'mod diġitali.

Protezzjoni tad-"Data"

Jiena konxja li kull informazzjoni li nagħti hija kunfidenzjali u li tkun aċċessibbli biss lir-riċerkatriċi, Paula Caruana, u lit-"tutor" tal-istudju, Prof. Angela Abela.
Nifhem li din ir-riċerka ser tiġi pprezentata lill-Università ta' Malta.
Mhux ser jintużaw ismijiet veri waqt l-intervisti.
L-ebda informazzjoni personali u privata mhu' ser tiġi ppubblikata u l-ebda informazzjoni privata mhu' ser tintwera lil ebda organizzazzjoni oħra.
Nifhem li l-ebda informazzjoni li tista tindika l-identita' tiegħi mhu' ser tinkixef fl-ebda rapporti dwar ir-riċerka jew lil ebda parti oħra.

L-“audio-recording” diġitali ser jiġi mħassar wara l-konklużjoni tar-riċerka.

Rinunzja mill-istudju

Nifhem li l-parteċipazzjoni tiegħi hija volontarja u li nista nirtira minn dan l-istudju fi kwalunkwe stadju, mingħajr ma nsofri l-ebda konsegwenzi.
Qrajt il-paġna ta’ informazzjoni u l-formola tal-kunsens, u ġejt mogħtija kopja tat-tnejn.

Firma tal-partiċipant

Firma tal-partiċipant

Riċerkatriċi - Paula Caruana
M. Psy Clinical Psychology Trainee
University of Malta

Tutor – Prof Angela Abela
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Appendix R

Consent Form for Third Party (Adult Children) – English Version

Research title: The perceived impact of maternal caregiving on the couple relationship, when an adult child has a severe mental illness.

Dear participant,

Thank you for your interest in participating in this study concerning the perceived impact of maternal caregiving as experienced by the couple, when an adult child has a severe mental illness. In order to proceed to the interview process, you are kindly requested to grant your consent below:

I, here the undersigned, give my consent for my parents to participate in the above stated research being conducted by Paula Caruana, Masters of Clinical Psychology student within the University of Malta, and supervised by Prof Angela Abela.

I confirm that this research project has been explained to me, and I have read the Information Sheet about the research study whose title appears above. I have had the opportunity to consider the information and clarify all my concerns about my parents' participation in the research.

I understand that agreeing to my parents' participation means that I am willing that they are interviewed individually and together, and asked about the perceived impact of maternal caregiving on the couple relationship.

Data protection

I am aware that any information I provide is confidential and will be accessible only to the researcher, Paula Caruana, and the tutor of this study, Prof. Angela Abela.

I understand that this research will be submitted to the University of Malta.

No real names will be used during the interviews.

No identifiable personal data will be published and none of the identifiable data will be shared with any other organization.

I understand that no information that could lead to my, or my parents' identification will be disclosed in any reports on the research or to any other party.

The digital audio-recording will be erased after the research is complete.

Withdrawal from study

I understand that my participation, as well as my parents', is voluntary, and I can withdraw from this study at any stage, without being disadvantaged in any way.

I have read the information sheet and consent form, and have been given a copy of both.

____

Third party's signature

__________________________ __________________________

Researcher - Paula Caruana Tutor – Prof Angela Abela

M. Psy Clinical Psychology Trainee
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Appendix S

Consent Form for Third Party (Adult Children) – Maltese Version

Formola tal-Kunsens għal Terzi Persuni (Third Party)

Titlu tar-riċerka: Kif l-għoti tal-għajnuna mill-omm tidher li taffettwa r-relazzjoni tal-koppja, meta l-wild adult ikollu disabbilita mentali severa.

Għażiż parteċipant,
Grazzi ta' l-interess tiegħek li tieħu sehem f'dan l-istudju dwar kif l-għoti tal-għajnuna mill-omm tidher li taffettwa r-relazzjoni tal-koppja, meta l-wild adult ikollu kundizzjoni ta' saħħa mentali severa. Biex ikun jista jibda l-proċess tal-intervisti, inti ġentilment mitlub/a tagħti l-kunsens tiegħek hawn taħt:

Jiena, hawn taħt iffirmat/a, nagħti l-kunsens tiegħi sabiex il-ġenituri tiegħi jieħdu sehem fir-riċerka msemmija hawn fuq li se'ssir minn Paula Caruana, studenta għal "Masters of Clinical Psychology" fl-Universita' ta' Malta, taħt it-tmexxija ta' Prof Angela Abela.

Nikkonferma li dan il-proġett ta' riċerka ġie spjegat lili, u li qrajt il-'Paġna ta' Informazzjoni' dwar l-istudju ta' riċerka li t-titlu tiegħu jidher hawn fuq. Kelli l-opportunità nirrefletti fuq l-informazzjoni u niċċara l-biżgħat kollha tiegħi dwar il-parteċipazzjoni tal-ġenituri tiegħi fir-riċerka. Nifhem li l-kunsens li nieħu sehem ifisser li jiena naċċetta li l-ġenituri tiegħi jiġu intervistati mir-riċerkatriċi; u nippermetti li l-intervisti jiġi rrekordjati b'mod diġitali.

Protezzjoni tad-"Data"

Jiena konxja li kull informazzjoni li tingħata hija kunfidenzjali u li tkun aċċessibbli biss lir-riċerkatriċi, Paula Caruana, u lit-"tutor" tal-istudju, Prof. Angela Abela. Nifhem li din ir-riċerka ser tiġi pprezentata lill-Università ta' Malta.
Mhux ser jintużaw ismijiet veri waqt l-intervisti.
L-ebda informazzjoni personali u privata mhu' ser tiġi ppubblikata u l-ebda informazzjoni privata mhu' ser tintwera lil ebda organizzazzjoni oħra.
Nifhem li l-ebda informazzjoni li tista tindika l-identita' tiegħi u tal-genituri tiegħi, mhu' ser tinkixef fl-ebda rapporti dwar ir-riċerka jew lil ebda parti oħra.
L-"audio-recording" diġitali ser jiġi mħassar wara l-konklużjoni tar-riċerka.

Rinunzja mill-istudju

Nifhem li l-parteċipazzjoni tiegħi hija volontarja u li nista nirtira minn dan l-istudju fi kwalunkwe stadju, mingħajr ma nsofri l-ebda konsegwenzi.
Qrajt il-paġna ta' informazzjoni u l-formola tal-kunsens, u ġejt mogħtija kopja tat-tnejn.

____

Firma tat-terza persuna (third-party)

__________________________	__________________________
Riċerkatriċi - Paula Caruana	Tutor – Prof Angela Abela
M. Psy Clinical Psychology Trainee	Faculty of Social Wellbeing
University of Malta	University of Malta

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