United We Stand, Divided We Fall:

Exploring the Quality of the Marital Relationship of Parents of Adults with Intellectual Disabilities Currently Making Use of Residential Care

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Declaration of Authenticity

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I, the undersigned, hereby declare that this dissertation titled: "*United We Stand, Divided We Fall: Exploring the Quality of the Marital Relationship of Parents of Adults with Intellectual Disabilities Currently Making Use of Residential Care" i*s an original study carried out by myself and the conclusions drawn herein are a result of my own work, unless otherwise acknowledged by citations.

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Abstract

This research explores the in-depth experience of parents of adult children with intellectual disabilities and how the disability affects the quality of their marital relationship. It looks at the challenges the couple has faced throughout their child's development and the evolvement of their of their marital relationship throughout the different stages of the family life cycle, as their child reaches adulthood and moves into residential care. Using a qualitative design, four couples were interviewed and the data was analysed using Interpretative Phenomenological Analysis [IPA]. The examined personal lived experience and meaning they gave to their experience indicate that parenting a child with a disability comes along with a number of challenges, which have an impact on the couples' marital relationships. The participants focused less on the targeted research topic of their marital relationship but rather focused on how their child's disability affected the marital relationship. The marital relationship itself was seen as secondary to the disability. Nonetheless, the couples expressed the mutual support they sought from one another throughout this process. The research elicits the couples' experience of seeking residential care and the change in their marital relationship following this decision.

Key Words: Intellectual disability, marital relationship, parental relationship, disability, residential care, family life-cycle

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Chapter 1: Introduction

This poem was written by one of the parents interviewed for this research study. John wished to share this poem through this study as an expression of his lived experience about parenting his daughter with an intellectual disability.

My One and Only Daughter

He gave her to us and took her away, without enjoying a little of her company.
The sweetness of a girl, the happiness she brings with her.
Because when she was born. I jumped, I cheered, I cried.
We had a girl Nin. We had a girl I told my wife.
But now she is no longer a girl. I only had one thing to say.
Because she didn’t come out well,
I buried myself with sadness.
But God if you are God, but God so you are great, give her well to us,
and sorrow becomes joy.

Binti l-Waħdanija

Taha lilna u ħadielna,
Bla ma gawdejna ftit.
Il-ħlewwa minn ta tifla, il-ferħ li magħħa iġġib.
Għax meta din twelditli, kemm qbiżt, kemm fraħt, kemm bkejt.
Ġiet tifla Nin. Ġiet tifla lill-marti jien bdejt ngħid.
Imma issa ma għadiex tifla. Biss kelli waħda ngħid.
Imma hi ma ħarġietx sewwa,
bid-dwejjaq taghħa infnejt.
Iżda Alla j’hekk int Alla, izda Alla hekk int kbir, għatija sewwa lilna,
u niket ferħ isir,

-John

1.1 Background of the Study

Raising a child with a disability is usually an unexpected experience for parents. Having a strong marital relationship is often regarded as one of the protective factors for positive adaptation to certain stressful situations, such as raising a child with a disability. Within families, a transition between one life stage and another represent periods of change where there are shifts in a family's lifestyle. The transition to parenthood is a major developmental period with important implications for parents, for the infant-parent relationship and the infant's development (Deave, Johnson, & Ingram , 2008).

Families may be faced with varying levels of difficulties related to having a child with an intellectual disability. Parents' marital relationship is essential for the emotional status in most families (Lohranpour & Chahartangi, 2016). Mills (2014), found that having a child with an intellectual disability, has resulted in a set of unique stressors that can impact all areas of parents' lives, particularly resulting in an increase in parental stress, financial difficulties, a decrease in the quality of marital relationship, and an overall lower level of well-being.

Through this study I aim at understanding the quality of the parental marital relationship and how parenting an adult child with an intellectual disability may affect this relationship. In doing so, I will be looking at any changes that may have occurred within the marital relationship through their child's different life stages, as they reached adulthood and moved into residential care or supported living.

1.2 Rationale of the Study

An interest in the topic has arisen through my working practice and experience within the disability field. Through my past experience working with children and adolescents with intellectual disabilities in an educational context and also working with adults with intellectual disabilities with the national Agency for persons with Disability in Malta, has led to identifying a gap in the research topic locally. Working with adults with intellectual disabilities as well as their families on a daily basis has allowed me to reflect upon and gain a better understanding of the lived experiences these families and has also allowed me to gain an understanding of the perspectives of both. Throughout my research on the topic, I found that there is a research gap related to adults with disabilities. I came across a substantial amount of literature focusing on children with intellectual disabilities, with a particular emphasis on education and the educational system for children with disabilities (Ghirxi, Borg, Camenzuli, Pace , & Schembri Muscat, 2019). I also found that an increase in literature has been directed towards the well-being and adjustment of individuals with disabilities themselves, and not enough support is provided to the families who care for them (Wasserman, Asch, Blustein, & Putnam, 2016).

I believe that siblings of individuals with intellectual disabilities within the schooling context are now being given more support as required to function within the family system. A vast amount of literature also supports this. Studies have shown that siblings of children with disabilities share a unique relationship with their brothers or sisters. It has been found that siblings of individuals with disabilities share both positive and negative aspects of this lived experience (Vella Gera, 2021). Across my interaction with these families, however, I have always felt that the parents were the neglected members within the family system. I feel that not enough emphasis has been given to the marital relationship and adjustment of these parents. Through my work experience, I often find that many parents are not aware of all the support and interventions that could be provided to help them with this challenge across their lifetime. In her research with a couple of a child with a disability, Borg found that the daily chores and responsibilities prioritize the relationship taking away time and energy, which otherwise could be dedicated to the couple relationship (Borg, The romantic love narrative of a couple who are also parents to a disabled child, 2019). This being said, very few studies have examined the relationship between having an adult child with an intellectual disability and marital adjustment, much of which appears inconclusive and shows conflicting findings (Hartley, Barker, Seltzer, & Greenberg, 2011). To date, there has been no local research which specifically addresses this and the changes that may occur within the marital relationship along the different stages of life- in particular, the transition into permanent residential care.

1.3 The Research Question

This study is aimed at understanding how parenting adult children with a significant disability affects the marital relationship. My interest in having parents with adult children as a target audience, is to be able to understand the parental experience across time and life-stages- in particular following a move into residential care or supported living. Through my experience in the field, whereby I currently work within the national agency for persons with disabilities, I often find that that when the time comes, parents may be supported to take the decision to look for a residential placement for their child, however once the individual moves out of their home, not much support and follow up is provided to these parents. This study will therefore focus on understanding these couples' lived experiences, determining any changes that may have occurred across their child's lifetime- with particular importance given following the transition of their adult child with an intellectual disability into permanent supported living or residential care. Furthermore, I will also be exploring what professional help these parents seek and the support given throughout this process. Such an in-depth understanding of these experiences would be beneficial to health care professionals working directly with these individuals and their families. The questions in research will investigate:

1. *How does having an adult child with an intellectual disability influence the parental marital relationship?*

2. *How do parents' co-construct meaningful and significant stories about the experience of parenting their child with a disability once seeking residential care?*
3. *How has the marital relationship changed following permanent placement in supported living/residential care?*

I believe that these questions are relevant in order to operate in a more family-oriented manner, a commonly accepted and recommended principle in practice (Hostyn & Maes, 2016).

1.4 Theoretical Frameworks

1.4.1 A Systemic Approach

A systemic perspective recognises that the entire family is influenced when something happens to an individual family member and that each family member experiences the phenomenon in a different way (Hastings, Kovshoff, Brown, & Ward, 2005). Through exploring the experiences and marital relationship of parents with adult children with intellectual disabilities within a systemic framework, I will be able to focus on the relationship between spouses and understand the changes in their marital relationship upon becoming parents of children with disabilities and how this has evolved across their life time (Keizer & Schenk, 2012). The marital relationship cannot be viewed separately for men and women but in light of the product of the dyadic context of their interdependent experience at work, at home and as parents (Attard Micallef, 2015). Changes in one of these aspects experienced by one partner will also affect the other partner, influencing the marital relationship, let alone when multiple changes in all three areas may be occurring to both partners during this transition (Keizer & Schenk, 2012).

The structural approach within a systems framework presents the family as hierarchically organized and particularly to families with children, two family sub-systems are found to be important- the parental sub-system and the parent-child sub-system, which are connected by a reciprocal relationship to the larger macro-system (Cox & Paley, 1997). Maintaining boundaries between these two systems supports families to avoid spilling over difficulties that may arise in one system to be projected into the other (Minuchin, 1974). For the purposes of this study, I decided to interview the parental sub-system and focus on understanding each parents' experience of parenting a child with a disability and whether this has changed their marital relationship. By interviewing the parents together, I will be able to observe their pattern of interaction as it unfolds throughout the interview and appreciate their experience as individuals, as well as a couple. This will allow me to appreciate how the couple respond to one another, supporting their same and different views, while sharing their lived experiences of parenting their child with a disability.

1.4.2 Locating my Thinking within a Social Constructionist Framework

I will be interpreting the experiences and marital relationship of parents with adults with intellectual disabilities within a social constructionist epistemology. This postmodern philosophical framework invites us to understand the personal and shared constructs of a married couple, which are co-constructed through language and culture (Anderson & Goolishian, 1988; Freedman & Combs, 1996). Parents' meanings, feelings and emotions are also evolved from socially constructed discourses embedded in day to day conversations (Hedges, 2005). Some of these meanings are shared with others of the same culture and gender, but other more relevant intimate narratives develop within one's family experience. Thus, I will be using this framework to explore the constructed nature of the disability, and also to explore the experiences of the parental marital relationship along different stages in their family life cycle.

The social construction of disability is a vast topic. Birenbaum (1979) suggests that not only do individuals construct their subjective reality and that ideas are constructed from social interaction, but also that social interactions differ, since social contacts involve inequalities in power to define subjective reality. The work of Barnes (1993, 1997, 2003) and Griffiths (2001) highlights how as a society we are constantly subjected to negative, often stereotypical representations of disability as a tragedy to be pitied (Griffiths, 2001). It is this representation of persons with disabilities preserved within the media that consequently shapes a society's understanding of, and attitudes towards, disability. Thus parents of children with an intellectual disability may be shaped by such ideas and social interactions and are faced with conforming to these social norms and expectations.

During the past 40 to 50 years there have been numerous changes and developments with respect to attitudes of society towards persons with disabilities. This being said, I believe that a lot of work needs to be done for persons with disabilities to feel included in society and to remove the stigma that is still associated. Despite the introduction of anti-discrimination legislation, through conversations I often have with others about my work with persons with disabilities, also amongst different professionals, I often find that not everyone regards persons with disabilities to be equal. In a research conducted by Cardona (2013), participants with intellectual disabilities noted instances when they were often perceived as objects of charity. Conversations which are still very present locally, such as referring to persons with disabilities as 'less fortunate', 'angels sent from heaven' and 'blessed by god' suggests that, for some, disabled people can never be allowed to be ordinary people.

By making use of a social constructionist perspective in this study, I will be analysing and understanding couples' experiences through my personal subjectivity as an observer and researcher- also brought up in and aware of the societal attitudes towards persons with disabilities. I acknowledge that my own feelings, emotions and stories with which I connect to, are crucial in determining what I hear and what I miss out on throughout the conversations. This has a considerable impact on the findings of this study (Hedges, 2005). Averill (1982, 1992), says that the words and phrases we use when we talk about feelings, actually create the way we feel. This leads to the questions: What feelings were created when I joined the system and provided space to talk about the marital relationship of those parents with adult children with intellectual disabilities? What emotional discourse was facilitated to surface and discuss, and what were those held peripheral?

1.4.3 A Strengths-based Perspective

This research is guided by a strengths-based approach, which provides a contrast to the problem-focused frameworks that commonly steer research exploring relationships in couples with an intellectual disability. Such research emphasises negative outcomes, such as poor relationship satisfaction, marital conflict and separation or divorce, and overlooks the capacity of couples to display positive adaptation despite challenging circumstances. In contrast to this, a strengths-based approach attempts to understand individuals and families in terms of their strengths and resilience. By promoting this, people can discover their own solutions and adapt to change (Sim, Maintaining Relationship Satisfaction in Couples Raising a Child with Autism Spectrum Disorder, 2018). The use of language is particularly important when making use of such an approach, since the language we use creates our reality (Hammond & Zimmerman, 2012). The language used when developing the questions asked were created to understand the unique capabilities and competencies that determine the couples' evolving story, which may define who they are.

This perspective involves seeing the experience of the couple, showing the family's strength at different points during their life cycle, their flexibility and also how they adapt to different circumstances. Importantly, this perspective does not disregard family challenges but acknowledges them as vehicles for testing family capacities. Through making use of this approach I aim at supporting the importance of understanding how couples raising a person with an intellectual disability have managed challenges, the resources they have utilised and the constructive learning experience that restores hope and highlights new possibilities.

Chapter 2: Literature Review

2.1 Introduction

Parents are often the main source of support for adults with an intellectual disability (Birtha & Holm , 2017). Floyd and Zmich (1991), found that the marital relationship is similar for parents who have children with and without a disability, however, parents of adults with an intellectual disability are likely to experience significantly higher levels of parenting stress than are parents of typically developing individuals. Despite the reality of these findings, it is also found that parents of a child with an intellectual disability vary considerably in the levels of stress they experience and most parents still enjoy typical levels of well-being (Gerstein, Crnic, & Baker, 2009). Given the lifelong nature of intellectual disabilities, the parenting challenges faced are often longstanding and extend into the son or daughter's adolescence and adulthood (Seltzer, Almeida, Greenberg, Savla, & Hong, 2009).

2.2 The Disability Context in Malta

An intellectual disability is defined by having difficulties in both intellectual functioning- such as learning, problem solving, and judgement, and in adaptive functioning- activities of daily life such as communication and independent living (Parekh, 2017). Persons with intellectual disabilities may have a reduced ability to understand new or complex information and to learn and apply new skills. As a result this may lead to a reduced ability to cope independently. Most intellectual disabilities begin before adulthood, with a lasting effect on development.

The Parliamentary Secretary for Persons with Disability and Active Ageing and the Commission for the Rights of Persons with Disability (CRPD) represent persons with disabilities in Malta. The aim of the CRPD is to:

“render Maltese society an inclusive one, in a way that persons with disability reach their full potential in all aspects of life, enjoying a high quality of life thanks to equal opportunities… In fulfilling this mission, CRPD works in order to eliminate any form of direct or indirect social discrimination against persons with disability and their families while providing them with the necessary assistance and support.”

To date the CRPD registers 18,989 persons with disabilities over the age of 18, 2770 of which have an intellectual disability. These statistics do not include those individuals who do choose not to register themselves with the CRPD in Malta.

2.3 Marriage and Parenting in the Maltese Context

Traditionally, Maltese couples have been found to give an increasing importance to the interpersonal bond within their marital relationships. Marital quality is defined as an evaluation of the functioning and success of a marital partnership (Spanier & Cole, 1976). The quality of the marital relationship is most commonly assessed through self-reported ratings of overall happiness, adjustment or satisfaction of one’s own marriage. In their study, Abela, Vella and Piscopo (2020) found that couples value respect, communication, trust, love, and fidelity in their relationship. It was found that young and middle-aged couples valued communication and trust the most, whilst older age groups valued forgiveness and understanding most. The interplay between various contextual and personal factors influencing a couple’s relationship and marriage satisfaction in Malta has also been examined. Key factors involved were perspectives of relationship formation and maintenance beyond “living happily ever after”, flexibility in gender roles, approaches used when handling conflicts, shared enjoyment, as well as attending to the needs of and appreciating one's partner (Piscopo, Vella, & Abela , 2020).

In Malta, females tend to give higher value to family life than to work and responded more automatically to becoming a parent. Attard Micallef (2015), found that women tend to enjoy family life more than men, while men were more relieved from family commitments. This being said, cultural discourses are continually changing, and while traditional values are still echoing, a multitude of new ideas are gaining ground. The launching phase, in which children are conceived is being postponed to later on in life, now that of 28 years for women (Azzopardi, 2007). The traditional ideas towards marriage are also changing, where marriage is no longer the ultimate expectation in life. Rates of cohabitation and reconstituted families have also increased and changes in the ideas around love, work and home life balance, gender roles and expectations contribute to the shift in perspective of what makes a family. Despite this, family has remained by far the highest value for the Maltese (Borg, The romantic love narrative of a couple who are also parents to a disabled child, 2019).

2.4 Parenting a Child with an Intellectual Disability

Raising a person with a disability can be both a challenging and rewarding experience. Having a child with an intellectual disability can have a significant physical, emotional and financial impact on the entire family system and its ability to function, thrive and support the person with the disability. For many parents, the stress begins prior to diagnosis and the challenges faced with parenting are often longstanding and extend into the son or daughter's adolescence and adulthood and have also been described as "never-ending" (Sim, Maintaining Relationship Satisfaction in Couples Raising a Child with Autism Spectrum Disorder, 2018). Parent stress has been attributed to the unique direct and indirect demands of raising a child with a disability, in addition to the everyday stressors experienced by all parents.

Studies have demonstrated lower health related quality of life for parents raising an individual with intellectual disabilities, compared to parents raising children without a disability. Research has found that parents often experience poorer psychological wellbeing, particularly increased anxiety and depression (Hartley, Barker, Seltzer, & Greenberg, 2011). Parents also often express increased difficulty having to meet the physical needs of their family member as they grow bigger and parents get older. The need to care for other siblings may also contribute to this and parents often express feelings of guilt about the lack of time and attention they were able to give to their child without disabilities (Mirfin-Veitch, Bray, & Ross, 2003). Stress and compromised mental health can in turn lead to less effective parenting practices and increased behavioural difficulties. Family relationships are often affected by the stressful demands of raising a child with an intellectual disability.

In view of the increased demands and stressors, Friedrich and Friedrich, (1981) emphasise how the marital relationship needs to be considered as a crucial factor for families with children with disabilities. Knowing that the cycle of enduring stress keeps reappearing along the developmental milestones, as these are not achieved at a typical rate, the importance of the family's personal adjustment is crucial. Mutual marital support is indicative of less stress when parenting persons with disabilities and that marital satisfaction tends to project increased positive coping strategies (Friedrich, 1979). Parents' marital satisfaction has been found to influence parenting and consistency in parenting in family contexts (Stroud, Durbin, Wilson, & Mendelsohn, 2011).

2.5 Disruptions to the Family Life Cycle

The family life cycle divides family development into six life stages, starting with families with young children, progressing to families in the later life. Carter and McGoldrick (1982), described a sequence of life-cycle transitions that create stressors within a family system, as individuals are confronted with change and must reorganize themselves. Such transitions may include the birth of a child, going to school, leaving home and the later life. In the case of this research, this starts off with the diagnosis of the disability.

A central issue for families who have a member with disabilities is that the sequence of life events is often different to those of families without disabilities. Transitions may seem 'out of synchrony' in families with a member with disabilities. Some stages may be elongated, shortened, or never experienced. For example, adults with disabilities who live with their parents for much of their adult life are often faced with their first transition out of the family home rather late in life, after parents die or become ill. This stage may be referred to as *'postponed launching'*- a situation whereby a move out of the home occurs later on in life than for most member of society. The launching stage is most pertinent to this study.

Parents are also often faced with having to make the decision for their child to move on to life outside the family home, rather than the person taking the decision for himself. In cases where a person with high care needs is moving out of the family home, it is common for parents to experience a degree of guilt that they are no longer primary caregivers as well as a deep sense of loss (LeapIn, 2020). Securing a future plan may be complicated for parents of adult children with a disability, as "any action affecting one side of the partnership will have implications for the other" (Bowey & McGlaughlin, 2005). Parents may be faced with empty nest syndrome, whereby they experience feelings of loneliness, grief, and loss of purpose when their children leave home. Although this may be experienced with typically developing children, this may be more difficult for these parents since their children have developed such a dependence on them (Crettenden, Wright, & Beilby, 2014). Thus, when adults with an intellectual disability are encouraged to move to alternative accommodation, their parents support should also be reviewed.

Through my experience with parents of adults with disabilities, I often find that parents prolong this decision as they often feel they are 'getting rid' of their children. More often than not, culturally, parents state that they will care for their children as long as their health persists them to. This however, may not necessarily be the right decision, as difficulty may arise, should a parent suddenly fall ill or no longer be able to take of their child. This in turn may lead to a double loss, whereby the person taken into care may be left to grieve the loss of parent, as well as the loss of their home.

Although this often proves to be a very difficult decision for most parents, parents who seek residential care or supported living accommodations for their children are usually very satisfied with their decision. Parents expressed that their mind would be at rest as their children would be provided with specialized medical care, therapeutic treatment and developmental support, which would be readily be available for their adult children (Hostyn & Maes, 2016). Such living arrangements allow the person with the disability to learn responsibility and independent living skills, develop goals and ambition for the future, such skills that sometimes may not develop to their potential when living within the family home. This provides parents with reassurance following their decision to seek out-of-home support (Crettenden, Wright, & Beilby, 2014).

2.6 Support and Coping

It is also important to understand how the coping resources of parents with children with disabilities alleviate the effect of parenting stressors on marital interactions (Hartley, Seltzer, Barker, & Greenberg, 2011). Despite the multitude of demands associated with raising a child with an intellectual disability, many parents have been found to demonstrate effective stress management. Coping is influenced by the meanings given to family experiences and even when faced with stressors, parents of adults with intellectual disabilities can often describe positive gains associated with caring for their child. In a previous study, couples identified the importance of staying positive as a means of coping with service delivery experiences and provided examples of how they chose to reject the negativity of others, be less critical, and focus on the strengths of their child and situation (Weiss , MacMullin, & Lunsky, 2015). Research has shown that the impact of experiencing child-related stressors on the parental psychological wellbeing is reduced when adaptive coping mechanisms are used (Hartley, Barker, Seltzer, & Greenberg, 2011).

Social support is another beneficial coping resource for parents with children with intellectual disabilities. Couples who have high levels of family and friend social support and who employ adaptive coping strategies to deal with child-related stress may not be at risk for negative marital interactions, whereas parents who employ maladaptive coping strategies may be at a higher risk for marital discord (Hartley, Barker, Seltzer, & Greenberg, 2011). Partner support may also be valued due to the need to “live it to understand it” (Benson P. , 2013). Parents raising a child with disabilities share many of the same experiences that people outside of the family simply cannot comprehend. It has been argued that social support is more effective when provided by those with similar values and characteristics, and who have experienced similar stressors (Weiss , MacMullin, & Lunsky, 2015). Parents with strong marital relationships may mitigate the impact of stress through a coordinated approach to parenting in which responsibilities are shared and challenges are jointly addressed.

2.7 Conclusion

The complexity and lifelong course of parenting a person with a disability has implications for future research. Studies are required to gain a better understanding of the lived experiences of these couples, as well as to develop effective services that are relevant to the needs of these families. This study thus aims at exploring the marital relationship of parents with adults with disabilities making use of residential care or supported living.

Chapter 3: Research Methods

3.1 Introduction

Throughout this section I will be discussing the procedures and methods used to conduct this study. I will start by exploring the rationale behind choosing a qualitative approach, particularly an IPA approach to understand the marital relationship of parents of adult children with disabilities. I will then show how the participants were recruited and continue by describing how the data was collected, organized, analysed and interpreted. I will also give space to highlight the ethical guidelines I adhered to throughout the study, as well as my self-reflexive stance as a researcher during this process.

3.2 Rational for Adopting a Qualitative Methodological Approach

Since my interest is positioned towards the quality of the marital relationship of parents of adult children with disabilities, the use of a qualitative design is deemed a more appropriate method of analysis, for the purpose of conducting of research and attaining results. People interpret and understand their world by creating meaningful stories (Alase, 2017). Exploring these from a statistical perspective may avoid considering a number of intangible factors, such as social norms, socioeconomic status, gender roles, ethnicity and religion (Richie & Lewis, 2003). In addition, qualitative research also aims at understanding how the participants derive meaning from their surrounding environment, and how their meaning influences their behaviour (Willig, 2008). It also brings to light, the couple extracts, reflections and makes meaning of the life cycle of their marital relationship which was tinged by expected stages, such as marriage and becoming parents, as well as the unexpected experiences that may be present when parenting a child with a disability.

I chose this method because it aims to provide a better understanding through first-hand experience, truthful reporting of these experiences, and through the use of quotations of actual conversations, gives clarity to the given research (Creswell, 2013)

3.2.1 Choosing IPA over other Qualitative Methodologies

After considering other methods within the qualitative paradigm, such as discourse analysis, thematic analysis and grounded theory, I came to the conclusion that Interpretative Phenomenological Analysis (IPA) would be the best fit for this research. My particular interest, that of exploring the quality of the marital relationship of parents of adult children with intellectual disabilities making use of supported living, was in having a detailed account of the perceived experience of the couple and their meaning making process (Smith, Flowers, & Larkin, 2009). This aim would not have been served by discourse analysis- which looks into the language chosen by people as they constitute and re-constitute their identity (Burck, 2005), by thematic analysis- which focuses on finding patterned meaning across the data (Sprenkle & Piercy, 2005) or by grounded theory- which aims to generate theory around social processes (Glaser & Strauss, 1967).

3.2.2 Rationale for Adopting IPA

IPA is an approach explicitly aimed at understanding experiences in a specific context. IPA is influenced by a postmodern epistemology, and thus it fits within the framework I have chosen for this research. The phenomenological aspect of IPA is embedded in its aim to explore the participants' personal experience and the meaning they make out of this experience (Smith, Flowers, & Larkin, 2009). Thus, IPA provides an opportunity to delve into the personal meanings and experiences of the participants, which are influenced by social norms and understandings of the wider system (Smith & Osborn, 2003). This approach invites participants to give a detailed, first person account of their experience of parenting their child with intellectual disabilities, expressing their thoughts, reflections and feelings. Additionally, it offers a space for participants to develop their ideas and express their concerns about the research question and anything they would like to link to it (Smith, Flowers, & Larkin, 2009).

IPA is also interpretative and makes use of ‘double hermeneutics’, in which the researcher tries to make sense of the participants’ personal world. Osborn and Smith (1998) state that IPA does not declare to produce a ‘true’ interpretation of the participants’ experience. On the contrary, the results of this analysis are a co-construction between the participants and the researcher because they emerge from the relationship built between the researcher and the participants, which started off during the initial contact when the participants were asked whether they were interested in taking part in this research. Prior to conducting this research, I was aware that each participant has a unique experience and that each couple perceives the quality of their marital relationship differently. All the participants’ experiences were considered valid, and all knowledge was taken as being specific to the participants’ particular situation.

Thus, since this approach allows the flexibility and opportunity to understand the lived experiences of couple raising adult children with intellectual disabilities, IPA appeared to be the most suitable method to address this research question.

3.2.3 Self-Reflexivity of the Researcher

Apart from an understanding of how the participants make sense of their personal and social world, Smith and Osborn (2007), emphasize that “IPA also emphasizes that the research exercise is a dynamic process with an active role for the researcher in that process. The researcher is also involved in the research process because he/she is also a part of the context and therefore takes an active role in the discovery and construction of knowledge (Jaeger & Rosnow, 1998). In qualitative research, the researcher is not seen as objective but instead brings his or her own assumptions, biases and beliefs to the data analysis (Willig, 2008). From a social constructionist view, each experience is a result of a co-creation between one individual and another, in this case, me as a researcher. The journey of co-constructing this research took place on a number of levels; both my personal and professional interest, as well as the relevance of the research on a local level. Therefore, throughout this research my own beliefs are taken into consideration and genuinely phenomenological.

Throughout the data collection process, I took note of my own personal thoughts and my experience during the conversation, trying to separate these from those of the participants'. I made every effort to identify and be aware of the preconceived notions I might have and reflected on how these influenced the way the data was being analysed (Smith & Osborn, 2003). This is a typical position for postmodern, social-constructionist self-reflexive practitioners, who strive to become aware of how they affect and are affected by what they do and think and feel, and how they, together with the participants, construct the situation (Cooper, 2009).

Another important perspective in my self-reflection is the awareness of the different roles I hold both in my personal and professional life. Throughout the research process, I thought about how I position myself as a female, daughter, non-mother, cousin of a person with a disability, professional within the disability field, trainee systemic family therapist and my personal relationship with disability, critically thinking about how my presence and probes may have influenced the interview and the subsequent data analysis.

My interest in this study was both a personal one, where I was curious about the experience of parents of adult children with disabilities and how this affected the marital relationship across different family life cycle stages which was also a professional curiosity. As a professional working with the national agency for persons with disabilities, also from where the participants were recruited, I worked with numerous families who may have had similar experiences of parenting a child with a disability. Having such working experience in the field, it was also crucial for me to remain curious and not to assume an expert position during the interviews. I required to question my biases and not remain with the 'normative' narrative that families with disabilities may have. Having said this, this position and my knowledge in the field enriched my questioning and fuelled my curiosity to find out more about the phenomenon being researched, asking deeper questions and leading to more interaction with the couples.

3.3 Research Design

3.3.1 Recruitment of Participants

When making use of IPA studies, due to its idiographic focus and attention on the quality of the detailed account, the sample size is usually very small. Generally, a sample size of three to six participants is adequate (Smith, Flowers, & Larkin, 2009). For the purpose of this study I recruited four couples on a voluntary basis.

The study aims to understand how parenting adult children with a significant intellectual disability affects the marital relationship. I chose convenience sampling as a procedure as I needed to identify participants with specific criteria who would be able to provide data that was relevant to the research question.

I first contacted the research department of the national agency for persons with disabilities in Malta- Agenzija Sapport, who, following receiving my Ethical Approval, agreed to disseminate an information letter to parents of those making use of their residential services, informing them about the nature of the study, including my contact details. A copy of this letter can be found in Appendix A. I was provided with the contacts of two potential participants. I also liaised with the Commission for the Rights of Persons with Disability (CRPD) Malta and the National Parents Society of Persons with Disability who also distributed this information letter to their members. One member reached out, however did not fit the required criteria. Having not received the required number of participants, I emailed the information letter to two other residential services in Malta, however got no response from these organizations. Having working at Agenzija Sapport, I asked whether it would be possible to distribute my information letter to the different services it offers, to reach more people. I was forwarded the contact details of three further participants, who fit the participant criteria.

After contacting the five eligible participants, one participant refused explaining that they were no longer in contact with his son. The other four participants voluntarily agreed to participate.

3.3.2 Recruitment Criteria

Since the study aims at exploring the quality of the marital relationship of adult children with intellectual disabilities, making use of residential care, participants selected for this study required to meet a set of criteria in order to obtain credible information.

The parents were required to have been married prior to having their son/daughter. Such a criteria was set to allow the possibility to explore how their marital relationship may have changed following marriage and prior to receiving their son/daughter’s diagnosis. Their son or daughter having an intellectual disability, required to be 18 years or older and their son/daughter was required to have been residing within a residence for at least 1 year. This stipulated period allows time for the parents to adjust to the changes that may come along when a child leaves the house (Banach, Ludice, Conway , & Couse, 2010).

3.3.3 Participants' Information

Couples' names	Couples' ages	Years married	Name of person with disabiliy	Age of person with disability	Diagnosis	Age when moved into residential care	Siblings
Jess **Vince**	78 80	47	Ann	44	Hearing impairment Autism-non-verbal;	27	2 brothers-1 older and one younger
Ray **Tina**	78 76	49	Maria	47	Epilepsy Intellectual Disability Non-verbal	36	None
Jane **Mark**	53 53	30	Neil	21	Landau-Kleffner Syndrome	10	2 elder brothers
Fran **John**	74 74	45	Roberta	36	Autism	19	2 elder brothers

3.3.4 Data Collection Process

Initially data was to be collected through the use of in-depth, semi-structured, face-to-face interviews, in order to seek profound information, knowledge and understanding of the parents' experience. Having to conduct the research during the Covid-19 pandemic, allowed for revision of the data collection method. Being in a quasi-lockdown whilst conducting the interviews, fortunately, all the participants agreed to conduct these interviews through virtual methods using different on-line platforms. Some of the participants required step-by-step direction in order to connect virtually. The different online platforms used allowed for the interviews to be recorded. In-depth interviews were chosen as the method of data collection since they provide a deep exploration of the respondent's point of view, feelings and perspectives. The use of semi-structured interviewing allows the topic to be further delved upon, without deviating from the explored topic (Pereira, Pedrosa, & Matovelle, 2009). All participants were given details about the nature of the study, and upon contacting the couples, a date and time for the interview was set up.

Issues regarding confidentiality, consent and anonymity were again explained prior to beginning the interview. The participants were also told that all information they revealed would be of great value and were assured that there were no incorrect answers to any question, making them feel at ease and creating an atmosphere of trust. The participants were re-informed that the interview was going to be recorded for the analysis of the data obtained and that the recording will be destroyed once the dissertation has been completed. Participants were asked to sign a consent form, (refer to Appendix B) agreeing to all the above mentioned details, which was sent to them by post, together with a self-addressed envelope when initially contacted, and mailed back prior to setting the interview date.

3.3.5 Interview Schedule

As required by IPA, open ended interview questions were asked to gain an understanding about the marital relationship when parenting an individual with intellectual disabilities across their lifetime were prepared (refer to Appendix C). Questions were formulated based on the context of literature previously reviewed, keeping in mind the theoretical frameworks used throughout this study. This semi-structured script served as a guide and led the participants to discuss matters related to these issues which they best preferred (Harrell & Bradley, 2009).

The first few questions were aimed at gathering background information about the participants. I then moved on to asking them about their experience of receiving the news about their child's diagnosis and how they perceived each other's reactions to this. The questions then proceeded to focus on the dynamics between the parents as a couple as their child grew up and how the experience was for the whole family. The aim of these latter questions was to find out about the perceived experience of the couple within the complex dynamics of the situation, in line with systemic theory. Circular questions were used as an aid to get a circular view of the experience within the different members of the family (Scheel & Conoley, 1998). The interview continued by probing about how the couple took the decision for their child to make use of residential care/supported living and any support they received throughout this process. The couple was also encouraged to pass on a message to any other couples who may be passing through a similar experiences.

Although the interview schedule was prepared beforehand, I was still able to delve into interesting areas raised by the participants themselves during the interviews. I listened actively to the participants during the interviews and did not stick rigidly to the interview guide. This helped ensure reliability of the data since I was able to clear up any misunderstandings in the questions asked, any inconsistencies in the participants' replies, assist the participants recall information from previous experiences, and elicit relevant and comprehensive data (Bailey, 2008). It also allowed me to create a comfortable atmosphere and build a close rapport with the participants. Concurrently, I tried to ensure that my use of probes did not contribute to leading questions that may have been more representative of my personal ideas, rather than those of the participants. The meaning given to the participants' experience was regarded as co-constructed by the participants and me as the interviewer, rather than as located inside of the participants.

3.4 Data Analysis

As previously mentioned, the data collected was analysed following Interpretative Phenomenological Analysis (IPA). Each interview lasted between sixty to ninety minutes. The recordings were immediately transcribed- verbatim, to maximise the reliability of the research findings. Transcriptions constitute rich data, which becomes the object of analysis and interpretation (Pietkiewicz & Smith, 2012). Following this, I read each transcript multiple times, to be able to identify codes, that is, describing the content discussed throughout the interviews, examining the language used by the participants and interpreting the meaning, before identifying recurrent themes (Hefferon & Gil-Rodriguez, 2011).While reading through the transcripts, I listened attentively to the audio recording to understand the experiences shared. The reading process was supplemented by listening to the participant’s voice and interview flow, including the couple’s interaction dynamics (Morgan , Ataie, Carder, & Hoffman, 2013).

The second step involved noting and commenting freely on the semantic content and language used by the couple (Smith, Flowers, & Larkin, 2009). I divided the transcript into three margins: the first for emerging themes, the second for the couple’s conversation and the third for my personal descriptive, linguistic or conceptual comments both throughout and after the conversation. The themes extracted were based on the participant’s experiences, however my interpretation as a researcher also emerged through my collaboration during the interview.

The themes were then organized to form sub-themes. Sub-themes were then linked to form groups of super-ordinate themes. This created a more comprehensive table with sub-themes listed under their corresponding super-ordinate theme, with quotes complementing each sub-theme. The elicited themes were then used to present the results (Smith & Osborn, 2003)

3.5 Ethical Considerations

Throughout this research, I took all the necessary ethical measures to ensure that the participants were not harmed in any way, especially since the topic being studied had the potential to give rise to revisited profound emotions.

Prior to commencing this research study, I presented the dissertation proposal, together with an Ethics Approval Form to the dissertation committee within the Institute of Family Therapy Malta for approval. Such approval was presented to the organizations which helped to recruit the participants. A list of the discussion guidelines were also discussed with my supervisor before initiating the interview process.

As previously mentioned, immediately when starting the interview, I reassured the participants that all information will be kept confidential and that any information that is disclosed during the interview and could identify the participant would not be used. They were told that their actual name will not be used and a fictitious name will be used in order to safeguard the participants' identity throughout the study.

All the participants were informed that the likelihood of any harm for participating in this research would be minimal. The couples were informed that I would be vigilant for distress throughout the interview process. Participants were informed that their participation is entirely voluntary. As previously mentioned, they were told that they have the right to refuse to answer any questions that may be sensitive to them and that they could withdraw from the study at any time, without having to provide a reason for their withdrawal. A consent form agreeing to this was signed.

I was aware that when interviewing the couples, the disclosure of the experience of parenting a child with a disability and the challenges that comes with this experience, may cause emotional distress. There were a number instances during the interviews where I had to pause, remain emphatic and wait for the participants to regain composure. There was one instance where I felt I had to discuss the possibility of stopping the interview, however the participant accepted to continue but move on to another question. Throughout the interview I did my best to equally involve both parents, mainly because I observed that most mothers tended to voice their opinions and recount their experience more than the fathers. Once the interview was over, I debriefed the couple about their experience of the interview, ensuring not to leave the interview if someone was emotionally distressed (Smith L. , 1992). The participants were also be informed about the available services which they could make use of should they require any support, however none of the couples deemed this necessary. .

3.6 Conclusion

This chapter presented a detailed description of methodology used throughout this study, including the rational for the chosen research design, the data collection methods and analysis process used, as well as the ethical and selfreflexivity procedures that were followed. The main findings elicited from the interviews will be presented and discussed in the following chapters.

Chapter 4: Results

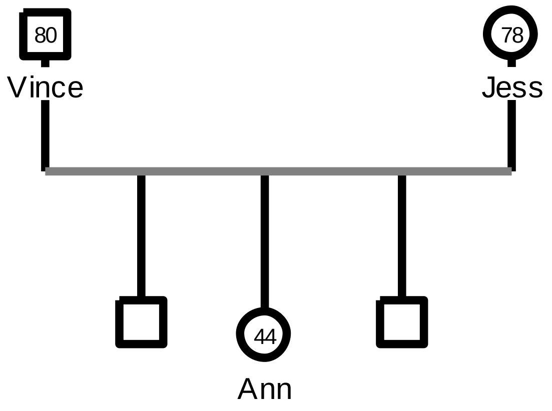
4.1 Introduction

This section presents the results based on the main themes which were elicited throughout the data analysis. The seven super ordinate themes together with the sub themes are presented in Table 4.2. This chapter presents the themes using verbatim extracts from the interviews, aiming to shed light at what is being co-constructed and interpreted between the participants and the researcher. I tried to give a voice to parents of adult children with intellectual disabilities who have been making use of a residential placement, by presenting their perceived experience of their marital relationship and the meaning they give to it as much as possible in their own words (Smith, Flowers and Larkin, 2009). I have consciously presented themes that are not directly related to the marital relationship and the particular focus of this research because these were given importance by the participants. All the couples interviewed seemed to have preferred narrating their experience of parenting their child with an intellectual disability whilst linking to how this affected their relationship, rather than directly focusing their marital relationship itself.

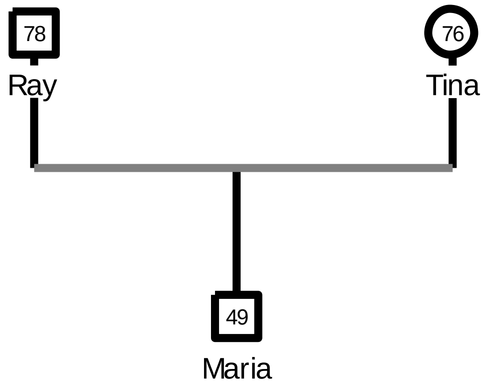
As discussed in the methodology section, pseudonyms are used throughout this study to protect the participants' confidentiality. Personal information that could lead to the identification of any of the family members were either altered or left out to ensure anonymity. All extracts and quotes have been translated from Maltese to English.

4.2 Genograms of Participating Couples

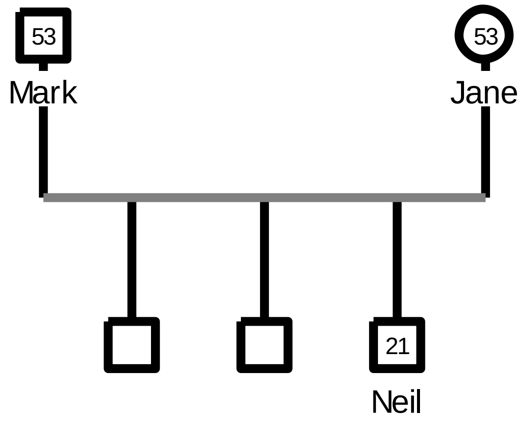
Couple 1



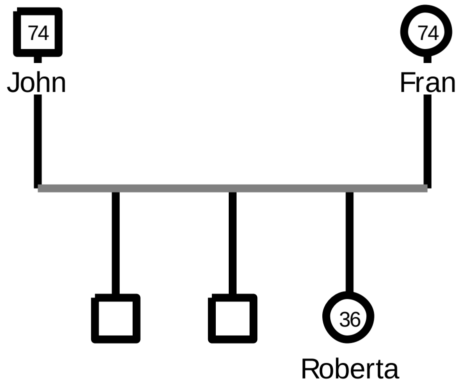
Couple 2



Couple 3



Couple 4



4.3 Super Ordinate Themes and Emerging Sub-themes

Managing the diagnosis as a multi-stage process	1. The couples' experience of the news giving process 2. The couples' experience of grief through the news giving process 3. Navigating through acceptance 4. The couples' marital relationship following their child's diagnosis
The marital relationship as obscured by the new many demands	1. Providing 24/7 care 2. Living with societal views around disability 3. Financial strain 4. Insufficient information about services 5. Limited support from external family
The couples' overwhelming preoccupations with the many fears and uncertainties	1. The couples' concern about the future 2. The couples' decision to seek residential care
The out of synchrony life-cycle of families with children with a disability	
The experience of the residential placement on the couples' marital relationship	1. The couples' re-lived grief process when their child moved into residential care 2. The couples' change in lifestyle following residential placement
Couples' perception about the quality of their marital relationship	1. Seeking support from one another

	2. Improved marital relationship following residential placement
Inadequate support network	1. Couples' perception of the professional support received 2. Couples' advice for other parents

4.4 Managing the Diagnosis as a Multi-stage Process

Whether or not the couples were aware of the child's disabilities beforehand, the news giving process is not embedded and is not limited to a one-time encounter with the news givers; however, it is a lifelong learning process for parents. However, the participants all claimed that they only had one encounter with the news giving team and there was no follow up to help and support the couple during the meaning making process following receiving the news.

4.4.1 The couples' experience of the news giving process

The couples spoke about the initial phases when they received the news that their child may have a disability. This encounter seemed to be somewhat different for all parents, given the nature of the disability and also the different situation each couple was experiencing. The meaning making process was different for each couple. One particular parent expressed her experience of living with the idea that her child may have a disability once finding out she was pregnant and her uneasy experience of holding this information throughout her pregnancy:

> Jess: *I wanted so much to have a child the second one [child]… and I didn't get my period and went to the pharmacy to carry out a test, and he told me Congratulations, you are pregnant, and I was so happy. Then he told me, what do you have on your face? That's not German measles right? And he started explaining, she can be born blind, she can be born deaf, she can be born with mental disabilities, heart problems etc.. then he told me it could*

> *be she won't have any of these, miracles can happen.. but you contracted it at a bad time, when the foetus is forming… and you can imagine how we spent the pregnancy.. I even started hoping to lose the baby because of the fear that I would have a handicapped baby, how will I cope? Then when she was born he told me I'm sorry she is deaf.. it was terrible*

A particular couple expressed not being given an official diagnosis and until this day, still not being aware of her child's condition:

> Tina: *We are not even sure about what she has and doesn't have. Nobody told us anything. Once they told me the cause of it was because they took long to assist me during birth*
>
> Ray*: We panicked a little aye..*

Another couple expressed spending the first three years of their son's life seeing him develop and grow the same way their other two sons did, however experienced a complete regression. The mother expressed:

> Jane*: When Neil* was around 3 and a half he got very high fever and after around 6 weeks we started noticing him regressing.. others thought we were obsessing, but I started realizing that instead of saying sentences, he started saying 3 words, then 2 words.. then nothing at all.. Then they [the doctors] realized he had seizures which caused brain injury.. and that he has a condition called Landu-kleffner Syndrome.. and only one person was able to diagnose him, I raise my hat to him.. because other doctors thought that it's so rare that it couldn't be the case*

4.4.2 The couples' experience of grief through the news giving process

All parents expressed grieving the child that might have been. They mentioned that the early years were the most difficult, especially when initially receiving the news. Most parents expressed the disbelief that came along with receiving the news:

> Tina: *I cried so much, I still cry till this day aye..*
>
> Victor: *I used to be so sad*
>
> Fran: *But you know what happened to John, because of the sadness he used to have, he didn't want to speak to anyone. He didn't want to be part of the rest of his family, he didn't want to speak to his siblings nor mine, but that's not right*
>
> John*: The heartache will remain forever. That my daughter will always be handicapped*

Some participants expressed being unprepared for this unexpected news, not knowing what to do and how to confront the situation they were facing:

> John: *We were so shocked by the news, we didn't know what to do*
> Jess: *It was as though it was the end of the world.*

Two couples experienced holding on to hope that their children's condition will improve. They expressed that this gave them reassurance about their future throughout the news giving process:

> Fran: *In the beginning we didn't think it would be something big, we would always think that she will improve, improve.. and then they started telling us that she would never be normal*
>
> Mark: *I used to think that the older he gets, the more he will settle...Forget that he is non-verbal and he can't be left alone, but I thought that the older he would get that the hyperactivity would reduce.. literature has failed me*

A particular participant mentioned how extended family also shared this hope and resorted to faith to help them gain a better understanding of the situation they were facing:

> Jane: *His grandma, the grandparents kept hoping that they would light up a candle and visit Lourdes and that he will be back to the Neil they know.*

One of the fathers also expressed feeling angry when receiving the diagnosis, which persisted throughout their daughters development, whilst his wife would worry about her husband:

> John: *I used to get angry. It used to get to me.*
>
> Fran: *I'm telling you, he spent a long time upset he remained angry about this, that our daughter turned out this way. Always saying "how did she come this way". I always told him, everyone had some sort of difficulty. I used to understand and empathise with him as well, but I used to worry about his reactions, and I used to tell him.. John not like that, slowly.. he was angry about this for a long time.*

Most couples spoke about having to change their lifestyle to care for their child, leading to them missing out on things that other couples would experience:

> Mark: *Whoever passes through a similar experience to ours- you need to forget about doing certain things. You can forget about having a hobby.. Even as a parent, It's no joke. I mean even the time you rest no longer depends on you. You sleep when he does.*
>
> Vince*: I didn't used to go out drinking or meeting up with friends or whatever you know, I used to go to work and that was it.*
>
> Jane: *Social life non-existent.*
>
> Jess: *We used to keep back on everything; we couldn't attend family weddings for example, as we wouldn't find anyone to leave her with.*

4.4.3 Navigating through acceptance

Acknowledging acceptance came to be seen as a relational process with the couple's support from one another, the perception of normative and non-normative behaviour of the child and the desire to get on with life. The participants said that at times they had to accept the disability to be able to help their child even though they remained uncertain of it.

> Jane*: You need to accept that even though Malta's population is less than half a million, these rare conditions, which theoretically shouldn't happen in such a small country, but they could still happen.*
>
> Ray: *We accepted [the circumstances] because if we didn't the problems would have intensified.. we accepted the situation as it appeared.*

Participants felt that they needed to accept the disability rather than overstating it in order to continue with life:

> Fran: *The way I understand it is that it is useless to stay worrying and exaggerating the situation, that way you'll only be making yourself more miserable and won't be able to get on with the family.*
>
> Tina: *You don't exaggerate the situation*

Most of the couples reflected upon how their faith in God helped them through accepting their child's diagnosis. One couple sought comfort in the belief that their daughter was sent to them by God:

> Tina: *That's what God wanted for us*

The participants also mentioned that having religious beliefs allowed them to get on with life when they found themselves is some difficulty:

> Fran: *We managed with help from God. I pray a lot to our lord to give us the strength to get through our day.. I believe in these things and I pray a lot and trust a lot in him. I leave it in his hands.. he guides us, otherwise we would not manage*
>
> John: *Whoever doesn't believe in God will find the situation more difficult and will be angrier. At least for us our lord has helped to console us and accept what we were facing*

4.4.4 The couples' marital relationship following their child's diagnosis

The couples reflected upon the idea that having a child with such complex difficulties and needs required focusing their energy on establishing what is best for the child, whilst taking care of their relationship. Although they had to care for their child, alongside managing their work, the home and caring for their other children, they mentioned that like other couples, they required to get on with the challenge that they faced to get on with life. Whilst some of the couples mentioned that their marital relationship stayed the same, others mentioned their relationship had changed, bringing them closer together:

> Mark: *I don't think it really changed. We had limitations but the relationship itself didn't change much*
>
> Tina: *Like every other couple, nothing to do about it. Every couple has it's problems and tries to solve the problems they have*
>
> Vince: *I think there were moments that it [the disability] brought us closer together because it happened to the both of us. Also, I think this was something that benefitted us since it brought us closer. More united together I felt.*

4.5 The Marital Relationship Obscured by the Many New Demands

4.5.1 Providing 24/7 care

All couples spoke about having to sacrifice their relationship to be able to care for their child. Most of them expressed that the disability required them to be constantly on the watch and having to care for all of their needs throughout the day. This being said, they all wholeheartedly took on this role as parents and also as couples' to provide for their child's needs:

> Ray*: We cooperated with each other as much as we could aye. I used to go to work and she used to care for her 24 hours a day. She depends on us for everything, she doesn't*

> *do anything independently. She doesn't walk, talk, not even eat. She depends on us for everything.*
>
> Tina*: She spent 36 years with me, carrying her and washing her, and changing her and feeding her. All myself. We also even had a hard time at night, we used to have her sleep in between us in bed.*

One of the couples mentioned having to be on call at any time of the day, even when their son was not particularly under their care at that time of the day:

> Mark: *So for us that was the biggest, the biggest headache. This of school.. they call you and tell you to come pick him up.*
>
> Jane: *Because sometimes at primary, they would call us up at 9am to go for him. At primary at 9am! In the morning! After an hour! So after an hour I need to leave work and find someone to replace me to go pick him up.*
>
> Mark: *Because he was impulsive, very fast, so you don't manage to keep up with him. So you need to be with him at all times with all eyes on him, like a security with a celebrity with him, you know. Keeping an eye if someone has an ice-cream or something in his hands, because off he will go.*

4.5.2 Living with societal views around disability

The couples seemed to be aware of how disability is socially constructed. Although they explain how they didn't wish to live with the way society views disability, they were still affected by these ideas on a day-to day basis because of certain experiences that they faced:

> Jess: *In my other son's class there was a boy, he was a neighbor of ours, and the minute my son got on his nerves, he used to tell him, "I'll tell others about your sister- that she is dumb"*
>
> Jess: *When she had tantrums they used to tell me, she looks like a junkie, what is she? Why do you take her out? Once we were having a drink and they chucked us out, because she threw a glass on the floor.*

> Mark: *You hear people speaking behind your back. I feel so bad for him [referring to his son]*

One of the couples expressed their frustration with how society views disability as someone who has a visible physical disability. They stressed that this societal construct did not help with their situation, whereby even though her son has a disability, this is not shown in his physical appearance. At times, they mentioned feeling judged by other parents because their son would act out, thus this would reflect negatively on them as a parents:

> Mark: *People used to look at us in a way- sort of take care that boy. That was one of the ways we felt hurt*
>
> Jane: *One of the things that angers me that you come across, let me mention 'Xarabank', because that's the most watched TV program. When they're raising money for persons with disabilities, to pull your heart's strings, they show someone in a wheelchair looking up to the ceiling not being able to move. The minute you see him on television you feel bad. But I used to tell people, I get frustrated when people show that image to represent disabilities. If my son were in a wheel chair he would be home until this day, because I would be able to take care of that disability*
>
> Mark: *They use them as a means of charity*

4.5.3 Financial strain

Whilst narrating their experiences, all the couples expressed the financial strain associated with upbringing a child with a disability. They expressed that parenting all children comes along with a financial responsibility; however, children with disabilities usually require the use of more professional support, services and adaptive equipment, which requires additional financial expenses:

> Mark- *I don't know what we didn't buy for him. Even with regards to software and learning aids. Until he was living at home, I don't know what we didn't buy for him. And speech pathologists, I don't know how many came*
> Jane: *So all those experts, we spent so much money. I think we visited all the experts there were available*
>
> Ray: *We bought a tailor made wheelchair to sit on, and experts came over from the UK to make this for her, to get her body mold*

One particular father expressed that although he spent quite an amount of money to attend to his daughter's needs, she was his priority and sought different employments to be able to provide for her:

> Vince: *But she was my priority. I used to work other jobs other than being a teacher. For example, we went to the UK twice, it cost quite a sum of money, you understand. To go the second time I had to find another part-time job, immediately.. It was an economical problem*

4.5.4 Insufficient information about services

Although all participants expressed seeking a number of different professionals to support them with their children's needs and receiving adequate help from them, two couples mentioned that there was not enough knowledge about the different available services and that they were not provided with this information from the professionals they sought. The services that were offered were focused on the medical needs of the person with the disability rather than also including the caregivers, thus showing that the overall care did not imply a systemic approach:

> Jane- *Look, I always say, we sought so many professionals and services, how did nobody tell me, from the very beginning, listen, make use of respite for 15 days a year and take a holiday. Nobody told us this. So all those experts involved, and we spent so much money, and nobody mentioned this to us.. I don't understand how no one*

> *mentioned this to us, how no one told us this: 'It cannot be that you don't have a social life, none, none at all, for seven years'*
>
> Jess: *But if at that point for example, someone told me 'let me keep her for an hour for you'. I would have been over the moon!*

4.5.5 Limited support from external family

Most couples spoke about their relationships with their external families, mostly their parents. Some of the participants mentioned that they did not feel that they could rely on their parents to support them with the upbringing of their child:

> Jane: *Sort of, even his grandparents, we couldn't really rely on them you know… They didn't know our struggles*
>
> Mark: *There was a shift in the grandparents. From having three grandchildren and fighting to spend time with then, to at a point nobody wanted him.. not nobody wanted him.. but none of them could understand him.*

One particular father expressed being heartbroken when his family didn't accept his daughter because she had a disability:

> Vince: *It was so difficult, for example, my family didn't accept my daughter. I used to go with her to my mum and they used to be afraid of her, afraid of her. As though she was contagious, contagious!*

4.6 The Couples' Overwhelming Preoccupations with the Many Fears and Uncertainties

4.6.1 The couples' concern about the future

The uncertainties and anxieties about the unknown nature of future implications presented differently to all the participants, however all of the participants shared this sense of fear about what were to happen to their children in the future. Some couples worried about what would happen to their children if they were to pass away:

> Tina: *I always held this thought, what's going to happen in the future? When I pass away, what will happen to her? She has no brothers or sisters.*
>
> *Ray: If I were still working and she [my wife] couldn't take care of her, what would happen? It was a massive headache aye.. I used to think about the future a lot.*

Some fathers seemed to have found it easier to come to terms with their child being placed in residential care and mentioned always being prepared for this instance. They expressed that having this as an option offered them a piece of mind:

> Ray: *I always knew at the back of my mind that she will end up there [referring to the residence] even though I was adamant to do all that I could for her not to go. Well, if God forbid I had a casualty at work or something of the sort, the problem would be worse. The thought was always there and this put my mind at rest.*
>
> Mark: *The writing was on the wall, that ultimately he would not remain at home. If you read literature about it, it is clear that they are all institutionalized*

The mothers seemed to share a different perspective to their husband's regarding this, whereby they did not prepare themselves the same way and expressed wanting to care for their child as long as they were healthy and able to do so:

> Tina: *I used to tell him, as long as I feel well enough to take care of her myself, she will remain here*

4.6.2 The couples' decision to seek residential care

All the participants anticipated the moment that they would need to seek a residential placement for their son and daughter, despite some feeling that they knew that this would happen in due course. Each of them mentioned how this was one of the most difficult decisions they had to make as parents and how this was one of the most challenging times they have faced throughout their lives. There were quite a number of factors which have led them to taking this decision. The most prominent factor that each couple mentioned was being challenged with certain behaviour of concern which their child exhibited on a daily basis:

> Jane: *For example, we spent a summer driving around with the car all day. In the middle of summer, spending hours going on drives. When we get home, he would hit and break, we ended up with the house all broken down. The bed being held on bricks*
>
> Mark: *Incredibly hyper and we changed his medication for him. I don't know what we didn't try, adding and reducing his medication.. I remember a particular doctor telling me, I think if we give the same dose to a horse it would sleep and he [son] wouldn't*
>
> Jess: *Another time I took long to take her down for her van and she ran away and as soon as she went out, bloom, you find a car and it ran over her*
>
> Fran: *Her autism was quite hyperactive, and the tantrums, that's why I couldn't keep her here at home, because she used to hurt us a lot. When she had a tantrum we wouldn't be able to handle her*

This being said, the couples expressed that handling this behaviour on a day to day basis, led to them feeling very tired, which was also a factor influencing their decision to look for a residential placement:

> Fran: *Because we were tired, very tired, and that's when he starting having his heart attacks… her behaviour used to tire us out and that's why we came to this decision*
>
> Jane: *You'll be lucky if he sleeps 4 hours out of 24 hours a day*
>
> Mark: *How do you explain it, he takes all your energy, all the time with him. And constantly waking up at night, he doesn't sleep and you need to stay with him.. and the next day you need to go to work*

Some of the couples expressed that they were facing health related difficulties. This required them to seek alternative options for their child's care as they were not coping with having to care for their child and focus on their health at the same time:

> Tina: *She spent 36 years with me, having to carry her, wash her, feed and change her, all myself. But then I had to place her at the residence because I needed to carry out a procedure, because having to carry her daily caused health problems*
>
> John: *Then the heart related problems started.. the heart attack was intense, massive. And I was boarded out then, and after another 5 years I had another heart attack so we needed to do something about it*
>
> Fran: *That's how his heart attacks started, because he used to worry about our daughter*.

Some of the parents heavily voiced that they had also experienced mental health difficulties associated with the overall experience of caring for their child. Looking back, they expressed how difficult this time was for them:

> Jane*: I'm not going to keep it in, we reached breaking point, so much that we were close to contemplating suicide*
>
> Mark: *Yes it was very difficult, very difficult. I spent two weeks on sick leave, taking medication. I wouldn't say depression, but close to it*
>
> Jess: *Taking antidepressants, I spent years taking antidepressants because of the stress. It became so difficult that you wouldn't be able to take it any more, and boom, I remember opening the drawer to take the medication. You pass from those terrible times. I used to tell myself, I will have to take antidepressants all my life, until I die*

4.7 The Out of Synchrony Life-Cycle of Families with Children with a Disability

Throughout the interview with the couples the difference in the life-cycle, with regards to the launching stage, whereby the children leave the family home was discussed. Most families highlighted that this is different to families whereby there are no children with disabilities. One of the couples tried to compare this experience to if their daughter were to get married and leave the family home, however found difficulty understanding it this way as they, as parents, had to make this particular decision:

> Tina: *Because he tells me, if she got married and left the house you would feel it as well. But if she were to get married, I would send her off with open arms.. But for me this makes a big difference, because if she would be getting married and starting her own family and what not, that's one thing. This way she is still going to have to depend on others to take care of her. That's the difference. So I cannot rest my mind the same way as though as she would be leaving to get married.*

This situation was different for one particular couple, whereas their 10 year old son needed to be admitted to an institutionalization following difficult behaviour experienced at home. The couple expressed having difficulty finding the meaning of their son having to be institutionalized at such a young age, following the trauma brought about with this experience:

> Mark: *..coming for him, in their white overalls, a scene that I see in front of my eyes until today… it happened within hours, I wasn't prepared for it.. to admit a 10 year old*
>
> Jane: *If my son had, well a drug related problem and made a scene because of withdrawals or what not, and they take him for that reason, you would understand that it's because of the addiction and it's easier to accept. But taking your son at the age of 10.. it's difficult*

4.8 Experience of the Residential Placement on the Couples' Marital Relationship

4.8.1 The couples' re-lived grief process when their child moved into residential care

All the couples disclosed that the decision for their child to make use of a residential placement was an extremely difficult period in their life. Following the placement, most parents spoke about the effect their son or daughter left on them:

> Mark: *That was the hardest moment for us, when he left home sort of.*
>
> Jess: *In the beginning I wouldn't be able to sleep because I was so sad. Wondering were she was and what not*
>
> Tina: *I used to take sleeping pills and still wouldn't be able to sleep*

Most parents expressed going through similar stages of grief that they had been through following the news about their child's diagnosis. Some parents expressed finding it difficult to accept this change, following the move:

> Mark: *In the beginning I couldn't accept it, I used to call every two or three days sort of.. I started feeling useless. I used to constantly wait for the time I used to be able to call him to check that he is all right*
>
> *Jess: Yes the heartache stays there and its something you can't live happily with*
>
> *Fran: It took us a while to a recover. We felt her absence so much*

Most parents voiced experiencing a sense of guilt associated with leaving their child behind them when visiting them:

> Tina: *Still, when you leave from there, you feel it.. that you left her behind you*
>
> Jess: *Certain thoughts come to mind, I wonder if she would be sad, I wonder if this step was the right choice or not*

> John: *[referring to carer].. She told us, today I have 8 hours with your angel John. So she is our angel, but not we are caring for her, someone else is. It hurts that she is our daughter but someone else is taking care of her*

One particular mother broke down stating that she felt as though she had failed as a parent when seeing her son settling into the institution that he had been residing in:

> Jane*: I remember in the beginning, after around a year of him residing in WPU, I started seeing that he was somehow under control. I remember feeling offended, that they had managed and somehow I failed. How is it that they are managing to control him and we failed?*

This being said, as time passed by, most parents mentioned having accepted the decision that they had made and started to adapt to the idea that their son or daughter had left home:

> Mark: *As time passed by, we accepted. You step down*
>
> Ray: *I was always prepared, not prepared really, but accepted the circumstances that we find ourselves in*
>
> Jess: *Then it was like the world took a right turn. Everything stated to settle down*

4.8.2 The Couples' Change in Lifestyle Following Residential Placement

Although the choice to seek a residential placement proved to be a very difficult decision for most parents, all parents explained being very satisfied with their decision now that they have adapted to it. Each of the participants mentioned how they were able to rest now that their child is being cared for by others:

> Fran*: And he [referring to husband] started to relax a bit in this life*
>
> Ray: *Yes we calmed down, we were able to rest.. we found a sort of relief and got along with life better*

Although the fathers all spoke about how difficult it was to see their children leaving their home, they disclosed how they were consoled by seeing their child settled into their new home, and knowing that their son or daughter had adapted well and was happy:

> Ray: *My mind was at rest, better because she was settled there. And we know that she is loved over there*
>
> Vince: *Our minds had rested, we knew she was moving forward, doing well and welcomed by everyone. The tantrums had stopped, we were good*
>
> John: S*he is not a patient over there, but she is one of them. They love her so much. My sadness reduced knowing this, that she is well cared for and that she is happy.*

Another important aspect which each couple importantly discussed was the difference they noted in their social life. Whereby when their child was still under their care, they expressed not being able to go out alone, go out with friends and have free time for themselves, they mentioned that they were now more liberal to do this:

> Jane: *[referring to psychiatrist] She told me, do you go out with your husband? Do you have a social life? I told her, eee what is that? She told me, it couldn't be this way, you cannot remain this way. After this changed…*
>
> Mark: *Ahh and this that you can go out, Saturday comes along and we can go for dinner at a restaurant, if we want to go spend three days at a hotel, or go for a day to Gozo, we take a day off work and just go*
>
> Jess: *We stated going out more, meeting with friends.. going to Sliema or Valletta often, going for a coffee. Our life improved, we were happy, very happy. The liberty stated. I stared making friends, going to cooking lessons, I got distracted.. I started keep fit lessons*
>
> Tina: *We were free and could go out aye*

4.9 Couples’ Perception about the Quality of their Marital Relationship

4.9.1 Couples seeking support from one another

When discussing the marital relationship between the couples, all the couples had a difficulty to distinguish the marital relationship as distinct to how their child’s disability affected the couple as parents and influence this had on their marital relationship. This being said, the couples’ reflected on the constant need to live this experience together, so that the meaning making is made together in context of parenting their child with an intellectual disability and their decision to seek residential care for their son/daughter. All couples mentioned the importance of cooperation present between them within their relationship in order to move forward when they were faced with the situation they were in:

> Fran: *Our relationship was strong. He used to help a lot with our daughter. Running around with her, helping me out a lot and helping me out with a lot of other things.*
>
> Ray: *We cooperated as much as we could aye. We never had any difficulty in our relationship thank god. We tried our hardest for our relationship to stay strong.*
>
> Jess: *Cooperating with one another. He helps out with house work, then we go out a little, everything together.*

When asking the couples about what they felt key factors were in their marital relationship. One particular couple mentioned that a key factor to a strong marital relationship is the importance of communicating with one another:

> Jane: *There needs to be good communication with one another between the couple for sure, otherwise the relationship will not succeed.*

The couple continued explaining that although they felt they had a strong marital relationship, when faced by the challenges the disability brought along with it, they felt that their relationship was put somewhat aside, so much so that their marital relationship itself did not afford to have any difficulties:

> Mark: *Somehow we didn't have any issues between us, actually, actually, we didn't have time for issues hehe. If I had to have an argument with her, during those times I didn't even have time to argue with her, he wouldn't give us the time to pick up an argument hehe*

The couples' also mentioned the importance to be there for each other when in need. All participants mentioned that they had experienced some emotional hardship at some point during their child's upbringing. A key factor they mentioned was being there to support their spouse whenever they were in some form of distress:

> Jane: *I always say we were lucky with one thing, that when I was very down and desperate, at that point my husband was strong and there for me. And when it was the other way around, when he was desperate, I was strong and there for him.*
>
> Tina: *When in difficulty, one tries to console the other aye, it's important*

Most couples explained that although they experienced a number of challenges throughout their child's upbringing, the difficulties they faced led them to become closer and mentioned that this result in a stronger marital relationship:

> Jane: *Luckily between us we remained close. It helped our relationship I believe.*
>
> Jess: *We didn't have anyone to turn to so we turned to each other, and so this brought us closer.*
>
> John: *Throughout our life, we were very close, because we remained united as a couple. Whatever happens, we remain united. Both between us and for our children*

4.9.2 Improved marital relationship following residential placement

Despite going through a difficult time taking the decision to seek a residential placement, and following their children's move into residential care, all parents noted a difference in their marital relationship. As previously mentioned, most parents expressed the liberty to be able to go out and socialize with friends, others started engaging in new hobbies, however most couples expressed an improvement in their day to day life, which led to an improvement in their marital relationship:

> Jane: *We became like any other normal couple, like other couples with two children you know.. So say if me and my husband wanted to just get up and go out we could get changed and leave immediately*
>
> Ray: *Our relationship improved, because we no longer had that headache of thinking about what to do with Maria. We got a sense of relief about that and our relationship improved.*
>
> Tina: *Any issues we may have had are no longer present now that she is being cared for.*

4.10 Inadequate Support Network

4.10.1 Couples' perception of professional support received

As mentioned earlier, the participants stated that they sought quite some professional support for their children, including speech therapists, occupational therapists and behaviour therapists in order to help them with their child's development. They stated that the quality of the service varied according to the personal qualities of the professionals, the severity of the case and the waiting lists that were present. Although most couples mentioned that they sought an amount of support from professionals for their children, three of the couples expressed that they were not aware of services that may have helped them as a couple and were not well supported by all the professionals. They wished that they were aware of such services, as these would have allowed them to be better supported and help them rest when needed:

> Jane: *There could have been much more support way back. Nobody goes out of his way to support you. I don't think there was much understanding you know…. I don't know how nobody told us to take some time to rest, to make use of respite services, all those professionals and nobody told us this*
>
> Tina: *We didn't find support from anyone because nobody was able to give us support. Everywhere we looked, we found closed doors.*
>
> Jess: *There were some very difficult times, very difficult. Everybody would need that little bit of help*

This being said, one of the couples expressed that they felt that they were able to cope without the help of other professionals and mentioned that they did not feel the need to seek any professional support or services other than the ones that they were offered:

> John: *But we didn't want it, we didn't seek it, we kept things between us. Really, professionals who approached us, we spoke to them but for a very short while*

4.10.2 Couples' advice for other parents

All the couples were open to offer their advice to parents who may be passing through similar experiences. The couples expressed the importance of not giving up when given the diagnosis of their child. They all expressed the importance of seeking professional help, both for their child and also for themselves and to make use of services available:

> *John: [the couple] needs not to get irritated, not to give up*
>
> Jess: *To look into the couple's needs. What they would need at that moment in time. Because sometimes all one would need to do is simply to just talk. Or for example, they*

> *would need someone to take our their child for one hour every now and then.. to make use of, what are they called? Community services*
>
> Jane: *They look for respite, from the beginning. He would have still needed to be institutionalized, but it might have happened later had we had support in the beginning*

One particular couple advised other couples to communicate between them as this was a key factor for their relationship when raising their child with a disability:

> Mark: *There needs to be clear communication between the couple for sure, otherwise you won't cope*

Chapter 5: Discussion of Findings

In the following chapter, I will discuss the findings that emerged from the participants' experiences in light of the available literature, my self-reflexive process and the chosen conceptual frameworks. This research is an in-depth Interpretative Phenomenological Analysis about the marital relationship of parents of adults with intellectual disabilities who are currently making use of supported living.

When speaking about parents of adult children with disabilities, the marital relationship between the couple is not what usually comes to mind. Parents of children with intellectual disabilities face extraordinary challenges and often experience high levels of parenting stress, which may in turn affect their psychological well-being (Seigan, Mailick Seltzer, Barker, & Greenberg, 2011). It is therefore easier to forget that the parents are also a married couple, who must also sustain their marital relationship, in addition to their role as parents to their child with a disability. Overall, the participants in this research expressed that they focused less on the importance they gave to their marital relationship and more on their overall experience of parenting their child with a disability and how this, in turn affected their marital relationship. This suggests that their marital relationship could not be seen as independent to their role as parents caring for their child. In addition, the couples voiced the need to talk about their experience of parenting their child with a disability as a journey of their marital relationship throughout their child's different life-stages.

5.1 The Diagnosis as Long-lived Relational Process

One of the recurring themes that underlies the results is that parents receiving the news that their child has a diagnosis is not a one-time occurrence; rather, it is more of a longstanding process which the couple goes through together. When initially starting this research, I thought of interviewing couples with adult children with disabilities, so that I would be able to understand their experience from the start of the diagnosis towards adulthood. One of the reasons for this was to allow time for the couple to process the diagnosis and gain an understanding of this experience. Working within the disability field, particularly with adults with disabilities, the way the couples' received the news about their child's diagnosis challenged my own beliefs about the news giving process. Although the couples had processed the news given about the diagnosis, this experience was still something they still lived with until this day. For most couples interviewed, the news about their child's diagnosis had been given between 20 to 40 years ago. The initial news had been given by a professional, and although a number of professional involvement was sought for their child, no support was given to the parents throughout this process. This implies that although the child was given the necessary assistance during the diagnosis, the couples' and the rest of the family were not supported, thus implying that care was medically viewed and not systemic in nature. Although this lived experience was the aim of this research, it was also important to note the development made in the disability field over the years, whilst also acknowledging the couples' encounters throughout the interviews.

5.2 Multiple Encounters of Grief

The parents' interviewed noted interchanging periods of well-being combined with prolonged grief, influenced by their personal response to their child's disability and their reaction to societal discourses about disability. Ongoing grief in disability may be regarded as a disruption to the staged model, with the loss of the expected child and the presence of their continuing disability maintaining the denial stage (Brown, 2013).

5.2.1 Ambiguous loss

All couples expressed an immediate and pervading shock and disbelief during the initial diagnosis – the expectation of a healthy child was confronted with the reality of their child with a disability. Although there was a wide variation among the participants in the internal and external manifestation of grief, there was a commonality with their intense focus on the news of the disability and their reactions to it. The parents' loss of personal dreams for themselves as a couple and those for their child, together with the limited practical and emotional support they received during the news giving, resulted in grief manifesting in shock, anger, blame and feelings of being 'a failure'. The couples also expressed holding onto hope that their child would make progress as they developed and grew older, however expressed that this hindered them towards accepting their child's disability. Notwithstanding this, the couples all expressed seeking support from one another throughout this meaning making process.

5.2.2 Re-lived grief following the move to residential care

Recurrent grief with developmental milestones was 'ever present' for all couples, linking the past and future. Although the initial diagnosis caused grief, this was re-experienced in the succeeding years, particularly when the parents took the decision to seek a residential placement for their child. The couples all expressed how this decision was the most difficult decision they had to make as a couple. They expressed encountering feelings similar to those whilst receiving the diagnosis of their child. The participants believed that placing their adult child into residential care induced their emotional stress and created the following symptoms: guilt, sadness, fear and worry, anger and frustration, and uncertainty (Crettenden, Wright, & Beilby, 2014). Some of the outcomes the couples expressed experiencing were the re-lived loss and grief. They revealed how they required to support one another throughout this process, and although they mentioned that there were downfalls, they were always there to pick each other up.

5.3 The Meaning Making Process to Couple Adaptation

Meaning making is a cognitive process that reinterprets events, which may not be amenable to solutions to minimize distress associated with stressful events (Park, 2005). Many parents are challenged with reorganizing family goals and altering their views of what is important in family life when parenting a child with a disability (King , 2009). Understanding the meaning making process about the couples' perceived experience of the initial moments they received the news about their child's disability, focused on the relational experience between parents. This experience seemed to be somewhat different for each of the couples, depending on the way the news was given to the parents, the nature of the disability, as well as the couples' different reactions and meaning making of the situation they faced. The couples' mentioned that the meaning they made out of the diagnosis together as a couple contributed to the acceptance of their child's disability.

All the participants identified their role as parents as a daily rollercoaster of emotions, demands, and fatigue. The more life altering the experience, the more driven parents may be to seek alternative meanings for their daily lives. The couples' spirituality was seen to be an important factor in the process of establishing meaning and accepting the disability. Most couples expressed that holding onto their belief in God, helped them cope with their situation. A previous study involving 16 families living with a child with an intellectual disability highlighted the importance of personal and family religious beliefs in assisting parents to make sense of disability (Pillay , 2010). The couples remarked that having faith in God, gave them the courage to accept their situation and face any challenges that they encountered.

The couples' belief systems are also considered to be among the most important factors affecting the adaptation and resilience of the couples (Larson, 2009). Literature on the adaptation of families of children with intellectual disabilities indicates that these couples cope by attributing positive meanings to their situations, defining them as manageable, and making efforts to regain a sense of control (King , 2009). Despite all the difficulties brought about throughout their child's development to adulthood, all the couples expressed that they managed to cope with these challenges. They mentioned that having made meaning of the disability and the situation they faced together as couple, allowed for a different position they took towards their parenting and their marital relationship.

During the interviews, I reflected upon the way the couples were narrating their story. Despite the challenges they faced, each couple communicated their story with a sense of pride. When discussing this with the couples, they all expressed that having agreed to participate in this interview and narrate their story was a process of sharing this meaning they made out of their experience.

5.4 Disability as a Social Construction

Studies of parents of children with intellectual disabilities uphold a personal joy and sorrow in parenting their child, whilst also noting the impact of social constructs of disability upon their lived experience (Kearney & Griffin, 2001). Barnes (2003) highlights how we are constantly subjected to negative and often stereotypical representations of disability as a tragedy to be pitied.

The couples appeared distressed when discussing how they were personally affected by societal views about disability. Contextual lack of awareness and an inappropriate societal responsetends to push the couples to make isolated social choices. At times, the participants mentioned that they got so upset by people's reaction and stares that they decided to leave a restaurant or stay at home in the first place. One particular father expressed that this led to feeling shameful about his child and himself as a parent, so much so that he would not talk about his child to his colleagues. The negative cultural reinforcement produces a negative social lens that leads to segregation and exclusion (Hamilton, 2019). It is this representation of persons with disability preserved within the media that consequently shapes a society's understanding of, and attitudes towards, disability.

Societal reactions to invisible disabilities can also be harsh. Literature found that some parents of children with hidden disabilities have found it difficult to be in public with a child whose disability is not physical, when they suddenly experience a tantrum because of apparent sensory overload. People stop and stare, offer unsolicited advice or reprimand the parents for their presumed abuse or indifference in the face of their child's outrageous behaviour (Siebers, 2001). One couple expressed their pain about this problematic representation of people with disabilities in the media, whereby they felt that locally, persons with disabilities are still represented by persons making use of wheelchairs, and that not enough awareness of other disabilities has been made on a national level. They spoke about how this hindered them as parents due to the different responses they received by society when their child showed certain behavioural difficulties when out in the community.

5.5 Life-Cycle of Families with a Child with a Disability

In many ways, families are organized in terms of life cycle developments. Life cycle stages such as the birth of a child, school entry, celebration of puberty, graduations, marriage, leaving home and child rearing represent developmental processes between the natural biological time line, psychological needs, and social convention (DeMarle & Le Roux, 2001). Families of children with disabilities go through life cycle stages, yet some stages may be elongated, shortened, or never experienced. A child’s disability may cause a family to become stuck in a life cycle stage (Dyke, Bourke, Llewellyn, & Leonard, 2013). Families may also experience suspended expectations of normal life cycle change. This may occur when families are told, for example, not to expect that their child will ever learn to read, reach sexual maturity, or be capable of raising a family of his or her own.

When narrating their experience, most couples seem to have accepted that their child will not follow the typical life-cycle stages, such as graduating from school and having a family of their own. The life cycle stage that unsettled the participants’ was the launching stage, where typically, the child leaves the family home. Most couples expressed how they found themselves stuck in this stage, having to make this decision for their child, whereby in other families, the adult would make their own decision to leave the family home. One particular mother found it difficult to find meaning out of identifying this life-cycle stage, whereas with her other children, she was able to “let go” because they were getting married. Having to take the decision for her daughter, and seek the residential placement for her herself, led to a sense of responsibility in this decision. Another couple appeared distressed about their child requiring to be institutionalized at the age of 10. They expressed how they were troubled by this decision because it was beyond their control. They mentioned how the decision was so sudden that they did not have time to prepare and adjust to this life-cycle change. The couple compared their son’s development and progress to different life cycle stages to those of their other children.

The couples all spoke about the ‘*empty nest’* that followed immediately after their child started making use of supported living. The parents expressed having to face renegotiating boundaries and redefining household roles whilst encouraging autonomy. Their role as caregivers for their child had been handed over, thus the couples mentioned having to reorganize themselves individually, as well as within their relationship as a married couple.

5.6 The Couples' Renegotiation of their Marital Relationship Over Time

Clearly, the demands of raising a child with an intellectual disability can place stress on the couples' relationship, however despite this, all the couples expressed how their child had strengthened their marriage. They spoke about how they worked well together, supporting each other through "thick and thin" and that the experience ultimately brought them closer together. Having faced the challenges that came along with the disability, the couples expressed that they were the ones to completely understand one other, which led them to feel more united as a couple. Studies have shown that many parents believe in the need to cooperate with one another to effectively manage the challenges of raising a child with an intellectual disability, and this requires coordinated parenting, healthy communication and a commitment to their relationship (Sim, Maintaining Relationship Satisfaction in Couples Raising a Child with Autism Spectrum Disorder, 2018), all of which each of the couples expressed being important factors of their marital relationship.

5.6.1 Marital relationship seen as secondary to parenting their child with a disability

During the ongoing conversation with the couple, when discussing the marital relationship between them, all the couples expressed having difficulty distinguishing their relationship separately to how their child's upbringing affected and influenced the couple as parents, and in turn their marital relationship. As stated in Kurdek (2005), the quality of the marital relationship has to be viewed in the context of the couple's experience as parents, at home and at work. The participants stated that having a child with such complex difficulties required them to focus on what is best for the child, making it difficult to focus on their relationship. The couples emphasized the need, as well as their readiness to be there to support each other when one of them was striving.

5.6.2 The couples' improved quality of life following the move to residential care

All couples acknowledged that the time following their child's move into residential care was difficult and challenging. Despite the challenges that came along with the decision to seek a residential placement for their child, all the couples expressed being satisfied with this decision, as this led to a change in their lifestyle. The couples experienced a reduction in their stress levels associated with their caregiving role, as well as an improvement in their mental health and well-being, consistent with previous research (Crettenden, Wright, & Beilby, 2014). The participants appeared to be more satisfied with the residential placement when they could maintain involvement with the residence and by trusting the residential staff to care for their adult child.

The couples expressed maintaining a healthy involvement by having balance in their lives, experiencing and coming to terms with healing from shame, maintaining a close relationship with their adult child in the residence by upholding a reasonable number of scheduled visits, facilitating support from other professionals, and expressing appreciation for the care of their child. Seeing the positive outcomes of residential care on their child, such as improvement in independent living skills and reductions in challenging behaviours, also reassured the parents for the decision they had made. Another important theme all the couples voiced was the difference they noted in their social life. All the couples expressed feeling "free" to go out whenever they wanted to, to engage in social activities and start new hobbies, as well as to dedicate more time for each other and their relationship.

5.7 Limited Support Network

Parks (2007), demonstrated how the positive relationship between the support network and commitment in personal relationships are consistent with healthy marital relationships, usually achieved through the communicative behaviours and activities between romantic partners.

Relating to the local context, it has been reported that 11.0% of the population seeks relationship support from family and friends (Zammit Said, 2016). Inconsistent with this research, only one of the four couples interviewed expressed seeking support from family and friends. The other couples suggested that this form of support was either not sought or not accepted by family and friends. This was a concern for the couples' as they felt somewhat isolated in the situation they faced. The couples' main network of support consisted mostly of supporting one another within their marital relationship. This goes to suggest the importance of their reciprocal relationship in upbringing their child with an intellectual disability.

When discussing whether they sought professional help for themselves individually or as a couple, all of the couples expressed that they had not received any help of the sort. Most couples were unaware of such services at the time that they required it. They mentioned that this would have been beneficial, especially during the time they received their child's diagnosis and when their child was placed in residential care. One couple expressed that although she was not aware of the available professional help, they would have not sought it, as they sought enough support from one another within their relationship. Most couples also expressed that they were not aware of alternative services that were offered on a local level, such as respite services and community services.

5.8 My Experience as a Researcher

Keeping in mind the circular influential nature between the researcher and the researched embedded in IPA (Smith et al. 2009), and as a witness of such encounters, some analysis of the co-created narratives of this research is due. Upon reflection of the research process, combined systemically with my personal and professional experience, I can observe my personal interest towards the grief process experienced by the couples, the meaning making process, the couples' mutual support, as well as the negotiation of responsibilities that took place from the start of the diagnosis, throughout their child’s development and following their child’s move into residential care. These constructs informed my thinking, subsequently the choice of questions asked and the enquiry that took place during the interviews. The data collected appears to resonate with these ideas, however, I am curious about what other themes could have emerged, if another set of questions were put forward. Moreover, how would I have influenced the interview differently had I been married or even been a parent myself? Would I have asked different questions?

I found it interesting that the couples did not speak directly about their marital relationship, but directed their conversation to how their experience of their child’s diagnosis affected their relationship, even though the questions were directed towards the couples’ relationship. This might have come as a surprise, not being married myself. Nevertheless, although I might have anticipated that the couple might prioritise their role as parents over that of a married couple, it was astounding that at times they found it difficult to distinguish or even associate themselves with socially constructed attitudes of married couples. I also found it interesting that the couple didn’t speak about their intimate life. The aspect of sexual attraction did not come up with any of the couples as an important element within their marital relationship. Possibly, the couples’ experience of raising their adult child with an intellectual disability identified different qualities within their marriage, which they perceived as more important.

5.9 Implications for Clinical Practice

There are several important implications of research findings on the marital quality for improving supports and interventions for couples of children with intellectual disabilities. There is often a gap between scientific research and beliefs in the general public.

This study suggests that there is a need for family-focused interventions that support the entire family and their ongoing needs throughout their children's life course. These efforts should include support for parents' marital relationship. Within the general population, couple interventions have been shown to be an empirically validated treatment for mental health conditions within one or both spouses (Hartley, Barker, Seltzer, & Greenberg, 2011). Moreover, research suggests that improvements in marital quality can lead to increases in positive parenting behaviours (e.g., Carlson & McLanahan, 2006; Gattis, Simpson, & Christensen, 2008). Parents of adults with disabilities should be supported in finding ways to strengthen their marriage throughout their child's transition to adulthood. Parents find themselves needing to cope with the often divergence of family structure, parenting roles and responsibilities of having to care for their child with a disability, together with the devotion to one's career and caring for their other children. Thus, interventions and supports aimed at strengthening the marital relationship have the potential to lead to improvements in the well-being of both parents and children with intellectual disabilities. Furthermore, there requires to be more awareness about support services aimed at families and couples of parents with disabilities on a local level. Making use of a systemic perspective, would lead to a number of different professionals working together, directly with the child with the disability, the couple, any siblings and external family who may also be impacted by the lived experience, as well as the available external services, to be able to provide a more holistic approach to supporting the family.

The study also indicates that there is a need for more national awareness since on a national level, society exhibits an inadequate understanding of the reactions and behaviours towards a person with an intellectual disability. It seems that, although parents comment that awareness campaigns are on the increase, when they are with their child in social situations, they are still met with stares, comments and a lack of consideration. This was especially highlighted with one of the couples whose child does not physically show that he has a disability. As one of the participants suggested, professionals might need to look into the idea of educating youngsters from an early age, to instil a culture which is knowledgeable, understanding and considerate.

5.10 Limitations of the Study

Whilst the nature of qualitative research contributes towards eliciting unique meanings and lived experiences, when combined with quantitative approaches, more representative information can be elicited. Furthermore, having only four couples participate in this research presents an inherent limitation, as the findings cannot be demonstrative of the entire population. Hence, even from a qualitative perspective, more participants would have been an asset to the research. Another limitation of the study is that all of the couples interviewed were married couples for the purpose of this research, thus the study is not representative of all parents of adult children with disabilities, but focused on those who have had a successful marriage.

Since the study aimed at understanding the quality of the couples' marital relationship, based on their retrospective experience of their child's upbringing, from a family life cycle perspective and keeping in the mind the different challenges presented to the couple along their child's different life stages, participants could have been chosen from different stages of the life-cycle. This would have created a different understanding of how the couples perceived their marital relationship to be, across the different life stages.

Chapter 6: Conclusion

This study aimed at understanding the in-depth experience of the quality of the marital relationship of parents with adult children with disabilities and how parenting children with an intellectual disability affects their marital relationship. It looked at the evolvement of their marital relationship throughout the different stages of the family life cycle and the couples' relationship with the disability.

By reviewing the results elicited through IPA and in light of the available literature, I challenged some presuppositions I had regarding the quality of the marital relationship of parents with adult children with disabilities. The research has shed light upon the couples' reactions and meaning making of the news giving process. It also highlighted the different couples' resources and mutual support the couples sought of one another, when faced with the number of challenges parenting a child with a disability brings along. The research also elicits the couples' experience of seeking residential care and the change in their marital relationship following this decision.

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Appendices

Appendix A: Letter of Invitation

Dear Sir/Madam,

I am currently reading for a Masters in Systemic Family Psychotherapy at the Institute of Family Therapy Malta. In part fulfillment of these studies, I will be carrying out a research with the aim of understanding the marital relationship of parents who have an adult child with a disability, who are currently making use of residential care or supported living. I am interested in understanding any changes that may have occurred across time and life-stages.

I am seeking parents of children with an intellectual disability over the age of 18 years, to help me with my research by participating in an interview. To make my study more consistent, both parents need to have been married prior to the diagnosis and your child must be currently making use of permanent supported living arrangements or residential care.

The interview will be approximately 1 hour long and due to the current situation, will either take place virtually or will take place at a place of your convenience, keeping in mind Covid-19 measures. The interview will be audio recorded and the recording will be destroyed after the final grade for the research is issued. Your participation in this interview is purely voluntary and you can stop the interview at your own will. Your participation will be anonymous throughout the study and your name will not be used, however, a fictitious name will be used in order to safeguard your identity. Should you agree to this interview, a copy of this research will be given to you upon completion of the study.

Thank you for considering my request. In order to confrim your participation, you can contact me on: 79895987 or aliabela@hotmail.com.

Yours sincerely,

Alexandra Abela

Appendix B: Consent Form

For ethical and sensitivity purposes the researcher and participant abide themselves with the following conditions throughout the data collection and the publication process:

(i) The participants name will not be used in the study

(ii) The participant will be free to withdraw from the study at any point and for whatever reason. In the case that the participant would like to withdraw, all records and information collected will be destroyed

(iii) There will be no deception in the data collection process

(iv) The interview will be audiorecorded

(v) The recording will be destroyed as soon as the final grade for the dissertation is issued

(vi) Confidentiality, anonymity and data protection procedures are to be ethically abided

(vii) A softcopy of the research findings will be provided to the participant

Considering the above conditions, I am willing to participate in this research by contributing actively in this interview.

Name of participants: ________________________ & ________________________

Signatures: ________________________ & ________________________

Researcher's Name: Alexandra Abela

Researcher's Signature: ________________ **Date:**_____________

Appendix C: Demographic Questionnaire & Interview Guide

Demographic Questions

Age of parents: ____________________ & ____________________

Age of person with a disability: ____________________

Disability diagnosis: ____

Age of child when diagnosed: ____________________

How many children do you have? ____________________

How long have you been married? ____

How long has your son/daughter been residing within a residence? ____________________

Interview Guide

1. How did you find out your child has a disability?
2. How did you perceive each other's reactions and needs at the time of this news?
3. How did you live it as a couple? How did it affect your relationship?
    - Did you look at each other differently?
4. What is important for me to understand of you as a couple?
5. What was it like for you as a couple as your child was growing up? How was it for the whole family?
6. How did you take the decision to admit your child into residential care?
7. How has your couple relationship changed after your child moved into support living or residential care?
8. What priority did your relationship have?
9. Did you receive any professional support when your son/daughter was moving into residential care/supported living and following this?
    - What support did you need/what do you need when admitting your son/daughter?
    - What support do you need now?
10. What would you tell other couples going through this?