

**The romantic love narrative of a  
couple who are also parents to a  
disabled child**

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I am hopeful that this thesis is proof of all the commitment invested.

# Abstract

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This case study explores the lived experience of romantic love of a couple, who are also parents to a disabled child. It tracks through the couple's developmental stages from courtship to parenthood, with focus on the relationship between romantic love and disability. It attempts an understanding of the couple's narrative of romantic love and how its expression evolved across the different family life cycle stages.

The couple researched has been married for sixteen years and has an autistic child. Aiming to portray the particularity of personal, human dimensions of experience within a systemic paradigm, which views narratives in relation to context and contextual dynamics, interpretation and analysis was undergone using Interpretative Phenomenological Analysis (IPA). Data was collected by means of a semi-structured interview and findings were also discussed with the couple.

Six superordinate themes emerged, connecting romantic love with; day to day life, time, growth and capacity for reflection, commitment and leaps of faith and staying serene despite the odds. Intimacy also emerged but was addressed indirectly.

The shared narratives bring forth the couple's negotiations to accept and reconcile their different personalities and ways of coping; together with resources of trust and maintaining their individuality within their identity as a couple.

**Key Words:** romantic love, couple relationship, parental relationship, disability, emotional exhaustion, emotional connection, individuality.

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# 1. Introduction

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He who knows nothing, loves nothing. He who can do nothing understands nothing. He who understands nothing is worthless. But he who understands also loves, notices, sees...the more knowledge is inherent in a thing the greater the love...Anyone who imagines that all fruits ripen at the same time as the strawberries knows nothing about grapes.

Paracelsus (Fromm, 1957, pg. 10)

## 1.1 Preamble

An ever-growing interest in love and interpersonal relationships was significantly felt in the field of psychology, in the last four decades. There is a vast array of definitions of love (Myers & Shurts, 2002), some emergent categories are romantic and conjugal love (Knox & Sparakowski, 1968); passionate and companionate love (Hathfield & Sprecher, 1986); intimacy, passion, and commitment (Sternberg, 1986); eros, the love of beauty; ludus, playful love; storge, as friendship. All depictions of a dyadic process that has at its foundation sexual attraction.

Nonetheless, all attempts to love are destined to fail, lest if all efforts are tried to develop oneself and grow. The ability of self-love cannot be attained without the gift of loving the other, through humbleness, courage, faith and discipline (Fromm, 1957).

This case study uses interpretative phenomenological analysis to explore the journey of romantic love of a couple, also parents to a disabled child. It considers salient theoretical underpinnings in relation to the family life cycle, attachment theories and resilience. The couple is in their forties, they have been married for 16 years and have been together for 21 years. They are parents to an autistic child.

This chapter introduces the area of study, aims, rationale, as well as the conceptual frameworks and theoretical understandings that guided my work.

## 1.2 Research Question

This case study aims at enquiring the following research question: *How does a couple, who are also parents to a disabled child, live the experience of romantic love?*

According to Miller (2000), despite the hardships, satisfied couples generally maintain happy marriages over time. Norlin and Brober (2013) reinforce this discourse and encourage further investigation into the connections between marital relationship quality and the well-being of parents of children with disabilities.

This elicited my curiosity about the couple's definition of romantic love, how it evolved throughout the family life cycle and how this may be the same and/or different for parents of typically developing children. A study by Floyd and Zmich (1991), defines marital satisfaction the same for parenting both disabled and non-disabled children, however, the parenting stressors of children with disabilities and the severity of the disability, tend to place higher stress levels. Hartley et al. (2010) add that parents of typically developing children have less divorce rates compared to parents of autistic children.

## 1.3 Area of Study

Fromm (1957, p. 14) asks; *Is love an art?* He goes on to reply; *then it requires knowledge and effort.*

Fromm explains that modern society views the main problem of love, as finding the right person to love, or to be loved from. Amongst several assumptions discussed, Fromm heightens the confusion of many, between the initial experience of *falling* in love and the permanent state of *standing* in love (Fromm 1957, p. 20).

In Victorian times, marriage was contracted, assuming that romantic love will develop once the marriage was concluded. This expectation denotes that romantic love is something that needs to be worked at. In today's western world, the belief is that once the right person is found, love is to flow easily and freely, almost effortlessly. Fromm further explains that if one wants to learn the art of loving, like any art; first they need to master the theory, from there, they need to move on towards the mastery of practice.

Considering the research supporting this study, I believe that Fromm's recommendation applies for both parents of typically and atypically developing children. Nevertheless, attempting to understand the complexity of the relationship between romantic love and disability (Singer, 2006; Olsson & Hwang, 2008) becomes an add-on to understanding the mastery of practicing love. A narrative where couples face increased levels of uncertainty about the future and increased amounts of chores, responsibilities and worries. Trying to figure their way with less time at hand, puts additional strain on the romantic relationship (Luijkx et al. 2017)

## **1.4 Rationale of the study**

### **1.4.1 My Personal and Professional Curiosity**

The interest in this research question originated from my personal inclination towards attempting an understanding of the different facets of love, with special emphasis on the romantic aspect of love. What supports love to thrive and what can slowly deplete it?

Another important element of this journey ties in with my professional role of manager to the family department within an NGO in the disability field; twenty-one years of working with different journeys of hundreds of couples who are faced with the reality of disability. Witnessing the exhaustion of families, many times resulting in the weakening of the interpersonal bond, possibly leading to separation, has urged me to undergo this study, with the aim to develop effective provision of services that can support couples who are also parents to a disabled child.

Linking the personal and professional enriched my personal views of romantic love, which in turn influenced my personal relationships and the lens through which I observe the parents I work with.

## **1.4.2 Understanding the Family, the Couple Relationship and Disability in the Maltese Context**

### **The Family**

Family in the Maltese context is represented by the Ministry for the Family, children's rights and Social Solidarity. The significance of the family unit in Malta also gave rise to the President's Foundation for the Wellbeing of Society, the 'National Centre for Family Research.' This is witness of what a strong cornerstone the family is for the Maltese. It expresses the importance of close, intimate and supportive connections in daily life. This is also stated by Dr. Anthony M. Abela (1991, 1995) who in his Maltese and European Values Studies, explains how the Maltese place family first, in their order of priorities.

### **The Couple Relationship**

Again, quoting Abela (1991, 1995), despite dissatisfaction in recent years, family has remained by far the highest value for the Maltese. Although demographics have changed, similar findings were again presented by Abela et al. (2005) and again by Zammit Said (2016).

Nevertheless, Malta is now witnessing a European shift of ideas and values of what constitutes a family and satisfactory life. During a conference held in 2018, the Couple Relationship in the 21st Century, discussions were held of how 20% to 25% of the Maltese report that their marriages are in distress and marital separation is on the increase. The traditional avenues to marriage are changing, where marriage is no longer the ultimate expectation in life. Rates of cohabitation and reconstituted families have increased and changes in the ideas around romantic love, work and home life balance, gender roles and expectations contribute to the shift in perspective of what makes a family.

Linking this concise picture of what the couple relationship looks like in the Maltese context generates the following questions:

- How does a disabled child affect the couple's romantic relationship in a reconstituted family?
- What if a disabled child is born to a couple in their subsequent union following separation/divorce?
- Whether the couple is married or cohabiting, does disability affect the couple differently?

## **Disability**

Disability for the Maltese is another field which is close to many hearts. It is represented by the Parliamentary Secretary for Persons with Disability and Active Ageing and the Commission for the Rights of Persons with Disability (CRPD). Out of a population on 401,846, 8% have a disability (Study on Member States' Policies for Children with Disabilities, 2013). A recent press release by CRPD states as follows:

CRPD is committed to rendering 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.

### **1.4.3 Marriage, Life Satisfaction and Disability**

A study by Grover and Helliwell (2017); contributes the following:

1. Those who marry are more satisfied than those who remain single.
2. The benefits of marriage persist in the long-term, but well-being benefits are greatest immediately after marriage.

3. Marriage seems to be most important in middle age when people of every marital status experience a dip in well-being.
4. Those who are best friends with their partners have the largest well-being benefits from marriage and cohabitation, even when controlling for pre-marital well-being levels.

In the meantime, Kersh et al. (2006, p. 891) say that; “the presence of a child with an intellectual disability cannot be viewed as the sole source of parents’ deleterious well-being”. Norlin and Broberg (2013) concur, as they express how the processes of families of typically developing children are not any different than those of families with disabled children.

Ramisch et al. (2014) support these findings, some salient factors that emerged from their study include: communication, care and love for each other, working out differences, commitment and working as a team sharing responsibilities.

#### **1.4.4 Definition of Romantic Love**

For the purpose of this case study research, Romantic Love will be considered within the context of marriage.

Romantic Love will refer to the ability of the couple to satisfy for each other the emotional need to feel of value to each other, the need for close attachment, and the desire for intimate, affectionate and sexual connection.

McCarthy and McCarthy (2006) elaborate on this by describing how successful marriages meet the need for intimacy and stability, they can enhance psychological well-being or undermine it. The pivotal factor is maintaining a satisfying relationship and one’s commitment to it. A process that entails communication, distribution of power and roles, attraction, parenting, sexuality, problem-solving and conflict management.

## 1.5 Conceptual Framework

### 1.5.1 Attachment Theory

Many of the most intense emotions arise during the formation, the maintenance, the disruption and the renewal of attachment relationships. The formation of a bond is described as falling in love, maintaining a bond as loving someone, and losing a partner as grieving over someone. Similarly, threat of loss arouses anxiety, and actual loss gives rise to sorrow; whilst each of these situations is likely to arouse anger. The unchallenged maintenance of a bond is experienced as a source of security and the renewal of a bond as a source of joy.

Bowlby (1979, p. 74)

Attachment relationships are distinguishable by their ability to provide feelings of security and a sense of belonging, without which there is loneliness and restlessness. This contrasts with relationships that provide guidance or companionship, sexual gratification, opportunities to feel needed, or to share common interests/experiences, feelings of competence, alliance and assistance (Ainsworth, 1985, 1991) (Weiss, 1974, 1982).

Adult attachment theory offers a strong theoretical framework to explain the relationship between attachment style, romantic relationship quality, its maintenance and subjective well-being. This theory, based on the theories of Bowlby (1969) and Ainsworth (1985, 1991) states clearly the importance of attachment in adult life. According to Bowlby, human attachment plays a vital role, as it provides the foundation of one's sense of security around others and impinges on how he/she handles basic emotions, including love. While Ainsworth focused more on the function of the attachment behaviour system in adult relationships, emphasising the secure base phenomenon. According to Ainsworth, a romantic relationship that also provides a secure base, enriches the couples' sense of security and comfort with one another. A secure attachment within the romantic relationship also facilitates functioning and competence outside of the relationship.

Bowlby's (1969) Attachment theory is based on the premise that attachment styles are developed during infancy and childhood, in accordance to parental responses. These responses will influence the development of adult 'internal working models' that serve as the groundwork for social and emotional connections in adult relationships.

By linking these findings to the research question, one can identify the significance of a good enough secure attachment, for the success of the adult romantic relationship. Hazen and Shaver (1987) who also refer to Ainsworth's attachment ideas on adult romantic relationships, describe three of the different types of adult attachment styles, these are: secure attachment, avoidant attachment, and anxious-ambivalent attachment.

More recently, adult attachment in interpersonal relationships has also been conceptualized using two dimensions. These are; anxiety and avoidance. Secure attachment occurs when both the anxiety and avoidance dimensions are low, anxious attachment occurs when the anxiety dimension is high, but the avoidance dimension is low, and avoidant attachment occurs when the avoidance dimension is high, and the anxiety dimension is low (Mikulincer et al 2003).

A secure attachment style has been positively associated with subjective well-being. This ties with the findings of Bretherton and Munholland (1999) who say that a person's conceptualisation of the world, of the self and of others are based on their 'internal working models', which will then shape their feelings, thinking and expectations in adult romantic relationships.

I believe that these findings are crucial to this case study, as the attachment style of the individuals forming the romantic relationship, determines the quality of the relationship, the well-being of the individuals forming the couple and the processes they will go through to achieve well-being, or vice-versa.

### 1.5.2 The Family Life Cycle

This influential model proposes that individual development always takes place in the context of emotional relationships, the most significant being family relationships (Mc Goldrick & Carter, 1989). The model also argues that the development and change within families happens when there are shifts in the internal demands, which includes childbirth and in the case of this research, getting to know about the disability diagnoses, and external demands such as; deciding to live far from family of origin, as the participants of this study. When considering that the emergence of problems, or further unison of the family, frequently arises with these life cycle transitions (Mc Goldrick & Carter, 1989), the inclusion of this model as part of the conceptual framework is pivotal.

Mc Goldrick and Carter (1999) also talk about; families joining through marriage and families with young children, these two stages, out of six, are the most pertinent to this study. Marriage signifies two individuals, who are coming from two different families, joining together to form their own family (Morris & Carter, 1999). Minuchin's (1974) ideas around establishing roles, rules and boundaries within the new family dynamics are very useful for the developmental progress of moving from one stage to another (Mc Goldrick & Gerson, 1988).

This model further contends that as early as the stages of couple formation, which is frequently perceived as an easy and natural process, is in fact one of the most complex in the family life cycle. This misconception, also discussed by Morris and Carter (1999), can lead to insufficient preparation towards marriage, that often leads to difficulties with the *couple identity* formation (Azzopardi, 2007) resulting in conflict between the couple. It is important to highlight that each life cycle stage is linked to two major components being:

1. Emotional process of transition from one stage to the next
2. Second-Order changes in family status required to proceed developmentally.

This theory helps the reader appreciate the complexities and challenges that each stage of the family life cycle brings along. It also attempts to normalise the challenges, rather than labelling them as dysfunctions.

### 1.5.3 A Systemic Paradigm

In view of the systemic nature of this case study, it is important to understand this dyad using systemic theories and ideas.

Starting off from Bateson's (1972) *ecology* of the system, where each member of a family system gives meaning to the actions and communication patterns that evolve within that system, making everything fit together. This sets the grounds to help us appreciate how the couple responded to each other throughout the interview, supporting their same and different views, while narrating their lived experiences of romantic love.

The notion of *cultural embeddedness* (Dallos & Vetere, 2009) is the higher context marker for intimate relationships and influential at the level of cultural discourse about the nature of and expectations around couple relationships. The above also ropes in feminist views (Hollway, 1989) such as significant cultural discourse around development and maintenance of relationships, including that of fidelity and male/female sexual drive discourse.

This evokes the term *gendered power* (Knudson-Martin, 2013). How societal gender inequalities can be replicated in heterosexual couple dynamics, creating a power imbalance between the couple (Goldner, 1985; Goodrich, 1991; Walsh, 1989; Walters, Carter, Papp, & Silverstein, 1988). One must understand that power is relational (Knudson-Martin, 2013) and is reflected in how the couple supports the needs, interests, and goals of each other. These sometimes unacknowledged and unquestioned gender arrangements influence the couple in co-constructing their ideas of romantic love and how romantic love is expressed and received within their romantic relationship. The boundaries and rules between and within the marital relationship and the struggle to control (Hayley, 1976) also vary when a third party (interviewer) joins the system.

The concept of intergenerational traditions (Carter & McGoldrick, 1980) are also highly relevant to understand how the couple formed their narrative of romantic love and how this evolved when they became parents and then learned about the disability. This relates to the vertical flow in the family system (Carter & McGoldrick, 1980), including the patterns of relating and functioning that are transmitted down the generations in the family. This comprises family attitudes, taboos, expectations and loaded issues the couple grew up with, within their respective families of origin.

Additionally, the horizontal flow, which relates to the predictable and unpredictable events, such as the disability, that disrupts the life cycle process and subsequently their lived experience of romantic love.

Finally, 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 in conversations. This has a huge impact on the findings of this study (Hedges, 2005), how my narrative of romantic love and disability and the un-lived experience of parenthood, coloured the interview and influenced its trajectory. Averill (1982, 1992), following Wittgenstein, 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 romantic love amid a context which is generally ruled by disability? What emotional discourse was facilitated to surface and what were those held peripheral?

### **1.5.3.1 A Social Constructionist and Constructivist lens**

Given the interpretative-phenomenological methodology of this case study, the uniqueness and at the same time, shared experiences of the couple, embedded in the Maltese context, cannot be ignored. This brings to the forefront, the social constructionist and constructivist ideas around the themes of marriage, romantic love and disability. The personal and shared constructs of the couple, co-constructed through language and culture (Anderson & Goolishian, 1988; Freedman & Combs, 1996). Their meanings, feelings and emotions which also evolved from socially constructed discourse embedded in ordinary 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.

I believe these ideas are pertinent since the participants are not Maltese but chose to set up their family in a Maltese context. How did this choice influence their lived experience of romantic love, parenthood and disability?

## 2. Literature Review

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### 2.1 Introduction

Several studies have addressed the increased levels of stress among parents of disabled individuals (Tossebro & Wendelborg, 2017). Despite the reality of high stress levels which correlate with disability, some studies still report that most parents still enjoy typical levels of well-being, reported by IASSID (2014).

According to Tossebro and Wendelborg (2017), given the heterogeneity among both disabled children and their families, rates of family dissolutions are more likely to be dependent on several different factors, such as type and degree of child disability, characteristics of parents and contextual factors, rather than limited to one single factor, being the disability. This in my opinion is relevant to the research topic, as the experience of romantic love is automatically affected by the continuity and/or termination of the marital bond.

This section provides an understanding of the literature around romantic love in the context of rearing disabled children. This appears to contribute towards the co-construction of romantic love, in a context which is predominantly ruled by disability.

### 2.2 Self-Regulation, Communication and Conflict Patterns

Dumouchel (1995) discusses the couple's choice to co-operate with each other or compete with one another. By co-operating there is the potential to negotiate disagreements and co-author new stories of intimacy (Strong et al. 2014), whereas competing is more likely to lead towards dysfunctional patterns of communication.

Wilson et al. (2005) elaborate on self-regulatory behaviours, which consist of: appraising the relationship, goal setting, and implementation of change. These three aspects have in turn, been operationalized into two distinct, but correlated concepts:

- How the couple implements behavioural changes to improve their romantic relationship.
- The effort and continued willingness to work at the relationship despite potential hardships or old patterns of behaviour, adeptness at changing behaviour, and responding to feedback from their partner.

In the meantime, Gottman (1994, p. 67) talks about four communicative behaviours that erode the relationship. Naming them the *Four Horseman of the Apocalypse*, these being; criticism, contempt, defensiveness and stonewalling, often leading to marital dissolution.

Gottman (1999) expands on these risky marital dynamics which include: a greater incidence of negative behaviours; universal negative emotions and negative connotations about one's spouse; elevated levels of the four horsemen; the experiencing of emotional flooding in response to spouse's behaviour, leading to disconnection and loneliness; unsuccessful efforts to mend arguments; Harsh start-ups, usually attempted by the wife and the tendency of husband's to reject wife's influence. Finally, gridlock instead of dialogue.

More respectful, empathic and validating responses correlate better with happy marriages. Harvel Hendrix (1988; 2008) elaborate on stretching and accommodating one's views in relation to his/her partner. While Eckstein et al. (2014) talk in more detail on the different aspects of respect, which entails: compromising in times of differences; responsibility, review and reflection of communication patterns and finally release, which refers to the willingness to forgive.

Linking to Scripts (Byng-Hall, 1985), specifically the process of emotion regulation, highly influenced by communication patterns enacted in family of origin and from attachment styles. Couples with secure attachment are more likely to regulate emotions and reflect on the emotional functioning of self and others (Fonagy, 2001), hence creating a process of *co-regulation*, where the couple can regulate and/or dysregulate each other's emotions, creating their own psychological well-being (Kuppens et al., 2007, p. 707; Houben et al., 2015). Keeping in mind the high stress levels of couples who parent a disabled child, self-regulation, communication and conflict patterns are useful to the research question. These qualities, or lack of, are key to determine how the couple negotiates constructively disagreements, and the repetitive struggles they face in their journey as parents to a disabled child. Consequently, these experiences will weigh onto their narrative of romantic love.

### 2.3 Power and Relationships

Studies of the couple's well-being in relation to marital power equality, state clearly how human beings fair better in equal relationships (Steil, 1997), which Steil links directly to the ability of the couple to influence one another. Partners who see themselves as able to influence each other, use direct influence approaches, whilst those who perceive themselves as less influential, go for indirect ways of action. Direct communication strategies are associated with intimacy, leading to increased marital satisfaction and well-being, however, Steil (1997) recognises how heterosexual couples can easily overlook inequality, resulting in depression and anxiety. These would then add on to heightened emotions in relation to the disability.

An equal balance of power in a relationship is a confirmation of each other's value (Greenberg & Goldman, 2008). Skills such as listening and responding validates worth and enhances identity. When this is mutual, the union supports the identity of both (Sirkin, 2010), while unequal distribution of power asserts the prevailing party at the detriment of the other. This pattern of behaviour corrodes intimacy and connection (Greenberg & Goldman, 2008).

Linking to discourse around marital conflict and family scripts, ropes in Singer and Skerret (2014) who discuss *relational wisdom*. This entails the development of reciprocity and acting in the best interest of the other, where the couple negotiates each other's perspectives (Skerret, 2003, 2004). This connects with the relationship between the emotional toll of parents of disabled children and their romantic relationship, highlighting the couple's ability to keep in mind each other's beliefs, pains and hopes. Especially important when negotiating important aspects of their day to day, such as; chores, responsibilities and expectations, all influencing how much they feel loved and supported throughout the process.

Chircop Richards (2017) talks about *we* consciousness and its relationship with trust. Gottman (1999, 2011) finds this essential to a sound *marital house*. Achieving *we* consciousness, brings forth the *interlocking influence process* (Gottman, 2011, p. 412). This is subtly connected to one's emotional history of handling communication and conflict, decision making, personal validation, trust and intimacy.

Several research by Gottman and Gottman, (2008); Greenberg and Goldman, (2008); Johnson, (2009); Mirgain and Cordova, (2007) explain how thriving couples are characterised by the ability to; perceive each other and respond accordingly, be sensitive to each other's emotions and be malleable to each other's influence. Believing that couples co-construct their romantic love narrative, opening themselves to the influence of the other and distributing power between them are important processes linked to the research question.

## 2.5 Intimacy

Intimacy is subjective and shaped by social constructs and life experiences. Social GRRAACCEESS (Burnham, 2011) (Roper-Hall, 1998, 2008) of gender, culture, religious beliefs and educational background are all influences that impinge on the meaning of intimacy. How does this influence the participants, also considering that the couple is not Maltese, but have attuned to the Maltese culture? One's understanding of intimacy can extend from love, to sex, emotional connectedness and trust, hence enveloping several connotations.

Lewis (2010) provides extended possibilities of the stages and levels of intimacy, including: physical, aesthetic, recreational, intellectual, spiritual, emotional, sexual and unconditional love. DeYoung (2003) speaks about *attunement*, saying it goes beyond emotional and cognitive understanding between the couple, it involves *opening oneself to another's emotional experience* (Knudson-Martin & Huenergardt, 2010, p. 370). This links with the notion of empathy discussed by Azzopardi (2007, p. 230) and how it influences the togetherness and separateness of the couple. What is the relationship between the couple's co-constructed beliefs around intimacy and being parents to a disabled child?

Sexual satisfaction is another strong component of intimacy. Gender differences do impinge on this, as Willoughby et al. (2014) report, husbands tend to express a substantial difference between their idealised and their actual sexual engagement, while this happens less with women. Keeping in mind research on increased stress levels for parents of disabled children, what is the couples' view on sexual satisfaction? What importance does it occupy in the day to day of the romantic relationship?

Moreover, it appears that for women there are different sexual and non-sexual stimuli to engage in sexual activity, which include, emotional intimacy and a sense of increased well-being (Mark et al. (2014); Maserejian et al. (2010); Murray et al. (2014). This was previously researched by Phillipsohn and Hartmann (2009), who explain that closeness is a necessary component of sexual satisfaction in the relational context of marriage. Linking the existing research on intimacy with the findings of this study is important to help understand how these fit with the couple's experience of romantic love. How does the couple negotiate the gender differences of sexual and emotional intimacy? What is the relationship between parenting a disabled child and sexual and emotional intimacy?

## **2.6 Family Resilience**

This valuable framework affirms the potential for survival, repair, and growth in all families faced by crisis and challenge. A theory that strengthens the belief in family resources and adaptive strategies (Walsh, 2006). This research presents the challenging experience of parenting a disabled child, hence the family resilience framework is very pertinent to the research question. Walsh (2006) explains how the difference between coping and mastery, or dysfunction and despair, lies in the belief systems at the core of each family. Beliefs are the tools by which meaning is constructed, the lenses used to view the world, which influence perceptions, what is seen or not seen (Wright, Watson, & Bell, 1996). What meaning does the couple give to the disability, how did this change over time, and how did they navigate their romantic relationship, in the light of disability?

Resilience is socially constructed, linked to one's social world, to cultural and spiritual beliefs, to multigenerational past, and to the hopes and dreams for the future. It evolves through a continuous process of transactions with significant others and the larger world (Gergen, 1989; Hoffman, 1990). Common lived experiences help to understand how beliefs are influenced by wider social connections and how interpretations of the alike lived experiences are construed in similar ways (Wright et al., 1996). It is important to understand what weight the participants give to social networks, their constructs around disability and how these influence their day to day of the romantic relationship.

As early as the beginning of courtship, every couple makes a relational bargain (Jackson, 1977; Walsh, 1989). This is an invisible contract that defines what the couple expects from each other. This unspoken contract organises interactions, maintains and regulates systems' behaviour and is fundamental to form the family identity, coping strategies and expressed rules, such as: "We never give up when the going gets rough". However, over time, mutual expectations need reappraisal and rules are altered in the light of changing needs and constraints, such as those of the disability. I question, what is the relational interplay between the unexpected experience of having a disabled child and their expectations and rules around marriage, parenthood and romantic love?

Meanings, beliefs and distress are expressed in the narratives the family constructs together to make sense of their world and their position in it. Researcher Elizabeth Stone views family stories as the DNA of family life (Stone, Gomez, Hotzoglou, & Lipnitsky, 2005). Additionally, when the family are immigrants, narratives help retain affiliation with their country of origin, reinforcing the dual identity. Over time, these stories need revision to gain narrative coherence and integrity (Cohler, 1991). How did the couple live their experience of revisiting their narrative of romantic love, parenthood and disability within the Maltese context?

Trust is then the binding agent for open communication, mutual understanding, and problem solving, all essential qualities for resilience, when having a disabled child. This links to Boszormenyi-Nagy (1987) and his concept of *merited trust*, which dovetails with Whitaker's important view (Whitaker & Keith, 1981) of *loyalty*, *accountability*, and *mutual commitment* in sustaining a strong relational foundation and buffering periods of stress and disorganisation. How is trust experienced between the couple and as parents to a disabled child? What is the relationship between trust, disability and the romantic relationship?

## **2.7 Marital Satisfaction and Disability**

Miller (2000) provides evidence from several longitudinal studies that show the consistency of marital satisfaction over the family life cycle. Hardships occurred, but these did not drastically impinge on marital satisfaction. This is a contradiction to long-held beliefs that there is a fluctuation of marital satisfaction during the childrearing years.

Linking to a study by Tossebro and Wendelborg (2017), who in turn cited several literatures, in addition to their own, report an overall impression of inconsistency in the findings so far, specifically for couples who are also parents to disabled children. For example; Hatton et al. (2010) report that socio-economic factors justify fully the increased rate of relationship breakdown among parents of disabled children, on the other hand, Loft (2011) demonstrates reduced effects of child disability when controlling for socio-economic variables.

Meanwhile, Eddy and Walker (1999) explain how the stress of parenting a child on the autism spectrum may lead to relationship breakdown, however, it doesn't necessarily mean it has to. Keeping in mind a family resilience framework, rather than focusing on failures, it is important that focus is on marital strengths that can reinforce the notion of success. Myers et al. (2009) highlight narratives that illustrate how having a child with autism, brought couples closer to each other and enriched their marriage. Further evidence was also identified, on how the stress of parenting a child with autism imposed significant changes within the couple relationship, that led to a new level of closeness (Hock et al. 2012).

Meanwhile, Dukmak (2009) brings in the context of a different culture, a study of parental adaptation to children with intellectual disabilities in Arab countries. Dukmak highlights the difference between emotional-focused and problem-focused coping and the relationship of these two approaches with family adaptation and well-being.

This evidence sheds light that child disability is less likely to be the entire reason for marital dissolution, but this is more subject to context (Grant & Ramcharan 2001; IASSID, 2014). The study by Fertig (2003) on low birthweight in children, leading to increased divorce rates in the US, but not in the UK supported this claim. IASSID (2014) emphasised that more attention needs to be given to family support, awareness and attitudes around disability, distribution of parental roles and responsibility, and the economic effect of child disability.

These different perspectives reinforce the need to keep investigating the intricacies that link the quality of the marital relationship with the well-being of the parents of disabled children (Norlin & Brober, 2013).

## **2.8 The relationship between the Impact of Marital Satisfaction and Child Development**

Discussing from a contextual perspective, numerous findings, express how parenting efficacy is highly affected by the quality of the marital relationship (Belsky, 1984; Cohen & Weissman, 1984; Wahler & Dumas, 1986).

While a child's difficult nature or behaviour that challenges can be a strain on the couple, if their relationship functions in a good enough manner, this may serve to stabilise the affects of the behaviour on child development and on the relationship (Cohen & Weissman, 1984). On the other hand, dysfunctional marital exchanges can channel more stress into the relationship, which will then interfere with the parent-child dynamics (Emery, 1982). Brody et al. (1986) found that some parents may counteract couple difficulties, by concentrating on their parental responsibilities. Other studies by Howes and Markman (1989) say that persistent couple struggles may have long-term negative effects on child development.

In view of the increased demands and stressors, Cummings et al., (1966); Farber, (1960); Friedrich and Friedrich, (1981); Tew and Lawrence, (1975) emphasise how marital satisfaction needs to be considered as a pivotal factor for families of disabled children. Also knowing that the cycle of enduring stress keeps reappearing along the developmental milestones, as these are not achieved at a typical rate (Wikler, 1981,1986). Nonetheless, the importance of the family's personal adjustment is emphasised by Benson and Gross, (1989); Byrne and Cunningham, (1985); Crnic et al., (1983), saying that significant differences occur in adaptations. These are grounded both in the functioning of the child, but also on the resources and skills of the parents. This is supported by McKinney and Peterson (1987), who say that mutual marital support is indicative of less stress when parenting disabled children and that marital satisfaction tends to project positive coping strategies (Friedrich, 1979).

Other influences may include: the number of children within the family and the position of the disabled child within the family (McGoldrick & Gerson, 1985); the capacity of parents to reflect in a circular manner on their own and the mental states of the child and how these are affecting the behaviour within the family (Sealy & Glovinsky, 2016). Pajulo et al. (2012);

the levels of post-traumatic growth of the parents, therefore, the ability to develop a greater sense of spirituality, patience, compassion and strength (Bayat, 2007; Ekas, & Whitman, 2011; Phelps, et al. 2009); parents' parenting confidence and aversiveness in parent-child interactions, how parents learn to adapt, communicate and negotiate with the disabled child (Floyd & Zmich, 1991); the availability of support networks of the family (Blair & Holmberg, 2008) (Parks, 2007, 2011); the couples' attachment style (Bowlby, 1969) and the attachment developed with their own children; finally, the notion of self-differentiation, which is the difference between emotional and intellectual functioning, subsequently the choice of one operational level or the other, to control and adjust one's behaviour in different situations. (Bowen, 1978).

# 3. Methodology

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## 3.1 Introduction

In this section I will be discussing the research method and the methodology utilised in this study. Attention will also be given to the ethical considerations, processes of recruitment used and the participants that took part in the study. Finally, I will also argue the tools used for data collection and data analysis.

## 3.2 Research Approach, Methodology and Rationale

### 3.2.1 Why a Qualitative Approach?

The decision to undergo a qualitative research, considers several authors. Firstly Stake (1995) who explains how the qualitative research hopes to portray the particularity of personal and human dimensions of experience.

The aim of this study is to have a closer look at the lived experience of romantic love of a couple who are also parents to a disabled child. Therefore, quantitative methods which aim is to look at figures and frequency, was inappropriate (Walliman, 2011; Mason, 2002; Merriam, 2009).

A qualitative approach seeks a comprehensive understanding, in this case of the couple's co-constructed narrative of romantic love. The stories used to make sense of the life context and how participants fit within that context. A narrative of sequential events, experiences and/or actions linked together in a meaningful whole (Czarniawska, 1998; Franzosi, 1998).

Qualitative information often brings to light what is important (Young, 1996), the couple extracts, reflects and makes meaning of the life cycle of their romantic relationship which was tinged by expected stages, like marriage and becoming parents and unexpected experiences of the disability.

### **3.2.2 Why a Case Study?**

Yinn (2000) explains how one would use the case study method to deliberately use contextual conditions, believing that they might be highly pertinent to the phenomenon of study. Additionally, considering a constructivist perspective of how knowledge is constructed, rather than discovered, a case study also helps to consider the relationship between the experiences shared and the specific cultural context. How the views put forward by the unit of analysis Yinn (2000), helped to organise information about how interpreted events were interpreted and the values, beliefs and experiences that guided those interpretations.

I wanted to pursue both a descriptive and explanatory enquiry. The descriptive lens assisted me to understand the couples' perspective of what helped them and did not help to keep their romantic love alive and why they believe so. While the explanatory lens invited the couple to share their co-constructed narrative of romantic love, linking to the beliefs and values shaped by their own lived experiences and by the wider social constructionist views, hence, understanding what values and constructs were left behind, to make space to the new.

### **3.2.3 Self-Reflexivity**

The journey of co-constructing this case study research took place on several levels; my personal and professional interest, the purpose of the research and the predicted challenges. Discussions took place with my colleagues and supervisor, at the place of work to link to the way forward of the organisation and my ongoing self-reflexivity. Also, discussions with the participants, when explaining the aims of my study.

It is understood that an in-depth study of a couple, is one of the limitations of the study. The decision relates to two predominant factors; the nature of the study, that of 'romantic love', considered highly personal within the Maltese context, which usually leads to a low turnout of participants, and the consideration of the population with whom the study is being undertaken, which are parents of disabled children.

As already discussed, and from professional experience, parents of disabled children, already have it tough to cope with their load of responsibilities. Had the research addressed the impact of the disability on the child, rather than the romantic relationship of the parents, the inclination to participate would have been higher. This is a struggle I face daily at work, when trying to encourage parents to seek personal support together with that for their children. Nonetheless, I will still look at how the data can be extended to similar situations of other couples. As explained by Yin (2000), case studies can be viewed as a starting point for theoretical propositions that can be extended to the lived experiences of other couples, by giving presence to the views that emerged from the couple's discourse and shaping them through the different theoretical stand points.

It is also important to point out that co-construction between researcher and researched was not limited to the gathering of data, but findings were also discussed with the participants and their feedback is included in the findings and discussion sections.

#### **3.2.4 Why Interpretative Phenomenological Analysis?**

McCormack (2000) and Norris (1997) both talk about methods of interpreting data and say that the means must be integral to the work, also Polkingrone (1997) who emphasises on the communication depth, complexity and contextuality.

This interpretation of data will employ Interpretative phenomenological Analysis (IPA) as developed by Jonathan Smith (1996). IPA is idiographic, meaning that it is concerned with the particular and unique experience of the unit of analysis, rather than analysing for example; the choice of discourse used by the participants, as studied in discourse analysis. Having said that, discourse analysis still ropes in valuable ideas around the choice of language used by participants to express their stories. It's the study of how sentences are combined to form text, that is, structure beyond the sentence (Mithun, 2015). It sees words as actions, related to a specific context (Potter, 1996; Potter & Wetherell, 1995). *Discourse Analysis sees past the sentence, the use of language and looks at a broader range of social practices that include non-linguistic and non-specific instances of language* (Jaworski & Coupland, 1999, p. 1–3).

Also, considering the systemic disposition of this study, therefore, the importance of viewing experience in relation to context and contextual dynamics, which is another feature of IPA (Smith, Flowers & Larkin, 2010; Shinebourne, 2011; Smith, 2004). IPA is an invitation to the participants to give a detailed, first person account of their experience of romantic love, by sharing their stories, expressing their thoughts, reflections and feelings. Additionally, a space to develop their ideas and express their concerns about the research question and anything they link to it (Smith et al. 2009).

Taking also a social constructionist perspective, IPA gives space to the researcher to delve into the personal meanings and experiences of the participants, which are influenced by social norms and understandings of the wider system (Smith, Harré, & Van Langenhove, 1995). Then, the epistemological assumptions of this approach (phenomenology and hermeneutics) also accords with a relativist and constructivist viewpoint. This is the belief that knowing is a function of human perception and intentionality; implying that the mind constructs what it already knows (Smith et al. 2009). Therefore, elucidating the relationship between the couple's subjective wellbeing and their idea of romantic love.

IPA also provides a double hermeneutic, in that the researcher is attempting to make sense of the participants, who in turn are making sense of their own experience (Smith & Osborne, 2003). A space that allows for the reflexivity of the researcher and the researched. Thus, IPA appears to be the most suitable method to address this research question. It allows the flexibility and the opportunity to understand the reflections of idiosyncratic experience of romantic love between the married couple, who are also parents to a disabled child.

### **3.2.5 Research Setting**

This study was conducted in partial fulfilment of the Masters in Systemic Family Psychotherapy within the Institute of Family Therapy (IFT), Malta.

The study is held with a foreign couple living in a Maltese context. The couple has one child, who is on the autism spectrum and receives therapeutic services from a local NGO in the field of disability.

### **3.2.6 Ethical Considerations**

As simply put by Smith et al. (2009), talking about sensitive issues might constitute *harm* for any particular participant group, therefore, ethical considerations need to take place. To balance out the different possibilities that may arise from sharing personal experiences, which can either elicit positive and/or negative emotions, anonymity, confidentiality and informed consent was adopted accordingly.

Consent was requested from both husband and wife, as recommended by Polit and Hungler (1995). Pseudonyms were used throughout the transcriptions to safeguard anonymity and audio-recordings will be destroyed after completion of this research study.

## **3.3 Research Design**

### **3.3.1 Recruitment**

Following the call for application to participate in the study, two couples have showed interest in participating. One sample was used as a pilot interview, while the other was then recruited as the actual study sample. Piloting the interview was a useful trial, concerned with getting the ‘questions right’ (Gillham, 2000).

### **3.3.2 Recruitment Criteria**

#### **3.3.2.1 Heterosexual couples**

Although recent legislation in Malta is stating that homosexual couples can opt for adoption, I preferred to conduct the study with a heterosexual couple. This decision was taken in order to avoid adding further complexities that may arise from the experience of couples of different sexual orientations and parenthood through the process of adoption.

#### **3.3.2.2 Marriage**

The interaction that takes place between married couples, ranges in various forms of emotional responses and intensity (Kupperbusch, Levenson & Ebling, 2003). I therefore decided to take an in-depth look at the lived experience of romantic love, which eventually was combined with the experience of parenthood and disability, within the framework of marriage. This way forward stems from my personal and professional interest of studying romantic love in the context of families of disabled individuals. Whilst the choice to conduct the study with a married couple, links with the presented demographics of Zammit Said (2016), research title; ‘Sustaining Relationships: Couples and Singles in a Changing Society’. This study states that two thirds of the representative sample reported to be in a long-term relationship. In my opinion this represents the preference of the Maltese to be in a committed relationship. Furthermore, although a bit further back, in 2011, another study by the National Statistics Office found that 78.4% were satisfied with their marriage, denoting a significant majority of couples who still opt to get married, rather than co-habit.

#### **3.3.2.3 Length of Marriage**

Informed by family life cycle theories, denoting the significance of family relations in relation to personal growth (Mc Goldrick & Carter, 1989), the chosen couple had to be married for a minimum of 10 years. This way the couple had several years of experience where to develop their thinking around romantic love.

### **3.4 Participants**

With the aim to select participants purposefully, to obtain insight in the specific shared experiences, the study called for a heterosexual married couple who has a disabled child. The requested age range of participants was from 35 to 50 years.

The couple is a heterosexual married couple who has an autistic child. The couple is in their forties and have been married for approximately 16 years.

### **3.5 Data Collection**

This qualitative enquiry took place in the form of a semi-structured interview, a purposeful conversation about the couple's romantic love (Smith et al. 2009). A process of listening and responding that facilitated interaction with the participants to express their views, beliefs and experiences (Smith & Osborn, 2007).

Guiding questions were asked to inquire about romantic love, in order to highlight the couples' understanding of the research question, allowing me to enter their world (Smith et al., 2009).

#### **3.5.1 Interview Procedure as data collection method**

The interview was conducted in the household of the participants as preferred by the couple. This arrangement did not disrupt too much their son's routine, hence gave them space to participate in the interview more comfortably.

The interview was audio-recorded and lasted around 90 minutes. This took place in English and was transcribed verbatim, to then be analysed accordingly.

In order to set the tone, the interview started off by asking the participants to share how they met and the initial stages of courtship. The experience of being interviewed was also discussed and the participants shared how the interview helped them look into the dynamics of their relationship in a non-threatening way.

The research findings were also discussed with the couple, feedback is included in the findings and discussion sections. This process was helpful for the co-construction of the narrative of romantic love, developed from the researcher's and the researched reflections (Flick, 2002).

### **3.6 Data Analysis**

The interview transcription was followed by the eliciting of themes (Smith, Flowers & Larkin, 2010) and then data analysis using IPA processes (Smith, 2007).

An inductive, iterative process of reading and rereading the transcriptions were used to produce subcategories for information analysis within the context of three research areas of interest, being; the husband's narrative, the wife's narrative and the relationship between the two narratives.

Statements were partitioned into units, grouped in common category headings, analysed, and summarized. Plausibility of subcategories were established by testing them with new information units, until all relevant information has been assigned to a category. In this way, common codes were identified, and differences noted.

Establishing the information analysis credibility, involved implementing interrater reliability coding checks, to uncover biases that might interfere with the researcher's perspective, then comparing obtained outcomes to previously published research findings.

Finally, themes were identified and reviewed to verify if they can be refined, and a discussion was produced to capture the identified themes and ensuring a good fit between the data and its interpretation.

### 3.7 Validity and Reliability

Yardley (2000) offers four pointers when it comes to establishing the validity and reliability of qualitative research:

**Sensitivity to context** – the link between the discussion of the socio-cultural context of the study, the present literature available and the data gathered. Opting for IPA, to study the narrative of romantic love of the participants, has the primary aim to stay sensitive to contextual factors. Additionally, the validation of the participants' subjectivities, together with my own, which becomes data, forming part of the documented interpretation. Also, acknowledging the negotiation of power between the research expert and the experiential expert (Flick, 2002).

**Commitment and Rigour** – commitment is measured by the attention given to participants during the interview and during the data analysis. Comfortability of participants is essential, which within this study was ensured by conducting the interview within the couples' household, venue chosen by the couple. Also, remaining attentive to participants language and remaining transparent with regards to sensitivity of context. Rigour refers to appropriateness of the participants in relation to the research question. This was assured by inviting participants who receive specific therapeutic services to support their disabled child. Moreover, specific recruitment criteria, was adhered to rigorously. Finally, a pilot interview was undergone to ensure as much as possible that a good interview was conducted, where a balance of closeness and separateness was maintained when it came to probing, alertness to important cues put forward by the participants and the appropriateness of digging deeper (Smith et al., 2009).

**Transparency and Coherence** – to safeguard transparency, the stages of the research process are described meticulously as part of the study. Coherence of this study will finally be confirmed by the reader, nonetheless, a preliminary read with a non-expert in the field was undertaken, in order to have a closer understanding of the layman reader.

**Impact and Importance** – the final conclusions depend on the reader, as to whether the research presents interesting, important and useful findings. Having said that, after 21 years of working with families of individuals with disabilities and witnessing different marital outcomes, I have a strong belief that the data gathered is in the least useful.

### 3.8 Reflexivity of the Researcher

*In everyday life each of us is something of a phenomenologist insofar as we genuinely listen to the stories that people tell us and insofar as we pay attention to and reflect on our own perceptions*

Halling (2008, p. 145)

Reflexivity of the researcher is pivotal in an IPA study. It injects what the researcher brings to the interview and research process. I am a 43-year-old female, who has been working in the field of disability for 21 years. I was in a relationship for 21 years, of which 14 years married. I am now separated and do not have children.

My interest in this study was both a personal one, where I was curious to learn about the evolvement of romantic love, for a married couple who has been together for several years, living through the different family life cycle stages. Also, a professional curiosity. As the Parent Relations Manager of the NGO from where the participants were recruited, I worked with numerous families who journeyed themselves differently through the experience of parenting a disabled child. What was helpful, or not helpful in relation to their romantic love?

Speaking from Heidegger's (1927/1962) perspective, that of *intersubjectivity*, being the shared, overlapping and relational nature of our engagements in the world, I recognise that my interpretations of the participants were shaped by many *GRRRAAACCEEESSS* (Burnham, 2011); my personal circumstances of marriage and separation, my professional background, my constructs, gender and culture. These in turn, possibly could have influenced the interview process and the extent to which the participants have shared, or not shared throughout the interview (Berg & Smith, 1988).

I also need to acknowledge that I have known the couple for 7 years prior to the commencement of the study, in my capacity of manager to the family department. This could have impacted the amount of not sharing, especially sensitive areas of the couple relationship, such as that of intimacy. Conversely, being that I have 21 years of experience working with disability, it could have helped the participants feel more at ease and understood, especially in relation to how the disability affects the family dynamics.

My cultural background is different from that of the participants. Me being Maltese and them English, however, I still lived abroad (Canada) for 9 years and then came to Malta. This helped me understand better their lived experience of re-locating in a new country. Nevertheless, the couple seem to have fitted well within the Maltese context.

Some meanings, explanations and interpretations of the participants were similar to mine, there were others which were surprising and different from my own. The fact that I lived differently the stages of the family life cycle, especially around parenthood was helpful to remain curious. At the same time, working with families for several years, helped me to be empathic of the family dynamics during parenthood and the diagnostic process. Other experiences, such as those of marriage and the dyadic processes, resonated with me, which might have hindered the extent to which I remained curious to elicit different stories.

I am also aware of my internal dialogue, when viewing the couple from different positions. That of researcher, that of wife, ex-wife, parent relations manager, therapist and the continuous interplay between all positions.

# 4. Analysis of Findings

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## 4.1 Introduction

This section introduces the main research findings. Participants' accounts are relayed in the form of excerpts, aiming to shed light at what is being interpreted and co-constructed between the participants and the researcher, later discussed in the discussion section. The names used are fictitious. Five superordinate themes and 14 sub-themes were identified, representing the major results. These are laid out in the table below:

Superordinate Themes	Sub-themes
The day to day of the romantic relationship	<ol style="list-style-type: none"><li>1. Chores, Responsibilities &amp; Expectations</li><li>2. Emotional exhaustion &amp; guilt</li><li>3. Sexual attraction &amp; friendship</li><li>4. Working around stereotypical gender roles</li><li>5. Supporting network of family &amp; friends.</li></ol>
Romantic love over time	<ol style="list-style-type: none"><li>1. Loosing track of time</li><li>2. Longing for time together</li><li>3. Life Cycle Stages: The expression of love over time</li></ol>
The relationship between romantic love, reflection and growth	<ol style="list-style-type: none"><li>1. Handling conflict &amp; letting go of emotional baggage</li><li>2. The continuum between togetherness and separateness</li></ol>
How commitment and leaps of faith sustain romantic love	<ol style="list-style-type: none"><li>1. Trusting each other &amp; believing in the relationship</li><li>2. What's important to him/her is important to me</li></ol>
The relationship between romantic love and the choice to stay serene	<ol style="list-style-type: none"><li>1. Taking life with a pinch of salt</li><li>2. Accepting disability being part of my life/child.</li></ol>

## 4.2 The day to day of the romantic relationship

### 4.2.1 Chores, Responsibilities and Expectations

The emergent theme of the fulfilling of chores, responsibilities and expectations are synonymous with this co-constructed systemic narrative of romantic love. This appears as an inherent need that provides security to the couple. The intensity seems to increase when having a disabled child, taking up considerable “mental space”. Jane explains how their mind is always “focused” on Jack, “even in their dreams”, while James explains his understanding of romantic love almost as a chore, when saying:

**James:** “Hmm. Romantic Love eh. I’m finding another word for romantic. I think...doing things for each other...”

Jane also shared that earlier that morning she took toast in bed for James, whilst he usually brings her coffee, noting reciprocity of these gestures. A beautiful resource I compliment when working with couples.

The couple also seem to value giving space to each other to express their thoughts and feelings. This surfaced during the interview when Jane, being the one who proposed their participation in the study, offered James to take the lead at the beginning of the interview:

**Interviewer:** “First of all I want to ask you, ehm, just to have a bit of an introduction from both of you, for how long you’ve been together, and how long you’ve been married?”

**Jane:** “Yeah, I’m gonna leave you to answer it”

Jane possibly wanted to be playful and help diffuse a bit of the initial tension, however, throughout the interview, the couple kept inviting each other to give their different or same constructivist and socially constructed views.

Jane also explained the need that chores, responsibilities and expectations are not always pointed out, evidencing the expectation of taking initiative. These actions help lighten the “emotional baggage”, the reality of being a parent to a disabled child.

**Interviewer:** “Is there anything else that you think is helpful? You know, to sustain the romantic relationship?”

**Jane:** “Actually the appreciation without being prompted”

**Interviewer:** “Like doing things for each other?”

**Jane:** “Yeah, James bringing me a cup of coffee in the morning or going picking up shopping back from work”.

**Jane:** “I think it’s the appreciation that you don’t live in your own world, but you live in the world...meaning that you live in that world and you need to help her.”

The latter excerpt links with stereotypical gender roles, where house chores are the wife’s responsibility and the husband is expected to help, rather than a distribution of all the work that needs to be done.

**Interviewer:** “...So not having to ask you and you just do it. And what would be helpful for you?”

**James:** “I think you’re right, not living apart, it helps the reaching out to each other.”

When linking chores to children and disability, Jane explains that nothing is straight forward. This tends to create more stress.

**Jane:** “trying to figure out and running here and there”.

**Jane:** “...because you have a child with special needs, it’s important it doesn’t impinge on... you just have to work around it and hmm when you get on with it, things get a bit easier.”

James emphasised the physical stress, but mostly the emotional toll this takes on both, hence how very little energy remains to dedicate to the romantic relationship. For James, withdrawal seems a typical response to this emotional toll. James confirms this and explains the subtle piling up of his emotions. What helps the couple live with this emotional toll?

**James:** “Generally always emotionally exhausted”

**Interviewer:** “What do you mean by emotionally exhausted?”

**James:** “Emotionally exhausted, what does it mean...when you’re physically exhausted you just push the world out. When you’re emotionally exhausted, it’s kind of similar... in my case, it’s just not wanting to talk too much...”

Responsibilities towards family of origin who live abroad and pay frequent visits also emerge. Very often they have extended family residing with them, meaning lesser time to dedicate to each other.

**James:** “Yeah. Another thing with parents, family, being here. Not them at all, they’re all lovely.”

**Jane:** “Meanwhile, they are here. Because my family, when they come, they stay here. Where James parents have a house here, but they’re not living here...When we wake up in the morning and we have people. We come home from work and there are people, and there continues to be people until you get to bed. The thing is, this is a flat...”

**James:** “Yeah, so that’s it...you are more aware of people. So you need that time.”

A different context to the Maltese, were relatives, live close and usually are a source of support. The couple does struggle with reduced family child-minding. Baby-sitting services are necessary, but the options are limited.

**James:** “One of the things of going out is.....it’s not going to happen very often...”

**Jane:** “There are the off days when we manage to go out, the baby sitter is there and then you’re exhausted “

#### 4.2.2 Emotional exhaustion and guilt

Juggling the different chores related to housekeeping, the responsibilities of Jack receiving his needed therapy and meeting each other's parental and marital expectations transpire as very tiring for the couple.

The term "emotional exhaustion" is used by James; "Generally always emotionally exhausted". Followed by "guilt". Avoiding activities that provoke "guilt" or "emotional exhaustion" seems a coping mechanism for James, confirmed when sharing the findings. James also adds that he doesn't notice emotions building up, until he sometimes gets an anxiety attack.

**James:** "Generally always emotionally exhausted"

**Interviewer:** "What do you mean by emotionally exhausted?"

**James:** "Emotionally exhausted, what does it mean...when you're physically exhausted you just push the world out. When you're emotionally exhausted, it's kind of similar... in my case, it's just not wanting to talk too much..."

**Jane:** "Awkward"

**James:** "Yeah, and what's the word ehm, guilty."

**Interviewer:** "Guilty"

**Jane:** "Yeah, you're going out, you got someone to look out for Jack and you don't feel like it, that, that added to a certain circle of..."

**Interviewer:** "So you want it, but you're worried of what the outcome might be...?"

**James:** "Its subconscious, yeah..... Subconsciously you try to avoid it"

**Interviewer:** "So would you agree that despite that it might be a quiet night, cause you will be tired, ehm, you think that the date night, or the walk, whatever it is, is helpful for keeping up the romantic relationship?"

**James:** “Yeah definitely, yeah, ehm, I don’t think that anyone can justify it.”

Jane appears to process the “guilt” differently. A learning curve she explained, when discussing the findings:

**Jane:** “When you have a set child care... then you’re going out whether you want it or not. Occasionally I had cancelled, if he got ill... You then come to learn to say, I’m sorry but tonight I’m quiet...”

For Jane guilt feelings appear when she needs to leave her son behind, especially considering his disability. This however changed with time:

**Jane:** “The thing is when Jack was younger, I was less keen on leaving him

**Interviewer:** “Leaving him on his own with childcare”

**Jane:** “...now I’m happy of leaving him, I feel less pressure that the date night will be successful.”

#### **4.2.3 Sexual Attraction and Friendship**

Sexual attraction and friendship are “cornerstones” that appear in the couple’s narrative of romantic love:

**Jane:** “I think about attraction and that’s part of romantic love.

**James:** “Yeah, that’s kind of the obvious one, is it? Given that it cannot be the only one, but also the friendship thing...possibly, I don’t know, what do you think, is it?”

**Interviewer:** “I think it depends on the individual how he wants to differentiate it, obviously as you said, the sexual attraction is a given, but it can be underestimated as well, so, although it’s a given, it is also very important that one lays it on the table.”

**James:** “No, absolutely, yeah. I mean, that being a factor that differentiates, between that and another type of love, definitely is a differentiating factor.”

**Jane:** “It’s the cornerstone, or you end up in your role...”

**James:** “Yeah there is the attraction. Personally, with family it becomes ....yeah that becomes more difficult because you got more stuff going, you know; work, more emotional weight to carry”

Although sexual attraction was mentioned as key to romantic love, the couple did not spontaneously get into detail about their sexual life and neither did I ask specific questions around it. However, when sharing the findings, the couple expressed how worries do affect their libido. When time passes where they haven't been sexually intimate with each other, they notice, but they are “ok” about it, they know that eventually they will get there. This also links with trust in the relationship and in each other.

Couple values prioritise family time over couple time, this links with the ‘unspoken’ discourse of couple intimacy, together with the couple’s awareness that they are not “very good” at making time for each other. Their shared narrative says they have matured along the years and they need less couple time to remain loyal and committed.

**Interviewer:** Is the measure right between you? (Referring to the measure of time spent together and individually)

**James:** “Ehh, I think we have to say right because you always want more... We need a day to go out...and I think probably that we both don't prioritise that, that much... we're lazy doing it.”

**Jane:** “I think to me that we're lazy doing it because I know I'm stronger to carry it through. I prioritise our time with Jack. I know that we don't need a lot of the relationship on our own, because ehm, we have a beautiful relationship.”

Additionally, their adult chores and responsibilities, take up a lot of their time:

**James:** “...we certainly matured, the things we have to get by, the parenting, being the adult.”

Trust, another emergent value which gives the couple a sense of safety. Their construct explicates that should their relationship be in jeopardy, they would then prioritise the romantic relationship.

**Jane:** “If we have less of a trustful relationship...”

**James:** “We’d be happy to work at it to make it be...it’s a bit of a double-edged sword...We’re actually aware about it, it does not surprise us.”

Curious to understand how the couple would recognise that their relationship is in danger, I asked them how they co-construct the narrative of a “beautiful relationship”. Jane answered; “Absolutely no idea...”. Possibly, another example of the couple relying on their “gut”.

#### **4.2.4 Working around Stereotypical Gender Roles**

The couple seems aware of how gender roles are socially constructed, and they did not want to justify how they operate within these socially constructed gender roles. They explain that there is no need to abide by these stereotypical gender roles, however they acknowledge that they are inclined towards them and recognise the differences that exist between male and female. Nevertheless, when sharing the findings, they also explain how society didn’t give them much choice either, such as maternal leave versus paternal leave. James says that one then gets “accustomed” to these stereotypical gender roles.

**Interviewer:** “So if I had to ask what was not helpful along the years, to sustain and hold the romantic relationship...it’s like both of you mentioned this grudge...it’s trying to understand the other rather than keeping a grudge on what is not similar to me, or to what is different to how I see it...”

**James:** “...it’s not whether I have been working or not thing, I’m sort of going to work and dealing with stuff that affect me.....working then coming home and my wife’s there. You know what...Jane’s got a different set of ideas, so I would feel a little bit...sort of not grudged...”

**Jane:** “I have to tell you though...we talked about it...you know he works all week, he needs his he time in the weekend, so it’s not that I am trying to justify male/female gender...but...”

**James:** “It’s a general thing, it’s a general societal thing ...”

**Jane:** “It’s the world we live in”

**James:** “Society is the same thing, it likes to divide hmm...mothers need to watch out the kids...”

Furthermore, as explained by James, unlike Maltese families, where parents generally support the mother to resume work, theirs live far. Jane then shares that when younger she felt “guilty” towards her parents, as she feels she did not pay back their investment in her studies. These emotions were processed and no longer bother her.

#### **4.2.5 Support Network of Family and Friends**

The support network seems important for the success as a couple and as parents to a disabled child:

**Jane:** “...for years it was so, so hard, really hard and we were able to come out on the other side because of friends...”

**Jane:** “I would talk to friends and vice versa...So these things strengthens friendships as well. You’re not an island, so our lives impact very much parents and friends.”

**Jane:** “I’m glad to be reminded. Like I go out with a friend, ...and she talks about the husband and going out and I say you’re right, when was the last time James and I went out, good point. That would make us go out for an evening.”

Widening the system is important to the systemic paradigm, evidencing the complexity of relationships. This strongly emerges when discussing the findings, where Jane confirms the importance of the support network, at the same time, she also faces questions of whether to open up to others. Fearing that she might trigger negative emotions in others, when they are trying to stay positive.

**Jane:** “an internal conflict...talk or not talk”

## **4.3 Romantic love over time**

### **4.3.1 Loosing Track of Time**

Time, another theme that emerged, particularly how much time flies. The couple has been together for around 22 years, married for 16 years. Interestingly, they struggled to recall the exact year they started dating and some specific details faded away.

**James:** “95, we’ve been together”

**Jane:** “I thought it was 96....really”

**James:** “No. What am I saying, slightly more.”

**Jane:** “22 then married for....eh... 16 years.”

It was difficult for the couple to remember dates, however, both agreed that it has been a long time and with all they’ve been through together, including the experience of parenting a disabled child, they didn’t see it go by.

**James:** “It must have been....15, 19. 19 years. Between 18 and 19 years.”

**James:** “No. What am I saying, slightly more.”

**Jane:** “When you see it in numbers, we never said...how long was that?”

**James:** “Yeah”

Discussing the findings, Jane said that usually they remember dates. Excitement must have affected them during the interview.

### **4.3.2 Longing for Time Together**

Another sub-theme is the longing for time together as a couple. Between the daily commitments, and when family is over, which happens quite often, the couple struggles to dedicate time together on their own, to kindle the romantic relationship. When sharing the findings, this theme reminded the couple they need a date night.

**Interviewer:** So you're feeling the need to go out with each other?

**Jane:** Hmmm, cause we do not do that thing very often.

**James:** One of the things of going out is....it's not going to happen very often.

**James:** "Another thing with parents, family, being here."

**Jane:** "When we wake up in the morning and we have people. We come home from work and there are people, and there continues to be people until you get to bed."

**James:** "Yeah, so that's it, so then you are more aware of people. So you need that time"

#### **4.3.3 Life Cycle Stages - The Expression of Love over Time**

The change of the couple's expression of romantic love from when they were young, appeared as important for James. The lightness of teenage love versus adult love which requires more hard work. Looking back, James explains how he does not enjoy demonstrating his love to Jane, in the same way he used to twenty years ago. Maybe implying that he is now an adult and adults no longer 'play'.

**James:** "In that thing, loving as a teenager, mind free, thinking about nothing practically....then 20 years later, it becomes a thing that you hate to do..."

Jane found this expression out of character for James, as she notices when he tries to be romantic. Strong emotions surfaced when the couple spoke about becoming parents, and more so, when their son was diagnosed with autism.

**Interviewer:** "In a way sort of the difference from being boyfriend and girlfriend and becoming a married couple and how does it change when you become parents? And being parents to a child with autism, how did that affect the romantic relationship?"

**James:** "Becoming parents...it becomes difficult to try and manage it...it's a long reality, but then you get used to that...The thing about parenthood...you get opened up to a level of emotion, you never thought of."

**Interviewer:** “Hmmm”

**James:** “Ehm, everything is relevant, isn’t it... Sort of you climb a hill you’re not ready to climb, a mountain, until you climb another one and then it’s nothing. Your achievement that day of climbing that hill...The thing is, when you’re young and your relationship is the only important thing and .....Then when you become parents, that introduces this giant order, so you kind of, it can sort of, it puts things in a certain perspective, ehm, which I think can be at a detriment to romantic love. To the actual relationship, to what it was.”

Also, Jane expresses her strong emotions about becoming a parent to an autistic child.

**Jane:** “When you have a child with special needs, when you have an extra layer of complication and definitely when you have that extra layer of complication thick...”

#### **4.4 The relationship between romantic love, reflection and growth**

##### **4.4.1 Handling Conflict and letting go of Emotional Baggage**

Working through their differences was a huge learning journey and a recurrent theme throughout the couple’s stories. It took years of different experiences to learn how to handle their differences constructively and accept these differences between them, helping each other to grow.

**Jane:** “I’m the one whose... we’re not explosive, but you’d know that something is up... that we’re not happy.”

**James:** “Ehe”

**Jane:** “When there are a lot of undercurrents going on, then you’d know that something’s up and there’s something that we need to work on it and I’m happy to...”

**James:** “Yeah we have, we have to work around the clock...”

**Jane:** “...because everything shifts”

**James:** “Yeah definitely, then all the other aspects of life move off, whether its work... truth is there are few external factors that had affected our relationship...”

Chores and responsibilities, especially those linked to the disability emerge under this theme as well. Jane expresses how this adds more “complication”.

**Jane:** “When you have a child with special needs...running here and there ... you come home and you need them to be less....so I had to accept that James and I are different...”

“Emotional baggage” also re-surfaces in this section. Highlighting the couple’s need to learn how to let it go, not to impact negatively their relationship.

**James:** “Probably you don’t wanna give much value to the emotional baggage and grudges.”

**Jane:** “When we’re going through a bad time, I’d rather that you tell me that there is something wrong...tell me and then I’ll let go, but tell me...”

#### **4.4.2 The Continuum between Togetherness and Separateness**

The couple also values their individual identity, together with the couple identity, but more importantly their identity of parents to a disabled child. The time they spend together, and time spent apart, where they take care of the self, believing that ultimately it sustains the couple relationship.

**James:** “If I’m stressed out at work, or if I don’t have my own time, I stop...I keep unravelling...”

**Jane:** “...he needs in his alone time, to function, to give me back space...”

These views appear to be constructed on more individualistic, socially constructed ones, being the importance of individual time to sustain the romantic relationship. However, not forgetting that they also form part of a very important whole. A lived experience with an extra layer, being the disability.

**Jane:** “...I think these were learnt through a really rough period, when we were younger, that we have to have individual time...”

When asked what helped through the rough patches, James added; "...not forgetting who I am".

**Jane:** "... he needs in his alone time, to function, to give me back space...am I right?"

**James:** "Ehe...I think I need quite a lot of that... I need that so I can function."

Reciprocity also features in the shared narratives:

**James:** "So you know, I am concerned that Jane gets on with her running, which is why, what is important to her, is important to me."

## **4.5 How commitment and leaps of faith sustain romantic love**

### **4.5.1 Trusting each other and Believing in the Relationship**

From early on, the couple appears to kindle a sense of trust in their relationship and at different stages in their life together, they found themselves following their "gut", taking leaps of faith by choosing to invest in the relationship.

**Jane:** "It's natural...yeah, you go out with your gut, yeah do it. Physical attraction and emotional attraction."

**James:** "...So I had always put a vow to come back to Malta. Left university...look...these are my plans. I'd love you to come, but this is what I am doing."

**Interviewer:** "Right at the beginning?"

**James:** "Yeah... You know, we've been together for a month, but that's what I was planning on doing and she decided to come."

**Interviewer to wife:** "How did that question impact you at that point, or that plan impact you at that point of courtship?"

**Jane:** "Oh I think...It's that phase when you're at university and you're living miles away from home and we were in our finals, we were thinking about the next step anyway. Well why not. Well....you do team up and go on a gut reaction"

**James:** “we went in pro. Towards the end, I think we were committed”

Awareness of each other’s needs and knowing what to do to satisfy those needs, also came across as important:

**Jane:** “I am a very tactile person and God forbid we do not have a kiss goodbye before he leaves in the morning and when he comes home, or I kick a fuss”.

**Jane:** “I think when you go through a relationship you got to look after yourself, as well as your partner in the romantic relationship, because none of the relationship will work”.

**James:** “...also the other thing we do fairly well is make sure with each other”

Having faith during rough patches, trusting their journey, learning together and individually and embracing the relationship, rather than looking at separate aspects of it, seem to have supported the couple to push through. Possibly also believing that the romantic relationship will naturally follow.

**Jane:** “I find it more important that our relationship is healthy, more than the romantic love relationship. That really. When we’re going through a bad time, I’d rather that you tell me that there is something wrong.”

**James:** “Yeah. The question was actually about romantic love. Which means I would agree with Jane”

Flexibility of thought seem to have helped the couple adjust to life’s unexpected happenings, such as not missing out on life opportunities:

**James:** “Jane had gone for an interview for a commercial. The interview ended coming up any way and she got a job, really good company in London”. “I end up staying and we moved down to London”.

**Jane:** “After that we spent 2 years travelling”.

This resource must have also been very helpful when they became parents and later on discovering that their child has autism.

#### **4.5.2 What's Important to him/her is Important to me**

Romantic love appears to also mean moulding individual goals and needs together with those of the couple. An example, which also featured above is when James makes sure that Jane gets her time to go for a run, he says; "...what is important to her, is important to me".

Also, Jane, who early in the relationship was very much aware of James' dream of returning to Malta. A dream she supported and followed; "James obviously has always wanted to come back to Malta".

These interpretations resonated with the couple, who also agreed that taking decisions together were important since early courtship:

**Jane:** "Then shall we get married? Or the travelling, and the travelling won..."

**Jane:** "...then there was 8 months of travelling and then we ended up in Malta..."

**Jane:** "Cause we were so wanting to go travelling..."

Also deciding to take part in this study, was a decision taken together.

### **4.6 The relationship between romantic love and the choice to stay serene**

#### **4.6.1 Taking Life with a Pinch of Salt**

The sense of shared humour came across as significant in the couple's narrative of romantic love. Despite the "emotional baggage" and all the responsibilities they have, they take life serenely and with a pinch of salt. When asked to briefly recount how they met, the couple took this opportunity to be playful with each other. The way they outlined the story and the descriptive phrases used gives the impression of a sense of peace and serenity:

**Jane:** "He was the boy next door"

**James:** "Yeah, the boy next door"

**James:** "So we were the pickle and the pear..."

**Jane:** "the pickle and the pear..."

This theme also links with that of support networks, having fun with family and friends. Another means of support I try to provide as part of the family support services, opportunities for parents to have fun.

#### **4.6.2 Accepting Disability being part of my Life/Child**

Giggles and playfulness were shared throughout the interview. Although at the beginning this might have been due to a bit of nervousness, as the interview proceeded, they both relaxed and took the opportunity to enjoy it together. In my professional experience, I see it as acceptance of their life as it is, including the disability.

**Interviewer:** "...who do you think benefitted from you two, hmmm you know, maintaining the relationship...the romantic aspect of the relationship?"

**James:** "Who?"

**Jane:** "Jack"

**James:** "Well I would hope so (both laughing). Like any child is gonna benefit from parents not being at each other's throat."

**James:** "So I think all of the best you can do, is not get in the way of your child's development."

The couple described this finding as a continuous cycle of learning to live with it, born after being fed up for so long, of feeling that they are "constantly losing".

# 5. Interpretation and Discussion of Findings

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## 5.1 Introduction

When speaking about parents of disabled people, romantic love is not what usually comes to mind. Parents of the disabled are primarily looked at as bearers of immense stress and responsibility (Baker et al. 2003; Neece & Baker 2008) it is therefore easier to forget that the parents are also a couple who still experience romantic love, or the lack of it.

This case study is an in-depth Interpretative Phenomenological Analysis of the narrative of romantic love of parents of a disabled child, over the family life cycle stages. Systemically, it investigates the significance and importance of romantic love, helpful and unhelpful behaviours and the different and same interpretations of the researched and the researcher within the wider system.

## 5.2 The day to day of the romantic relationship

### 5.2.1 Chores Responsibilities and Expectations,

Earlier research on attachment, demonstrate its importance in adult life Bowlby (1969) and adult behaviour in relationships Ainsworth (1985, 1991), both highlighting the secure base that facilitates functioning and competence in daily life. The participants' secure attachment narrative appears to need the fulfilling of chores, responsibilities and expectations, as Jane says; "...knowing that he can be there for you in thick and thin...". This was again confirmed when discussing the findings, possibly it represents their childhood experience (Cassidy & Shaver, 1999) and supports the findings on the importance of the *co-parenting alliance* (Konold & Abidin, 2001; Margolin et al. 2001) strong contemporary global discourse (Abela & Walker, 2014).

Norlin and Broberg (2013) say that raising a disabled child puts the *co-parenting alliance* (Margolin et al. 2001) to the test. It is more likely that the parental coping style (Lee, 2009) and the parental personality (Glidden & Schoolcraft, 2003; Vermaes et al. 2008) that will affect the wellbeing of the couple, rather than the disability. Protective factors may include ‘taking initiative’, where Jane seems to expect James, to be able to read her mind (Azzopardi, 2007). This expectation possibly helps Jane feel cared for.

Additionally, systemically linking to the wider system; the family of origin (Bowen, 1978) and systems theory (Sabatelli & Mazor, 1985), how did inherited parental ideas, influence the co-construction of meaning around chores, responsibilities and expectations? Did the couple negotiate, or was it a *natural progression* (Chircop Richards, 2017, p. 76)? How did they influence one another during negotiations?

James emerges as weighed by the “emotional baggage” linked to the disability, while Jane came across as more logical and practical, this was confirmed by Jane when discussing findings. Possibly this dynamic was another key factor for Jane to take up responsibility for caregiving chores, leaving James with the financial wellbeing of the family. Was this distribution the same before the couple became parents? Has it changed or become more distinct with parenthood and disability? When sharing the findings, the couple says they didn’t have much choice, society pressures families to operate this way.

### **5.2.2 Emotional Exhaustion and Guilt**

The couple appears to have their minds always weighed, even in their sleep, again explained when sharing the findings. This supports Maltese research on the parental role of the disabled, which presents itself with bigger challenges of ongoing care (Cachia et al., 2016).

James speaks about ‘emotional baggage’, a load of mental stress, possibly leaving him little energy to dedicate to romantic love. James was not able to elaborate on his emotions that weighed his baggage. Discussing from a systemic lens, maybe being supported to unpack his self-saturated narratives (Boston 2005), can help him look closer at his constructs around disability, and consider alternative and more useful thickened narratives (Carr, 2014) that help him carry the baggage better. A therapeutic skill I try to use with families and couples.

This ties with Halford et al. (1994), who say that couples who work on themselves are more likely to have good romantic relationships. Today's post-modern ideas speak about mindfulness (Goodman & Schorling, 2012) which helps receptive awareness of feelings, images and thoughts (Kabat-Zinn, 2009).

When sharing my interpretations, James agreed that his "emotional exhaustion" impinges on his sense of agency towards the romantic relationship, however, it does not affect his overall marital satisfaction. This fits with what Miller (2000) found in his longitudinal studies, that despite the challenges, marital satisfaction remains relatively intact throughout. Also reading Gottman (1994), who says that marital satisfaction is linked to spouses' psychological responses to one another. Furthermore, Grover and Helliwell (2019) who discuss marriage as a significant variable of wellbeing.

Jane recognises her struggle with "guilt". When sharing the findings, she agrees that identifying the specific emotions helps her understand their effect on her, today "guilt" affects her less. The ability to identify, describe and express emotion was studied by Halpern et al. (2012), in the context of paramedics, explaining how identifying emotions may offer a new approach to preventing adverse effects of occupational stress. The context is not the same, but relatable and provides a widened perspective. It highlights the circular pattern of working on the self, which will feedback into the co-parenting and romantic relationship (Barnes et al. 2007; Jones et al. 2011; Brobst et al. 2009; Hartley et al. 2010).

Also, a systemic consideration of gender is important. Women might find it easier to process emotions through language, reducing their effect. My intention is not to engage in gendered discourse (Baker, 2016) but more to see gender as something that naturally flows from a sexed body.

In conclusion, for the couple "time alone together" is linked with terms such as; 'worry', 'pressure', 'stress'. I wonder from where this language emerges? Considering that the theme of sexual intimacy was present, but not openly discussed, it may denote stress around such topic. Could it be fear of further pregnancies, or fear of unmet expectations?

### 5.2.3 Sexual Attraction and Friendship

The couple spoke about sexual attraction as a defining aspect of romantic love, however, at this stage of the couple's life cycle, it does not appear too important, as much as friendship and the *parenting alliance* (Konold & Abidin 2001). Similarly, Hock et al. (2012) discusses that couples that remain together whilst parenting a child with autism, develop new effective ways of interacting. Can this be the same for the participants? Whilst Pagano and Hirsch (2007) examine five interpersonal tenets that connect friendship and romantic relationships; mutual support, self-disclosure, hurtful conflict, fear of betrayal, and interpersonal sensitivity.

When discussing together my interpretations, the couple agreed that emotional weight affects their sexual relationship. The couple appears disappointed of the lack of time for sexual intimacy but at times worries are simply too much. Ramisch et al. (2014) interviewed husbands with autistic children; the evidence highlights the importance for husbands to meet the wishes and needs of their wives. Seen systemically, this evidence possibly explains the emotional weight James feels when he hesitates to plan date nights, fearing he won't meet Jane's expectations. Where the emotional weight affects the couple's sexual relationship, which circularly adds more worries, resulting in more emotional weight.

Nonetheless, when connecting sexual attraction to reflection and growth, it appears that the couple still manages to express their romantic love physically.

**Jane:** "...having a cuddle in the morning and a cuddle before we go to bed at night, if he's still awake... (laughing). I am a very tactile person and God forbid we do not have a kiss goodbye before he leaves in the morning and when he comes home..."

**James:** "Feels a little unbalanced there...(laughing)."

Jane emphasises her tactile needs, possibly hinting she needs more physical contact than James. Laughingly, she explains that sometimes James falls asleep before her, not giving her the cuddles, she enjoys. How does the couple experience and negotiates their seemingly different needs for physical contact?

Keeping in mind Gottman (1999) and his *four horsemen*, if during the above excerpt Jane was trying to ridicule James, when saying that he tends to fall asleep before her, this way of communicating can be harmful. Canary et al. (2002) also emphasise the need for healthy communication strategies within healthy relationships. However, if by such comment, Jane was taking their challenges playfully, (Betcher, 1981), using shared laughter to create connectedness and intimacy, this is positively correlated with an enhanced sense of well-being within one's relationship (Hall, 2017). Linking to Wilson et al. (2005) the couple demonstrates awareness of their partner's need for growth within their relationship, when saying; "I had to accept...", however, these are embraced, without taking away the expectation, or hope for change.

*Let's not talk about sex* (Love & Farber 2017, p. 1489), a projection I felt during the interview, where James kept directing the meaning of romantic love towards friendship, while Jane appeared willing to discuss physical intimacy. Discussing findings, the couple shared that their libido is affected by worries about their son, they also confirmed their awkwardness to speak about sex during the interview, but when discussing the findings, they felt more at ease.

Farber and Sohn (2007) explain that although sex and sexuality are quite universal topics, they still evoke feelings of shame and/or insecurity. The couple's constructs could possibly fit within these findings. Possibly, they could benefit from other scaffolding inquiries (Berbary & Boles, 2014), prior to addressing their sexual intimacy: What would help facilitate discussion around sexual intimacy? What does it mean, to talk/not talk about sexual intimacy? What can be the consequences of talking/not talking about sexual intimacy? What are the factors that inhibits them to talk about sexual intimacy?

These questions could have helped understand the interplay between couple's comfort level in addressing sexual intimacy, their perceptions of my attitudes toward sex and sexuality, and how these fit within the relationship?

#### **5.2.4 Working around stereotypical gender roles**

The couple agrees to operate within adapted, socially constructed, stereotypical gender roles (Piscopo, 2014), James the bread winner and Jane the caregiver, similar within the Maltese context (NCPE, 2006). Discussing together, they share that although aware of other alternatives, because of how society is constructed, they didn't have much option to operate as such. James shares how the "economical choice" was taken out of their hands.

Earlier research by Grote et al. (1996) demonstrates that traditional division of housework is correlated with wives' low-marital satisfaction and high-satisfaction for husbands. Further studies then discuss that wives' marital satisfaction is more enhanced by husband's emotional involvement rather than participation in housework (Bradbury, Campbell, & Fincham, 1995; Erickson, 1993). A recent Maltese study by Richards Chircop (2017) argues that couples who cherish mutual emotional connectedness, may invest less energy in trying to contribute in exact equal measure towards daily chores and focus more on their sense of *togetherness* (Azzopardi, 2007, p. 230). The latter is possibly influenced by the largest group of women in the Maltese context, the "adaptive women" (NCPE, 2006, p. 3), who are *secondary earners* and *homemakers* (NCPE, 2006, p. 3).

#### **5.2.5 Support network of family and friends**

Blair and Holmberg (2008) and Parks (2007, 2011) demonstrate how the positive relationship between network support and commitment in personal relationships are consistent with healthy couple relationships, this is usually achieved through the communicative behaviours and activities of the romantic partners and the support network (Parks, 2011). Connecting to the Maltese context, Zammit Said (2016), reported that 11.0% of the population seeks relationship support from family and friends.

Discussing findings with the couple they agree to engage at different levels with their support network. Both value this resource, but James seems to prefer individual time, whereas Jane finds shelter in her friends and tries to reciprocate. This positioning fits with research by Taylor et al. (2000), who explicates how women are inclined to turn onto friends when undergoing tough times. This is a source of protection to the couple relationship.

Taking a circular stance, VanderDrift et al. (2015), inquire the role of self-preservation when sharing information about one's relationship quality, which systemically feeds back into the relationship. Also creating a ripple effect onto relationships of the wider system.

On the other hand, the fear of burdening others also emerges when discussing the findings. This links to a study by Gray et al. (2000) in the context of men battling cancer. Perhaps, an alternative narrative of sharing the weight, rather than weighing others would be more useful. Providing support groups at my place of work, operates on this premise.

Also considering Jack's autism, which affects social interaction, the couple might have learnt to engage differently with their support network, not to exhaust Jack (Strunz et al. 2017).

## **5.3 Romantic love over time**

### **5.3.1 Loosing track of time**

Time seems to drag when one is feeling frustrated (Freedman et al. 2014), this doesn't seem pertinent for the couple, as they say, they lost track of time. This may suggest good relationship quality, or that stress linked to the autism (Ramisch et al. 2014) might be a crucible to their romantic relationship (Hock et al. 2012) alienating them from keeping track of time. Alternatively, priorities linked to the disability might give them permission to forget details of the relationship, affecting retrieval of memory (Roosendaal et al. 2006).

The couple shares that the excitement during the interview, together with tiredness, might have also caused their memory loss. Feeling more relaxed when discussing the findings, possibly brings forth the trustful relationship that developed throughout the research process and the couple's resonance with the interpretations.

### **5.3.2 Longing for time together**

Lack of couple time was a salient theme, complimenting the findings of McCann et al. (2012) and Luijkx et al. (2017), that parents of disabled children carry a significant caregiving burden in terms of time, resulting in family time and free time happening less often (Axelsson & Wilder, 2014).

This ties with the couple's value of trust, managing to "pull it through" with not enough couple time. This shared narrative, conflicts with literature by Strelan et al. (2017) who explain how closeness and trust are circularly connected. Therefore, I question how the lack of couple time influences their closeness and trust? The co-construction of having a 'beautiful relationship' possibly allows the couple to dedicate more time towards their son, believing their romantic love can handle it. It is then interesting to understand the ambivalence of the couple when asked, how do they know they have a "beautiful relationship"? An attempt to deconstruct what gives the couple safety and fosters trust. The couple was not able to answer my question. My systemic intention was to put forward an embedded suggestion; what can help them identify difficulties?

Again, referring to the study by Ramisch et al. (2014, p. 979), relationship quality is highly important to maintain a 'sound marriage'. Wives reported the need to 'spend time to be a couple', whilst the husbands referred to 'the need of love, trust, and a willingness to meet the needs of their wives, especially emotionally'. The overall wellbeing of the couple heavily rests on their connectedness, making sure they are not 'navigating on the border between the ideal and the real'. (Djikic & Oatley, 2004, p. 199).

### **5.3.3 Life Cycle Stages - The expression of love over time**

Carter and McGoldrick (1999) say that families usually lack time perspective when they are having difficulties. They tend to magnify the present moment, overwhelmed and immobilized by their immediate feelings. Freedman et al. (2014) share similar findings, when they explain that perceptions of the duration of events can be inaccurate, affected by the feelings elicited during the experience (Droit-Volet & Meck 2007). This may seem to contradict with the theme of 'loosing track of time'.

James perhaps makes a huge distinction between the ways he demonstrates love now, from how he used to when he was twenty years younger.

**James:** “In that thing, loving as a teenager, mind free, thinking about nothing practically....then 20 years later, it becomes a thing that you hate to do.”

When discussing findings, the couple could not recall James saying this, Jane also found it out of character. My interpretation explains that at this life cycle stage, James shows his love by being a provider to the family, but less as a romantic partner. It's as if James' ability to engage in activities that are socially constructed as romantic is obstructed. Jane said; “James is a different level of romantic”, you need to know him to understand he is being romantic.

Becoming parents, and more so, when their son was diagnosed with autism, could have changed the couple's interpretation and/or expectation of love. James appears to have changed his view about romantic love, whilst Jane needed to change her expectations of closeness. (Carter & McGoldrick 1989). Soloski et al. (2013) discuss the influence of the parental relationship on one's love expectations. Lower levels of parental conflict, contributing towards higher levels of love and marital expectations. Possibly, James' parenting experience of getting 'opened up to a level of emotion', might have been a huge discovery, which invited him to re-evaluate romantic love.

Other possible hypotheses could be that through parenthood James has come more in touch with his emotions, which then led Jane to shift to more of a cognitive position. Alternatively, Jane, being the caregiver who handles Jack's day to day, she needs to be more rationale, not getting overwhelmed by emotions, this possibly led her to change her expectations of coupledness as parents of an autistic child. Ben-Ze'ev and Brunning (2017) talk about emotional complexity which tends to influence emotional behaviour. They explain how emotions are not detached theoretical states but are circularly linked to one's personal concerns.

## 5.4 The relationship between romantic love, reflection and growth

### 5.4.1 Handling conflict and letting go of emotional baggage

Walsh (2006) explains how family resilience is forged through crisis and involves strengths under prolonged periods of stress and adversity. Parenting a disabled child; handling conflicts, dealing with one's own and the couple's emotional baggage and at the same time trying to hold intact the couple's connectedness, with limited resources of time (Sirgy, 2012) supports the family resilience framework, within the systemic paradigm.

Jane appears to be the relationship signifier, the one who highlights conflict and difficulties. It also seems that Jane along the years needed to re-evaluate her views and expectations about marriage and learn to navigate their differences constructively. James says, he learnt how to not allow grudges impact negatively their relationship. Aware that they are parents to an autistic child, and they carry substantial emotional baggage, he learnt to let it go. Mcubbin et al. (1986) explain this as the ability to shift towards healthy responses in stressful situations. While Shafer et al. (2016) talk about *relationship self-regulation*. I wonder though, if rather than just letting emotional baggage go, this is therapeutically processed, individually and between the couple. How would the relationship be different? Fredman (2004) elaborates how deconstructing emotional discourse gives the opportunity to share more intimate detail which informs better dialogue. Key to systemic thinking.

Further elaboration on what other "external factors" had affected the relationship, would have also been interesting to understand. What values were so important to Jane and James, to have affected the coupledness? How did the couple experience and overcome the conflict related to these "external factors"? What was the relationship with the disability? Unfortunately, further detail was not elaborated.

#### 5.4.2 The continuum between Togetherness and Separateness

From the standpoint of *couple identity development* (Azzopardi, 2007, p. 227) the couple gives the impression to be continuously moving along the continuum of *togetherness* and *separateness* (Azzopardi, 2007, p. 230). I observed that when it comes to parental responsibilities, including those related to the disability, the couple functions from a *unified couple identity* (Kwang, 2010). When it then comes to relaxation and fun time, separateness seems to come into play. The couple appears to agree and describes this as valuing their individual identities, or as James specifically describes it; "...not forgetting who I am". These ideas fit within more individualistic social constructionist views of family behaviour regulation (Abela et al. 2005), also discussed in international literature on enduring marriages (Parker, 2000 cited in Parker, 2002; Mansfield, 1999). Also, findings from Ramisch et al. (2014, p. 980) where wives express the importance of; *we do things for ourselves*.

This interpretation could have different meanings and could originate from different possibilities. Maybe it's necessity, not much people can look after Jack in their absence together; the disability of their son might have led them to lose touch with fun couple time; possibly, over identification with their parental roles, projects guilt when they see themselves as a romantic couple; otherwise, individual activities can be viewed as ways to recharge, to go back energised to parental roles, whereas, fun together, cannot be sufficiently justified. Finally, it could be because they simply have different interests.

Interpreting from a 'togetherness' lens (Azzopardi, 2007, p. 230), Jane perhaps learnt to understand that her husband's 'alone time' was not out of lack of love, but a means to re-charge to be able to demonstrate his love for her and their son. James possibly had to learn to give back love to his wife and son the way they want to receive it. Not in ways defined by society, such as bringing the pay check home, to which he might got "accustomed to".

Ramisch et al. (2014, p. 975) also discuss parents' *individual methods* of dealing with autism associated stressors, who in turn link to Kersh et al. (2006) who report that low parenting stress and reduced depressive symptoms correlate better with marital quality. Maybe indicating that quality individual time *separateness*, is more likely to sustain *togetherness*, but then, how does this equate in the romantic relationship? Are spouses possibly feeling disconnected from each other, due to lack of couple time, as suggested by Woodgate et al. (2008).

## **5.5 How commitment and leaps of faith sustain romantic love**

### **5.5.1 Trusting each other and believing in the relationship**

Trust is another shared narrative, listening to the couple talk about their early days, how they followed their “gut” and taking leaps of faith, kept reinforcing my understanding that this resource was kindled very early in the relationship. Perhaps, meeting at such a young age was fundamental in building and strengthening their trust. Also, parenting a disabled child could have helped build mutual trust. Myers et al. (2009) share how having a child with autism can bring couples closer together and enrich their marriage. Maybe they believe that only them two can love their child the most, and so they invest their trust in each other.

A study by Strelan et al. (2017) talks about the pivotal implications of trust in relation to forgiveness. These findings are significant being that transgression, conflict and the willingness to forgive (Eckstein et al., 2014) is a circular systemic pattern couples repeatedly live through.

Furthermore, from a family life cycle perspective (Carter & McGoldrick, 1989), since the couple was young when they started dating, teaming up maybe helped them feel safe during their travelling. Thus, choosing to adventure the world together, perhaps made it easier to take that leap of faith. This could mean that their trust originated out of need for security, or the need for trust. Although in a different context, the need for trust was studied by Schaepe and Ewers (2017). I believe it’s also important to highlight that the choice to travel the world, before getting married, is a different experience to steady Maltese couples twenty years ago.

The couple also appears to share another strong narrative that delineates a faith; that what they need as a couple, as parents and as individuals, will be met and supported within the relationship. This security presumably stems from the couples’ secure attachment, developed in their families of origin (Bowlby 1969) and eventually replicated (Byng-Hall 1985) in their adult relationships (Ainsworth 1985, 1991) (Sibley & Liu, (2006).

Trust kept being fortified along the years, perhaps through their *parenting partnership* (Floyd & Smich, 1991, p. 1435) and *co-parenting quality* (Thullen & Bonsall, 2017, p. 878) where their needs and expectations kept being met in a *good enough* manner (Winnicott, 1988), especially during rough patches.

Believing that the rough period will pass, keeping the relationship at the forefront (Gottman, 1999), consequently working together against their challenges (Gubbins et al. 2010).

Finally, keeping in mind my hypotheses that currently the couple may be struggling with their sexual intimacy, it could be that this narrative of ‘trust’ helps them direct their focus on other characteristics of the relationship, being their friendship. Holding onto hope (Flaskas, 2007) that they will push through this phase and rekindle their romantic love.

### **5.5.2 What’s important to him/her is important to me**

This theme ties in with trust, but also involves overcoming self-interest (Engelen, 2008; Rosas, 2008), and building reciprocity (Gouldner, 1960). The couple appears to make sure that their partner will manage to undergo their *individual methods* (Ramisch et al. 2014, p. 975) of dealing with autism associated stressors and subsequently keep investing in the couple relationship. The couple agrees that this is partly taking care of each other, but also self-care to cope with the day-to-day (Qian et al. 2014). Again, as per the findings of (Ramisch et al. 2014, p. 979) mothers reported; *We do things for ourselves* and *We encourage positive qualities for the marriage*. From professional experience, this is something I encourage parents to do.

Arguably, this resource also involves the ability to share responsibility for decision making and problem solving especially in relation to the disability, another belief I regularly emphasise with parents. Gottman (1979) and Hahlweg and Jacobson (1984) say that most marital dysfunction correlates with the inability of couples to solve problems together. More recent studies conceptualise problem-solving as an adaptive emotion regulation strategy (Aldao et al. 2010) which when seen circularly, it can support the *relationship self-regulation* (Shafer et al. 2016, p.1145).

## **5.6 The relationship between romantic love and the choice to stay serene**

### **5.6.1 Taking life with a pinch of salt**

A good sense of humour in relationships emerges as a crucial component of bonding between romantic partners (Betcher, 1981), apparent between the couple. Hall (2015, p. 306) speaks about *shared laughter* which denotes *romantic attraction*, while humour indicates quality, closeness and support (Kurtz & Algoe, 2015). The couple laughed when I shared this theme, saying they do their best, although sometimes it's hard. Humour can help to diffuse negative emotions; it can help remember beautiful memories; it can invite one another for some playfulness; maybe passing messages with humour. Perhaps, despite that their energy and time for intimacy is limited, this playfulness still maintains the spice in the relationship. Whatever the combination of reasons is, from my twenty-one years of working with disability and families, infusing life adversity with humour, helps handle life better. Schneider et al. (2018) found that consistent use of self-enhancing humour to regulate emotion, can be particularly beneficial to mental health.

Systemically speaking, laughing and having fun ropes in the wider system of family and friends. The couple, especially Jane ensures socialisation with friends. Also, with Jack's professionals, since our organisation provides these opportunities too. This was emphasised again, when sharing findings.

### **5.6.2 Accepting disability to be part of my life/child**

The couple explained that some of their giggles, reflected their excitement at the beginning of the interview, however, they recognise their capacity for self-enhancing humour (Martin et al. 2003), they explain that they are; "learning to live with the disability".

Martin et al. (2003) also speak about affiliative humour, which establishes and strengthens social bonds. Seeing the couple laugh at each other's jokes, such as; "the boy next door...", it seemed as if that phrase meant something deeper, shared by them only.

As an aspiring systemic family therapist and as manager to the family department, this is something I recommend to couples. Humour is something I also try to practice during clinic sessions and even during family support groups at work. A resource I not only use to tentatively diffuse negative emotions, but also an attempt to model behaviour, supporting families to take on board this skill.

### **5.7 Connecting the themes systemically**

A systemic appreciation can be noticed, where the different themes are not only discussed separately, but are also an influence on each other. Where the day to day of the romantic relationship is connected to time, which then urges for reflection on how to best handle emotions and find togetherness. This growth fosters commitment, which then leads to trust and leaps of faith. A faith also towards life and choosing to live it serenely, which then feeds back in the day to day of the relationship.

### **5.8 The relationship between social constructionism and the co-constructed narrative of romantic love**

This link is equally important, where the researched and the researcher co-constructed a narrative of romantic love influenced by views of the wider system, including family, friends, professionals, colleagues and the general social discourse. These ideas weighed on choices related stereotypical gender roles, on emotions, resilience and ultimately subjective wellbeing. Feeding back difference into the elicited themes.

## 5.9 Reflexivity

Keeping in mind the circular influential nature between the researcher and the researched embedded in IPA (Smith et al. 2009) and as witness of such happening, some analysis of the co-created narrative of this study is due.

Upon reflection of the research process, combined systemically with my personal experience, I can observe my inclination towards ideas of commitment, mutual support and negotiation of chores, responsibilities and expectations. These constructs informed my thinking, subsequently the choice of questions and the probing that took place during the interview. The data collected appear to resonate with these ideas, however, I am curious about what other perspectives could have emerged, if another set of questions were put forward. Moreover, how would I have influenced the interview differently, had I been married, rather than separated, or even if I had children.

I found interesting how the couple didn't speak about their intimate life, rather their emphasis was on how friendship and trust are the most important to them. The aspect of sexual attraction did come up as a 'matter of fact' of romantic love, accompanied with statements about the lack of couple time. Possibly, the couple is currently tapping into other resources and needed to portray their relationship as beautiful, despite the circumstances. Also, gender imbalance in the room (two females, one male), may have hindered for such a conversation to take place.

This ties with the surprise I experienced due to the seemingly diffused boundaries between the couples' identity as parents and as lovers. This might have come as a surprise, not being a parent myself. Nevertheless, although I was expectant that the couple might prioritise their identity as parents over that of lovers, it was almost shocking that at times they found it hard to distinguish or even associate themselves with socially constructed attitudes of passion and sexual attraction and expression. In addition, the wife seemed to give more importance to the need of physical contact than the husband. From a social constructionist point of view, men are portrayed as more sexual beings, however, literature also highlights a different perspective, where women are highly sexual beings as well (Kaestle & Evans, 2018; Kralik, 2001).

The couple's strong narrative of having a "beautiful relationship" was highly influential for me. Accepting to be questioned around their romantic love, placed them in a position of evaluating their strengths and challenges, however, they stood in unison aware of their struggles. Witnessing this was comforting and inspiring.

My reciprocation was the opening of a *dialogical space* (Rober, 2015, p. 107) a collaborative systemic enquiry using language that inspired curiosity, negotiation and resilience. Hopefully enriching the participants narrative of romantic love. A space where they can allow to see themselves as lovers and not only bearers of immense stress (Baker et al. 2003; Neece & Baker 2008) and caring responsibilities linked to the disability. A thickened narrative that hopefully will increase their personal wellbeing and that of their son (Ramisch et al. 2014).

Personally, I learnt a lot, this study challenged my perspective of romantic love and helped to refine my self-reflexivity, both personally and professionally. A co-construction where the feedback gathered will loop back into the couple's narrative and possibly in a future romantic narrative of my own, creating even more feedback. Where information is difference and difference is a relationship, or a change in the relationship (Palazzoli et al. 1980).

### **5.10 Limitations and ideas for future research**

Whilst the nature of qualitative research contributes towards eliciting unique meanings and lived experiences, when combined with quantitative approaches, more representative facts can be obtained. Furthermore, being a case study posits 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.

Also, the already existing professional relationship with the couple, might have hindered what and to what extent the couple might have decided to share during the interview. Moreover, I did not interview the couple individually, as well as together, this too could have altered the depth and amount of data shared. I would recommend the latter for future studies.

Although the couple has been living in Malta for several years and seem to have settled well within the Maltese culture, it remains that their origins are not Maltese. Therefore, the results might not be the same or pertinent to the journey of romantic love of a 'typical' Maltese couple with a disabled child. The length of the relationship, age, number of children and boundaries with families of origin are all characteristics that can be considered for different population samples.

Speaking from a family life cycle perspective and keeping in the mind the notion of journey of romantic love, future sample participants can be chosen from different stages of the life cycle, aiming to create a time line of the different stages of romantic love, maybe exploring where they meet and overlap.

## 6. Conclusion

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This study aimed at an in-depth exploration of the lived experience of romantic love of a couple who are also parents to a disabled child. It looked at the evolution of romantic love throughout the different stages of the family life cycle and the relationship with the disability.

The results portray how chores and responsibilities prioritise behaviour, especially in relation to parenting and disability, taking away time and energy, which otherwise can be dedicated to the couple relationship. Also, the challenges of negotiating family time, individual time and couple time, which involves a process of understanding each other's perspective and letting go of 'emotional baggage'.

'Trust' is pivotal in this process. It provides a sense of safety and security, it reinforces the connectedness of the couple, hence the narrative of having a "beautiful relationship", that accompanies them through the rough patches.

Taking life with a pinch of salt is another resilient factor that emerged, where despite the difficult reality of parenting a disabled child and the several sacrifices the couple undergoes to do so, they still find time to be playful with one another.

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# 8. Appendices

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## Appendix 1: Invite

Dear Sir/Madam,

I am a student at the Institute of Family Therapy - Malta, currently undergoing a MASTERS in Systemic Family Psychotherapy. In part fulfilment of my course, I am undertaking a Case Study Research, which enquires;

‘How is romantic love experienced by couples who are parents of a child with disability?’

The aim of this study is to frame meanings, processes and reflections that are specific to the experience of romantic love between a married couple, who are also parents of an individual with a disability.

The data needed for this study shall be collected through an interview, which will last for approximately 90 minutes. All information gathered will be recorded, transcribed and analysed. Once the final grade for the dissertation has been issued, all recordings and transcripts shall be destroyed.

Please note that participation in this study is entirely voluntary and participants can change their mind at any time without the need to provide a reason for doing so. All information collected will be held confidential and participant’s identity will remain anonymous.

I thank you for your time and consideration of participation, should you have any queries, please do not hesitate to contact me on [76282414c@gmail.com](mailto:76282414c@gmail.com) or mobile 79051241.

Kind regards,

Charlene Borg

## Appendix 2: Consent Form

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

1. Only the supervisor and examiners will have access to the data.
2. The participants will remain free to withdraw from the study at any time without having to provide any reason. In the case of withdrawal, all the records and information collected will be deleted.
3. The participants, although being the sole proprietors of the data provided, they are granting that such data is processed for this study only.
4. The data collection process will be a transparent process.
5. All data, once exhausted are to be deleted.
6. Confidentiality, anonymity and data protection procedures are to be ethically abided.
7. The researcher would provide a soft copy of the study to the participants if required.

Considering the above, I \_\_\_\_\_ as a participant, am willing to participate on a voluntary basis in this research by contributing actively in this interview. I am consenting for this interview to be recorded, which however, once the research is printed, all the material will be deleted.

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

Signature and Date: \_\_\_\_\_

Researcher's Name: \_\_\_\_\_

Signature and Date: \_\_\_\_\_

## **Appendix 3: Guiding Questions**

### **The main questions the researcher wishes to answer**

- How is romantic love experienced by couples who are parents of a child with disability?
- How did the couple manage their romantic relationship in spite of the demands of the child?
- Who benefits from keeping alive the romantic love between the couple?
- From what is this recognised?
- How does the parental relationship benefit from the romantic relationship?

### **What the researcher wants to find out**

- Is the investment in romantic love linked to the couple's idea of life satisfaction and coping better with life and the disability?
- Does the couple believe that keeping alive the romantic love between them, is only of benefit to themselves?
- Who else do they think benefits from this investment?
- What makes them think so?
- How is this observed?

### **The questions that will be asked to address the main question**

- What understanding do you have of romantic love?
- How do you distinguish it from other love?
- How has this changed when you became parents to a disabled child/individual?
- What happened to romantic love when your child/ren with a disability was/were born in the family?
- Do you feel that romantic love is still alive between you?
- How do you know this? How do you measure this?
- How do you explain this?
- What was helpful to keep the romantic love alive?
- What was not helpful to keep the romantic love alive?
- What effects does romantic love have on your life?
- How is this related to the romantic love between the couple?